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ABSTRACT

The guide for new parents of infants with Down's Syndrome contains 11 entries by parents, pediatricians, and educators. The following topics are addressed: typical initial parental reactions; the causes and effects of Down's Syndrome; reactions of 18 pairs of parents initially and after at least 1 year of living with their child; guidelines on daily care tasks and ways of stimulating development; language stimulation; training in socially acceptable behaviors; muscular development; eating habits, toilet training, hygiene, rest habits, and dressing; the importance of play; and planning for the future. (GW)

TO GIVE AN EDGE:

A Guide for New Parents of Down's Syndrome (mongoloid) Children

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This booklet is dedicated to parents of Down's Syndrome (mongoloid) children everywhere.

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INTRODUCTION

This booklet was written for new parents of Down's Syndrome children parents who face soul-searching questions such as "Should we place our Down's Syndrome child in a foster home or institution?" "If we raise him at home will our other children come to dislike or even hate him because he will require so much of our attention?" "Will he ever be able to walk or talk and be toilet trained or will he be unable to care even for his own simplest needs?" "Will grandpa and grandma love him, and what about the reaction of our neighbors?" "What effect will he have on our marriage will he bring us closer together or drive a wedge between us?" "What will happen to him when we die who will care for him?"

These have always been common questions for parents of Down's Syndrome infants. The major difference in their case, however, as distinct from your own, is that they had to go through a laborious search process to uncover the information necessary to make decisions. The purpose of this booklet is to help you make decisions with greater assurance because you will have facts about the condition and knowledge of how other parents of Down's children have coped with it.

It will *not* be our purpose to try and convince you either to rear your child at home or to have him reared in a good foster home or institutional setting. There may be compelling reasons to recommend either of these alternatives, but your personal circumstances and beliefs based on facts will be the deciding factors. In this vein, you will find that *both* sides of questions and issues will be presented throughout this booklet, since an alternative really can't be an alternative in a true sense without considering various, and sometimes opposing, points of view.

THUMBNAIL SKETCHES OF AUTHORS AND CONTRIBUTORS

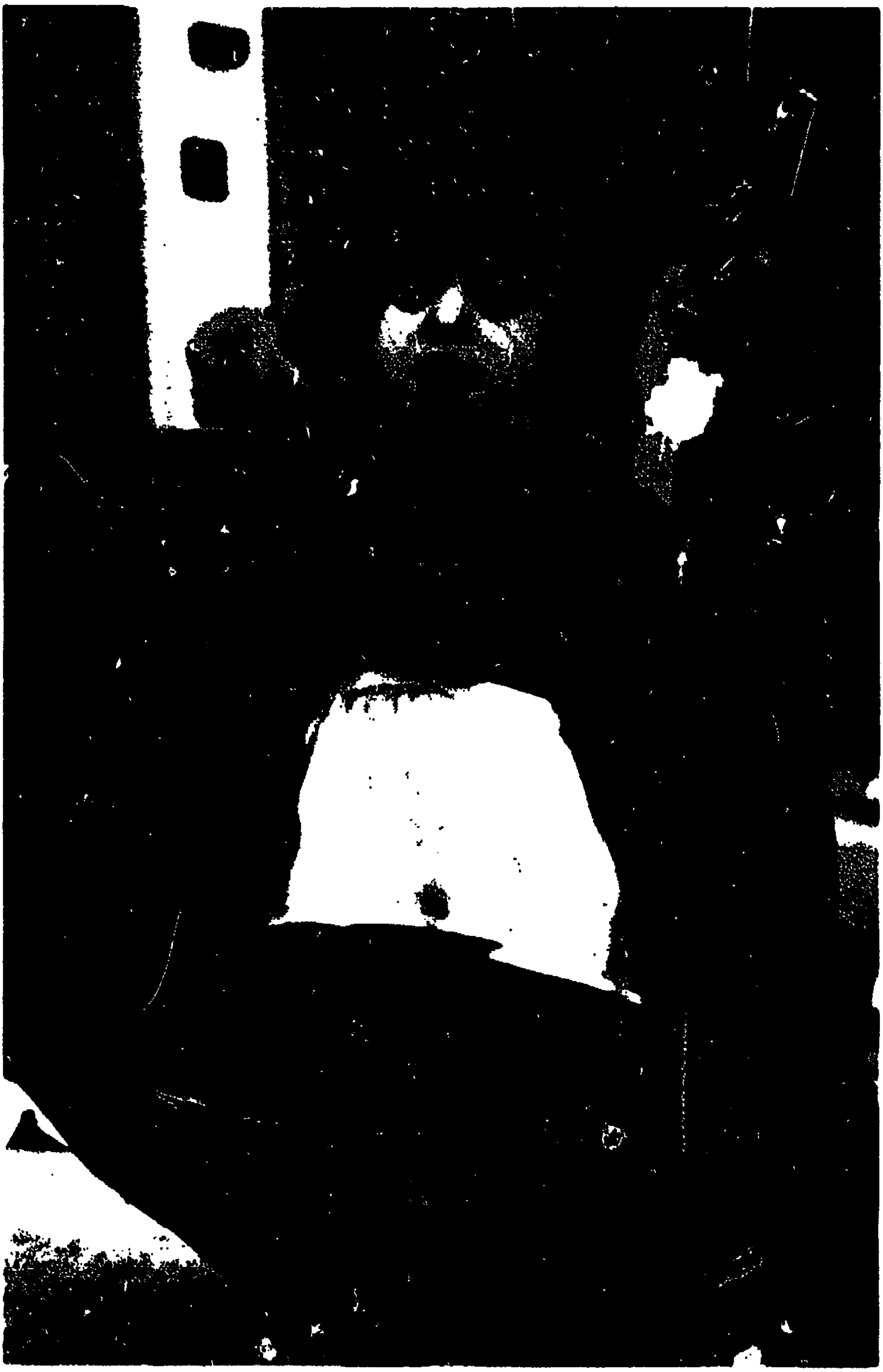
Barbara Thomes is the mother of a five year old Down's Syndrome boy. After the birth of her son she became active in her local Association for Retarded Citizens, serving as its president for two years. Through the ARC she helped establish morning coffee hours for mothers of retarded children in the county. She is part of a county-wide parent counselling group. The counsellors, on call through hospitals, doctors, ministers and social services, visit with parents who are finding it difficult to cope with mental retardation. Together with her son, she has been part of Project EDGE since her son's birth.

Margaret Horrobin, codirector of Project EDGE, is a native of England, where she received her training as a physician. She came to the United States in 1964 and has been on the faculty of the University of Minnesota since 1965. Presently an Assistant Professor in the Department of Pediatrics, one of her areas of concern is the Birth Defects Clinic. Because of her known interest in families with a child with Down's Syndrome, the majority of the children seen in this clinic for the past several years have been children with Down's Syndrome. Much of her professional life is devoted to counselling parents of retarded children, helping them to provide a sound program of health care.

John Rynders, codirector of Project EDGE, is an Associate Professor at the University of Minnesota in the Department of Special Education. He has had several years of experience in teaching retarded children and was a school principal in a state institution for retarded individuals before entering the University of Wisconsin for advanced study in special education. On the faculty at the University of Minnesota since 1968, his major teaching responsibility is to train educators of young retarded children.

Marylee Fithian has extensive training in special education and is currently a doctoral candidate in the Department of Special Education at the University of Minnesota. She directs the home training and preschool aspects of Project EDGE, and has considerable experience as a teacher of retarded children fashioning one of the first programs in Minnesota designed to help mildly retarded children remain in regular classrooms rather than being segregated in special classes. Her special interest is in the social development of retarded children.

Judith Wolf, a language therapist, is presently a doctoral student in the Department of Special Education at the University of Minnesota. In addition to coordinating the measurement efforts of Project EDGE, she conducts language training workshops for teachers and paraprofessionals and has been active in developing language training materials for parents of retarded children.



PROLOGUE:
A LETTER TO PARENTS

Barbara Thomes, Mother

You have given birth. New life is a wondrous event. But the world does not glow and radiate joy as it should for you because something in nature is not right. You have been saddened by news which one always suspects could happen, for which one thinks he or she has prepared himself, but for which one never really is prepared, whether it be your first child or eighth. Your baby has a chromosome mixup, a congenital mishap which has affected its whole being. The mishap is known as Down's Syndrome, or mongolism.

We would like to tell you who we are, before we continue talking with you, for it might help you to know that we do really understand what you are experiencing. We are parents of Down's Syndrome children. Some of us have many normal children in our families as well as our Down's Syndrome child, and others of us have just our one Down's Syndrome child. We are an assortment of ages and backgrounds. But we have a two-fold common bond love for our Down's Syndrome children and a dedication to helping them become useful persons, as whole as possible. We want you to know that we experienced all of the feelings after the births of our children that we know you too are experiencing. There was shock. And there was fear. There were bitterness, rejection, confusion and sadness. For a fleeting moment we wondered if we could love our little ones with all their imperfections. And that's the beauty of it all. We love them with a special love.

Let's examine these feelings that we have mentioned above. Shock is undoubtedly the first. Certainly, the amount of shock you experience at the news of your child's condition depends a great deal upon how gently or how bluntly you have been told about it. However, after examining our own reactions, we know that there really is no easy way to be told. We are grateful that today we are usually told as soon after birth as possible, for there is a greater shock of finding out a year or so later, a frequent happening in the past.

Fear might be present for a number of reasons. Perhaps this is your first contact with retardation of any kind. Or perhaps the only contact you have had with retarded children has been in an institutional setting where you were aware of many very severe cases. Maybe you have only heard fairy tales about Down's Syndrome children. "They all look alike" is one tale we can readily dispel for you right now. Our children are all individual persons with definite family traits and characteristics. They are anything but docile, sad-faced, dull-eyed little people. They tear up newspapers, open up cupboard doors and haul things out, get into big brother's things, and in general create as much havoc as any normal child.

Perhaps you feel bitterness. Don't feel alone in this. It's hard to understand why Mrs. So and So, who didn't take care of herself and neglects her other children, has a perfectly healthy little baby. It's hard to reconcile the fact that this is perhaps your one and only child when someone else you know has had many normal babies. It's hard to rejoice with the other mothers in the maternity ward when you feel very little to rejoice about. But the joy you will know when your child accomplishes as simple a thing as smiling will help you to ward off this feeling and replace it with gratitude.

You may feel guilty because you have had thoughts of rejection toward your own flesh and blood, an infant. It does not seem terribly odd that this feeling should assail you. It assailed us too. But it will be short-lived, for all you need to do is to fondle your baby, talk to him, and again parenthood will take charge and you will love him.

Confusion and sadness are all a part of the above mentioned emotions. They flow from one another, it seems. Confusion will exit quickly when you get into the everyday routine of feeding, bathing and clothing your baby. Sadness may remain, for deep down it will always hurt a bit to think that the future of this little one will not be the same as it is for other children.

How should you handle all of these feelings at a time when you are physically and mentally low? One good bit of therapy is to ask your doctor or the hospital to recommend the names of other parents who have a Down's Syndrome child and then to visit with those parents. They will let you know that indeed they do understand your situation. And they can give you the encouragement and hope you need now. Also, seek out a close friend or clergyman who you know will listen to you with compassion.

It would be unfair to tell you that life will be a bed of roses for you and your baby. There will be challenges all along the way. Perhaps we can help you to foresee and be ready for some of them. First of all, there will be decisions to make. There may be forces tugging and pulling at you, some telling you to institutionalize your baby immediately and others telling you to take him home. We chose to take our babies home, for we felt that they needed our love, had a right to our love, and that they would thrive on that love. Your decision is something that must be reached by both mother and father.

If there are other children in the family, they must be told about the baby. It seems to solve a lot of problems if it is done immediately, in a gentle and factual way. Children are amazing, and will astound you with their acceptance of the situation and the matter of fact way in which they will tell their friends and teachers and classmates. And best of all, they will amaze you with their love for the baby. When they come home from school each day, they will gravitate toward the baby's crib or playpen or wherever he may be. Your baby can truly teach all of you the wonderful, much sought-after quality of selflessness.

You will also have to set about the task of telling other people about your baby. There are grandparents who must be told and helped. Some grandparents disbelieve the diagnosis, a few reject their grandchild, and some love the child more than all of the other grandchildren. Example and patience are needed by you to teach the disappointed grandparent not to be bitter, or the unbelieving grandparent to accept the facts.

There are friends and neighbors who must be told. You may be waiting for them to come to you, but if they don't come, you will have to realize that perhaps they are hesitant because they don't know how you are bearing up and they don't know what to say. Some friends, in their kindness, might offer you sympathy and condolences. But, almost without fail, they will open their hearts to your child.

In all of these relationships, there is one big factor which will determine how your baby is accepted That crucial factor is you. If you love and accept your baby, he will be loved and accepted by others. Do not hide him. Show him to people and encourage them to hold him. Be honest about his condition. Tell them that he is retarded, that he has a condition known as Down's Syndrome. Also encourage them to ask questions about your baby. Your family and friends will be relieved to see how naturally you handle the situation and will react to the baby as you do. If you refuse to admit what is wrong, or try to hide it, you will have closed a door in your life which will shut off some of the most beautiful, rewarding relationships that a person can experience. You will learn a lot about people, too, even those people whom you thought you knew so well.

The medical aspects of Down's Syndrome will be discussed in another portion of this booklet. We are interested in sharing thoughts with you on the mental growth of your child. One of the most important contributing factors toward that growth is stimulation. From the time you bring him home from the hospital, make an effort to keep your baby out where you are and where family life is active. The amount of time he can be with you will of course increase with his age. Have him watch you bake a cake, wash the dishes and sweep the floor. Talk to him as you do these things. Put objects in his hands so that he can touch and feel them. Be a teacher to him and show him the way to learn. Never take for granted that he will learn something on his own. His little eyes will sparkle and he will begin to take an interest in life around him if you constantly show him the way. Unlike normal children, Down's Syndrome children need much guidance in exploring the world around them.

We can't stress enough the need to talk to and read to your baby.

At first, it will seem almost ridiculous to you to sit and read to your baby who doesn't seem the least bit interested in what you're saying. But if you pursue the reading, you will soon know the joy of having that same little child climb up on a chair, take a book and "read" to himself. The language stimulation which flows from your reading to him is of great value, for this is an area where the Down's Syndrome child will need the most help.

The age at which normal children accomplish physical and mental tasks varies with each child. So, too, does it vary among Down's Syndrome children. Some of our children walked at one year of age; others not until well into their second year. Some of our children said words before they were one year old; others took much longer. We tell you this in the hope that you will not stereotype your child and expect him to accomplish things at the same time another child does. Often it will require much patience on your part, for sometimes it seems that the child will never learn. But in his own good time, with your help, he will learn, and then you will rejoice.

If we have given you some encouragement we are indeed grateful. There are other sources of help, however, which we would recommend to you. Join your nearest ARC (Association for Retarded Citizens) group and exchange ideas and experiences with the members. Contact your Social Services Department for counselling. This counselling, which is offered by the Family Service Agency of the Welfare Department, may prove invaluable to you in many ways, but particularly regarding the future education of your child. Seek the advice and help of your local Public Health nurse who will be able to serve as a resource person for you, guiding you in matters of nutrition, growth and development of your baby, and in the understanding of retardation. Try to secure the names of other parents in your area who have Down's Syndrome children because it always helps to be with someone who understands your problems through experience. And refer to the list of materials and resources at the end of this booklet. They will encourage and buoy you up when the days are difficult. Lastly, try to think positively. One positive thought we can all share is that we are so lucky to live in this decade when very wonderful things are being done for us and for our children.

We wish you and your baby the very best of health and happiness.

Sincerely,

Barbara Thomes

Barbara Thomes & Minnesota Parents in Project EDGE

WHAT IS DOWN'S SYNDROME?

J. Margaret Horrobin, Pediatrician

As parents of a child with Down's Syndrome you naturally have many questions concerning your child. We hope to answer some of them here.

What Makes the Doctor Think Your Child has Down's Syndrome?

Children with Down's Syndrome have a characteristic appearance including somewhat slanted appearing eyes, skin folds covering the inner corner of the eyes, a broad nasal bridge and have a tendency to protrude the tongue. There are many other bodily characteristics including short stature, small head, stubby hands with inward curved little fingers, often a single crease across the palm, joints which are unusually flexible and generally poor muscle tone ("floppiness"). Mental retardation is almost always present.

You should know that no child has all the possible features of Down's Syndrome (there are more than fifty), and any single feature seen in Down's Syndrome can also be found in normal children. By the way, "Down" is the name of the physician who first described the condition and "Syndrome" means a cluster of characteristics.

What Causes Down's Syndrome?

First, understand that nothing you did, or did not do, caused the syndrome and nothing you could have done would have prevented it. It has been found that children with Down's Syndrome have an extra chromosome. Normally there are 46 chromosomes in each cell, arranged as 23 pairs. Twenty-two pairs are concerned with physical features such as height, body build, eye and hair color, and are called autosomes. One pair determines the sex of the person, XX for a female, XY for a male. For convenience of identification in laboratory studies the chromosomes are customarily arranged in pairs in decreasing size, and numbered one through 22. Clusters of pairs with some similarities are grouped together, A through G. In Down's Syndrome there are three Number 21 chromosomes instead of two. The condition of three autosomes instead of a pair is called a trisomy. As the Number 21 pair is part of the G group of chromosomes, Down's Syndrome is also called Trisomy G or Trisomy 21.

How Does This Happen?

The egg and the sperm each contain half the usual number of chromosomes in order that, when they unite at fertilization, there will be a normal complement of 46. If, in the process of splitting of pairs in the formation of the egg, separation does not occur properly, an extra chromosome may be carried over into the egg, thus causing a total of 47 chromosomes (instead of 46) after the sperm, with 23, has united with the egg containing 24. The failure of correct separation is known as "nondisjunction" and is responsible for 95 percent of Down's Syndrome births. In the other 5 percent the extra chromosome is not floating free, so to speak, but is attached to another chromosome. This is called a "translocation". In rare circumstances, a child will have a type of Down's Syndrome called "mosaicism." Mosaicism means that some but not all of the cells in the body contain the extra chromosome. Children with the mosaic form tend to have higher IQ scores, but there appears to be little or no relationship between the percentage of normal cells and the child's IQ score. At this time we do not know what causes nondisjunction, translocation, and mosaicism.

How Often Does it Happen?

Down's Syndrome occurs in all races and happens approximately once in every 600 births. The nondisjunction type, however, becomes more common as a woman gets older, so that the chance for any particular pregnancy is mainly dependent on the age of the mother. For a woman in her early 20's, the chance may be as low as 1 in 2000, whereas for a woman in her late 40's it may be as high as 1 in 20. Below the age of 35 the chances are quite small.

Will It Happen to Us Again?

The type of Down's Syndrome caused by nondisjunction does not seem to be hereditary, and the chances of it happening again are primarily determined by the mother's age. The risk for a young woman would thus be small, but may be considerable for a woman in her forties.

The rare translocation type of Down's Syndrome may be, but is not necessarily, hereditary. Where one of the parents is a carrier of this type, there is a high risk for future pregnancies and the advice of a genetic counselor should be sought.

Whose Chromosomes Should be Examined, And is It Necessary?

First, the baby's. If the baby's chromosomes show the usual nondisjunction Trisomy 21 arrangement there is generally no need to go further. You can be sure that this is not familial.

If the baby has the translocation type of Down's Syndrome, the mother's and the father's chromosomes should be examined to see if either of them is carrying the translocation.

Sometimes we do not feel it is essential to do a chromosome examination. If a woman is older, has had normal children, has no family history on her or the father's side of Down's Syndrome and the child's diagnosis appears clear on physical examination, then the likelihood of there being a hereditary translocation is just about nil. Therefore, we and the parents may feel that the expense of the test is not justifiable. If the woman is young, especially if this is her first baby, we feel that the test should be done even though in the overwhelming majority of instances the nonhereditary nondisjunction Trisomy 21 will be found.

How Early in Life Can Down's Syndrome be Diagnosed?

In most cases the diagnosis can be suspected and made in the newborn period and the blood for the chromosome test, if indicated, can be taken at that time. It is rather uncommon these days for the condition to remain unsuspected after the newborn's nursery stay.

Will Our Child Be Severely Retarded?

Most children with Down's Syndrome are not severely retarded. There is an enormous range of intellectual development among the children. Just as their physical appearances are not identical, neither is their mental development. There are some, a few, who are profoundly retarded, while there are also some, very few, whose intelligence is in the borderline normal area. Most of the children are ultimately moderately retarded, i.e., their IQ test scores will generally fall between 40 and 54 (a normal IQ test score is around 100). More information about IQ scores will be provided in the next section.

Is There Such a Thing as "A Touch of Down's Syndrome?"

No. A child either has Down's Syndrome or does not have it. This term, or others similar to it, is sometimes used by well-intentioned people to imply that the child's progress or development is better than might have been expected, forgetting that there is a very wide range of development among children with Down's Syndrome. Along these lines it should perhaps be mentioned that by and large the physical appearance, or number of diagnostic characteristics present, is not an indicator of mental development or potential.

Is There a Cure?

No. As is true for many conditions that cannot be cured, parents of children with Down's Syndrome may be unduly susceptible to claims of quacks, charlatans and mistaken people that a cure can be effected, or that a particular treatment will remarkably improve a child's development. Through the years a host of drugs and diets of various kinds have been promoted. Objective evidence as to their effectiveness is lacking.

How Alike are Children with Down's Syndrome?

It is true that children with Down's Syndrome have enough physical characteristics in common that they can be recognized by their appearance. However, through the years many stereotypes have been attached to them, such as that they are placid, docile, obstinate, cheerful, friendly, not destructive, have a natural talent for mimicry, innate rhythm and love of music. The research that has been done suggests that these stereotypes are more fantasy than fact. Actually there is tremendous variability among children with Down's Syndrome rather than uniformity of traits. Not all characteristics have been specifically researched, but, in every case where evidence has been gathered about a particular trait, it has been found not to be more common in Down's Syndrome than in other children with a similar degree of retardation.

Do Children with Down's Syndrome Grow Up?

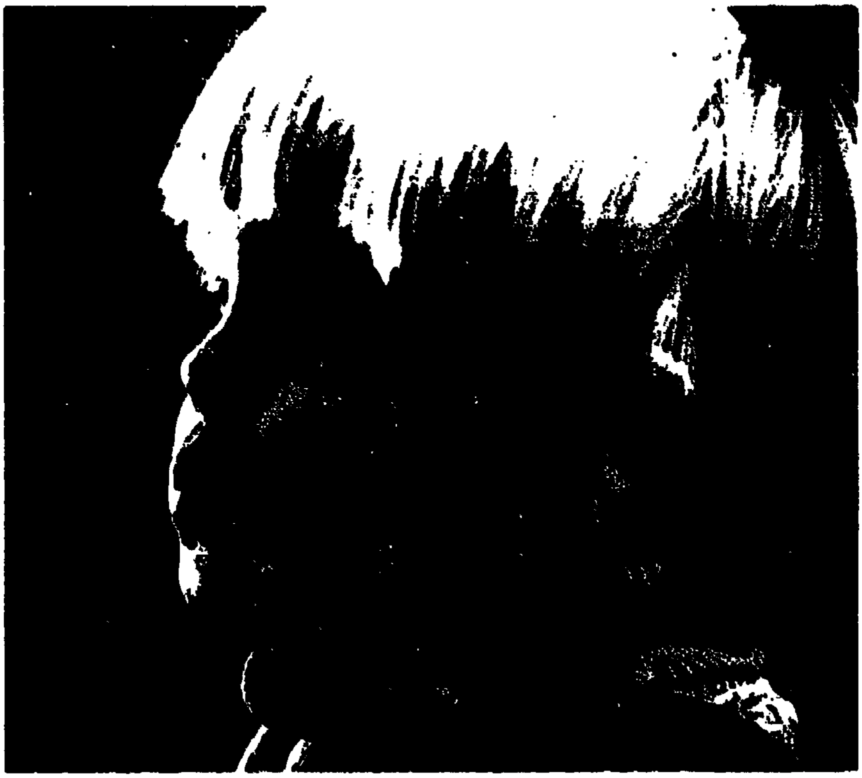
In bygone days, few children with Down's Syndrome grew up. The major causes of death were heart disease and infection. With advances in medical knowledge, the advent of antibiotics and improved care for heart defects, including surgery, the outlook has changed drastically. There is still an appreciable risk in the first year, especially for children with a heart defect, but after that time is past, you can probably expect that your child will grow up.

Can They Have Children?

There is no instance that we know of where a man with Down's Syndrome has fathered a child. Women with Down's Syndrome have conceived, though infrequently, and naturally they have an extremely high expectation (50-50) of giving birth to a child with Down's Syndrome. So it is important for the parents of a girl with Down's Syndrome to realize that she may be fertile.

What About Menstruation?

The onset of menstruation in a girl with Down's Syndrome will pose some dilemmas for the parents which may be hard to resolve. Certainly no general recommendations are applicable. A mildly retarded girl can learn perfectly well how to take care of herself during menstruation. A more severely retarded girl may find this a frightening and distressing occurrence. With the onset of menstruation also comes the possibility of pregnancy. The best moral training at home cannot insure that, away from home, a retarded girl may not be taken advantage of, or because of her limitations, may exercise poor judgment. Many parents ask for contraceptive advice for their daughters to guard against the uncommon, but possible, tragic pregnancy for a girl with Down's Syndrome. Some request sterilization for their daughter and some a hysterectomy particularly where the girl is more severely retarded and where menstruation is frightening. These are serious and carefully considered requests on the part of the parents which merit sympathetic consideration.



What Can We Do to Help Our Child?

You can help your child reach his or her potential by refusing to accept some of the old stereotypes attributed to the child with Down's Syndrome, such as "very passive," or "content to lie in his crib from feeding to feeding." By accepting these stereotypes as fact, some parents have deprived their children of the stimulation which all children need in order to progress adequately. The infant with Down's Syndrome needs more, not less, good stimulation from the people and objects surrounding him. He needs to be played with regularly, touched and exercised, to hear music and voices, to see bright colors and movement, and especially to experience warmth and love from his family. Specific suggestions for making your child's life more interesting can be found in later portions of this booklet.

DEALING WITH PROBLEMS

John E. Rynders, Educator

and

J. Margaret Horrobin, Pediatrician

There is no doubt that having a Down's Syndrome child is rough on a family. From the moment of his birth, parents face agonizing decisions attended by serious doubts as to their ability to make the necessary decisions. How have parents coped with the news that they have a Down's Syndrome newborn child?

We asked our 18 pairs of Project EDGE parents in Minnesota to give us their reactions to having been told that they had a Down's child. We sent each of them a confidential questionnaire. At the time, all 18 sets of parents had been rearing their Down's child at home from one and one-half to more than three years. The fact that they had been rearing them at home for some time presented us with a unique opportunity to obtain impressions about their initial reactions along with their feelings about having lived with a child for a long while who has Down's Syndrome. These "back-to-back" reports will be of special interest to parents who have a newborn Down's child and are asking themselves, "If I take him home now will I regret it when he's older? Will he wreck my personal life, make my other children's lives unbearable, drive a wedge between my husband and me?" Sixteen of the 18 sets of parents returned the questionnaire to us. Because of the importance of their replies to other parents of Down's children, as well as for their own genuine human value, we present all 16 of them as written.

Initial Reactions

Mother A

Couldn't believe it, felt guilty about even having him. Felt sorry for the baby. Knew I had to take him home because he belonged to me and a mother seems to have an instant love for her child.

We've said many times it's too bad you don't realize how simple your life was before!

Father A

Can't believe it, wonder why and what happened, and whether you're going to put him in a home or what.

Mother B

I felt very sorry for the baby. All I could think of was him being hassled by his peers for all of his life. I cried whenever I looked at him. After a few days I realized *I* was the one that was hurting and that this child would more than likely be happier than a lot of normal children.

Mother C

Realizing that Tim's growth after four months did not follow the pattern of our other children, the shock was not quite as devastating as that of unsuspecting parents. However, our fear and anxiety for Tim's future swept over us like a bad dream. Complicated questions flooded our minds:

1. Will it be possible for us to handle such a child?
2. Do they ever get violent?
3. Can they ever go out on their own?

Mother D

We were told the day our baby was born that she had a handicap. We were too shocked to even ask what the handicap was. By observing her we were able to guess the problem. At first we feared that our relatives and friends would never accept her; however, she was accepted with open arms. It certainly was difficult telling everyone.

The doctor indicated that in all likelihood she would have be put in a "home" by the age of six so therefore "don't get too attached to her." In fact, the implication was quite strong that placement was an immediate option and that we didn't have to take the child home from the hospital.

It was difficult to watch other families bubble with joy over their "normal" babies. We certainly felt isolated from the rest of the parents. It would have helped to have a parent of a Down's Syndrome child to talk to.

Mother E

The immediate reaction of course is one of being stunned or shocked because it is something you are unprepared for. Then we recall the confusion because we were not knowledgeable about Down's Syndrome; we were being pressured to "place" David before the realization and implications were even "digested." One of the most difficult areas was lack of support from the hospital staff, of being totally on our own in attempting to reach a decision that was being forced upon us; whether to take David home or to place him, all this before any realization of what had happened was allowed to be absorbed. The isolation was very hard to accept isolation imposed because the staff was unable to cope and simply avoided the subject of David's handicap we, as parents, had to be supportive of them rather than vice versa. Another frustration was the lack of information available to us so we could become somewhat enlightened on Down's Syndrome. If you want a few words of initial reaction we feel some would be: shock, confusion, avoidance, isolation, and frustration because of inaccessibility of reading material and knowledgeable or empathetic staff.

Mother F

I had not known what Down's Syndrome meant. We were confused and deeply hurt, mostly because of the doctor's reaction.

Mother G

Bryan was 5½ months old when we learned he was Down's Syndrome. It was approximately 3 weeks before Christmas, and being child-like about Christmas myself, the spirit of Christmas was in its heights in our home. The news hit like a bomb and shattered all of our Christmas spirit and plans. My husband and I didn't discuss it very much at that time, subconsciously he didn't believe it and our talking sessions always ended with nothing gained but crying and consoling. For a week I walked around in a daze crying and praying for a miracle that I didn't really expect. I tried hard not to question the whys of it all, but the bitter pill was still hard to swallow. The household chores were left undone and the daily routine of baby care that had once been so pleasant became a painful experience filled with pity. I tried to justify my feelings by keeping him spotless despite his constant spitting up. I was also concerned that someone might think I was neglecting him because of his condition. The turning point came in my life after about 2 weeks. While sitting and thinking, "Christmas is almost here," I realized that life for us must continue, and as normal as possible. Why be concerned about what people might say or think when I never had before? I had always loved him, and realized I would continue to love him. The only difference now was that I knew he was Down's Syndrome, but he was still the same Bryan. From that point I no longer prayed that the mountain be removed, but that God would give us strength to climb it.

Mother H

My very first reaction on hearing of Tom being Down's Syndrome was disbelief in fact, it took over 6 months to believe the doctors or that the chromosome test was correct.

Mother I

"Saddened"
"Scared Stiff"
Fear of unknown
Feeling more sorry for ourselves

Mother J

Some way the doctor got me to say, "You mean the baby is a mongoloid?" "It's a possibility," was his answer. During the four months it took to get positive diagnosis, our feelings fluctuated from disbelief to possibility, but never to certainty. Our immediate concern was what effect this would have on the two children we already had after all they had been with us for eleven years and nine years, respectively. Fortunately the doctor did not suggest we give the baby up. He said, "After all a baby is a baby." So we took the baby home and all learned to love him before we knew positively that he was Down's Syndrome.

Having a Down's child is an awesome responsibility. Here is a child that may be dependent on you for the rest of your life so our second concern was what educational things were being done with Down's children to help them become useful adults. We went looking for a program that would help our baby and us. There are many things being tried but information was difficult to find. We were able to find a program that suited our needs.

Mother K

Shock. This followed by deep concern for one another . . . husband for wife and wife for husband. Also, a desire to talk to someone who would understand what we were experiencing. It could not be just anyone. A parent of a five-year old Down's boy visited us at the hospital and proved to be our emotional salvation.

Mother L

Shocked. Why us why our baby frightened. Who can help us what do we do with our baby. What had we done to cause this was it our fault who can help? Institution foster home our home? Concern about hereditary aspects as my older brother is also Down's.

Mother M

I can only say they were the blackest days of my life. I kept looking at our tiny little boy that we waited so long for and I wanted it all to go away. One afternoon I was rocking him to sleep and he looked so peaceful I wished I had something to put him to sleep so no one could hurt him ever (at that point I was certain I was crazy). I felt we had no direction, no one to turn to. Of course the thing that helps the most is time and there are many wonderful people only too willing to help you and your child.

Mother N

Our reaction was shock and disbelief a wish not to believe the doctor's diagnosis. Although our group of pediatricians described the syndrome and the many characteristics we were still dazed and had an enormous number of doubts and questions.

A secondary reaction initially that I recall was that the term "mongoloid" seemed to set up an estrangement between the baby and me: as though he, a mongoloid could not truly be ours (a strange reaction for me, since I was already a mother of an adopted child with whom I'd never felt strange or foreign. He'd always belonged) I hasten to add that this feeling of not belonging did not occur when I was *with* the baby, but only in those first days we were discussing him and his condition as "mongoloid" as apart from the baby as a *person*. Perhaps the term "mongoloid" helped to create this feeling. A "merely" handicapped or retarded or Down's Syndrome child didn't hold (for me) the same strangeness or separation as did the word mongoloid.

Mother O

I had certain convictions about severely retarded people a long time before I had a retarded baby myself. It is hard for me to see the value of human life for someone who can never comprehend it. I have always thought that many of the inmates of institutions would be better off if not suffering.

After the birth of my Down's Syndrome child, I felt angry at society for forcing me to rear the child. I could not put her into an institution because I knew if she lived, she could develop her potential better at home. In this horrible first year I kept asking myself over and over: now that I am emotionally involved with the baby, do I still maintain the same convictions? And the answer is still yes I think as a society, we should reexamine some of our moral ethics regarding mental retardation.

Mother P

My first reaction was complete hopelessness. As an R.N., I had toured institutions and really believed that this was Alex's future. However, I couldn't reconcile this normal-looking and acting baby with that future being that seemed more animal than human. I pictured myself changing diapers when he was 6 or 7, having to feed and dress him for a long time, being embarrassed by his looks and behavior in public (or never getting out of the house at all).

Subsequent Feelings

Mother A

I'm very surprised at how well he is doing. Still wonder what the future holds knowing that the easiest time must be now. I didn't know anybody retarded or Down's so had no idea what to expect. But *he is* a person and has his own likes and dislikes and a mind of his own!

Father A

Didn't realize there was so much Down's Syndrome. Or that I'd get so attached to the child.

Mother B

I think the fact that we had worked with retarded adults before he was born helped us accept him better.

Mother C

We now believe that some Down's Syndrome children can live a happy, productive life with proper love, education and training. However, there are many factors that complicate and dampen this desire:

1. The degree of retardation
2. Hostility in the family.
3. Lack of neighborhood acceptance.
4. Emotional maturity of parents.
5. Ability to handle extra financial burden.

In most cases "Where there is a will, there is usually a way." With the help of *God* you seem to find the extra help you need to endure such a situation.

Mother D

We have discovered that not all Down's Syndrome children are the same. Like any other child they have a wide range of abilities and personalities. Down's Syndrome children cannot be stereotyped.

Mother E

David is now 4 years old and about one year ago, the necessity of keeping him in perspective of the total family became a realization to me. As a mother, I can't stress this enough for the total well being of the family. I can see where it would be very easy to over-indulge yourself in this child, but guard against it for his welfare, and that of the rest of the family. We probably weren't aware of this sufficiently for the first 3 years and with our participation in the Project. David consumed hours and hours of my time this occurred during the precious and formative pre-school years of our other 2 children. Now when observing disturbing behavior in our children the question naturally arises: How much of an influence was David's handicap and subsequent Project participation a factor in the development of the other children? On the positive side, David adds *zest* to our lives he has a winning smile that can bring sunshine to any day. He has an abundance of charm and an unlimited ability to keep our household in a spin but we can't imagine life without him anymore.

Mother F

We feel she is an especially sweet and lovable child and very eager to do things.

Mother G

Now that Bryan is older other physical problems have developed making him multiply handicapped. However, our increased knowledge of Down's Syndrome has enabled us to better cope with the situation, and as a result has helped erase some of the stereotypes others have had concerning Down's Syndrome.

Of course, we still regret the fact our son is not normal, but our increased love for him makes us even more determined to give him as fulfilling a life as possible.

Mother H

It is still always on your mind about what is going to happen when the child is older will he be able to care for himself as an adult? Will he be able to communicate? etc...

Mother I

Future problems!
Comparing DS child to other children!
Loving her more and more.
Giving her same opportunities as normal children.
Seeing possible response and developing as an individual!
Very pleased!

Mother J

A more lovable, pleasant child would be difficult to find. At age two he responds well to us and everything around him. We must keep reminding ourselves that he is retarded and will never be a "normal" child. He feeds himself and is in the process of being potty trained. He does not walk yet but gets everywhere he wants to go by "swimming." At this age he is like taking care of a live doll.

Mother K

The sound of "mongoloid" conjured up in our minds the picture of something grotesque since our knowledge of the condition was one of hearsay only. We had to rid ourselves of this myth-picture, and it was not hard to when handling our lovely little baby. We now know that our child is slow in all of his growth, but we also know that he is indeed a child who has a charm all of his own and who had made a definite spot in our family for himself. So, we no longer fear the Syndrome, or look upon it as the worst affliction as so many might like to have us do. The picture of our child's manhood is probably the hardest for us to accept, for we have seen many Down's adults who are fat and sluggish and quite without any sparkle. We do not dwell on this, though, for we realize that the adults we see are the product of little schooling and social contact. Our hopes are much higher for the future of our child for we have confidence in society's new, refreshing attitude toward retardation. For now, we enjoy our son, day by day. We will always regret that he will be unable to enjoy the fullness of life, but realistically we are dealing with things as they are, making the best of all that our child does have going for him.

Mother L

Biggest help is a knowledge of what Down's is. Very glad we have raised Wayne at home. Our greatest concern for him is what can we expect from our education system and how will he fit into the world. Don't think of him as Down's so much as just a child with a handicap We feel there are many types of physical and mental handicaps worse than Down's. Feel fortunate that Down's can be diagnosed at an early age.

Mother M

Now that Bobby is 2½ years old, the two words that come to mind when I think of him are "hope" and "love."

He has taught me both. I know that he will never be normal, but we will do our best to make him reach his fullest potential.

It is his right as a human being. He has taught us the real meaning of life.

Mother N

It's difficult to believe now, 3 years later, that we grieved when

Ardy was born. I feel ashamed of the fact. I'm sorry that we didn't celebrate in those first few days after his birth and even after receiving the diagnosis. It seems that we were cheated or robbed of the normal joy that should have accompanied those days. I'm well aware that Down's Syndrome people are handicapped or limited and that in itself is no occasion for celebration. But the fact that we had given birth to a new life an enjoyable, loving human being whatever his IQ or potential *is* occasion for great happiness. If we had known *then* what an enjoyable person he is as well as how much ability he has developed, we feel the news of Down's Syndrome would not have been grim.

Mother O

Actually I have to admit the situation is not as bad as I anticipated, if one could just live for the present and not grieve for the future. Every little accomplishment gains in importance with a retarded child, mainly because one is never sure if he or she will be able to do certain skills. We are very fortunate to have an active, inquisitive, affectionate little girl. We have renamed her Miss Sunshine, because she radiates happiness. I think our family is much closer knit because of her.

Mother P

After having met many other parents of retarded children through MARC, I feel almost lucky. Alex's development, though slow, is almost normal. I do not have to deal with seizures, hyperactivity, etc.

As these statements show, most parents experienced shock and grief upon receiving the news that their child had Down's Syndrome. Fortunately, their feelings after living with a Down's child at home for some time are, in general, quite positive. As one views these reports, it is well to keep in mind that these parents have been participating in Project E D G E , a project in which they and their children receive considerable educational stimulation and support that may make them feel more positive than parents would feel who have not had this form of support. Our impression, though, is that the project by itself has not made that much difference in their attitudes. Rather, we think that these parents, as well as those living in Illinois, have unusual courage and tenacity. Somehow, they have dipped into their own spiritual, emotional and physical resources — resources they possess as individuals and as couples — and have made a victory out of a situation that has defeated many parents in the past. They made the decision to raise their Down's child at home during his early years and appear to have done very well, but not all parents with a newborn Down's child can or should make the same decision. As we said earlier, parents should seek an alternative to keeping their Down's child at home if they cannot accept him or if he presents severe physical or medical problems that the family cannot cope with.

At this point, it would seem useful to present a brief overview of how persons other than parents in Project EDGE react to the news that a newborn child has Down's Syndrome.

Physicians, grandparents, friends, and clergy sometimes increase parents' anxiety by offering naive or ill-chosen advice. In a recent publication[1] 100 parents reported their reactions to being told by physicians that their child was Down's Syndrome. Of the 100 parents of Down's Syndrome infants interviewed, 64 complained that they had been told either too harshly, or with little or no explanation. On the other hand, some were pleased with the manner in which they had been told the news by physicians. Eleven parents felt that although the doctor had been blunt, perhaps even harsh, they had wanted the truth and had gotten it; two of these were glad that they had not "shopped around" for a lot of opinions. Five satisfied parents felt that the doctor had been neither kind nor harsh; he had simply explained what Down's Syndrome was.

Frequently both parents lack basic information about the condition, even about its cause. For example, in the same study the majority of parents reported that they thought that the baby had Down's Syndrome because he had been injured by something that had happened to the mother before or during her pregnancy, such as illness (measles or a severe cold), a bad shock (one mother had witnessed a suicide), nervous strain, hard work, a rundown condition, menopause. Seven parents said they believed it was caused by something the doctor or hospital attendant had done (a forceps baby, or treatment for jaundice). Six felt it was caused by "bad seed" on the mother's side; two, by "bad seed" on the father's side; and three by the father's ill health (war fatigue, goiter). These "causes" are, of course, mistaken impressions.

Clergymen frequently become involved in parents' early reactions especially as they help (or hinder) the adjustment process. In the same study, 12 parents said or implied that their Down's child must have been sent by God either as a punishment or as a test of their faith. Clergymen at times like these must help parents wrestle with the problems convincing them that God does not cause a Down's Syndrome birth in order to punish the parents for bad behavior. If this were a sign of God's vengeance why would some of the most kind and faith-filled women bear a Down's child? The birth of a Down's Syndrome child can, however, strain one's faith almost to the breaking point. In a recent edition of the *Atlantic Monthly*, a father of a newborn Down's child wrote "... I prayed for my child's death, cursing and damning myself as I did (p. 61)."[2]

At approximately the same time as the article in the *Atlantic Monthly* was written, parents of a Down's infant admitted to Johns Hopkins Hospital refused permission for routine intestinal surgery, allowing their child to expire. When asked by a surgeon for permission to operate, the parents reportedly replied: "Why burden society with a Mongolian child? Why not let God's will be done? [p. 1-A]."[3]

We have not cited the cases in this section to condemn the motives of those involved. We are trying to illustrate that some parents have extremely low developmental expectations for Down's children. Are these low expectations warranted? From what you have read already — which was written by parents in the Project you would probably say, "No, the low expectations are *not* warranted. These parents and their Down's children are doing pretty well together." In the remaining portion of this section we will attempt to show that many commonly accepted assumptions about Down's Syndrome, from which spring the low expectations, are partially or in some cases entirely false, and that the integration of the Down's child into his family can be achieved effectively in many instances.

Commonly Accepted Assumptions About the Development of Down's Children

Assumptions about Down's Syndrome have developed over a long period of time. Down's Syndrome was described mistakenly as a form of cretinism, or lack of thyroid hormone, by Seguin in 1843. In 1866, in an attempt to find a relationship between race and mental retardation, J. Langdon Down classified a large group of mentally retarded individuals according to their supposed resemblance to Mongolian people. This is how the syndrome received its name. Currently everyone agrees that the term "mongolian idiot" is unfortunate and obsolete for the reason that most Down's Syndrome children do not fall into the "idiot" category, showing wide differences in ability, and are found in every race. This leads us into the first of the assumptions.

"Down's Syndrome children are extremely similar in appearance."

It has been widely believed that Down's Syndrome children are extremely similar in appearance, resembling one another possibly more than they resemble their own normal brothers and sisters. Evidence proves otherwise, however, showing that even the diagnosis of the newborn may present a problem.[4] Furthermore, older Down's children do not show consistency in the diagnostic signs of the syndrome,[5] but reveal a large variety of signs.

In an interesting study,[6] characteristics of fifty Down's Children were compared against a list of 55 characteristics most commonly ascribed to the condition such as almond shaping of the eyes, speckling of the iris of the eyes, flat nasal bridge, large furrowed tongue, hypotonic (floppy) muscles, high-arched palate, etc. Results of the study showed that there is wide variability in every single physical characteristic of Down's Syndrome as well as in the sum total of characteristics in each individual child. The authors conclude that they agree generally with the opinion that a great deal of similarity in appearance exists among Down's children; however, they are convinced that Down's children differ from one another at least to the same degree that normal children do and in many respects to a far greater extent.

"There is a direct relationship between the physical appearance and the IQ of Down's Syndrome children."

Simply counting the number of physical features that are supposed to be diagnostic and then trying to predict a child's IQ score has not been useful. Factors other than the sheer number of physical signs appear to be far more important in determining the child's ultimate development. One of these more important factors seems to be the stimulation quality of the child's family

"Down's Syndrome children are uniformly slow in their accomplishments."

In the study of 50 Down's Syndrome individuals previously mentioned, the authors found great variability with respect to the age at which various developmental "milestones" were passed. For example, some Down's children did not raise their heads until the age of two and one-half years while others did so at two months of age. While some did not walk until they were three, four, and even four and one-half years, others began to walk at the age of one. Tooth eruption also showed great variability; some had their first tooth as early as five to six months of age, while some were delayed in the eruption of a tooth until two years of age. Language development showed the greatest variability: Words were spoken as early as one year of age and as late as six years of age.

"All Down's Syndrome children have very low IQ's."

Of all the commonly accepted assumptions about Down's Syndrome, this one is probably the most in error. While it is certainly true that almost all Down's individuals have IQ scores which fall into the retarded range, the range *within* the group is very great. And, as we said earlier, most Down's children have IQ scores in the moderate range, not in the severe or profound range of functioning.

Research Related to Prevention and Treatment of Down's Syndrome

Since 1886, when J. Langdon Down described a set of characteristics which were later to be called Down's Syndrome, researchers have sought to prevent, treat and cure Down's Syndrome. Recently, a special conference sponsored by the National Association for Retarded Citizens and the National Institute for Child Health and Human Development brought the research findings up to date. Some of the content for this section comes from that special conference.

Research Into the Cause of Down's Syndrome[9]

Many factors have been proposed as causes for Down's Syndrome. One of the first was a theory which sought to link Down's Syndrome to another racial group (Mongolian) or to a more primitive racial type. There are no data to support this theory.

Maternal age has been linked to Down's Syndrome and, of course, it is well established that the incidence of Down's Syndrome increases as mothers grow older. Unproven theories advanced for this have been: exhaustion by many pregnancies, hypo- and hyper-thyroidism in the mother, maternal emotional factors, and inadequate transfer of Vitamin A from mother to the developing fetus.

Other researchers have tried without success to link Down's Syndrome to familial factors such as alcoholism, syphilis, TB, or a background of mental illness.

Still other researchers have attempted to link Down's Syndrome to some characteristic of the developing fetus such as an immature or over-aged ovum, arrested fetal development, hypo- or hyper-thyroidism, or adrenal or pituitary deficiency.

And, some have tried to link it to genetic change. One genetic change, namely a chromosomal abnormality is, of course, present in Down's Syndrome, but, researchers have not yet determined why the chromosomal abnormality occurs in the first place.

At the present time, medical techniques for preventing or curing the chromosome abnormality have not been successful but research goes on at an ever increasing pace in hope of a breakthrough.

Amniocentesis.[10]

Currently it is possible to look at the cells of a developing fetus during the fourth or fifth month by taking a sample of amniotic fluid from the mother's womb. The developing fetus sheds cells into the amniotic fluid which can be drawn out and analyzed at virtually no risk to the fetus. Once the cells have been withdrawn and cultured, they can be examined and the chromosome abnormality, if present, can be positively identified.

Chemical treatment of Down's Syndrome.

Over the years a number of chemicals, vitamins, enzymes, minerals and other agents have been given to Down's Syndrome children as treatment. One of the most popular in recent years has been a chemical known as 5-hydroxytryptophan (5-HTP), which is converted to 5-hydroxytryptamine (known also as serotonin) in the body. In the Down's Syndrome child, the level of serotonin is usually very low. This low level often results in poor muscle tone. Therefore, some researchers have speculated that if the chemical were replaced in the child's body his muscle tone and possibly his other developmental signs might improve.

A few years ago, a researcher published an article in which she showed that the administration of 5-HTP could improve muscle tone in Down's Syndrome children.[11] However, in later studies she found that Down's children who received 5-HTP actually had poorer muscle tone at the time of measurement than children who had not received the chemical at all. She and other researchers concluded that 5-HTP is not effective in improving muscle tone or IQ score. Furthermore, there were harmful side effects found in some Down's Syndrome children who received fairly high dosages of the chemical. Fortunately, she found that these side effects could be minimized or eliminated by reducing the amount of 5-HTP.

Educational Research with Down's Syndrome Individuals

In beginning to examine the educational research one might ask, "Does a better educational environment produce better achievement in the Down's Syndrome child?" Relative to this question, it is now well-documented that children with Down's Syndrome who have been placed in inadequate institutions generally do more poorly on all measures of development than Down's children reared at home with their own families.[12] Therefore, parents should examine a residential setting or foster home with great care if they decide that they must place their Down's child outside their own home.

Another way of looking at the question of whether or not Down's Syndrome children profit from good educational stimulation at home is to look at two case histories. The first is that of Nigel Hunt, a Down's Syndrome individual raised in Great Britain. Nigel's parents spent a great deal of time stimulating his language development and providing him with educational experiences. His mother spent many hours teaching him to read by employing phonic instruction and his father, an educator, took him on numerous trips. Nigel became a very good reader and in fact, typed the manuscript for his own book, an autobiography. A second Down's individual, Paul Scott, also received a great deal of educational stimulation at home and also became a good reader and typist. Thus, at least based on these two cases, educational stimulation appears to be very helpful to Down's Syndrome children.

Turning now to educational research with Down's individuals, one author[13] compared the development of institutionalized Down's Syndrome children with home-reared Down's Syndrome children at five, six, and eight years of age. Five-year results of the study showed the home-reared children to have better mental and social developmental quotients than the institution-reared group. Between the five and six-year tests, an intensive language stimulation program was provided for the institutionalized group. Results of the six-year comparison showed definite increases in the scores among the institutionalized children. At that time the home-reared group was still significantly superior on the social scale, but not on the mental and motor measures. At the eight-year comparison, the mental and motor scores were essentially identical for the two groups. The social scores, however, continued to favor the home-reared group.

Language stimulation has been of concern to several investigators. One study[14] described an early training program for Down's children, with emphasis on language stimulation and on learning through the senses. Children were also involved in a muscular development program. After approximately three years of educational stimulation, a group receiving the stimulation was significantly advanced on almost all of the measures. The author concluded that early education benefits Down's Syndrome children not only in the development of language skills, but in muscular development as well.

In the state of Washington, several investigators are studying the effects of behavior modification techniques on the development of language in young Down's Syndrome children.[15] This program accepts Down's children in early infancy and provides a wide variety of learning experiences for them until they're through kindergarten. Results so far are quite encouraging.

Having talked about IQ scores, we should define what IQ is and, beyond that, what the term, "mental retardation," means since the IQ score is part of that definition.

What is an IQ Score?

The terms "intelligence" and "IQ score" are often used as if they have the same meaning. Not at all. The IQ score is obtained from an IQ test. (A common one for children is the Wechsler Intelligence Scale for Children [WISC].) The IQ test is a series of tasks such as object naming, puzzle assembling, information giving, and number repeating from which a score is obtained. Scores from these tasks are totaled and converted to an IQ score by referring to a set of tables in a test manual. It is common practice, once the IQ score is obtained, to call that test result "intelligence." This procedure is not entirely correct though because intelligence is really the individual's sum total of abilities to live happily and productively with himself and others. No one-hour test can possibly measure even a fraction of a person's intelligence since most tasks in the test are not sampled from real life situations, and the amount of behavior sampled is so minute. Should we ignore IQ tests then? No. They are useful, *if not abused,* for predicting in a general way how well a child will advance in school tasks. They will be of limited use, however, in predicting his school adjustment, his feelings of self-worth, vocational potential, and his desire to achieve qualities that will be far more important to him as an adult than his IQ score.

Let us now see how IQ fits into the term, "mental retardation."

What is Mental Retardation?

The most widely accepted definition comes from the American Association on Mental Deficiency which describes mental retardation as significantly "subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior, and manifested during the developmental period [p. 7]."[16] Explicit in this definition is the requirement that no person should be labeled "mentally retarded" on the basis of an IQ score alone. To be called mentally retarded a person must have *both* an IQ score in the range of mental retardation (generally an IQ score of less than 70) and also be significantly impaired in adaptive behavior (impaired in maturation, and/or learning and/or social adjustment). In less technical terms, the mentally retarded person is one who experiences unusual difficulty in learning and, particularly, in adequately applying whatever he has learned to the problems of everyday living.

How Many Retarded Persons Are There in The United States?

It is estimated that there are about six million mentally retarded persons in the United States (3% of the population). By 1980, natural population growth is expected to increase the total number of retarded persons to about seven million.

Of the six million retarded individuals, most have IQ scores in the mild range of retardation (IQ score 55-69), many have IQ scores in the moderate range of retardation (IQ score 40-54), and a few have IQ scores in the severe (IQ score 25-39) and profound (IQ score under 25) ranges of retardation. As we said earlier, most Down's children have IQ scores in the moderate range (IQ score 40-54) of retardation.

About 7,000 Down's Syndrome children are born in the United States each year. Of all the types of congenital mental retardation, it is among the most common.

The Down's Child in His Family

New parents of a Down's child have at least two questions to wrestle with: (a) shall we take our child home or should we seek immediate institutional or foster home placement for him, and (b) if we take him home how will he affect our husband-wife relationship and our relationship with our other children?

Couples in Project EDGE decided to keep their Down's children at home during their children's early years. As we said earlier, not all parents of Down's children can make the same decision.

It's only fair to point out that our bias favors keeping the Down's child in his own family during the early years unless he presents severe management or medical problems or cannot be accepted by his parents. This bias is shared by the World Health Organization.

In 1954, the World Health Organization (WHO), published a monograph, *The Mentally Subnormal Child*, in which some forward-looking principles were outlined.[17] Regarding the decision which must follow immediately after the diagnosis of Down's Syndrome is made, WHO members said:

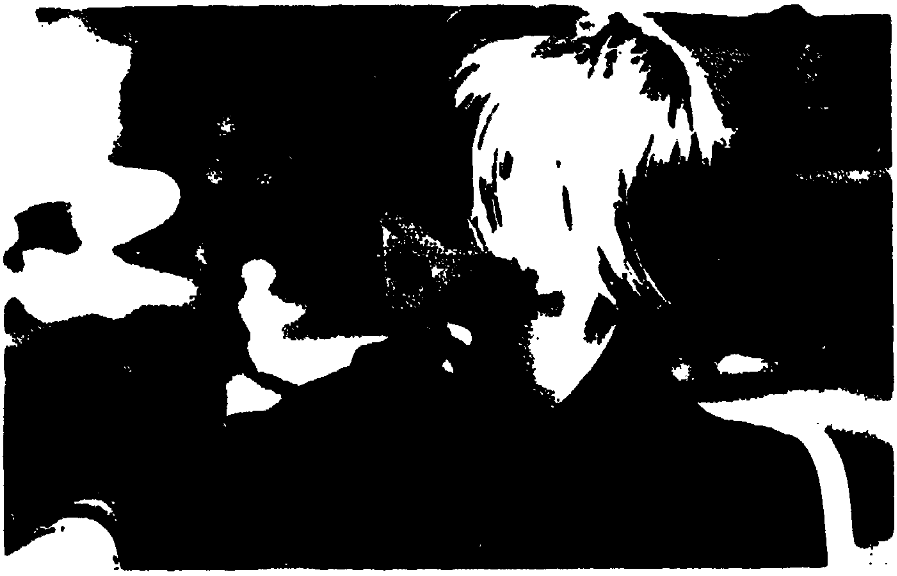
> The committee was of the opinion that, in coming to the decision to recommend institutional placement, three aspects should be considered: the actual condition of the child; the mental health of the family, the competence of the mother, and the possible effect on the family of retaining a subnormal child in its midst; and the living conditions and financial circumstances of the family.
>
> The committee does not look with favour on the growing practice of very early institutionalization. In many instances the parents are advised not to take the child home from the maternity hospital, a decision which constitutes a real hazard to the mental health of the family unit. It must be remembered that parents make a heavy emotional investment in all pregnancies and when an abnormality occurs they invariably experience feelings of guilt. The immediate admission of the infant to an institution not only fails to relieve the stress but may even intensify it. The placement is likely to be interpreted by the troubled parents as a confirmation of their own feelings of guilt and an irrevocable rejection of the child. No institution can provide an adequate substitute for the essential emotional interaction between parents and child, and this opportunity for interplay is of paramount importance in the case of the handicapped child whose parents can only slowly evolve a realistic and constructive attitude towards the situation. As a matter of fact, there are many instances of defective children being accepted by and thriving with their families. It can be denied categorically that all such infants should be institutionalized at once. In each instance the decision concerning the proper time for such placement must be made on the basis of the psychological needs of each individual family constellation [p. 56-57].

The adjustment (or maladjustment) of brothers and sisters begins in the early reaction of their parents. If parents are not filled with hostility, fear, guilt and ignorance, the Down's infant's chances of being accepted by brothers and sisters are good. Once the initial adjustment hurdle is overcome successfully, however, brothers and sisters will be faced with additional problems, some of which are external to the home. As one author[18] points out, brothers and sisters cannot escape the unkind words of thoughtless peers or expressions of pity which make them feel awkward, nor can they easily handle their sense of disappointment when friends boast of the achievements of normal brothers and sisters, or their feelings or embarrassment at large family affairs where they feel stigmatized by association with their retarded brother or sister.

Margaret Adams[19] presents some information about the adjustment of brothers and sisters that we think may be especially useful.

Her first point is that mental retardation has to be viewed as a "total family handicap" because of its adverse social consequences. If the pressures of caring for a handicapped child overwhelm the normal needs of other children in the family, there is real danger that their development will become blighted by emotional neglect, distorted family roles and relationships, and curtailed opportunity for social contact. As a result, they may grow up disabled in their capacity for self-fulfillment.

Second, fostering the development of the normal children in the family is valuable in neutralizing the feelings of disappointment that parents experience through having a Down's Syndrome offspring. Normal, healthy children contribute to the parents' feeling of well-being and thus also help create an emotionally stable family environment for the retarded child. In a nutshell, if the whole family feels and acts positively, both the Down's child and his family will benefit. Conversely, of course, if the whole family feels and acts negatively, they and the Down's child will all be greatly diminished in their total development.



Third, there is evidence that having a retarded brother or sister is an experience that most normal children can adjust to without too much stress, although they do encounter difficulties that require special understanding. In this regard, Adams reports that pre-adolescent and teenage children generally show a fairly high degree of constructive acceptance toward their retarded brother or sister.

Adams goes on in her article to analyze the problems brothers and sisters of a retarded child face at various ages. We think the analyses are interesting and helpful and offer them to you for your consideration.

Preschool

In the preschool period, disturbances of the parent-child relationship, and resulting mishandling, are the major hazards that the normal brother or sister faces. Because of pressures on them to meet the needs of the retarded child, parents may unintentionally neglect the normal child. The normal child may react to this treatment by reducing his own demands on the parents who may accept this helpful behavior with relief, failing to understand the psychological consequences to the normal child when he suppresses his own needs. On the other hand, the normal child may protest the parents' seeming over-indulgence of the retarded child. This results in parents feeling overwhelmed by too many problems so that they perceive the normal child's behavior as a deliberate aggravation rather than a normal reaction for a preschool child.

Early School

During the early school period, the normal five-year-old is faced with the usual difficulties of school adjustment and separation from home. At this transitional stage, the presence of a handicapped brother or sister may adversely affect the normal child's self-image, making him wonder about the cause of the damage, why he has escaped, whether he will remain immune, and why the handicap has not occurred in other families. At a deeper psychological level, there is the possibility that the normal child will experience guilt feelings at being whole and anxiety that his "bad thoughts" about his brother might have caused the handicap. Parents need to draw these feelings out and deal with them in a gentle, factual manner.

Elementary

During the elementary years, the normal child must balance an increasing social life outside the family with his responsibilities to the family. A recurring problem is that of how much the normal child is expected to share in the responsibility for care of the Down's child who often presents some hindrance to the normal child, mishandling personal possessions, interrupting homework sessions, and disrupting social sessions with the normal child's friends. Parents will need to lead the way in establishing reasonably equitable routine household task assignments for *all* children in the family.

Adolescence

The adolescent period presents special problems for a normal child. Though there may be no known hereditary factor causing the retardation associated with Down's Syndrome in a given family, the fact that a handicapped child has been born to his parents inevitably casts some doubt on the teenager's feelings about his own capacity for healthy parenthood. It is particularly important, therefore, that teenagers receive accurate and complete information about the causes of mental retardation. The frequent complaint by teenagers that a retarded child at home makes it difficult for them when they're dating would be alleviated if they had a factual explanation to give to their dates. Also, this would help to dispel the unfortunate aura of mystery that persists about retardation

We shall close this section by giving examples of how parents in Project EDGE feel their child has affected their husband-wife relationship, the lives of their other children, and neighbors

We asked the 18 sets of Minnesota parents in Project EDGE to respond to three questions: (1) What effect has your Down's child had on your husband-wife relationship? (2) What effect has he had on your other children? (3) What effect has he had on your neighborhood? At the time of their responses, which were anonymous, their Down's children were between the ages of 18 months and 4 years. Sixteen of the 18 sets of parents responded. We have selected a few of their responses for illustrative purposes.

Effect of a Down's Child on the Husband-Wife Relationship

Most of the parents reported that, in general, their Down's child had a positive effect on their husband-wife relationship though there were some difficulties for most to overcome:

> "We feel that our Down's child has strengthened our relationship with each other and our children, although it has dampened our desire to have more children. We find it necessary to pick our baby sitters with care as a 29-month-old Down's child can be extremely inquisitive, temperamental and exhausting."

> "In the beginning we clung together and then we drifted apart. Always Dick was stronger than myself. Now we probably are closer than we ever were in our 12 years of marriage. I have a respect for Dick I never thought possible. I had to learn how to drive, which means a change in our life-style. Change can be for the good too."

The Down's child does produce some strain on the husband-wife relationship:

> "It has undoubtedly added some stress. We would not be honest if we didn't say so. Our son requires more supervision and more training than a normal child does. The mother, upon whom so much of the child-training falls, must be careful not to become exclusively wrapped up in the child and put husband aside. The husband must be understanding of the time that is absolutely needed to carry out the day's doings with the child, too. With understanding, it can be worked out. Our dream of our future was momentarily shattered by our child's birth, for we had grandiose plans about world travel. We thought that all dreams of our golden years were ended. Now we view it entirely differently. We feel it is unfair to our child and to ourselves to make us all totally interdependent upon one another. For our child's sake, we will allow him to be as independent as possible . . . a sheltered workshop and a group home facility if possible. We have seen too many white-haired and sad-faced parents accompanied by equally sad-faced retarded adults to think that it is a necessary part of the Syn-

> drome. However, in fairness to those people just described, they had recourse to so little in the way of training and guidance that they had no choice but to be burdened. Our activities have been super-saturated in the field of retardation since our child's birth, and we are finding out that it is not good to give up interests that one enjoys to dwell exclusively on one thing. We do not regret the time spent learning and giving and doing, but we do regret our neglect of some of our friends for whom we have had neither time nor energy."

A mother whose Down's son has chronic and severe arthritis reports:

> "Our marital relationship had always been good. However, we just took each other for granted. Things seemed to work out without our really trying. Like all people we thought we had problems, but looking back we realize the things we considered problems were not problems at all. Our Down's son being stricken with Rheumatoid Arthritis, and giving us many sleepless nights, found us leaning more and more on each other. As a result, we became more considerate and much more appreciative of each other. Our communication developed intensely. There was so much to talk about, so many plans and decisions to be made, and yet so many problems to face. But our son, this long awaited child, which we so deeply love has given us a bond of strength that we think will help us tackle and conquer whatever may befall us."

Effect of a Down's Child on Brothers and Sisters

As was the case with the husband-wife relationship, almost all parents felt that their Down's child had had a positive effect on their other children, though in some cases there were problems:

> "None of our children's friendship patterns have been affected to our knowledge. Young people are open about almost all abnormalities, and so when friends come to our home, they delight in playing with our Down's child. They openly ask questions about his condition and then proceed as though nothing were wrong. It's wonderful. Our children love their Down's Syndrome brother very much, and in order to keep it this way we try not to overburden them with his care. Sometimes we purposely hire a babysitter to free the others if we are going to be away for an evening, even though our children are old enough to baby sit. The children do find their brother a nuisance on occasion, for which we don't blame them. He is a terror sometimes, and gets into their prized possessions. We find that we must be careful to give equal attention to all of the children in our family and not let the needs of one take precedence always. (A computer would be helpful sometimes in figuring this out . . . it is harrowing to figure out where you should be if several people in the family need you at the same time.) We have tried to instill in the children the idea that whatever we invest in their Down's Syndrome brother now will reap benefits when they're all grown . . . he will not be considered a burden but a brother to love when he is grown. We do not ever want our

> other children to think that they must be responsible for their retarded brother when he is grown and we are no more."

Older children may perhaps have an easier time adjusting to a Down's infant than brothers or sisters close in age to the new Down's child:

> "Both of our children are teenagers. They have had a wonderful attitude toward the baby. I think the fact that their little sister is retarded and may need their help for a long time has had positive effects on the kids. They are more sensitive toward suffering and toward handicaps. So far I could only cite positive attitude."

Parents must exercise care to see that their normal children get their fair share of attention:

> "The only effect I can see in our eight-year old daughter caused by our Down's son, is that she demands more attention. She was an only child for five years, and with her brother receiving a much larger percentage of attention, this is understandable. She seems to love her brother dearly. She does not care to have him live in any home other than our own. She does not seem embarrassed by his physical features or limitations, but find joy in any small accomplishment or hearty laugh. She does not hesitate in telling friends her brother is retarded, and eagerly shows his pictures at home and school. Her friends seem to accept Bryan as she does. We do, however, try very hard to keep her brother's retardation and physical condition from hindering her mental growth and exposure."

Acceptance from the extended family is especially welcome:

> "He is accepted by every member of our family including grandparents, aunts, uncles and cousins a much easier acceptance than I would have believed possible. . . ."

Acceptance in Neighborhood

As with the other two areas of acceptance, most Minnesota parents of Down's children in Project EDGE report that neighbors generally are quite supportive:

> "Our neighbors have been interested and supportive from the beginning. They have showed a continuing interest in Andy and his progress. They inquire about him often and are sometimes surprised by what he can do how normally he behaves, lives and plays but they're always pleased. Other children in the neighborhood especially his brother's friends (ages 6-8) play with him often. Three children closer to his own age (3-4) come occasionally too. At this stage at least they don't seem to see Andy as different from any other child. His speech is slow but they don't seem to have much trouble in understanding what he says in words or gestures. He knows how to play and they enjoy each other."

Neighborhood children can be very important to the Down's child's adjustment:

> "If he's outside, he's welcomed into the group of kids like anyone else and ostracized if he does something they don't like, like anyone else. I do feel

this could be a problem in the futur though. The adult neighbors seemed curious and some even a little a id of him at first. One neighbor took the opportunity to come over wh nother neighbor was babysitting. She seemed amazed that he wasn some sort of monster and now is accepting and interested in him."

"The neighborhood children have a protective attitude and are most helpful when he escapes from the fenced yard. They sometimes take time to play a few minutes with him and are as delighted with his accomplishments and language development as we are."

DAY-TO-DAY CARE

J. Margaret Horrobin, Pediatrician

The ordinary principles of health care apply to children with Down's Syndrome no less than to normal children. In fact, such routines as immunizations are probably more important because of the innate susceptibility of children with Down's Syndrome to infectious diseases. Your baby should receive regular immunizations at the normal time, though it may take a little longer to complete the series if your child has frequent upper respiratory infections.

In this section topics that are particularly applicable to Down's Syndrome are mentioned. At the end of the booklet there are some references for further reading about child care and suggestions for handling problems that apply to retarded children in general, not Down's Syndrome in particular — problems such as discipline and toilet-training.

Bathing

While following your normal child care routines, bear in mind that your baby's muscle tone is likely to be poorer than that of a normal baby, so that he tends to be limp. This may make you uneasy when handling him in the bathtub so that you may prefer, for a while at least, to bathe him on a towel using a soft wash cloth or sponge and not put him in the water at all. This is perfectly satisfactory. Many young babies do not like to be in a bathtub and in the early months it is unlikely that he will be going anywhere to get very dirty.

Skin Care

As your child gets older the problem of dry skin often arises. This may be a problem all year round but is generally aggravated in winter when chapped faces and lips are common, and the skin of the arms and legs often feels very rough. The drying effect of soap and water can make this worse so we recommend using as little soap as possible. If soap is absolutely necessary use a superfatted preparation. Regular use of skin cream to keep his skin as soft as possible will help to prevent the skin from cracking. Vaseline or lip salve will help chapped lips. If the chapped skin problem becomes very extreme your doctor may need to prescribe special medication to help clear it up.

Feeding

A special diet is not generally considered to be necessary for a baby with Down's Syndrome. The feeding advice contained in any sensible baby care book is applicable to your baby. There are several points to remember, however. First, your baby may be slower to feed, taking longer to finish than a normal baby, thus requiring extra patience on your part. Though it may be tempting at times please do not prop the bottle and leave your baby unattended while you do something else. It is too easy for the baby to inhale some of the milk into the lungs causing what could be a very severe problem. Furthermore, it has been shown that babies who lie flat when drinking a bottle are more likely to have milk enter the middle ear from the throat, which may be a responsible factor in recurrent hearing problems. Apart from this a propped bottle is a very unstimulating, impersonal way to be fed.

Patience is also needed when you start to give solids from a spoon. The tongue and mouth action required to swallow solids taken from a spoon is different from that when swallowing liquid from a nipple. If the food is put too close to the tip of the tongue the normal tongue action may push the food out of the mouth; on the other hand if placed too far back the baby may gag. Learning the idiosyncrasies of your baby in this regard takes time.

Children with Down's Syndrome frequently are too fat. Whether this is simply a matter of too much food or too little exercise or is due to a more complicated metabolic upset is not clear. However, obesity should be avoided by not encouraging high calorie snacks and by setting a limit to the amount of carbohydrates (starchy foods) that are given.

Constipation is sometimes a problem which can usually be handled satisfactorily by such dietary manipulation as increasing the amount of water given and giving more fruits and roughage.

Normal babies generally begin to chew by nine months of age so that by this time they can manage foods containing more lumps than are present in strained baby foods. Children with Down's Syndrome learn to chew later and therefore, are likely not to be able to manage lumpy foods before one year of age. This varies with the individual child however. Do not fall into the trap of infantilizing your child and permitting him to continue to take strained foods after he is able to learn to manage lumpy foods. Once a child's development has reached the point where chewing is possible it must be encouraged.

Medical Problems Associated with Down's Syndrome

Naturally a child with Down's Syndrome may have any of the medical and management problems that a normal baby may have, but there are some problems found more commonly in children with Down's Syndrome. In their early months many Down's Syndrome infants have a stuffy nose causing noisy breathing. The nasal passages are small and so are more easily blocked. Generally this is not a major medical problem but more of a nuisance (unless the nose is totally blocked, at which time feeding difficulties will result).

Frequent upper respiratory infections are a common problem, as is pneumonia. Many children with Down's Syndrome are unusually susceptible to such infections, and beyond normal common sense measures you cannot prevent such occurrences. Making sure there is enough humidity in your house will help greatly in warding off and alleviating upper respiratory infections. Many families, especially in the dry Northern winters, find that an ordinary humidifier does not provide enough moisture and run a cool vaporizer in the child's room constantly during the winter.

Some infants with Down's Syndrome are "spitty." They spit up a mouthful or two or even more after every meal so that their mothers are at their wits' end with the constant minor mess. Often no cause can be found: perhaps incoordination of the swallowing muscles is responsible, but you may be reassured that it will likely pass and that eventually, generally by two years of age, your child will grow out of it.

True vomiting is different from spitting of course and always needs to be looked into more thoroughly for a cause. In the newborn period vomiting may be a sign of blockage of the duodenum (part of the small bowel), which requires surgical treatment. This condition, though quite rare, is more common in babies with Down's Syndrome than in others.

Congenital heart disease is quite common and varies in severity from a symptomless heart murmur to a severe malformation of the heart leading to an early death. The most common type of heart defect is a "hole in the heart" between the ventricles (chambers of the heart). Often, the heart murmur may not be heard in the early days but becomes apparent later. Generally speaking, if your doctor has not heard a murmur by four months, it is unlikely that one will show up later.

Acute leukemia is a very rare childhood disease that, while still a rare condition, occurs more often in children with Down's Synarome for reasons that are not clearly understood.

Stimulating Development

Affectionate rubbing, handling, positioning and talking received from a mothering adult are essential to every infant's development.

Picture a mother holding an infant on her shoulder, rubbing his back, talking to him, and walking about the room with him. Is she stimulating his language development through talking to him, his social development by rubbing his back and talking to him, or his muscular development by carrying him about and changing his position constantly? The answer of course is that she is stimulating language, muscular and social development *all at the same time*. Nevertheless, for the purpose of taking a close look at each of these crucial stimulation factors, we will examine them separately.

LANGUAGE STIMULATION FOR THE DOWN'S SYNDROME CHILD

Judith M. Wolf, Language Therapist

Language can be thought of as having two important parts: receptive and expressive.

Receptive language means understanding or comprehension of words the child hears. Psychologists often refer to receptive language as input, or the ability to decode. We can't hear the child use his receptive language, but we can see it in action. Every time a child responds correctly to verbal instruction, or completes a command, we observe that he has receptive language. Receptive language learning begins at birth and continues throughout a person's lifetime. All of us have more receptive language than functional expressive language.

Expressive language is the speech part of language. It is sometimes called production, output, or encoding. It's the part of language we can hear (and sometimes see, as when we use gestural language).

All language can be thought of in terms of phonology, (speech sounds), syntax (word order, what we used to call "grammar"), and semantics (word meaning). Speech sounds are only a very small part of what we are calling language. Language is a total system of receiving, understanding and producing meaningful symbols.

What Are the Functions of Language?

Language has two interrelated major functions: communication and thought. Interpersonal communication is essential to the emotional and social development of the child. Being able to express ideas and verbalize feelings enables the child to handle his day-to-day problems.

The second major function of language concerns its relationship to intellectual development. Our society places a premium on academic skills such as reading and mathematics intellectual achievements which are important in order to express thoughts and solve problems. Language is very much a part of academic skills.

How Do We Learn Language?

Language appears to be learned in an orderly, individual, step-by-step manner. Language learning is dependent upon an interaction between the child's ability to learn and a responsive, stimulating environment. The important thing to remember is that language is learned through interaction with the environment. The child is active in his world, listening, organizing, and carefully structuring a little working language system of his own. As he grows, he will "match" his system with the adult model in his environment, and slowly begin to approach the adult language system of his culture.

How Do Down's Syndrome Children Learn Language?

Studies of the development of grammatical rules in Down's children reveal that, just as with normal children, they are able to express a sentence or phrase only after they have understood the language.[20]

In our work with Down's children in Project EDGE, we have found that various types of words develop in the child's understanding at differing levels. We have studied this development through the use of a picture test. Down's and normal children are asked to point to photographs of common objects and toys to show that they understand labels and concepts.

Preliminary findings indicate that two, three, and four-year old children, both Down's and normal, do best in responding to labels (ball, doll, spoon), next best with ordering words (biggest, smallest), and next best on temporal relationship words (first, last).

Regarding expressive language development, several authors have found great variability among Down's children with respect to the time at which they say their first word. The findings of one of these studies[21] are summarized in Table 1. As can be seen in this table, Down's Syndrome children develop language at a slower rate than normal children and show marked individual differences in their development.

TABLE 1

Language Development in Down's Children as Compared with Normal Children*

Ability	Average age normal child does it (mos.)	Average age Down's child does it (mos.)	Range in which Down's child does it (mos.)
1 Says "mama" and or "dada"	10	24	12-40
2 Obeys simple commands	18	41	26-60
3 Combines 2 or 3 words spontaneously	21	42	24-69
4 Utters 3-word sentences	24	46	30-60

*Figures in column two have been rounded from the study.

How Can I Provide a Stimulating Environment?

The child learns most of his language through interaction with adult models (mother, father, grandmother) in his environment. It is important that adults provide the language-ready child with a variety of environmental labels, as well as a good sample of phrase and sentence structures. The growing child will use listening, imitation and practice to learn words, and will learn how to put words into sentences.

Language stimulation should become part of everyday activities, both at home and school. There are few tasks which do not lend themselves to language stimulation. Describe what you are doing as you do it, and tell your child what he is doing as he does it. Make words meaningful by attaching them to real objects and activities.

A stimulating environment is reinforcing to a language developing child. When your child speaks or understands, you can reward him in two ways. First, by responding correctly to his request, and second by expanding upon his words. He will feel good about communicating successfully, and gain additional linguistic information at the same time.

What Cautions Must I Observe in Providing a Stimulating Environment?

Do not expect too much in a short period of time. Children learn language on a receptive level first. There is a natural gap between a child's understanding and his production, and this gap is more noticeable in the Down's child. This means that when a child learns something new, we should not demand a verbal response. Give the child lots of receptive experience first; then after he understands the task or word, offer him the opportunity of talking.

Should I Correct My Child's Language?

It is important to encourage any attempt on the child's part to speak. We all make a number of errors in our language, and in young children mistakes are not only acceptable, but normal. The most useful information you can give your child is to provide a good language model, and not be critical of his attempts.

Just as we do not encourage the child who is just beginning to walk to try to run, likewise, we should not correct speech sounds during the time when the sounds are just beginning to be produced. Remember that speech, as with running, is a very complex ability and requires considerable time for adequate learning and refinement. So, when do you seek help for his pronunciation difficulties? That's a tough question but a rule of thumb we use is to provide pronunciation help only after he has all of his first teeth and is at least talking in simple three-word sentences. Even at this stage help should take the form of *encouragement*, not criticism.

Am I Talking Too Much?

As long as you attach the language you use to meaningful objects and situations, the child will benefit. However, when we flood a child with language, he is overwhelmed, cannot comprehend, and loses interest. All of us need some private, quiet moments. Respect this need in your Down's child as well.

SOME SOCIAL ASPECTS OF DOWN'S SYNDROME

Marylee C. Fithian, Teacher

Those of us who have children, whether or not they are retarded, have a great concern for how they fare in life. We want them to have a happy, comfortable and rewarding life, with as few problems as possible. We especially want them to be liked and have friends — or, at least, to get along with and be accepted by others.

I would be less than honest if I said that social adjustment will be of no greater concern for parents of Down's children than for parents of normal children. With the birth of a retarded child, there is also the birth of a host of problems that the parent and child are going to have to face *together* through the ensuing years. Not the least of these is the social acceptance and adjustment of the child.

As we look at the broad field of *social acceptance*, let's begin by talking about discipline for a retarded child — an area of great social concern.

We are all aware of how important appropriate social behavior is to adjustment and acceptance in our society. Sometimes we are not aware of ways to help our children to develop the necessary social skills and habits, and we search and search for answers. When parents are faced with the knowledge that their child is mentally retarded, somehow the task may seem overwhelming. The following question and answer session with a group of parents may be useful in helping you begin to deal with this responsibility.

QUESTION:

Why do strange mannerisms and behaviors seem to occur more often with retarded children?

ANSWER:

Mannerisms which are often manifested by retarded children are not necessarily inherent in retardation itself, and there can be more than one reason for such behavior. Some of it may be due to a lack of stimulation from the environment. When a child is not receiving appropriate stimulation he may try to provide it for himself through behavior such as rocking, head banging, hand play, etc.

Some strange mannerisms are attention-getting devices. Very often they are the result of improper rewards for "cute" behavior and are quite unnecessary. It is not uncommon for retarded children to be looked upon as babies far beyond babyhood and for others to be amused by and accept behavior which would not be accepted from a normal child of the same age. Let me give you some examples of what I mean.

A group of young retarded persons came to my home one night after a band concert for cokes and a snack. One young man spent the entire evening opening closet and cupboard doors looking for my "white pipe" (dryer vent) and any other appliances I might have. His interest in mechanical objects was admirable, but his behavior as a guest in my home was deplorable. Even more deplorable was the fact that his chaperones (teachers from his school) thought his behavior funny and laughed at him.

On another occasion I was visiting a school at the same time the fire department was making an inspection. A student raced to the window to see the fire engine, yelled out to the firemen, and then rushed to the building entrance. As the firemen came in the student insisted that each one shake his hand before going further. This might be considered "cute" in a very young child, but this particular student was nineteen years old.

Inappropriate behaviors can be eliminated even when very well established. However, the more ingrained they are, the more difficult it will be to eliminate them. For that reason it is important to begin discipline at a very early age and provide a proper foundation for age-appropriate social behaviors.

QUESTION:

What do you mean by "discipline"?

ANSWER:

There are several elements to discipline.[22] The first is LOVE RIGHTLY EXPRESSED. Because a child, even a retarded child, needs to learn to be as independent as possible, a parent's true expression of love is to train the child to help himself. This kind of training will result in a constructive independence rather than a destructive dependence.

A second element of discipline is SECURITY. Security means having protective limits. Parents need to set limits and standards *for the family, and children need to know what those limits are. In addition, they need to know what the consequences are for going beyond those limits.*

A third element of discipline is RESPONSIBILITY. Children will not become responsible without some help. They need to be TAUGHT to accept responsibility, and this is not possible unless it is given to them.

QUESTION:
When should I begin to discipline my child?

ANSWER:
Right from the start you should allow your baby to learn that he's a member of the family as a sharing rather than a receiving member. He should not be allowed to cause NEEDLESS changes in the living routine or to feel he's the sole reason for the family's existence. It is not a kindness to anyone concerned to make him the hub of the universe.

QUESTION:
Will I need to use special discipline techniques with my Down's Syndrome child?

ANSWER:
Most children with Down's Syndrome can be disciplined (and learn self-discipline) in the same manner as normal children. The important thing is that discipline be thought of as a normal part of life and that the methods used in discipline are consistent.

Expectations are important, too. It helps to let your child know that you believe he will make the appropriate choices about his behavior. I remember a teacher friend of mine who told me this story about her sixth grade class. She said they had been misbehaving all day, and she felt the day had been a complete waste. Finally, in desperation she told her students that "even the special class children" behaved better than they. At that point, a child in the class piped up, "That's because Mrs. J expects them to behave." Unfortunately, my friend didn't catch what the child was trying to tell her, i.e., Mrs. Jones had limits and standards and objectives for her class, and she believed her children would live up to them. Because she believed it, her pupils believed it too and tried not to disappoint Mrs. J or themselves.

QUESTION:
Doesn't a retarded child need a little EXTRA love, protection, and security?

ANSWER:
In a sense you are right. That is, you want your child to feel good

about himself and have a sense of his worth as a person, and this is often a problem for the retarded. However, it is not an uncommon reaction for the parent of a handicapped child to, in a sense, pity him or want to "make it up to him" for his condition. But, feeling sorry for the child, while a normal reaction, can add problems to an already difficult situation. As with all children, your child needs to learn to develop independence and responsibility. Overprotection deprives the child of the experiences which help him to develop these, and he stands a good chance of becoming an overly dependent and demanding child.

QUESTION:

My child is a problem eater. He is fussy about what he eats and we usually have to plead with him and beg him to eat.

ANSWER:

I do not believe in begging a child to eat or in making threats to get him to eat. This is a needless power struggle. As a parent, it is YOUR RESPONSIBILITY to provide your child with food (a well-balanced diet, by the way), but once you have set the food in front of him, it becomes HIS RESPONSIBILITY to choose to eat or not to eat. If he chooses not to eat, he faces the natural consequence of being hungry. No child, not even a retarded child, will choose to go hungry for very long.

QUESTION:

Sometimes our child picks up his dish and dumps out the food. What should we do?

ANSWER:

If the child is doing this toward the end of the meal, he may be trying to tell you he's full and can't eat more. It may be that you are giving him portions that are too large and need to reduce the amount you serve. However, no matter when the child does it, it *can develop into an attention-getting device depending on your reaction. It is important not to make a big fuss. Quietly get a cloth and have the child clean up as much of the mess as he can himself. Then remove the child from the table and tell him that since he's not hungry, he may be excused. HIS mealtime is over.*

QUESTION:

My child misbehaves so much, and I tell him repeatedly that he mustn't do things like that. He doesn't seem to understand. Am I expecting too much?

ANSWER:

There are a couple of possibilities here. It may be that he doesn't understand what you are saying to him and you need to find some new way to communicate his limits to him. However, most adults tend to underestimate what a child actually understands — especially when they are aware the child is retarded. What probably has happened is that your child has developed a common childhood ailment "Mother Deafness." The treatment is fairly simple. Talking, as discipline, should be limited. Actions speak louder than words.

In addition, misbehavior is often the method a child uses to gain attention By repeatedly reprimanding him, you are giving him attention for inappropriate behaviors. It would be better to ignore as much of his misbehavior as you can, and give him more attention when he is cooperative. In other words you should make cooperative behavior more profitable than uncooperative behavior.

QUESTION:

My husband and I have a disagreement with our son's preschool teacher. We feel he should have the opportunity to express his anger whenever he needs to. His teacher often squelches him when he does and tells him his behavior is inappropriate. Who is right?

ANSWER:

It's a little hard to answer you since I don't really know the details of the incidents involved. However, I suspect both you and the teacher are right in certain respects. Let's look at what I mean.

We all need to work frustrations and anger from our system. If we don't, we are likely to get ulcers. As an adult you have learned that you can't scream and holler or lie down and kick your feet everytime you get angry. Perhaps you'd like to, but what you probably do is go scrub your floor or something of that sort.

So it is with our children. We have to help them learn to channel their anger in such a way that it is not damaging to others or does not infringe on the rights of others. For example, if every child were allowed to scream in the halls of the school everytime he was angry, there would be many people whose work would be disrupted. Certainly, for another example, it's infringing on the rights of others when a child spits his milk all over the table at lunchtime. These are inappropriate ways for him to deal with anger and frustration.

It may appear to you that your son's teacher is preoccupied with discipline. However, she is quite aware of the importance of appropriate social behavior for your son's future success. As an adult, it will not really matter how well he can read or write or solve problems, nor will his vocational skills be of much value if he cannot work well under supervision, if he cannot get along with his fellow workers, and if he cannot assume his responsibilities in his social setting. The foundation for successful adulthood must be laid in early childhood.

QUESTION:

Are there some general rules that parents of retarded children should follow to develop a good pattern of discipline?

ANSWER:

A good pattern of discipline is extremely important for the retarded person because his social behavior is one of the most important variables in determining his life chances. Although training in essential skills and habits may take longer, the general rules of discipline one would follow for the retarded person are no different than for a non-retarded person. Let me summarize here what I see as a general outline of ways to deal with children.

1. Remembering the elements of discipline, it's important that "discipline" begin as soon as the newborn child comes home from the hospital.

2. Establish limits, standards and objectives for the FAMILY. These are the means by which the child will develop a sense of order and begin to grow into responsibility.

3. Help the child to understand that he has rights, but in exercising those rights, he may not infringe on the rights of others.

4. As he grows, help him to learn independence. Give him opportunities to make decisions when appropriate, and allow him to experience frustrations.

5. Rudolph Dreikurs[23] reminds us that "a child needs encouragement as a plant needs water." This means having faith in your child as he is, not in his potentiality. Your positive expectations will be communicated to your child and he will begin to develop positive self-expectations.

6. Recognize misbehavior for what it is — the sign of a discouraged child who believes he can't succeed by useful means.[23] This misbehavior becomes a bid for attention or for power.

7. Restrict your talking to friendly situations. Talking should not be used as a disciplinary means.

8. Finally, enjoy your child and allow him to enjoy his relationship with you. Working and playing together and sharing new experiences will provide many opportunities to try out this relationship. If it's based on MUTUAL respect, love and trust, enjoyment will come easily.

Social Acceptance of Retarded Individuals

In a number of studies peer acceptance has been shown to be related consistently to intelligence and other ability measures, whether the peer group is in a regular class, a special class, or a residential institution.[24] [25] [26]

A major study done in 1950 indicated that retarded children in regular grades are less accepted and more rejected than their normal peers.[27] The interesting thing,though, was that the rejection did not appear to be due to the fact that the retarded children were less intelligent per se, but because they exhibited socially unacceptable behavior. Several studies have corroborated that finding.[28] [29]

In one study that specifically refers to Down's Syndrome children, the investigator states that in a residential setting, at least, persons with Down's Syndrome were significantly less accepted than the remainder of the group.[24] Although the study doesn't indicate why this was so, it may be possible to come up with some ideas about it by looking at what we know about peer acceptance in general.

Studies with physically handicapped children have indicated that children with more visible defects are the least accepted.[30] It may then be true that because the Down's child looks "different," he will be less accepted. Parents and child will have to learn to live with stares, whispers, and quickly averted eyes. To some people the Down's child will be an object of fear and misunderstanding.

As adults, retarded individuals tend to lose jobs less for inability to perform the required tasks than for inability to get along with co-workers and supervisors (President's Committee on Mental Retardation, 1969). Therefore, a major factor in social acceptance seems to be appropriate social behavior. This would seem to indicate a need to work on social behavior very early. It must be remembered that there comes a time when "cute" behavior is no longer "cute" and needs to be replaced with more appropriate behavior.

Often, mentally retarded children display mannerisms which are either repugnant or perplexing to others. This brings to mind a couple of students I had in my special class for two years. It happened that both were functioning academically better than their mental ages would predict, yet neither of them had any close friends, and, in fact, were rejected by their classmates. Kevin often walked bent over from the waist and pointed his finger in front of him muttering, "hoot, hoot." Barbara made strange faces and noises, and when she wasn't mumbling, she was sucking on a dirty head band. In both cases, their strange behavior certainly contributed to their low peer acceptance.

A number of studies with normal children of different ages have looked at the relationship between peer acceptance and dependency. The findings of these studies seem pretty consistent, but they are not something which can be described simply. First, dependency on *adults* may interfere with peer acceptance, but dependency on *peers* may be an attribute of more accepted children. Second, if the overtures a child makes are socially mature, he may be more accepted than if his overtures are immature, such as too much affection-seeking or negative attention-seeking.[11] This would imply that we must help the Down's child to become as independent of parents as possible. In my school I taught a boy, Jimmy, who was the "baby" of the family. His parents were determined, perhaps unconsciously, to keep him that way by making absolutely no demands of him. It was easier and faster to do things for him than to let him do things for himself. Consequently, when he came to my class at age twelve he was not tying his shoes or zipping his trousers or jacket. He also was not walking down stairs using alternate feet on the steps. Because of this he received a great deal of teasing and the children didn't want to include him in their games. We were able to teach him these simple self-help skills very quickly, but there was no cooperation from the home, so we made only partial headway in Jimmy's use of these skills and in the way his classmates accepted him.

Grooming and appearance are closely related to social acceptance. An appropriate haircut and clean, well-fitting clothes can do wonders for a child, and yet, it's surprising how many poorly groomed retarded children there are around town.

Finally, social visibility has been shown to improve acceptance of and change attitudes toward the retarded. As people are increasingly exposed to the retarded in positive ways, old attitudes about and barriers to social acceptance disappear. Therefore, take your child places and let him interact with others.

There is hope for the Down's child to be accepted. We have a retarded young man in our neighborhood who attends the junior high Friday night dances. With that age group, this could have devastating effects. But I have been singularly impressed with the way he has been accepted by his peers, and by how many of them want to learn more about his problem. When I have asked my daughters and their friends about their feelings toward him, their answers have been, "When you get used to the way he looks, you can see that in spite of his problem he is a neat person. He's friendly, considerate and fun. We like him, and we're glad he comes."

With a lot of hard work from an early age, perhaps you too will have a child who is a "neat person."

YOUR DOWN'S SYNDROME CHILD'S MUSCULAR DEVELOPMENT

John E. Rynders, Educator

The newborn Down's child's muscle tone is usually characterized by "floppiness." For example, when pulled to a sitting position from a lying position, his head will usually lag behind the rest of his body. Mothers picking up their Down's infant for the first time note the characteristic "rag doll" feeling of their baby. In one study of 86 Down's newborns, 84 were found to have poor muscle tone, so this is a common condition.[12]

With regard to overall muscle development, your child will usually be delayed in development of muscular abilities such as crawling, standing and walking. In this regard three authors[21] compared the development of 71 home reared Down's children with the test norms of the Gesell Developmental Scales (a well known development test for young children). On the average, they found Down's children to be delayed in their development, as compared with normal children's development, that the differences became greater with age, and that the differences carried over into self-care skill areas (see Tables 2 and 3).

TABLE 2

Muscular Development in Down's Children as Compared with Normal Children*

Ability**	Average age normal child does it (mos.)	Average age Down's child does it (mos.)	Range in which Down's child does it (mos.)
1 Rolls over	5	6	1- 6
2 Sits unsupported for one minute	8	11	6-30
3 Creeps	10	17	8-34
4 Pulls self to standing position	10	18	12-30
5 Stands at rail	11	17	9-36
6 Stands alone momentarily	14	22	12-44
7 Walks with support	13	22	11-48
8 Walks unsupported	15	25	15-50
9 Walks upstairs unsupported	18-24	38	26-48
10 Walks downstairs unsupported	24-30	42	32-52

*Figures in column two have been rounded as they were taken from the data of the original table.[21]

**Some of the abilities in the original table[21] have been omitted.

TABLE 3

Development of Self-Care Skills in Down's Children as Compared with Normal Children*

Ability**	Average age normal child does it (mos.)	Average age Down's child does it (mos.)	Range in which Down's child does it (mos.)
1 Feeds self in part	9	24	9- 42
2 Drinks from cup or glass unassisted	21	30	18- 48
3 Feeds self "fully"	18	35	18- 58
4 Dresses simple garment	24	44	22- 86
5 Dresses self except for tying shoes, buttoning	36	66	36-102
6 Toilet training begun	36	66	36-102
7 Bladder training begun	18	24	12- 40
8 Bowel control	24	38	15- 50
9 Washes hands and face unassisted	42	56	39- 86
10 Brushes teeth unaided	48	58	48-69

*Figures in column two have been rounded as they were taken from the data of the original table [21]

**Some of the abilities in the original table[21] have been omitted

What Can be Done to Improve My Down's Child's Muscular Abilities?

Affectionate handling is stremely important to the infant. For example in a recent child study review[13] the authors found that alertness in normal infants is highly related to the amount of handling by a caretaking person. In another study,[14] investigators observed that normal newborn children had their eyes open most when being held and much less when left unhandled.

In one of our own investigations,[15] we studied the effects of mother-child interaction on the exploratory behavior of Down's Syndrome infants. In this experiment, groups of Down's Syndrome and normal children between one and one-half and three years of age were presented with opportunities to handle interesting objects. In one group children handled objects without the presence of the mother; in a second group mother was present with the child but did nothing; in the third mother was present and gently helped her child manipulate materials, talking with him about them in a pleasant conversational manner. The results demonstrated generally that both normal and Down's children spent more time looking and or handling objects when the mother was active with the child than when she was neutral or absent. These findings point out the importance of affectionate, intimate adult-child interaction.

Precautions in Stimulating Muscular Development

One has to be cautious not to become over-zealous in instructing a young child. Some well-meaning parents may be so active in their instruction that they virtually "sap" their children's energy. A child faced with such a situation may withdraw eventually from social interaction. Focused, calm, interesting, intimate adult-child interaction seems best in enhancing a young child's development.

Parents should work with their children on tasks and materials that offer the greatest opportunities for comfortable parent-child engagement and task mastery for the child. Simple materials, without useless detail and electrical circuitry, hold interest longest because children can easily gain competence in using them. Witness the child who receives an exotic electric toy for Christmas and, after a quick inspection, prefers to play with the box the toy came in. Relative to this point, one author[16] says that gaining competence in dealing with the environment provides a child with an exceedingly rich source of enjoyment. He writes:

> Being interested in the environment implies having some kind of satisfactory interaction with it. Several workers call attention to the possibility that satisfaction might lie in having an effect upon the environment, in dealing with it, and changing it in various ways. Groos (1901), in his classical analysis of play, attached great importance to the child's "joy in being a cause," as shown in making a clatter, "hustling things about," and playing in puddles where large and dramatic effects can be produced. "We demand a knowledge of effects," he wrote, "and to be ourselves the producers of effects. (p. 180)"

A critical aspect of interaction, therefore, should be that of arranging tasks so that they enhance the child's chance of *task mastery*.

TRANSLATING PRINCIPLES OF CARE AND DEVELOPMENT INTO EVERYDAY TRAINING ACTIVITIES

John E. Rynders, Educator

Self-care skills are viewed by normal persons simply as means to more interesting and important ends. But for the Down's Syndrome child and his parents, the development of each self-care skill is a significant event in and of itself. Furthermore, a normal person usually develops self-care skills to such a high degree of precision that he no longer has to think about them. They become reflexive. For the Down's Syndrome child, however, self-care skills are difficult to acquire and often require sustained, conscious practice in order to be maintained.

In this section we will describe procedures for helping your Down's Syndrome child to: (1) learn good eating habits, (2) become toilet trained, (3) learn good habits of grooming and hygiene, (4) develop good rest habits and, (5) dress himself. (Some of the information for this section comes from the book, *You and your retarded child,*[5] and from materials prepared by the State of Minnesota, Department of Public Welfare, Social Services and Medical Services Division.)[6]

Learning Good Eating Habits

The infant's first food will be milk or some other liquid which he draws from a nipple. Fortunately, for most children, including Down's children, the ability to suck is usually present at birth. A bit later, when your infant is old enough to swish milk around in his mouth, he will do so, finding it an enjoyable learning experience because nature provides the newborn with many nerve endings in his mouth. In fact, the only place where the newborn has more nerve endings is in the cerebral cortex (large carpet of cells) of the brain. This is why he will spend a lot of his time squishing liquid and soft food around in his mouth and why he puts all sorts of objects into it, including some things which you don't want him to put there.

As he grows out of the newborn period he will begin to show signs that he is ready to start feeding himself. Some of these signs are: sufficient head control to keep his head erect when sitting in an upright position; ability to balance his trunk reasonably well while sitting in a chair, even if you have to prop him up with a soft cloth tied comfortably around his stomach and to the back of his chair; and most importantly, indications that he wishes to feed himself.

As you help him learn to feed himself, it is very important that you carefully prepare the eating environment for ease and efficiency. First of all, make certain that the atmosphere is one of pleasantness and quietness. Turn off the TV near your eating area and make your child and yourself comfortable. As you place him in his highchair or push him up to the table, be certain that you have prepared all the food in advance that you will need and that it is easily within your reach but not within his reach. Check to see that the glass and spoon you have chosen are the right size and can be managed easily by your child. As you prepare to instruct, sit beside your child, don't hover over him. Even with foods he likes very much, begin training using small quantities. And by all means expect accidents, but handle them matter-of-factly.

Eating time lends itself well to helping him sharpen his language abilities. Thus, as you help him learn to feed himself, talk with him about what he's doing and what he's eating. Speak with him in short, simple, complete sentences, emphasizing words that he will be most likely to learn first such as labels and the attributes of objects, that is to say, words such as "cup," "spoon," "milk," "cold," "hard," and "white." Don't worry at this stage about whether he says these words for you. The important thing is that you help him to engage and understand his environment through your focused instruction.

As he begins to feed himself, provide him with soft finger foods that he enjoys such as bread, or a soft cookie, or a cooked vegetable. (Don't forget to move to more chewable foods when your child is ready for them so that he'll get chewing practice and keep his gums healthy.) Begin with pieces of food that he can grasp adequately, remembering that he will not be able to make the precise thumb and finger kind of pinching grasp that an older child can make.

Drinking from a plastic glass. Learning to use a glass is a skill that is usually acquired early in life, but a lot of trial and error occurs before the young child learns just how far to tip a glass in order to obtain some liquid without getting drenched. In the early stages of learning, a small plastic juice glass will be helpful. And be certain to allow enough time for him to swallow and breathe as you hold the glass to his mouth. Speaking of holding the glass to his mouth, when he's first learning to drink, help him by physically guiding him with your hand when you see that he's having difficulty. Then, as he begins to show better control, turn more of the task over to him. During initial sessions, drinking a milk shake or a malt can be easier for him because the liquid moves more slowly out of the glass than does milk or water. When you use milk or water, commercially available cups with covers that release liquid slowly may be useful. Above all, as you hold a glass to his lips, don't tip his head back very much. A slight incline will be fine, otherwise he'll choke.

Using a spoon and fork. For a young child a spoon must be regarded as an "instrument of torture." It involves filling, lifting, aiming, emptying, and refilling, all with precise movements and requiring good aim and split second timing, accomplished frequently by frustrating spills and dribbles. To help, use foods that will stay on the spoon more easily than others, such as chopped or blended foods. As you begin training place your hand very gently over his hand, and grasping the spoon with him, dip it into the food and guide it to his mouth and then back to the dish. As with using a glass, gradually let him assume more and more control himself.

If he is having difficulty grasping the spoon, build up the spoon handle with tape and/or try different sizes and shapes of spoons. Because a spoon is used to scrape across a plate, it may be helpful to put a guard on the edge of the plate so that the spoon will have something to strike against. It may also help to use a plate with a suction cup on the bottom so that it will stick to the highchair top, or perhaps you will want to wrap a wet towel around the outside edge of the plate to give it more stability.

Learning to use a fork is similar to learning to use a spoon but also included are the operations of piercing and cutting. Additionally, it is much more painful to miss one's mouth with a fork than with a spoon, so use a fork with discretion and only after your child has good mastery of the spoon.

Helping Your Child Learn to Become Toilet Trained

Every parent looks forward to the time when his child will be toilet trained. Fortunately, almost all children will learn eventually to take care of themselves at the toilet. Nevertheless, toilet training often proceeds slowly, sometimes with performance plateaus and even some regressions, because the process of controlling elimination requires sophisticated use of muscles.

What are some of the signs indicating that the child may be ready for toilet training? First of all, and here is where the importance of communication becomes apparent, does he understand what you are asking of him when you talk with him about using the toilet? Does he show willingness to go into the bathroom with you? Does he show signs of discomfort when soiled or wet? Is he sometimes dry for as long as an hour or two at a time? These are all signs that he is ready for training.

Helpful Hints For Toilet Training

1. Concentrate on one toilet habit at a time.

2. Keep his outside clothing simple. Trousers with elastic waist bands can be pulled down quickly.

3. Use training pants instead of diapers. These can be removed quickly and will help him to feel more grown up.

4. Don't flush the toilet when your child is on the toilet seat. It may frighten him. Instead, let him flush it with your help when he gets off of the seat and after he's pulled up his pants.

5. If you wish to use a potty chair keep it in the bathroom. Some parents feel that a potty chair is unnecessary and may wish to put the child on the regular toilet. However, when a child is put on the regular toilet a child-size toilet seat may need to be put on first. If using the adult-size toilet,support his feet using a box or a footstool to make him more comfortable.

6. Children should not be left unattended while on the toilet. Go into the bathroom with your child and stay with him. Five or ten minutes will usually be sufficient. If elimination does not occur in five or ten minutes remove him without showing emotion.

7. While he is sitting on the toilet seat do not distract him with stimulating toys, but a non-stimulating washable, favored toy that he can hold quietly may be useful. If nothing else works, a candy sucker on a safety stick will probably serve as a rewarding distraction for him while he's seated. And, if the sucker is used only while he is on the toilet he will come to associate toileting with pleasantness. Do not use a sucker more often than absolutely necessary, however, because it contributes to tooth decay and excessive weight gain.

8. A good diet is important for prevention of constipation. Give him fruits and roughage that will help keep him regular and will minimize the use of laxatives.

9. Accidents will happen during and after toilet training. Sometimes these accidents will be associated with illness or a change in family routine or a feeling of insecurity. But remain calm when accidents happen and don't give up your training because soon he will be making progress again.

10. When your child is sitting on the toilet seat show him that you are pleased when he eliminates. Do not frown or show disapproval. When he shows interest in his bowel movement, remember that the bowel movement is "part of him" and so is important to him. Therefore, don't hurry to flush the toilet and if possible let him do the flushing himself.

11. Playing with genitals or a bowel movement is normal behavior. Do not react to this behavior with anger or punishment. Rather, respond with a firm but gentle "no" and an appropriate substitute task. You can minimize this problem by not leaving him unattended while he's in the bathroom.

12. Reward your child for progress. Praise, a smile, caress or hand clap are all appropriate rewards and will be well received by your child. Remember to reward immediately after the desired behavior occurs but don't overdo it.

13. If your child makes grunting sounds or shows other signs that he is in the process of a bowel movement don't rush him to the bathroom as if the house were burning down. Rushing will make him tense and when you get to the bathroom the elimination process is likely to be delayed or stopped altogether. Instead, lead him to the bathroom quickly but calmly and gently.

14. Boys and girls must learn to wipe their seats from front to back. Front to back wiping is particularly important for girls to avoid possible vaginal infections.

15. Conclude toileting session with hand washing and drying. Cleanliness is part of toilet training and should be taught with it.

16. Make a habit of getting your child to the bathroom at times when his bladder is likely to be full. Some of these times might be on rising, after meals, mid morning, mid afternoon, and before bedtime. If he's having difficulty urinating, giving him liquids just prior to taking him to the bathroom may help to prime the response. It cannot be over-emphasized that you must establish a *schedule* for your child and stick to it or he will not get on a schedule himself.

Helping Your Child Learn Good Habits of Grooming and Hygiene

Learning grooming and hygiene skills will be facilitated if established regularly in your schedule. The routine will help your child learn which acts follow each other in a day.

Equipment and materials should be within easy reach of the child and if he cannot comfortably reach the wash bowl or see into the mirror, a stable footstool or box should be provided. There should be a shelf which is comfortable for him to reach to hold his comb and other toilet articles.

Washing Hands. For the first couple of times he uses the sink you will want to control the water faucet yourself since children can get carried away with this fascinating object. If he doesn't spontaneously wet his hands in the water as you are running it for him, ask him to do so. Then, describing what you are doing, put the soap between his hands and see if he knows what to do. If not, apply some soap to the palm of one of his hands and, gently holding the backs of his hands, rub them together. Then help him to rub over the back of his hands and on the wrists. Help him to rinse, talking about what you are doing and making it as much fun as possible as you proceed. Allow him to do as much as he can for himself and only guide him where he needs it. But don't "leave him in the lurch" if you see that he can't do something. Lower your standards of cleanliness a bit as you begin this training, and if he's trying, reward him even though he may not get his hands perfectly clean.

Washing Face. After he has learned to wash his hands the next step is to help him learn to wash his face, a much more complex task, for, in contrast to washing his hands he cannot see his face constantly as he washes it. And, if he's looking into a mirror, everything is backwards. Furthermore, he may also be plagued by a small child's problems such as getting soap in his eyes, wash water dripping down his arm and running off his elbows, and missing parts of his face with the washcloth. As you begin teaching him, squeeze the cloth out for him and then spread it over one of his hands, and standing behind him, help him rub the soap over the cloth. (Perhaps initially you'll want to use a wet washcloth without soap.) Remaining behind him, guide his hand with the washcloth over his face very gently. Rinse the cloth and repeat the process, gradually relinquishing the task to him as he progresses.

Bathing. Bathtime can be particularly enjoyable for a young child especially these days when there are so many interesting things available commercially to play with in the bath water. Initially, the job of turning on the bath water and regulating its temperature must be your responsibility. Eventually, however, he can begin to take over, and when he does, a strip of colored tape can be used on the inside of the bathtub to show him at which point he should turn off the water. But, he'll require supervision for a long time in the tub; there's nothing quite so discouraging as watching water from the bathtub drip down through the ceiling into the living room. Besides that, there is a serious possible hazard in the child bathing by himself if he is young, has seizures, or is physically handicapped and does not have good postural support. It is possible in these circumstances that he could turn on the hot water by mistake and scald himself, or swallow a good deal of water, or even drown.

The same general training suggestions apply for bathing as they did for washing hands and face. Again, it's a good idea to set up a definite procedure and time for bathing so that your child will get accustomed to a sequence of events. At the end of bath time, be sure to teach him how to clean out the bathtub and where to put his dirty clothes both important components of his training.

Combing hair and brushing teeth. As with face washing, it's a good idea to stand behind your child so that both of you can look into the mirror at the same time. A medium sized comb is often easier for a child to handle than the small pocket combs where his fingers may get in the way when combing. Initially, you should help by gently putting your hands over his and carefully help guide the comb through his hair. Parting hair is a task with which many older normal children have difficulty, so do not hold up unreasonable standards for your young retarded child. When you begin tooth brushing, brush your teeth and let him observe; then help him by using the same type of "show and tell" instruction and physical guidance as you used with other self-care skill training activities.

Helping Your Child Develop Good Rest and Sleep Habits

A young child grows quickly and uses up a great deal of energy in vigorous play. Generally, the younger he is, the more rest he will require. Some retarded children need more rest than a normal child of the same age. Frequency and length of the rest period ought to be adjusted to your child's requirements. However, he should not be allowed to nap so long that he is unable to fall asleep at his normal bed time in the evening.

Get him in the habit of regular periods of rest and sleep. If he understands that a rest time regularly follows lunch he will more readily accept the routine. And, he will probably be more willing to go to bed right after lunch than if you wait an hour or so and call him from play to take a nap. When it is apparent that he does not need to sleep after lunch, he should be provided with an opportunity to rest for 10 to 15 minutes after lunch. If he has trouble sleeping don't force him to lie on his bed for long periods of time. This will only make him associate his bedroom and his bed with unpleasantness and you want to avoid this negative association as much as possible.

Provide a quiet activity before rest. It is difficult for children to settle down to rest immediately following very active play. For quiet activity you may want to read him a story or play soft music for him or allow him to look at picture books.

Encourage him to fall asleep and to rest without your assistance. If he is very tense, however, you may sit by him, gently rubbing his back, helping him to relax and fall asleep. Just your presence alone may be enough to calm him. Gradually, you should fade from the picture so that he doesn't become overly dependent on your presence to fall asleep.

Discourage him from excessive talking or noise making at rest time, because rest time is a quiet time. If possible, he should sleep in a room by himself where he will not be disturbed or distracted by other children or adults. If he wants to take a toy to bed there is no harm in it, in fact it is a good idea. However, don't allow him to take any toy to bed that might injure him if he rolls over on it, and discourage toys that make a loud noise if rolled upon.

Helping Him to Learn How to Dress Himself

Operations involved in dressing and undressing provide a rich opportunity for a child and his parents to engage in problem solving together. In the initial stages of learning to dress a child is often frustrated if he is faced with complicated zippers or buttons which somehow refuse to go through button holes. As adults, we have developed our own dressing skills to such an extent that they become automatic and we no longer have to think about what we do. Thus, when we analyze what we have to do in order to dress ourselves so as to be able to help our child dress, we have difficulty breaking the task into the required steps. This problem is analogous to asking the centipede, who is moving very well across the floor, to describe how he moves each of his 100 legs in sequence. When he stops to think about each step, he gets all tangled up in his legs and collapses. Nevertheless, the skills of dressing can and should be broken down into small steps and this kind of planning can be an interesting one for you.

One of the most useful training techniques for parents of retarded children is called "backward chaining." Using this technique, you start with the final act or product of your teaching and work backwards. We will look at a few dressing activities and see how backward chaining can be employed in each one.

Putting on underpants. As we said, backward chaining means to "begin with the end." For this task begin by putting on the child's underpants entirely except for leaving them down around his knees. Then simply teach him to pull them up over his hips. At first you may need to physically guide this behavior but eventually he should do what's expected with just a verbal invitation. Next, remove one leg from his underpants and teach him to stand on one leg and put the other one through the empty leg hole. You may have to help support him for a while or let him work while seated because this kind of balance is not easy at first. Each time that he gets the leg of his underpants on properly be sure to have him complete the activity by pulling them up over his hips. Next, hand him his underpants in the proper orientation, that is, with the front facing away from his body, and have him put in both legs and pull them up over his hips. Finally, when he is able to put on his underpants independently and correctly, hand them to him in the wrong position, that is backwards, and let him put them on improperly then show him why they are not on properly. The idea is to develop this skill so that it becomes automatic and self-correcting, because your child will have practiced it frequently and will have worked himself out of all the aspects that can go wrong, and hence will become increasingly independent.

Putting on a t-shirt. Using the technique of backward chaining, begin by putting the child's shirt on for him except for pulling it down in front and back, asking him to do that final operation. When he can do that on your command, remove one arm from its hole and teach him to replace it in the sleeve and pull it down as before. Following this, remove both arms and have him proceed one more step by putting first one arm in the sleeve and then the other and then pulling the shirt down front and back. The final step of course is to teach him to put the shirt over his head when you give it to him. By the way, a clear marking or label on the inside, back of his shirt will be helpful. Always require that he go through all of the steps that he has already learned on each try and don't mov [illegible] a new step until the earlier ones are mastered and can be done at your command.

Putting on socks. For your child putting on a sock may be like trying to put a wet noodle into a keyhole. Begin the activity by having him seated comfortably, you seated behind him with your thumbs inside his sock. Place the sock over his foot, pulling the top up around the heel, and then have him just pull it up over his ankle upon your command, "pull up your sock". When he will do this on command put the sock partially on his foot, that is just over his toes, and have him pull it up all the way. The next step is to fold it like a tube squashed from the top and require him to put his thumbs inside the top, place it over his toes, and pull it all the way up by himself. Finally, teach him to fold the sock into his palms before putting it over his toes. Having mastered these dressing activities your child is ready for some of the more complex dressing skills such as tying shoelaces and zipping.

Tying shoelaces. While your child is unskilled, provide him with shoes without laces, or, if you use shoes with laces, tie them for him. And, if you use shoes with laces you'll want to tie double bows in them so they won't become untied, causing him to trip over loose ends. Some mothers find it convenient in the early stages of teaching tying to not put the shoe on the child's foot at all but demonstrate on a table in front of him, or use a commercial or homemade shoe tying board. By using instructional aids you place the problem close by and avoid having him spend a good deal of time in a bent over position.

Zipping. The hardest part of learning to use a zipper is learning how to get the slide started on the track. In the early stages, some mothers put a small safety pin near the bottom of the zipper so that the child pulls his zipper down only to a point near the bottom (but not disconnecting the slide from the track) and then slips out of his coat as he would a pullover sweater.

If he's having great difficulty with zippers on his clothing, a commercial or homemade zippering board may be helpful so that he can have the zipper in front of him and operate it more easily than when it's under his chin. When he learns how to hold onto the fabric so as to produce tension as he pulls the slide up and down, you can train him to start the slide on the track himself. This is a complex step, however, and will probably require a great deal of time for mastery on his part, and a great deal of patience on your part. But, in the long run, your patience will be rewarded when he dresses himself independently.

Summary

In closing this section, let's highlight a few principles:

1. Self-care skill development is crucial to your child's eventual overall social development. It's the basis, actually, for eventual independent or semi-independent living.

2. Self-care tasks, such as eating properly and dressing appropriately, provide useful, instructional tasks through which your child can sharpen his language, social, and muscular skills if you plan them properly.

3. *You* are the most important "instructional material." Do not underestimate your importance as your child's first teacher. Specific things you can do as his teacher are:

   a. Set the stage for learning; eliminate sources of distraction, such as a loudly playing radio, and have all the articles you'll need for training close at hand.

   b. Make yourself and your child comfortable.

   c. Before you begin a training task involving several steps, analyze the task by going through it several times yourself so that you can teach it step-by-step without confusion and hesitation.

   d. Decide if the task proceeds best from beginning to end (shaping) or from end to beginning (backward chaining).

   e. When your child completes a task successfully, reward him with your voice and with a smile. Avoid giving him candy or some extraneous reward unless it's absolutely necessary.

4. When your child learns a self-care skill, provide him with an opportunity to practice what he's learned until he can do the task automatically. Then when he can perform the task automatically, begin to vary the problem slightly. This is important because problems are almost never identical from time to time and place to place and you don't want his learning to be "brittle" and non-transferable. As you vary the problem you and he can have fun by making a game out of "fooling the teacher" and other variations of affectionate give and take.

5. As you continue to instruct him, gradually withdraw your verbal and physical directions, substituting cues that are part of the task itself. This is really the end point of self-help training, that is, to have him help himself completely without your assistance. As a practical matter, you will not always be available to lead him through every task with your voice and physical guidance so he needs to become as self-reliant as possible for his own sake.

6. Finally, to the greatest extent possible, try to treat your Down's child as you would a normal child. Do not abandon sound principles of normal child training because your child is mentally retarded. There is an old saying that "children usually become what you expect them to be." Expect them to be as self-reliant as possible.

THE IMPORTANCE OF PLAY FOR YOUR DOWN'S SYNDROME CHILD

Marylee C. Fithian, Teacher

There is a story recounted by a medieval writer of an experiment conducted by Frederick II, Holy Roman Emperor in the thirteenth century. It seems Frederick wanted to know what manner of speech children would have when they grew up if they spoke to no one beforehand. So he ordered foster mothers and nurses to suckle the children, to bathe and wash them, but in no way speak to them. He wanted to know if they would speak Hebrew which was the oldest language, or Greek, Latin or Arabic, or perhaps the language of their natural parents. But the experiment failed because the children all died. The storyteller concludes, "For they could not live without the petting and joyful faces and loving words of their foster mothers."

Centuries later a whole series of studies of children raised in inadequate institutions remind us of the importance of "the petting and joyful faces and loving words" of mothers and foster mothers. In these studies it was found that infants who were raised in inadequate institutions, where they received little more than routine physical care, were slower to reach almost every significant milestone of child development.

Recently, Benjamin S. Bloom, an educational psychologist at the University of Chicago, summarized the results of a thousand different studies of infant growth and development which were done during the first half of this century. These results agreed closely that the child's most active period of growth, both physically and intellectually, takes place during the early years of life. He suggested that environment will have relatively more impact on a characteristic when that characteristic is undergoing rapid change than when very little change is taking place. The implication of this is clear: careful attention must be paid to the development of a growth-fostering environment during your child's early years.

Educational play may be particularly important for Down's Syndrome children who have difficulty from their earliest years in profiting from the environment because of muscular, language and intellectual limitations. Thus, much of the environment may "pass them by" unless play is more structured, that is, more carefully planned to ensure focusing of attention and engagement with materials.

Time to Begin Play

The day you bring your child home from the hospital is the day you become his teacher as well as his mother. You will not, of course, begin a systematic lesson with him at this point, but you can do all the things with him that you would do with a child who does not have Down's Syndrome. You can talk and sing to him as you feed him. You can "coo" to him as you rock him in your arms. You can tickle his feet and tummy and make funny noises at him as you change his diaper. You can laugh and get excited when he babbles or smiles.

It is not unusual for the mother of a Down's Syndrome child to comment on the fact that her child is such a "good" (quiet and not fussing) baby that she almost forgets he's around. Because of this, it is important to begin early to set aside a special time each day to play with your child. By the time he is three or four months old you will want to begin daily "lessons" with him, and you will find it quite easy to find the time to do them because you will have established a play routine with him

Planning the Play Period

Play is children's enjoyable work, so the activities which a mother plans should be fun for baby (fun for mother, too). This will take a little planning ahead of time. There are some books available in your local bookstore which can help you, and at the end of this section you will find a list of some toys and objects you might consider using. Many good toys are available commercially, but commercially-made toys are often costly so you may want to make some things yourself, or look around your house for some interesting alternatives. There are a few suggestions of this sort at the end of this section also, as well as a list of some good children's books and records.

When you plan your lesson activities there are a number of principles which should be observed:

1. Because learning is an active process for a young child, activities should involve him in an active fashion. A child comes to know an object by grasping it, putting it in his mouth, dropping it, picking it up, shaking it, and transferring it from hand to hand. The activities should minimize the parent's doing things for the child. He will not learn about his world unless he has an opportunity to explore it *himself*. In our own research[19] we've found it useful to teach teachers to use instructional strategies in a hierarchy, that is, in an order from the least direct to the most direct, so as to offer children the greatest opportunity to succeed on their own. For example, in teaching a child to pile a red block on a blue one, begin by briefly offering the two blocks to him without any verbal direction at all. If he does not get the idea of what you want say to him, "Put the red block on top of the blue block." Verbal direction may not work either, so then demonstrate what you're seeking as you verbalize, "See, I'm putting the red block on top of the blue block." If this doesn't produce the desired response, we think that it's a good idea to help the child produce the response so that he and his teacher find themselves able to feel good about satisfying each other. Help by gently taking his hand in your own, placing it over the red block, and moving it on top of the blue one, while at the same time saying, "See, we're putting the red block on top of the blue block." Having virtually eliminated the problem for him, proceed immediately to the beginning of the teaching hierarchy allowing him another chance to solve the problem on his own without direction or with only minimal direction from you.

2. Activities should be planned which have an observable result or effect on the environment. This is how the child will receive feedback from the

environment which will help him to learn. For example, when he shakes a rattle, he hears a noise; when he fingerpaints, he leaves a trace on the paper; when he pulls the string on a toy animal, it moves toward him. There is considerable evidence that a retarded child derives a great deal of enjoyment from "controlling" his environment[illegible] and should be allowed to do so when he can.

3. The words you use during play activities should emphasize a number of things. First, objects should be given a label(*"this is a ball"*)so the child will be able to give objects a name. Second, emphasis should be given to what the object can do or what the child can do with the object ("when you *push* the ball, it *rolls*"). Next, attributes of the object should be emphasized. This will help the child learn to describe objects and to understand the meaning of descriptions used by others ("the *ball* is *red, round, small, smooth*"). There should be opportunities for the child to put objects into categories, that is, to explore how things are alike and how they are different. Simple number concepts can also be introduced. ("These are all *balls*. This *ball* is *red* and this ball is *yellow*. This *ball* is *big* and this one is *little*. *Two* of the *balls* are *hard* and *one* is *soft*. There are *many balls* on the table.") Keep the content of what you say simple at first, moving gradually to more complex language concepts later[illegible]

4. Plan enough activities to involve your child as long as his interest is high. It is also a good idea to stop when interest has begun to wane, but is not completely lost.

5. By the time your child is about a year old use should be made of books, pictures, and records. This will help him to begin to make an important transition from an actual toy to a picture of the toy, and finally to a written representation of the toy. Let him help hold the book and help turn the pages as you read to him or talk about the story or pictures.

Play time — When

It is important to set aside some time every day to play on a one-to-one basis with your baby about an hour a day is recommended. Unless you systematically plan a play time each day it becomes very easy to let things slide, and your child does not receive the stimulation he needs so badly. You will want to try to choose a time when your baby is happy and in a receptive mood. When he is quite young you will probably have to break the hour up into a number of shorter sessions. Sessions should not run less than ten minutes at a time, however, because activities become too fragmented if the play period is too short.

Play time — Where

There are a number of factors which will determine where you play with your child such as his level of muscular development, ease of presenting the objects, and your child's and your comfort. You may want to place him on the floor, on his back or his stomach, or you may want to hold him on your lap at the kitchen table. Perhaps you will want him propped between your legs on the floor or sitting in his infant seat or high chair. If you are planning a water activity, you may want to schedule it at bathtime. At times you may even want to step into the tub with him. Whatever makes you and him happy and comfortable is fine.

You will probably find that during an hour's time you will have to change positions and locations several times. Babies tire easily and need to have their position changed quite often. In addition, a change in position provides him with the opportunity to view objects and people from different perspectives.

Play — How

It has been noted several times that it is important for the child to be actively involved in the lesson, doing as much as possible for himself. For this reason it is a good idea to build a positive habit of teaching with this in mind from the very beginning.

It is important that you provide a good language model for your child. Use simple complete sentences when you can and be consistent in your use of labels, especially for the first year. Later on he'll be able to see that a "doll" and a "baby" can have the same meaning in certain instances, or that "dog" and "puppy" refer to the same general class of animals. Make what you have to say more interesting by changing your expression, volume, and tone once in a while.

As you talk with him don't talk too much or too fast. Speak slowly so that he can understand what you are saying and pause once in a while so he has time to digest what you have told him before going on. You don't want him to get verbal "indigestion" because, if he does, he may "turn off" the talk around him.

One of the most important things to remember is to show your approval when he accomplishes something. This can be done very simply with a smile, a show of happy excitement, a little hand clapping, a touch and words like "good" or "I like that." As you show him that you value what he has done, he will realize that you value *him* and he will begin to develop a sense of self-worth and accomplishment and will try things over again as well as want to try new things to please you and himself.

Beyond the Play Lesson

Of course, a one-hour-a-day play lesson is not the only source of stimulation for your child. Rather, it is a means by which you can assure that he systematically receives something from the environment. What happens during the rest of the day is important, too, and some attention should be paid to that.

Provide him with opportunities to look at interesting things. A colorful mobile on his crib or some bright balloons hung around the room or bright wallpaper might be some ways to start. Don't overdo it, however. A few interesting things that he can cause to move are better than "drowning" him with all sorts of sights and sounds.

Bring him into the center of family activities as much as possible. Let the other children in your family play and "roughhouse" with him. Let him watch some of the good children's programs on television such as *Sesame Street* and *Captain Kangaroo*. Make a concerted effort to get him out of the three-by-three world of the playpen during the day so that he can explore the larger world around him.

Give him an opportunity to meet and relate to other people by taking him out of the house. Trips to the supermarket, walks around the neighborhood, excursions to the zoo, park or beach and stays in the nursery at your church will afford him this kind of experience.

None of what has been suggested is very mysterious or difficult. In fact, it can best be thought of as common sense used systematically. Certainly, there will be some moments of frustration when it will seem as if neither you nor your child are getting anywhere. But the joy of the many moments of success you share together will far outweigh any bad times you might have.

What you will be accomplishing with your baby will always be his, for he will develop basic language, muscular and social skills and will use these skills in exploring the world around him. He will learn that learning is fun. He will learn that the world is a fairly orderly, consistent, and interesting place. He will learn that *he* affects what happens in the environment. Most importantly, he will *not* know what it is to live "without the joyful faces and loving words" of his mother and father and others who love him.

Books for Children (with Notes about Each Book)

Art Seiden's Book of Toys. McLoughlin Brothers, Inc., 1965. (Color pictures of children's toys with minimum of text.)

Baby's First ABC. Platt and Munk, Publishers, no copyright date. (Thick cardboard pages that can be turned easily by a young child.)

Baby's Mother Goose. Grosset and Dunlap, 1959. (Heavy cardboard pages. Traditional nursery rhymes, colorful pictures.)

The Bear Scouts. Random House, New York, 1967. (A funny story filled with rhyming words.)

The Berenstain's B Book. Random House, 1970. (A funny story based on the letter B. Humorous illustrations.)

Best Word Book Ever. Richard Scarry, Western Publishing Co., 1963. (Vocabulary development, early sight reading skills, classification skills.)

The Big ABC Book. Renwal Products, Inc., 1968. (ABCs, picture-word matching. Heavy cardboard pages.)

Counting Rhymes. Grosset and Dunlap, Publishers, 1959. (Heavy cardboard pages. Traditional nursery rhymes which emphasize counting.)

Ding-a-Ling Book. Golden Press, 1970. (Printed on cardboard, emphasizes different sounds.)

The Ear Book. Random House, New York, 1968. (Rhyming words and interesting sounds.)

The Early Bird. Random House, 1968. (A cute story about a bird who hunts for and finds a worm. Lots of animals — vocabulary builder.)

Egg in the Hole Book. Golden Press, 1967. (Heavy cardboard pages.)

Faces. E. P. Dutton and Co., Inc., 1970. (Photographs of faces and parts of faces that teach body parts and use.)

The Foot Book. Random House, 1968. (How feet are alike and how they're different, emphasizing descriptive words, e.g., wet, dry, small, big, etc.)

Funny Bunnies. Platt and Munk, Publishers, 1969. (Cute animal story with color photos of rabbits.)

Go, Dog, Go. Beginner Books, a Division of Random House. (Funny pictures, language development emphasizing size and space relationships.)

The Great Big Car and Truck Book. Golden Press, 1951. (Picture book for vocabulary development and development of classification skills.)

Hi Diddle Diddle. Scholastic Book Services (paperback Mother Goose, 1966).

I Can Fly. Golden Press, 1958. (The joy of make-believe as seen by a preschool child. Language development, animals and their names.)

I Want to be a Bird. Houghton Mifflin, 1964. (A funny story which deals with feelings.)

I Want to Read. Golden Press. 1970. (Early reading skills: sight vocabulary development through use of signs in book.)

Katy No-Pocket. E. M. Hale and Co., 1968. (One of the most popular children's stories ever written.) Out of print, available at libraries.

The Look Look Book. (Printed on cardboard, an action book which emphasizes language development, e.g., fast, slow, dark, light, etc.)

My House. Golden Press. (Cloth with non-toxic ink that a baby can mouth. Vocabulary development.)

My Toys. Golden Press. (Cloth book with non-toxic ink that a baby can mouth. Vocabulary development.)

Old Hat, New Hat. Random House, 1970. (Funny story with humorous illustrations emphasizing descriptive words, e.g., old, new, fancy, shiny, etc.)

One Fish, Two Fish, Red Fish, Blue Fish. Random House, 1960. (Counting, colors, rhyming words and fun and nonsense.)

Peter Rabbit. Grosset and Dunlap, Publishers, 1971.

Pickles Don't Grow on Trees. Random House, no copyright date. (Picture book about where food really comes from.)

Pop-Up Mother Goose. Random House, no copyright date. (Mother Goose stories with pop-up illustrations.)

Red and Blue. Platt and Munk, Publishers, 1965. (Colors and vocabulary development.)

See What Baby Can Do. Golden Press. (Cloth with non-toxic ink that a baby can mouth.)

The Sesame Street Alphabet Book. Little, Brown and Co., 1970. (Letter recognition.) *The Sesame Street Book of Shapes.* Little, Brown and Co., 1970. (Shape identification.) *The Sesame Street Book of Puzzles.* Little, Brown and Co., 1970. (Problem Solving.) *The Sesame Street Book of Numbers.* Little, Brown and Co., 1970. (Counting, number concepts 1-10.)

Snow. Beginner Books, a Division of Random House, 1962. (Language development — tall-short, etc. Rhyming words.)

Soft as a Bunny. Holt, Rinehart and Winston, 1969. (Language development — hot-cold, wet-dry, soft-hard, etc.)

Ten Apples Up On Top. Random House, Inc., 1961. (Counting and numbers.)

The Touch Me Book. Western Publishing Co., Inc. (A Golden Press Book), 1961. (Printed on cardboard, offers opportunities for child participation. Language development, textures, e.g., rough, smooth.)

The Three Bears and Goldilocks. Platt and Munk, 1962.

The Three Little Pigs. Platt and Munk, Publishers, 1961.

Up and Down. Wonder Books: Grosset and Dunlap, 1965. (Beginning reading, spatial concepts.)

Where's My Baby? Houghton Mifflin, Co., no copyright date. (Fold-out illustrations of farm animals and their babies.)

Who Lives Here? Western Publishing Co., Inc. (A Golden Press Book). 1961. (Printed on cardboard, offers opportunities for child participation and teaches the association between animals and their homes.

Why I Built the Boogle House. Random House, 1964. (A story about pets that get larger and larger. Good photographs.)

Zip-Zip Book. Golden Press, 1970. (Vocabulary development based on things that zip.)

The Zoo Book. Platt and Munk, Publishers, 1968. (Color photos of animals; beginning reading.)

Phonograph Records

Children's Creative Playsongs, Vols. I & II. Stepping Stones Records.
Ella Jenkins Records, Folkways Records
  Play Your Instruments and Make a Pretty Sound
  Early, Early Childhood
Hap Palmer Records, Educational Activities, Inc.
  Learning Basic Skills Through Music, Vols. I & II
  Learning Basic Skills Through Music, Building Vocabulary
  Learning Basic Skills Through Music, Health and Safety

A Suggested List of Toys and Objects

Toys Which Are Available Commercially

balls of different sizes
Nerf ball
wiffle ball
blocks
nested kegs
dolls
spring castanets
rocking stacking toy
toy animals, rubber, stuffed
Fit-A-Group, Match-The-Pegs
4-5 piece puzzles
large wooden beads for stringing
flannel board and objects
pull toys, plastic bracelets
farm set
tom-tom, drum
rattles
bells
zipper, button, snap toys

crayons
paste
paper (construction, drawing)
children's scissors
floating toys
tambourine
spinning top
bubble soap
puppets
graduated sizes and shapes
plastic snap beads
bean bags
nut and bolt toy
ABC and number games
clay
bus with people
large whistle
finger paints
harmonica

Toys Which Are Easily Made at Home

- dolls
- beanbags and board
- picture books
- color objects
- finger paint (see below)
- milk carton blocks
- paste (see below)
- graduated shapes
- puppets
- texture books
- flannel board, flannel objects
- clay (see below)
- thread spool beads
- toy animals

Objects Found Around the House

- thread spools
- plastic jars
- masking tape
- pulley, clothespin
- brush, comb
- poker chips
- cotton balls
- boxes of all sizes and shapes
- plastic bowls
- paper bags
- gloves
- sandpaper
- suitcases
- "L'eggs Eggs"
- typewriter ribbon spools
- sponge
- coated electrician's wire
- mirror
- straws
- pipe cleaners
- old purses, bags
- measuring cups, spoons
- foil pans
- rubber bands
- magazines
- key chain with old keys
- pots and pans, lids
- baskets

Materials Which You Can Make at Home

Finger Paints

Add color to liquid starch. Pour it on wet surface.

Instant or cooked pudding makes interesting finger paint.

Put soap flakes into mixing bowl and add water gradually while beating with egg beater. Beat to consistency of stiffly beaten egg whites. Add color.

Clay

2 cups flour
1 cup salt
small amount of liquid oil

Use enough water to moisten flour and salt into a dough. Add food coloring to water to color the clay. Consistency is like cooky dough.

Paste

½ cup sugar
½ cup flour
½ tsp. powdered alum
15 drops oil of cloves

Mix water with sugar and flour to make smooth paste. Add alum and cook until thick, stirring constantly. When thick, add oil of clove. Let it cool before storing in jar with lid.

LOOKING AHEAD

Marylee C. Fithian, Teacher

The Roman philosopher, Seneca, said, "As is a tale, so is life; not how long it is, but how good it is, is what matters." Certainly, most people would agree with this sentiment, but it is only recently that society has begun to apply this philosophy toward the retarded. Little by little the "Normalization Principle" is taking hold as the guiding principle for programs and agencies serving the retarded. This means that we are slowly beginning to make available to the mentally retarded "patterns and conditions of everyday life which are as close as possible to the norms and patterns of mainstream society."[40] This principle can be applied to all retarded pesons no matter how severe their retardation or what related physical handicaps they might have.

The School Years

During the school years the principle of normalization is implemented through public education of the retarded. Recent legislation in Minnesota recognizes the right of all retarded children "who may reasonably be expected to benefit socially, emotionally, or physically from a program of teaching . . . ," to a public education.[41] School districts are required to provide a program for a retarded child when he reaches age five, which they may do in a number of ways, such as by providing special classes, instruction at home, or contracting with public, private or voluntary agencies.

Programs which are available vary to some extent in content and in quality. Most, however, have certain basic goals in common.

First, they attempt to provide stimulating and rich experiences which will help the child see the world as an orderly, consistent, and interesting place.

Second, the programs help to develop basic skills which are the foundations for life. These include development of muscular abilities and basic self-help skills such as eating, dressing and toileting. There should be a great deal of emphasis on language and communication skills which include work in listening, verbal and gestural expression and functional reading. As the child grows older, pre-vocational and vocational training is introduced.

Third, the programs provide experiences that are useful in enjoying, exploring and living in the world.

Finally, and most importantly, the programs help the child attain a feeling of personal identity and self-regard. They provide opportunities for him to try out his skills in relationships with others, and he will learn that he is a sharing member of society.

Adulthood

In past years there were few options available to the retarded person usually it was a choice of living out his years at home with his family or in an institution with little opportunity in either situation to make any useful contribution to society. Today, the options are not as limited nor as limiting.

Some of the programs for persons in the later school years (15-21) provide channels of transition from childhood to adulthood responsibility through a work-study program or a job-station training program for those persons who are able to pursue an independent life situation. In this type of program school personnel assist in job placement and evaluation. They also provide on-the-job support and follow-up. Individuals receiving this form of training often find competitive employment in jobs such as dishwashers, bus boys, and assembly-line workers.

For severely retarded individuals who are capable of productive work but cannot compete on the open job market, sheltered workshops can provide employment. A sheltered workshop facility provides an habilitation program using a controlled working environment. The work provided is usually subcontracted from a business in the community, and wages are determined by the person's ability to produce.

There are severely retarded persons who are not able to meet the minimal standards of sheltered workshop programs but need to develop basic vocational skills. These skills are developed by performing very simple tasks in Work Activity Programs. Work activity programs also provide training in self-help, social, and leisure-time skills.

For those persons who are profoundly limited in their work skills but are still able to remain in the community there are Daytime Activity Center programs available. These programs emphasize self-help, social, and leisure-time skills and provide some training in communication skill development.

For persons who can take advantage of these programs, the options for living arrangements are also expanding. Some will live at home with their families, others in community residences. Still others will be members of small group homes and some will be helped to live in their own apartments. There are still retarded persons being placed in our state institutions, but they are usually those persons whose needs cannot be met in community programs.

The life of a retarded person can be productive and self-satisfying through programs which are now available and which will be developed in the future. As with members of mainstream society, the life of a retarded person can and should be looked at in terms of how good it is for him, that is to say, *how happy he is and what he contributes to himself and to others.*

EPILOGUE: LOOKING TO THE FUTURE

Barbara Thomes, Mother

We have spoken with you of our emotional reactions to the births of our Down's Syndrome babies, of the medical explanation for the births, of the social repercussions affecting both the child and his or her family, and of the educational needs of our babies. But what of the future? What do we expect of our children as they grow older? What may we realistically expect of them?

The expectations and predictions of the past have been quite simple. Expect nothing! If we refuse to accept that view, then we will at least expect something. We will rejoice over each small accomplishment of our child be it crawling, walking or feeding himself. But should we not go a step further? Should we not expect that he accomplish many of the tasks that a normal child does, even though they may come later? Why shouldn't the young Down's Syndrome child learn to walk and run? Why shouldn't he feed himself and drink from a cup at a fairly early age? Why shouldn't he be toilet trained? But beyond the basic self-help skills, what should we expect? Acceptable social behavior, for one thing, which does not exclude the need for discipline. To excuse our children's bad behavior because they are retarded is selling them short. The need to be accepted by the normal world is a very necessary part of their growth, and to be shunned because of annoying or repulsive habits will cut the children off from the normal world immediately without allowing their other achievements to shine forth. We cannot underestimate the importance of training them in the social graces, and that training will demand much patience and perseverance.

We hope that our children experience many of the joys of life. We hope that they will develop recreational skills such as skiing, skating, swimming and ball playing. We would like to encourage them in the fields of art and music, two wonderful media of self-expression which will supplement their lack in the area of verbalization. These are some of the things we want for them. Maybe they will tell us what they want for themselves! One young eighteen-year-old Down's boy, whom one of us met recently, had set his hopes on driving a car. His parents wisely told him to learn all there is to learn in the driver's manual and then take the test. So, the boy is studying hard. At least if he is turned down, his parents will have given him the chance to prove himself.

We want to build the desire to learn in our children. This is where early stimulation, mentioned previously, proves itself. If, from birth, we have encouraged them to be curious, and have opened up every reasonable avenue of exploration to them, we can expect a great deal more than has ever been thought possible. We have before us the examples of many courageous parents who, despite the dismal prognosis of their doctors and the stigma cast on their children by society, have forged ahead doing what they instinctively knew should be done stimulate, teach, and expect something. The children of these parents are now adults, contributing to society in many ways. They are using public transit systems, working at steady paying jobs, making longdistance telephone calls, and paying taxes. Those are things we too hope for. When we see how parents have inspired their children without guidance and frequently against the trend of society, how much more we should expect of our children now that we have the benefits of research, of increasing social acceptance, and of schooling that parents and interested educators everywhere are striving for. The whole outlook is one of hope. We have come a long way from the past, and we have far to go, but that we live in this time of awakening is a reason for being grateful.

Discouragement will inevitably be a part of our parenthood. It is a part of rearing normal children, and will be more pronounced with our handicapped children. We may set goals too high for them to reach. We may have to abandon our hopes because of physical impairments that arise. We may, as Pearl Buck illustrates so vividly in her beautiful book, *The Child Who Never Grew*, find that we are taxing our children so much that the strain on them and us becomes unbearable, and at the expense of their and our happiness. We may always hope, but when, with our eyes wide open, we see that our demands are futile or even destructive, we must have the strength to admit that we have exceeded reality.

We have hope. We expect that our children will contribute to society in some way, even though the way is not yet clear to us. We pass our hope on to you.

Sincerely,

Barbara Thomes

Barbara Thomes and Minnesota Parents in Project EDGE

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SELECTED REFERENCES AND RESOURCES FOR PARENTS

A. Facts About Mental Retardation and Down's Syndrome

Attwell, A. & Clabby, D. *The retarded child: Answers to questions parents ask*. Burbank, Calif.: Fire Press, 1969

Helpful information about causes and treatment of mental retardation, family relationships, schooling, and vocational planning. It is comprehensive and readable.

Sarason, S. & Doris, J. *Psychological problems in mental deficiency*. New York: Harper & Row, 1969.

A textbook that examines the issues and problems which have dominated the field of mental retardation in terms of research and program development. It describes how theories and practices which characterize a field at a particular point in time reflect the nature of society at that time. Deals with biological and medical factors and their relationship to psychological and social aspects of mental retardation.

Wolfensberger, W. & Kurtz, R. *Management of the family of the mentally retarded: A book of readings*. Chicago: Follett Educational Corporation, 1969.

A collection of articles which cover such topics as causes of retardation, counseling, therapy, education, and family management.

Kramm, E. *Families of mongoloid children*. Washington, D.C.: Children's Bureau, U.S. Department of Health, Education and Welfare, 1963.

A very readable pamphlet describing the results of a study involving 50 families who had a Down's child living at home. Through case studies the pamphlet offers a description of how these families faced problems, handled them, and what their ultimate adjustment has been.

B. Personal Experiences of Parents with Down's Syndrome Children

Buck, P. *The child who never grew*. New York: John Day, 1950.

A moving story about the author's Down's Syndrome daughter.

Hunt, N. *The world of Nigel Hunt: The diary of a mongoloid youth*. New York: Garrett Publications, 1967.

An autobiographical essay written by a Down's Syndrome youth. A poignant account of the world as seen through the eyes of someone with mental retardation. It offers great encouragement and challenge to parents of Down's Syndrome children.

Perske, R. *New directions for parents of persons who are retarded*. New York: Abingdon Press, 1973.

Beautifully illustrated. Written in a delightfully tender yet practical manner.

Roberts, N. & Roberts, B. *David.* Richmond, Va.: John Knox Press, 1968.

An extremely sensitive account through words and excellent pictures, of the first four years in a mother's relationship with her Down's Syndrome child.

Seagoe, M. *Yesterday was Tuesday, all day and night.* Boston: Little, Brown, 1964.

A story about Paul Scott, a Down's Syndrome individual, whose father helps him accomplish many things through tutoring, travel and language training. Much of it is Paul's diary. The epilogue is a discussion about the pros and cons of residential placement.

C. Educating your Down's Syndrome Child

A helpful guide in the training of a mentally retarded child. New York: National Association for Retarded Citizens, 1968.

Available free, this pamphlet offers principles to follow in home training, discipline, feeding, and personal hygiene. Developmental charts complement the text.

Bensberg, G. *Teaching the mentally retarded: A handbook for ward personnel.* Atlanta: Southern Region Education Board, 1965.

Principles and methods for teaching basic skills. The teaching method described is positive reinforcement (reward). Detailed, illustrated lesson plans are provided which show the step-by-step process of backward chaining.

Connor, F. and Talbott, M. *An experimental curriculum for young mentally retarded children.* New York: Teacher's College, Columbia University, 1964.

This curriculum guide contains a listing of general objectives for basic skill areas such as self-help and communication development and breaks them down into specific tasks. Each task is defined so that the goal is clear and is rated from easy to difficult. A program is described by which the child can move from an easy level to a more difficult level.

Dreikurs, R. & Grey, L. *Logical consequences: A new approach to discipline.* New York: Hawthorne Books, 1968.

The authors examine parent-child relationships and develop an approach to disciplining the child through the use of logical or natural consequences.

Dreikurs, R. & Grey, L. *A parent's guide to child discipline.* New York: Hawthorne Books, 1970.

Presents practical step-by-step directions for dealing with child discipline problems which apply to children from birth to maturity. Numerous case histories.

Molloy, J. *Trainable children: Curriculum and procedures*. New York: John Day, 1963.

Offers a great deal of helpful general information about planning training programs for a retarded child. Deals with evaluating the effectiveness of educational programs and the child's progress. A comprehensive bibliography and lists of resources are also included.

Spache, G. *Good reading for poor readers*. Champaign, Ill.: Ganard Publishing, 1970.

Lists many types of books in annotated bibliography form. Provides information about how to choose books to help teach the child about himself and his surroundings. Most of the books are for fourth grade reading level and above.

Strang, R., Phelps, E., & Withrow, D. *Gateways to readable books: An annotated graded list of books in many fields for adolescents who find reading difficult*. Bronx, N.Y.: H. W. Wilson, 1966.

This book has over 1000 titles covering a wide variety of interest areas (adventures, animal life, aviation, humor) for adolescent boys and girls. Books are rated according to reading difficulty, with most books at the fifth, sixth and seventh grade level. Also contains a short bibliography of recommended books for mentally retarded readers.

D. Speech and Language Development

Battin, R. & Haug, C. *Speech and language delay: A home training program*. Springfield, Ill.: Charles C. Thomas, 1964.

Designed for parents, it describes normal speech and language development and causes of language delay. It offers a simple instructional outline for a day-to-day stimulation program.

Molloy, J. *Teaching the retarded child to talk: A guide for parents and teachers*. New York: John Day, 1961.

This book will be of help to parents and teachers of very young retarded children. In a clear and concise manner, the author discusses the causes of speech difficulty as well as the process of learning to speak. The successive steps that the parent or teacher should follow in developing the speech of a retarded child are set forth. There is a special chapter on helping Down's Syndrome children.

F. Art, Music and Science

Alvin, J. *Music for the handicapped child*. London: Oxford University Press, 1965.

Deals with the handicapped child's social and emotional well being and describes helpful musical experiences. Written for parents, teachers, social workers, and other professionals, it is basically a therapy approach to music.

Antey, J. *Sing and learn*. New York: John Day, 1965.

This colorful book of simple songs related to everyday life (food, rain) includes teaching instructions designed to make the songs more meaningful to retarded children. The first section presents songs and simple music activities. The second section is about making simply rhythm instruments, and the third section is concerned with the use of teaching aids such as a toy piano and tape recorder. A very practical and enjoyable book.

Ginglend, D. & Stiles, W. *Music activities for retarded children: A handbook for teachers and parents*. Nashville: Abingdon Press, 1965.

A helpful guide to incorporating music into the classroom and home for teachers and parents with little or no formal background in music. It includes simple songs, folk dances and instructions in the use of instruments such as the record player, autoharp and percussion instruments.

Haupt, D. *Science experiences for nursery school children*. Washington D.C.: National Association for the Education of Young Children.

Provides basic instruction in adapting science experiences for a young child's understanding. Written with the teacher in mind, it suggests classroom "experiments," all of which can be carried out at home with some modifications.

Hunter, H., Wahl, A. & Willmans, R. *Arts and crafts for retarded children*. New York: Know Publications, 1962.

A useful book of arts and crafts ideas. Most of the materials are easily obtained and inexpensive. The crafts activities vary in complexity and can be used with both young and older children. Some games to play with hand-made materials are included.

Jones, E. *What is music for young children?* Washington, D.C.: National Association for the Education of Young Children, 1969.

Another teacher-oriented pamphlet that can be adapted for home use. It suggests types of instruments and songs to use and presents anecdotes about each musical event.

F. Religious Training

A selected bibliography on religion and religious education. New York: National Association for Retarded Citizens, 1971.

Lists resources for parents of Catholic, Protestant and Jewish children.

G. Sex Education

Lerrigo, M. & Southard, M. *A story about you.* Chicago: American Medical Association and National Education Association, 1964.

A booklet that can be read by a mildly retarded young adult with help from an adult with normal reading ability. Covers the topics of: How life begins, gestation, birth, and provides a general picture of human development through adulthood.

The sex educator and moral values. Sex, science, and values. Masturbation. Sex Information and Education Council of the U.S., Northfield, Illinois, 1959.

These booklets are prepared for the adult with normal reading ability, probably the retarded individual's parent or teacher. Materials are factual and interesting.

Kempton, W., Bass, M., & Gordon, S. *Love, sex and birth control for the mentally retarded: A guide for parents.* Syracuse: Planned Parenthood Association of Southeastern Pennsylvania, and Family Planning and Population Information Center, Syracuse University, 1972.

An excellent booklet for parents to use in instructing a retarded child. (A parent would be well advised to also obtain the book: *Facts about sex for exceptional youth* by S. Gordon, Printing House of Charles Brown, Inc., 1969, for their retarded adolescent or young adult because the illustrations are identical in both books while the printed matter is simplified in the latter).

Sex education: Required reading. The Child Study Association of America, Inc., 1969.

An extensive annotated bibliography for parents of exceptional children. Contains materials to be read by parents, for parents to read to their child, and for children to read for themselves.

Andry, A. & Schepp, S. *How babies are made.* New York: Time-Life Books, 1968.

A beautifully illustrated and tastefully written book which explains reproduction clearly and simply. A book that parents could use with their young retarded child and one which the retarded child could use himself since it's written on about the first-grade level.

H. Clothing

Bare, C., Boettke, F., & Waggoner, N. *Self-help clothing for handicapped children.* National Easter Seal Society for Crippled Children and Adults, 1962.

A practical, illustrated guide for parents in the selection and adaptation of clothing for physically handicapped children.

Karroll's, Inc. Institution Division, 32 North State Street, Chicago, Illinois 60602. (Catalogue). Shows many types of clothing that retarded individuals will find easy to use.

I. Dental Care

Green, A. *A preventative care guide for multihandicapped children: Dental care begins at home.* National Easter Seal Society for Crippled Children and Adults, 1970. (Free)

Tips for parents to help keep their handicapped child's teeth healthy.

Young, W. & Mink, J. *Dental care for the handicapped child.* National Easter Seal Society for Crippled Children and Adults, 1965.

Describes special dental problems of handicapped children.

J. Furniture and Equipment

Handi-Chair and Equipment Development, Inc. 116 Salem Drive, Ithaca, New York 14850. (Catalogue). Presents descriptive material about furniture and equipment for physically handicapped persons.

Hofmann, R. *How to build special funiture and equipment for handicapped children.* Springfield, Ill.: Charles C. Thomas, 1971.

An illustrated, step-by-step set of plans for constructing special furniture and equipment.

Kalt, B. & Bass, R. *The mother's guide to child safety.* New York: Grosset and Dunlap, 1971.

Instructs mother in arranging a safe living environment.

Rehabilitation International, 219 East 44th Street, New York, New York, 10017.

Catalogue of hundreds of physical aids and pieces of equipment for handicapped individuals.

Rosenberg, C. *Assistive devices for the handicapped.* American Rehabilitation Foundation, 1968.

A two-part document that describes how various devices can be used to help a physically handicapped person move about and utilize opportunities for work, recreation, etc.

K. Recreation Activities, Toys and Materials

Carlson, B. & Ginglend, D. *Play activities for the retarded child.* Nashville: Abingdon Press, 1961.

A guide for parents and teachers. Activities are grouped according to social, physical, language, and intellectual requirements and are arranged in order of increasing difficulty. Within each group are specific games and activities that will improve abilities. Many of the suggestions can be implemented at home with simple hand-made materials.

Clepper, J. *Growing up with toys.* Minneapolis: Augsburg Publishing House, 1974.

This book has just the right amount of solid useful information for parents about choosing toys and using them. It is flavored with many interesting notes from history, anthropology and from educational research.

Recreation and physical activity for the mentally retarded. Prepared by a joint committee of the Council on Exceptional Children and the American Association for Health, Physical Education and Recreation, 1966.

Explains what play can do for the retarded, what type of program can be instituted and offers practical hints about getting children to participate. An annotated bibliography is included.

Recreation for the mentally retarded: A handbook for ward personnel. Atlanta: Southern Regional Education Board, 1964.

Focuses on recreational and arts and crafts activities and provides a selection of games. One hundred eighty-six specific games are described along with thorough instructions for participating.

Toy book. Alpha Chi Omega, 1960.

Provides patterns and directions for making inexpensive but excellent entertaining and educational toys.

Water, sand, and mud as play materials. Washington, D.C.: National Association for the Education of Young Children, 1959.

Explains how simple natural materials can provide enjoyable learning opportunities.

L. Planning for your Child's Future

Beck, H. *Social services to the mentally retarded.* Charles C. Thomas, 1969.

Primarily written for social workers who deal with retarded individuals and their families. It is written simply and concisely.

Begab, M. *The mentally retarded child: A guide to services of social agencies.* Children's Bureau Publication #404, 1963.

Written for parents and professionals, it describes problems faced by parents of retarded individuals and the ways in which social service agencies attempt to deal with these problems. It offers some alternatives for lifetime planning.

Marino, F. & Green, B. *How to provide for their future.* New York: National Association for Retarded Citizens, 1963.

Suggestions for parents concerned with providing life-time protection for their retarded child.

M. Suggested Places to Write for Information:

National Society for Crippled Children and Adults
11 S. La Salle
Chicago, Ill. 60603

Public Affairs Pamphlets
381 Park Ave. S.
New York, N.Y. 10016

Association for Childhood Education International
1201 16th St. N.W.
Washington, D.C. 20036

National Association for Retarded Citizens
420 Lexington Ave.
New York, N.Y. 10017

Council for Exceptional Children
1411 Jefferson Davis Hwy., Suite 900 Jefferson Plaza
Arlington, Va. 22202

The President's Committee on Mental Retardation
U.S. Government Printing Office
Washington, D.C. 20207

American Association on Mental Deficiency
5201 Conn. Ave.
Washington, D.C. 20015

National Association for Education of Young Children
1834 Conn. Ave., N.W.
Washington, D.C. 20009