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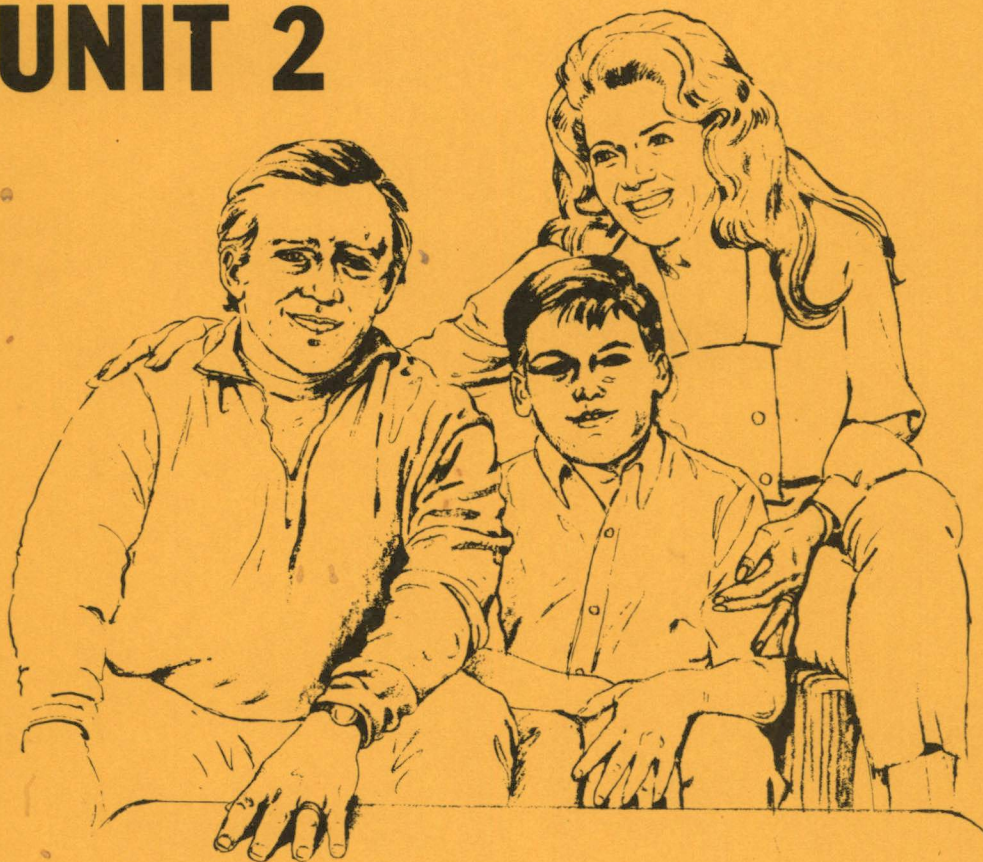
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INSTRUCTION

FAMILY STAGE

UNIT 2



PARENTAL SKILLS PROGRAM HANDICAPPED CHILDREN



SELF-INSTRUCTION WORKBOOK

UNIT II

FAMILY STAGE

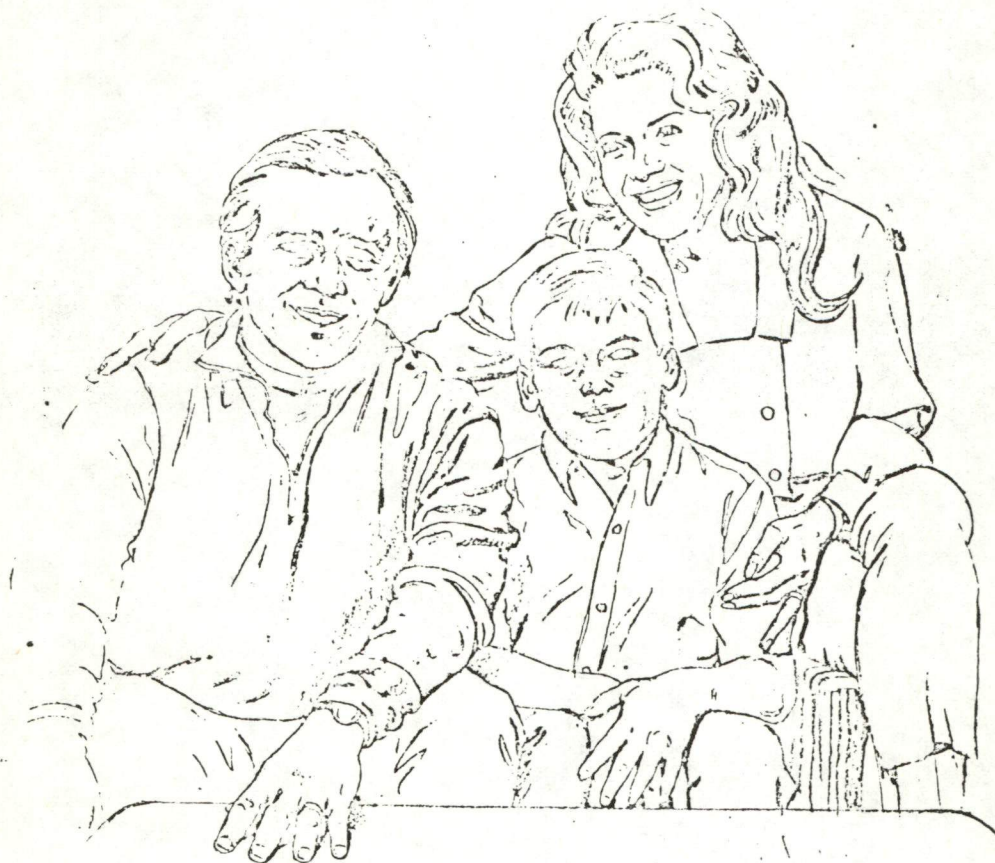
PARENTAL SKILLS FOR PARENTS OF
HANDICAPPED CHILDREN

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FAMILY STAGE



INSTRUCTIONS: Turn the page and begin reading. Take a sheet of paper and slide it down the page as you read. Throughout the unit, you will come to exercises marked with a big circle. You should complete each exercise as you come to it. Then slide the paper down and check your answer with the answer provided immediately following the exercise. If you are not satisfied with your answer, go back and read the part just before the exercise and then redo the exercise. When you are satisfied with your answer, proceed with your reading.

UNIT 2

THIS IS THE SECOND UNIT IN THE PARENTAL SKILLS PROGRAM. IT DEALS WITH THE PROBLEMS AND PATTERNS THAT OCCUR ON THE TYPICAL FAMILY STAGE WHERE THERE IS A HANDICAPPED CHILD.

FAMILY STAGE

ALL FAMILIES OPERATE ON WHAT MIGHT BE CALLED A FAMILY STAGE. WHERE MANY DIFFERENT FAMILY SCENES ARE ACTED OUT.

FAMILY STAGE

- ACTORS
- PARTS

EACH FAMILY STAGE HAS A NUMBER OF ACTORS WHO ARE IN REALITY THE PEOPLE IN THE FAMILY. THESE ACTORS USUALLY PLAY MORE THAN ONE PART. THERE IS A PERSON WHO ACTS THE PART OF BOTH HUSBAND AND FATHER, OR WIFE AND MOTHER. THE YOUNGSTERS ACT THE PART OF BOTH CHILD AND BROTHER OR SISTER.



Think of your own family. List the names of the actors who play each of these parts in the blanks below:

Mother _____	Father _____
Wife _____	Husband _____
Child _____	Child _____
Sister _____	Brother _____
Child _____	

(You should have the same name by mother and wife; by father and husband; by child and your son; by child and your daughter, and if you have only one child, he plays only one part: that of child.)

FAMILY STAGE

- ACTORS
- PARTS
- SCRIPTS

THESE ACTORS FOLLOW SCRIPTS. THE SCRIPTS ARE IMAGES THEY HAVE IN THEIR MINDS CONCERNING HOW THEY SHOULD PLAY THEIR PARTS. FOR EXAMPLE, MOTHERS HAVE IMAGES OR SCRIPTS THEY FOLLOW FOR BEING A MOTHER. FATHERS HAVE SCRIPTS TOO. PARENTS ALSO HAVE OTHER SCRIPTS TO FOLLOW IN THEIR PARTS AS HUSBAND AND WIFE.



Check (✓) the one statement below which best describes a script for an actor on a real family stage:

- _____ 1. People in real life don't follow scripts
- _____ 2. People in real life follow only one script
- _____ 3. A script involves the ideas we have in our mind about how we are to play our part. We usually have a different script for each part we play.

(#3 is correct. The main difference between a real life script and one in a play is the real life script is not a word-for-word description of what to say and do. Instead we decide how to act and what to say from the ideas in our mind which make up our script.

FAMILY STAGE

- ACTORS
- PARTS
- SCRIPTS
- AUDIENCE

PEOPLE WHO ARE NOT DIRECTLY INVOLVED WITH THE FAMILY ARE THE AUDIENCE FOR THE FAMILY STAGE. THESE PEOPLE WATCH WHAT THE FAMILY DOES. THEY ALSO JUDGE AND EVALUATE PERFORMANCES. THE AUDIENCE CAN CRITICIZE OR APPROVE OF THE ACTORS AND THE WAY THE ACTORS ACT THEIR PARTS. SOME MEMBERS OF THIS AUDIENCE ARE FRIENDS....SOME ARE ACQUAINTANCES....SOME ARE PROFESSIONALSAND SOME ARE STRANGERS.



Think of the different people outside your family who are interested in and who watch what happens on your family stage. We can think of these people as our audience watching our family play.

List some of the people in your audience:

(Some members of family audiences are: (1) friends, (2) neighbors, (3) co-workers, (3) ministers, (4) counselors, (5) doctors, (6) in-laws, (7) relatives.



HANDICAPPED
CHILD

WHEN A HANDICAPPED CHILD APPEARS ON THE FAMILY STAGE A NEW PLAY BEGINS. MANY FAMILIES HAVE GREAT DIFFICULTY IN ADAPTING TO THIS NEW SITUATION.

3 ACTS

ACT I
ACT II
ACT III

BY USING THE STAGE CONCEPT, WE CAN ANALYZE THE EVENTS THAT OCCUR AND THE PROBLEMS THAT ARE FACED BY MANY PARENTS WHO HAVE HANDICAPPED CHILDREN. THESE EVENTS AND PROBLEMS TEND TO FALL INTO THREE ACTS.

ACTS

I CRISIS
II PUZZLE
III RESOLUTION

IN ACT I, THE CRISIS, STRESS PROBLEMS OCCUR WITH THE INTRODUCTION OF THE HANDICAPPED CHILD INTO THE FAMILY. ACT II, THE PUZZLE, DEALS WITH THE IMPACT OF THE HANDICAPPED CHILD ON ALL FAMILY MEMBERS AND ON THEIR RELATIONS WITH OTHERS. AND IN ACT III, THE RESOLUTION, THE ACTORS ON THE FAMILY STAGE STRUGGLE TO RESOLVE THE PUZZLE.



The most common problems and events which occur on a family stage where there is a handicapped child can be thought of as occurring in three acts.

In the blanks below, write the name of each act:

Act I _____

Act II _____

Act III _____

(Act I - The Crisis; Act II - The Puzzle; Act III - The Resolution.)

ACT I
THE CRISIS

ACT I BEGINS WHEN PARENTS BECOME AWARE THAT THEIR CHILD HAS A HANDICAP. THIS AWARENESS MAY OCCUR AT THE CHILD'S BIRTH OR LATER IN HIS DEVELOPMENT. IT MAY ALSO OCCUR AT THE TIME OF A SERIOUS AND PERMANENT INJURY. BECOMING AWARE THAT A CHILD HAS A HANDICAP CREATES A CRISIS FOR THE PARENTS.

INITIAL REACTION

THE INITIAL REACTION MOST PARENTS FEEL IS ONE OF TREMENDOUS STRESS AND GRIEF.

- SHOCK
- MOURNING

MANY PARENTS RESPOND TO THE CRISIS WITH A FEELING OF SHOCK THAT THIS COULD HAVE HAPPENED TO THEM. THEY ARE IN A STATE OF DISBELIEF THAT CAN LAST QUITE A LONG WHILE. PARENTS ALSO GENUINELY MOURN FOR THE LOSS OF THEIR DREAMS AND HOPES FOR THEIR CHILD.

- SHOCK
- MOURNING
- GUILT

ANOTHER FEELING PARENTS OFTEN HAVE WHEN A CHILD BECOMES HANDICAPPED IS GUILT. PARENTS MAY BLAME THEMSELVES FOR THIS MISFORTUNE; THIS MAY LEAD TO FEELINGS OF ANGER AND RESENTMENT TOWARD THEMSELVES AND THEIR CHILD. BUT SINCE THESE NEGATIVE FEELINGS TOWARD THE CHILD ARE UNACCEPTABLE TO MOST PARENTS THEY ARE EXPRESSED AS FEELINGS OF GUILT.

- SHOCK
- MOURNING
- GUILT
- ANXIETY

OFTEN PARENTS DEVELOP ANXIETY BECAUSE THEY DOUBT THAT THEY WILL BE ABLE TO COPE WITH WHAT HAS HAPPENED TO THEM. AS THEY LOSE CONFIDENCE IN THEIR OWN ABILITY TO DEAL WITH THE CRISIS, THEIR ANXIETY ABOUT THE FUTURE GROWS.



Put a check (✓) beside the statements below which describe your own reactions upon learning of your child's handicap:

_____ shock

_____ guilt

_____ mourning

_____ anxiety

(You may have checked every statement because most parents upon learning of their child's handicap have some or all of these reactions. These feelings are natural and there isn't a set time for getting over them.)

DESTRUCTION OF

- DREAMS
- PREDICTABILITY
- SELF-CONFIDENCE

THE CHILD'S HANDICAP OFTEN DESTROYS THE PARENT'S DREAMS, SENSE OF PREDICTABILITY AND SELF-CONFIDENCE.



DREAMS

ALL PARENTS HAVE DREAMS FOR THEIR CHILDREN. IN THESE DREAMS MOST PARENTS SEE A PERFECT CHILD GROWING UP AND GOING THROUGH THE NORMAL STAGES OF CHILDHOOD, ADOLESCENCE AND MATURITY. IF THEIR CHILD IS BY BIRTH OR ACCIDENT HANDICAPPED, THE PARENTS SUFFER FROM A LOSS OF THEIR DREAMS.



Many parents upon learning of their child's handicap say it was a very difficult time for them. Check (✓) the statements below which describe how you felt at that time.

- _____ Your dreams about your child were destroyed
- _____ You felt a loss of predictability
- _____ Confused and bewildered
- _____ Did not know how to behave in this new situation
- _____ Afraid
- _____ Did not know what to expect or which way to turn
- _____ Knew nothing about the handicap
- _____ Whole life plan suddenly shattered
- _____ Knew nothing about caring for a handicapped child
- _____ Everything seemed different
- _____ Had problems getting information about the handicap
- _____ Loss of self-confidence
- _____ Feelings of not being able to cope

(You may have checked all the blanks. Many parents report feeling all these things and more. It is only natural to feel these ways because the situation is so new and you do not know what to expect.)

PREDICTABILITY

THE PARENTS SENSE A LOSS OF PREDICTABILITY. THEY ARE CONFUSED AND BEWILDERED; THEY DO NOT KNOW HOW TO BEHAVE IN THIS NEW SITUATION. THEY DO NOT KNOW WHAT TO EXPECT OR WHICH WAY TO TURN. THEIR LIFE PLAN IS SUDDENLY SHATTERED. EVERYTHING IS DIFFERENT.

SELF-CONFIDENCE

THE PARENTS' SELF-CONFIDENCE IS ALSO AFFECTED; THEY RECOGNIZE THAT THIS SITUATION IS LIKE NOTHING THEY HAVE EXPERIENCED BEFORE. BECAUSE THEIR NEW SITUATION IS SO DIFFERENT, THEY FEEL THEY WILL NOT BE ABLE TO COPE.

PITFALLS

AFTER THE INITIAL REACTIONS, MANY PARENTS FALL INTO DIFFERENT TYPES OF PITFALLS IN A DESPERATE ATTEMPT TO ADAPT TO THE NEW FAMILY PLAY. PARENTS MAY DENY THEIR CHILD'S HANDICAP, SEARCH FOR A MAGIC CURE, OVERCOMPENSATE BY DOING MORE THAN IS NECESSARY FOR THEIR CHILD, OR REJECT THE CHILD.

DENY HANDICAP

SOME PARENTS DENY THEIR CHILD'S HANDICAP. THEY EITHER FOCUS ON WHAT MIGHT HAVE BEEN OR BELIEVE THE CONDITION WILL CHANGE. BY SO DOING, PARENTS ESCAPE INTO A DREAM WORLD AND AVOID FACING REALITY.

MAGIC CURE

OTHER PARENTS SEARCH FOR A "MAGIC CURE". THESE PARENTS MAY FEEL THAT THE DIAGNOSIS IS WRONG OR THAT THERE IS SOME SPECIALIST, CLINIC OR MAGIC CURE THAT WILL SOLVE THEIR PROBLEM. THESE PARENTS QUITE OFTEN GET ON A MEDICAL MERRY-GO-ROUND, MOVING FROM DOCTOR TO DOCTOR AND CLINIC TO CLINIC, THUS INTERRUPTING ON-GOING SERVICES AND ASSISTANCE.

OVERCOMPENSATE

MANY PARENTS RUSH TO OVERCOMPENSATE. THEY TRY TO DO EVERYTHING FOR THEIR CHILD. THIS IS ESPECIALLY TRUE WHERE THE CHILD'S HANDICAP IS THE RESULT OF A PHYSICAL INJURY. PARENTS REMODEL THEIR HOMES, PURCHASE EXPENSIVE EQUIPMENT AND SPEND LARGE SUMS OF MONEY ON DIVERSIONARY ACTIVITIES. THROUGH SUCH OVERCOMPENSATION, THE PARENTS NOT ONLY EXHAUST THEIR FINANCIAL RESOURCES BUT CREATE AN UNREALISTIC ENVIRONMENT FOR THEIR CHILD.

REJECT CHILD

OFTEN A PARENT BECOMES OVERWHELMED. AS A RESULT, HE TEMPORARILY MAY LOSE SIGHT OF HIS CHILD, AND THE HANDICAP BECOMES LARGER THAN THE CHILD. SUCH A PARENT MAY REJECT THE CHILD AS HE SEEKS TO RID HIMSELF OF THE PROBLEM. THE CHILD MAY BE PLACED IN AN INSTITUTION OR DIVORCE MAY OCCUR.



There are some rather common pitfalls which many parents of handicapped children fall into. In the blanks below list four of these pitfalls:

1. _____
2. _____
3. _____
4. _____

(Parents: 1. deny their child's handicap, 2. search for a magic cure by going from clinic to clinic, doctor to doctor, 3. overcompensate and often spend much of their money in the very beginning, 4. reject their child. Many parents have reported that they have tried one or more of these ways to adjust to the problem. Sooner or later most realized that these tactics weren't helping their handicapped child, their family or themselves.)



CLIMBING OUT

THERE APPEARS TO BE NO SET TIME FOR CLIMBING OUT OF THE CRISIS, BUT EVENTUALLY MOST PARENTS ARE ABLE TO COPE WITH THIS PERIOD OF TREMENDOUS STRESS.

ACT II
THE PUZZLE

DURING THE SECOND ACT, THE PUZZLE, THE FAMILY TRIES TO PUT THE PIECES TOGETHER AGAIN BUT RUNS INTO TROUBLE. IN THIS ACT PROBLEMS TEND TO DEVELOP AMONG FAMILY MEMBERS, AND BETWEEN FAMILY MEMBERS AND THE AUDIENCE. OLD SCRIPTS DO NOT SEEM TO FIT THE NEW SCENE.

FAMILY
• PARENT AND
HANDICAPPED CHILD
• HUSBAND AND WIFE
• OTHER CHILDREN
• RELATIVES

ALL KINDS OF PROBLEMS ARISE IN THE FAMILY. THERE ARE PROBLEMS OF PARENTING THE HANDICAPPED CHILD, PROBLEMS BETWEEN HUSBAND AND WIFE, AND PROBLEMS WITH THE OTHER CHILDREN. THERE ARE EVEN PROBLEMS WITH RELATIVES, FRIENDS, AND STRANGERS.

PARENT AND CHILD

MANY PROBLEMS DEVELOP BECAUSE PARENTS LACK INFORMATION AND SKILLS TO SUCCESSFULLY PARENT THEIR HANDICAPPED CHILD. OTHER PROBLEMS DEVELOP BECAUSE PARENTS HAVE MIXED FEELINGS ABOUT THEIR CHILD. ON ONE HAND THEY KNOW THE CHILD IS THEIR RESPONSIBILITY, AND ON THE OTHER THEY SECRETLY WISH THEY DIDN'T HAVE THE CHILD. THESE MIXED FEELINGS TEND TO MAKE THEIR PARENTAL JOB CONFUSING AND DIFFICULT.



Describe some mixed feelings parents can have for their children. For example, some parents love their children but at times may resent them.

Positive feelings

Negative feelings

(Here is a list of some mixed feelings that parents may have toward their children; most parents do not feel the same about their children all the time.)

Positive feelings

Proud
Patient
Love
Happy
Glad to have

Negative feelings

Embarrassed
Impatient
Resent
Angry
Don't want

HUSBAND AND WIFE

SOMETIMES PROBLEMS ARE CREATED THAT SEPARATE THE HUSBAND AND WIFE. THE MARITAL RELATIONSHIP MAY BECOME SO STRAINED BY STRESS, GUILT, AND TIME PRESSURES THAT THE MARRIAGE SUFFERS. THEY OFTEN DISAPPOINT EACH OTHER AS THEY FAIL TO FULFILL OLD EXPECTATIONS.



List two ways in which the presence of a handicapped child can affect the relationship between the husband and wife.

1. _____
2. _____

(Having a handicapped child may make it more difficult for parents to talk openly with each other. They may have less time to spend together because of the child. There may be more arguments about the family budget. These are just a few ways in which the presence of a handicapped child can affect the relationship between a husband and wife.

OTHER CHILDREN

THE HANDICAP OF ONE CHILD ALSO HAS AN IMPACT ON THE RELATIONSHIP PARENTS NORMALLY HAVE WITH THEIR OTHER CHILDREN. THE HANDICAPPED CHILD'S NEEDS TEND TO REDUCE THE AMOUNT OF TIME PARENTS GIVE TO OTHER CHILDREN. THE STRESS OF THE PARENTS AFFECTS THEIR ACTIONS TOWARD THESE OTHER CHILDREN. NO ONE KNOWS WHAT TO EXPECT.



List two ways in which the presence of a handicapped child can affect the relationships between the parents and the other children in the family.

1. _____
2. _____

(Having a handicapped child may limit the time parents can spend with their other children. It may effect the amount of money available for the other children. And it may make it harder for the children to communicate with their parents.)



RELATIVES

THERE ARE OFTEN PROBLEMS BETWEEN THE PARENTS AND RELATIVES OF HANDICAPPED CHILDREN. ALTHOUGH THERE ARE USUALLY DIFFERENCES OF OPINION CONCERNING CHILD REARING OF A NORMAL CHILD, IN THE CASE OF A HANDICAPPED CHILD THESE DIFFERENCES ARE MORE PRONOUNCED. AS A RESULT, CONFLICTS ABOUT THE CHILD TEND TO OCCUR.

AUDIENCE

- ACQUAINTANCES
- PROFESSIONALS
- STRANGERS

PROBLEMS TEND TO ARISE WITH FRIENDS, ACQUAINTANCES, PROFESSIONALS AND STRANGERS, WHO MAKE UP THE AUDIENCE FOR THE FAMILY STAGE.

ACQUAINTANCES

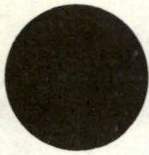
FRIENDS AND ACQUAINTANCES CREATE PROBLEMS FOR THE FAMILY, AND THE FAMILY CREATES PROBLEMS FOR FRIENDS AND ACQUAINTANCES. UNDER THE NEW CIRCUMSTANCES THEY DON'T KNOW HOW TO ACT TOWARD ONE ANOTHER. NORMAL SITUATIONS BECOME STRAINED.

PROFESSIONALS

PARENTS OFTEN HAVE PROBLEMS INTERACTING WITH PROFESSIONALS, WHETHER THEY ARE TEACHERS OR HEALTH PROFESSIONALS OR OTHERS. DIFFERENT PROFESSIONALS RESPOND DIFFERENTLY TO THEIR PROBLEMS, AND PARENTS MAY HAVE GREAT DIFFICULTY SORTING OUT CONFLICTING INFORMATION AND ADVICE.

STRANGERS

EVEN STRANGERS CREATE PROBLEMS. THEY EITHER STARE OR ASK EMBARRASSING QUESTIONS OR IGNORE THE CHILD ALTOGETHER. THEIR PROBLEM IS THAT THEY DON'T KNOW WHAT TO DO UNDER SUCH CIRCUMSTANCES. IT OFTEN CAUSES PARENTS TO FEEL EMBARRASSED.



List two ways strangers can act which might make parents of handicapped children feel hurt or irritated.

1. _____
2. _____

(Many parents are irritated when strangers stare at or try to ignore their child. Some strangers are supercritical of the way parents manage the child in public. Strangers can also ask embarrassing questions.)

ACT III
THE RESOLUTION

DURING THE THIRD ACT, THE RESOLUTION, FAMILIES WORK OUT AN ADJUSTMENT OR RESOLUTION TO THE PUZZLING PROBLEMS.

RESOLUTION

- . GOOD
- . BAD

DEPENDING ON THE COMPLEXITIES OF THE PUZZLE AND THE FAMILY'S ABILITY TO ADAPT, SOME RESOLUTIONS ARE POOR AND SOME RESOLUTIONS ARE GOOD.

CLING TO OLD
SCRIPTS

GENERALLY, POOR RESOLUTIONS RELATE TO THE FAMILY'S DETERMINATION TO CLING TO OLD SCRIPTS IN A SITUATION WHERE OLD SCRIPTS NO LONGER WORK.

FAMILY

1. CONTINUE CRISIS
2. WITHDRAW
3. MEMBER BURDENED

IN ATTEMPTING TO MAINTAIN OLD SCRIPTS THE FAMILY MAY CONTINUE IN A STATE OF CRISIS, WITHDRAW FROM THE WORLD, OR.... ONE FAMILY MAY ASSUME THE TOTAL BURDEN OF CARING FOR THE CHILD.

DEVELOP NEW
SCRIPTS

ON THE OTHER HAND, FAMILIES WHO DEVELOP A GOOD RESOLUTION TO THE PUZZLE TEND TO DEVELOP NEW SCRIPTS. PARENTS REDEFINE AND CREATE NEW PARENT SCRIPTS THAT ALSO FIT THE NEEDS OF THEIR HANDICAPPED CHILD. THEY ALSO DEVELOP A NEW SET OF SCRIPTS THAT MAINTAIN A BALANCE BETWEEN THE NEEDS OF THE FAMILY AND THE NEEDS OF THE HANDICAPPED CHILD.



Are you trying to develop a new parental script to follow?

Yes _____

No. _____

(The answer is that you are trying because you decided to participate in this program. In the next eight units, many new concepts will be presented. These concepts should help you develop new skills and will be an important part of your new script.)

IN THE FOLLOWING SECTION, YOU WILL FIND
PRACTICE ACTIVITIES. THESE ACTIVITIES WILL
PROVIDE AN OPPORTUNITY FOR YOU TO APPLY
WHAT YOU HAVE LEARNED IN THIS UNIT
TO PROBLEM SITUATIONS WHICH ARE SIMILAR
TO THE PROBLEMS PARENTS OF HANDICAPPED
CHILDREN FACE.

"THE LITTLE PIECE OF PIE"

THIS EXERCISE IS DESIGNED TO DEMONSTRATE THAT FEELINGS YOU MAY HAVE FOR YOUR HANDICAPPED CHILD ARE NOT SO DIFFERENT FROM THE WAY OTHER PARENTS FEEL ABOUT THEIR CHILD.

Terry Thompson is the mother of three children. One of her children, the middle child is handicapped. This child has been a puzzle to the family since they became aware of her handicap. The child, now nine years old, reacts to her frustration by frequently exhibiting obnoxious, selfish behavior. Terry seems to be constantly agitated in dealing with the child.

Terry has always realized that this child was difficult because of her handicap; but it never occurred to her until recently that she had strong negative feelings for the child.

The realization came one morning when serving a breakfast of cereal and sliced bananas to all three children. When she put their plates on the table she realized that she had automatically placed the skimpiest portion in front of her handicapped daughter.

Being a thoughtful and compassionate mother, she recalled similar acts in the past. She felt a deep sense of guilt because she didn't love her handicapped daughter as much as she loved her other children.

In order to learn more about the way parents feel about their handicapped children, answer each question below.

1. Are such feelings and actions as described by Mrs. Thompson uncommon when one has a handicapped child? Yes _____ No _____

2. Make a list of some negative and positive feelings parents have toward their children, handicapped or not.

NEGATIVE FEELINGS	POSITIVE FEELINGS

(The answers appear on the next page)

ANSWERS

1. No.. They are not uncommon. When other parents were asked this question they said they have experienced both negative and positive feelings toward their children, whether handicapped or not. Negative feelings are common for any parent.
2. Below are some suggestions made by other parents of both negative and positive feelings they have had toward their children.

POSITIVE FEELINGS	NEGATIVE FEELINGS
Fulfillment Love Enjoyment Pleasure Self-Confidence Pride	Frustration Resentment Displeasure Boredom Self-Doubt Embarrassment

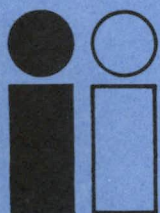
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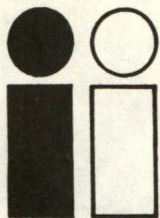
FAMILY STAGE

UNIT 2



PARENTAL SKILLS PROGRAM HANDICAPPED CHILDREN





interaction inc.

3802 Las Palmas Drive
Houston, Texas 77027
(713) 621-8171

FIRST DRAFT

TEXT

UNIT II - FAMILY STAGE

PARENTAL SKILLS FOR PARENTS OF

HANDICAPPED CHILDREN

PROGRAM

By

Charlotte A. Clifford

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UNIT II

FAMILY STAGE

Parents of handicapped children face unique parenting situations. (a) No one needs to tell you what a tremendous impact a handicapped child has on parents, brothers and sisters, grandparents and other relatives. A handicapped child also affects relationships with friends, neighbors and strangers.

Follow A Pattern

In this unit we will be looking at the problems and reactions that occur in families where there is a handicapped child. In talking with parents about their experiences, problems, reactions and adjustments to their handicapped child, it is apparent that most families follow a pattern, and that a rather typical series of events occur. This pattern is confirmed in literature and research on the subject and by professionals who work with handicapped children and their families.

You may feel that your reactions and problems are unique. As you read this chapter, you may be surprised to find that what happened to you and how you and other people in your family reacted were rather typical of most parents who have a handicapped child. Parents tend to react in typical ways, fall into a series of rather common pitfalls and experience a set of common problems.

Let us look at some of the ways parents react and some of the problems families encounter when there is a handicapped child.

(a) See 21, 22, 23, 26, 29, 30, 36, 37, 40, 47, 50, 59, 62, 64.

THE FAMILY STAGE

A good way to get an overall idea about the series of events and reactions is to look at them as occurring on a family stage.

Life versus Theater

When we think about it, families operate on what might be compared to a theater stage. On a family stage many different scenes are "acted out". As on a theater stage, families have a number of actors ^(b) who are actually the people in the family. These family actors play parts ^(c) and in most families have more than one part to play. For example, men act the part of both husband and father. Women play the parts of mother and wife. Youngsters portray both child and brother or sister.

Family Actors Follow Scripts

As in the theater, people on the family stage follow scripts. ^(d) The scripts are images they have in their mind concerning how they should play their parts. For example, mothers have images or scripts they follow for being a mother. Fathers have scripts for being a father. Men and women also have other scripts to follow in the parts as husband or wife.

Family Audience

Like the theater, the family stage has an audience who watches what is happen-

^(b) See 67.

^(c) See 6, 45.

^(d) See 6, 7, 27, 49, 56.

ing in the family. The audience is made up of co-workers, friends, neighbors, professionals and even strangers.

Life Script and Cultural Timetable

Unless something unusual happens, most actors on family stages more or less follow a life script and the cultural timetable. That is, what happens in one family is in many ways like what happens in others. The actors generally follow similar scripts they learned from the culture and their own parents. There are differences in all families, but there are many more similarities than differences.

WHEN THERE IS A HANDICAPPED CHILD

When a handicapped child appears on a family stage, a whole new play begins in most families. The actors on the family stage have great difficulty in adapting to this new situation and playing their parts. ^(e) In many cases they are actors without scripts.

Three Acts

The stage concept is one way to get an overall picture of the most common events and problems which occur in families where suddenly there is a handicapped child. These events and problems tend to fall into three acts. ^(f) Act I is the crisis. Act II is the puzzle, and Act III is the resolution.

^(e) See 2, 5, 6, 7, 11, 13, 14, 15, 16, 17, 18, 19, 20, 23, 27, 28, 32, 34, 39, 41, 46, 47, 54, 62.

^(f) See 27, 63.

ACT I - THE CRISIS (g)

For most families, Act I begins when the parents become aware that their child has a handicap. This may occur at the child's birth, or later in his development. It can also occur at the time of a serious and permanent injury. Becoming aware that a child has a handicap creates a crisis for parents.

Initial Reaction

For most parents, the initial reaction is one of tremendous stress and grief. (h) There is usually a reaction of shock and disbelief. Most parents cannot believe this has happened to them. They think they are dreaming, that they heard it all wrong. Many parents stay in a state of shock for quite a long time. They are numb. Parents have described their initial reactions by saying, "I couldn't believe what they were telling me," or "Everyone was going around acting so tragic that it scared me to death," or "For eight months doctors, nurses, other parents, everyone told me my son would never walk, and I refused to believe them."

Some parents reported that they withdrew. Such comments as "I just stayed in the house and sat on a chair and stared at my baby " or "I just couldn't bring myself to talk to anyone" were heard in this group.

FEAR

After the initial shock wears off, fear sets in. Parents tell of how little they knew about their child's handicap. Some say they never heard of it before and they didn't

(g) See 3, 5, 6, 8, 16, 17, 22, 25, 27, 32, 37, 38, 62, 63.

(h) See 6, 8, 12, 20, 25, 50, 52, 59, 60, 62, 65.

know what it meant. Some parents have had unfortunate experiences and terrible images come to their mind. One mother told how she had had only one experience with mentally retarded people and that was when she was very young. All she could remember were old men in an institution trying with little success to feed themselves. Whenever she thought about her child and his future, this was all she could think of.

The fear parents experience is partially due (in most cases) to a lack of information. They don't know what the handicap involves and what it means to them or their child. So they fear for both themselves and their child.

MOURNING (i)

Aside from the shock and fear, parents mourn for their lost dreams. Since most parents have dreams of a perfect child growing up into an active youngster and teenager and participating in life as others do, the sudden realization that their child may not walk or perhaps not see or talk makes reality seem very different from their dreams and expectations. (i). And parents mourn for the loss of their dreams and their hopes. They cry, they pace, they feel hurt, they feel singled out. They want to know why this has happened to them. They say, "Why me?"

Some parents mourn for "what could have been" for a long time. One mother, for example, says that whenever she looks outside at other children doing things

(i) See 3, 5, 8, 9, 10, 16, 25, 28, 32, 34, 37, 42, 49, 55, 56, 58, 66.

(i) See 8, 14, 17, 49, 55.

her child cannot do, she feels sick. She continues to mourn for her lost dreams, and her child is nine years old. However, for many parents, mourning for lost dreams ends long before that.

Guilt (k)

Guilt is also a very common reaction by parents. Many parents feel that somehow they are the cause of their child's handicap. This is a common reaction when a child is born with a handicap. It is especially common when the handicap is genetic in nature. As Poznanski (1973) says: at birth, "children tend to be seen as an extension of the parents; hence to bear a defective child is experienced by the parent as a personal failure" (p. 323).

Other parents feel guilty in a different way. In seeking a cause for their handicapped child being born handicapped or becoming handicapped they conclude that they are being punished for something they did in the past. They say such things as, "I knew there must be a reason I was being punished in this way. I looked and looked at all the things I had done to find out what I had done wrong that I deserved this punishment." Some parents reported deciding what it was they had done wrong and why they were being punished.

(k)

See 5, 25, 26, 30, 36, 38, 49, 61, 63, 68.

Still other parents experience tremendous guilt because of their negative feelings toward their child. Being human, they wish this had not happened to them, and they wish they didn't have their child. Some parents tell of wishing their child would die and then feeling guilty for having these thoughts.

These reactions of guilt are so common, so unjustified and so tragic for parents that a few words need to be said concerning guilt. First of all, few if any parents would knowingly cause a child to be handicapped. Even parents who took a chance when they were aware of remote possibilities of having a handicapped child should not feel guilty. Many young parents are optimistic and think only good things will happen to them. People can't make foolproof decisions and guesses.

Parents who go back into their past and look for things they did wrong to account for being punished by having a handicapped child are only following a thought process which is very common in our culture. When we are small we are taught that if we do or think something bad, we will be punished. Consequently, some parents of handicapped children do a bit of backtrack thinking and decide if something bad happens it must be their punishment for doing something wrong. Of course, this is not the case, but following such a thought process can cause parents to feel guilty.

The guilt caused by negative feelings is very damaging to parents. They fail to realize that most people would have negative feelings just as they do. Parents with handicapped children, when talking about their negative feelings, often express surprise that other parents sometimes hate their handicapped child and wish he would just go away or that he had never been born, and that others too have thought that if their child died, the stress, the problems and grief would go away. Of course, they don't want their child dead; they just want to be rid of the problems. These parents also fail to realize as Sawrey and Telford (1967) say,

Even the best parents are ambivalent in having mixed feelings toward their normal children. Parental attitudes, while dominantly positive, have overtones of resentment and rejection. The restrictions of activities, the additional responsibilities, the minor disappointments of parenthood, the anxieties and the irritations which are a normal part of the bearing and rearing of offspring inevitably produce ambivalent parental reactions. Parents accept and love, but they also reject and dislike their children. (p. 78)

If parents have negative and mixed feelings about their normal children, is it any surprise that parents of handicapped children have more mixed and negative feelings toward their handicapped children who create more responsibilities, more disappointments, more anxieties and irritations than even normal children do?

These negative and mixed feelings are so common that parents should not feel guilty or different when they have them. No parent likes and wants his child all the time.

ANXIETY (1)

Many parents suffer from a great deal of anxiety. They are in stress, sometimes it is very profound. There is little wonder parents suffer from anxiety. Look at their dilemma. Their mental plans and dreams and sense of predictability seem to vanish. Because very often they have little knowledge about their child's handicap, they do not know what to expect. They can't predict what is going to happen to them. They had a script for their life. Suddenly, it looks impossible that they can follow it, and they have nothing to replace their old script. Most parents while they are in anxiety and stress do not understand the overall picture of why they feel as they do. They report feeling helpless. They don't know what to plan on, what to expect, and they don't know how to do what needs to be done. Consequently they begin to have self doubts. They report feeling that they can't cope, can't manage.

Some parents reported that they reacted with anger and outrage. Their anger was aimed at anyone handy: doctors, nurses, spouses, parents, themselves. Others said they just wished they could run away.

At this point many parents have no idea what the future holds for their child, or what to expect of him or for him. Their lack of knowledge about the handicap leads them to be unrealistic, either in terms of over-optimism or extreme pessimism. As Froyd (1973) pointed out parents have "no conceptual background on which to

(1) See 5, 12, 16, 36, 38, 63, 65.

base their hopes or control their fears... There is no reality oriented basis on which to build realistic expectations" (pp. 251 - 252) ,

UNPREDICTABILITY (m)

These feelings of extreme anxiety are primarily caused by the absence of predictability. While parents of non-handicapped children know what to expect in general terms, parents of handicapped children often have few guidelines in the beginning.

There is another kind of unpredictability for many parents. This is the lack of agreement among doctors or professionals concerning the nature of their child's disability. Many parents go for several years suspecting there are problems with their child and cannot get a handle on what it is. These parents have a real problem. If their child has a disability, he may need special help. If he doesn't, then he may not. Consequently, they don't know what to do.

PEOPLE ARE GENERALLY ANXIOUS WHEN THEY DO NOT KNOW WHAT TO DO. Most people, once the course is clear and they know how to do what is required, feel less anxious. It is not knowing what to expect, or how to accomplish something, that gets most of us down.

LACK OF SELF-CONFIDENCE (n) ALSO CAUSES US TO FEEL ANXIOUS. Being unsure about our capability to do something correctly, being unsure about how

(m) See 1, 3, 23, 25, 33, 49.

(n) See 12, 36.

we'll react also creates anxiety. Usually, once parents get into a routine and learn the special skills they need for their child, they begin to experience less anxiety about themselves.

WHEN THE FUTURE IS A QUESTION MARK WITH FEW HINTS OF WHAT MIGHT HAPPEN, PEOPLE TEND TO BE ANXIOUS.

All these problems of predictability hit a parent with a handicapped child. Is there any wonder that you felt anxious, or perhaps from time to time still do? All parents face anxious times. Parents of handicapped children may face them more often.

PITFALLS

After the reactions we have been talking about subside a little, many parents take action. They get themselves together, more or less, and set out to do something. Let us look at some of the more common pitfalls or "overreactions" that happen to parents because they have no script, because they know little of the handicap, and because they are just human.

Deny the Handicap ^(o)

A very common pitfall is for one or both parents to deny the handicap. It is not surprising that disbelief occurs so often. Doctors many times are reluctant to "lay it on the line" when parents are in a state of shock. Sometimes the situation

^(o) See 37, 46.

is not merely black or white; it is grey, and professionals are unsure. At times parents can't find out for certain what it is their child has or can't get any agreement from anyone. All this only confirms their hope that the condition is temporary. Winterbourn (1971) points out that

Disbelief usually leads the parents to seek 'advice' which will bolster up their disbelief. They may hang on the words of friends who tell them that their child will 'grow out of it', and that he is 'a late developer', and so on. (p. 37)

Some parents report that evidence kept piling up that their child did indeed have the condition, but they could not and would not accept it. They kept on denying the handicap.

The problem is that in denying their child's handicap, parents may fail to do things that need to be done for the long-term growth and development of their child.

Magic Cure

Another common pitfall is for parents to seek a magic cure. What parent wouldn't get the advice of more than one doctor, or other professional? Who wouldn't want more than one opinion? But some parents keep on looking for something or someone who can cure their child. Many go all over the country from doctor to doctor, clinic to clinic, hoping above hope for a cure. Such parents cannot accept the fact that nothing can be done. Winterbourn (1971) says, "They may seek expert advice, and very properly get a second or even third

expert opinion; not so properly, they may try out various quack 'remedies'" (p. 37).

In seeking a magic cure, as in denying the handicap, parents are not facing the reality of the situation. It isn't the way they want it, and they somehow cannot say to themselves "this is how it is." It is difficult for most of us to accept reality. This is especially true when parents are young. They have planned, hoped and dreamed, as we all do. Because they perceive the future with a handicapped child as threatening, they can't accept it.

As Richardson (1971) points out "...aspirations for the child may be unrealistic because of their expectations of what modern medicine can do, and they may persist in believing that a cure is possible" (p. 1050). Thus, they do not begin to help their child learn the skills he will need. They often expect too much, and face disappointment when their child cannot live up to their expectations.

Overcompensate

Still other parents fall into the overcompensation trap. They try to make it up to their child for his handicap. They buy everything in sight, everything a baby or child could ever need or want. They may remodel the house or get the most elaborate and expensive equipment. Parents often exhaust their financial resources in trying to compensate.

Reject Child^(p)

Another overreaction to a handicapped child is rejection. A few parents report that they cannot even hold their child, and refuse to take care of it. Other parents report that although they care for the physical needs of their child, emotionally they reject the child. The child fails to live up to their aspirations and expectations, and is rejected.

Another factor in rejection is lack of knowledge. One result of not being able to predict, is that parents may ignore the handicapped child. Handicapped children often receive less stimulation than their normal siblings; they have less contact with the mother; they have less sensory stimulation; and they spend more time alone in a crib or playpen. This could be partly based on the fact that the parents feel inadequate regarding parenting a handicapped child - they don't know how to deal with or take care of a child with that handicap. ^(q)

CLIMBING OUT^(r)

For some parents, Act I continues in one way or another for a long time, sometimes for years. Some parents mourn for their lost dreams for a very long time. Some parents continue on the guilt merry-go-round; some parents' anxiety continues.

^(p) See 12, 38.

^(q) See 23.

^(r) See 8, 20.

Some parents stay in one pitfall or another. Parents report denying their child's handicap for years. Others continue year after year to search for a magic cure, and follow up on everything in sight. Other parents continue the pattern of over-compensation throughout their child's life. They feel they must make their child's life good by not requiring anything of him and just giving to him. Other parents cannot accept their child. Their rejection of their child frequently leads to divorce, premature institutionalization of the child, or such imbalance in the family that the results for everyone are disastrous.

On the other hand, for most parents the crisis gradually subsides. Reality is accepted to some degree, and family life takes on a more organized and routine nature. Family members begin to try to make order in their lives.

ACT II - THE PUZZLE

In Act II the family tries to pick up the pieces and regroup. All kinds of problems arise. ^(s) There are problems of parenting and caring for the handicapped child. Problems develop between the husband and wife. The other children begin to become difficult to manage, and they develop problems. Relatives cause problems, and there are even problems with co-workers, friends, neighbors and strangers.

^(s) See 6, 14, 15, 16, 18, 19, 23, 28, 54, 63.

Parent of Handicapped Child

Many problems develop because parents lack information and skills to successfully parent their handicapped child.^(t) Other problems develop because parents can't cope with their mixed feelings about their child. These mixed feelings make the parents job confusing and difficult. The time consuming nature of caring for and developing a child with a handicap often creates pressures on one or both parents. Suddenly the role of parenting the handicapped child requires all of one parent's time, sometimes most of the other's. The demands can create problems when other people and things get neglected and when parents neglect themselves.

In Act II, parents have not had long enough to learn to pace themselves, and have not had a chance to learn from other parents, from special education facilities, from counselors and other sources, skills which will allow them to manage well. This is a time of trial and error, of failure, disappointment, exhaustion. This is the time when it looks almost hopeless.

It is interesting that many young parents whose first child has a handicap tend to blame the child's handicap for many of the problems and demands on their time. Such parents, never having other children, fail to recognize that many of the things they are blaming on the handicap are occurring not because of the handicap, but because that is how most children are, handicapped or not.

^(t) See 3, 22, 23, 24, 25, 33, 54.

Husband and Wife^(u)

Sometimes a husband and wife are brought closer together as they struggle to jointly cope with the problems they face in parenting their handicapped child. More often than not, however, the marital relationship becomes so strained by stress, guilt and time pressures that the marriage suffers.

One of the first problems that occurs is the problem of expectations. In Unit I we talked about each person having his or her own ideas beforehand about how a part is to be played. After a while, husbands and wives tend to make some compromises about how they will play their part of husband and wife, and they know what to expect of one another. They have usually worked out a routine, have designated responsibilities, have compromised on the work, and know what each person is going to do.

When they get home with their handicapped child, neither of them can any longer operate under the scheme they previously operated under. They don't usually think about it, but all of a sudden they realize that the other person isn't doing what is expected. They are disappointing each other. The wife, who may have planned to go back to work so they could have the extra income, doesn't go back. The husband, who did some of the things around the house, may start staying away while the wife's workload has increased. Problems develop because they can't any longer fulfill old expectations.

^(u) See 14, 15, 16, 19, 23, 28, 35, 46, 63.

Another problem that may develop is a communication gap. One father explained how this gap can develop. He said, "I was angry and mad at my son's injury. I hated the problem, sometimes hated the kid, but I couldn't tell my wife how I felt about this. All of a sudden I found I stopped talking to her. When I stopped, so did she. Pretty soon all we talked about was who was going to do what. I was also hurt because she wanted to sleep in my son's room. I wanted her in our bed."

This leads to the next problem. Sometimes one parent may feel that he should devote all his efforts to the parent role. This leaves no time for the role as spouse. A neglected role in the family sooner or later causes a problem. When one person insists on using all his time and energy on being a parent, being a husband or wife is going to suffer.

Sometimes the parents' reactions to their stress create many problems. If a parent's style is to withdraw when under stress, this adds to the communication gap, to the feeling by the spouse of being neglected, or adds to the other person's responsibilities and workload. If a parents' reactions to stress tend to be aggression, the arguments, nagging and outright physical hurt to the other partner can be a real threat in the family.

In this period of trying to work out some suitable way for managing their problems and new life, many parents drift further and further apart. Sometimes, they go their separate ways in many respects. They develop a new set of expectations

which goes something like this: "Okay, wife, you be the mother. You take care of the house and the child. I'll go earn the money, which will take all my time, because we are going to need a lot."

Other Children ^(v)

The stress, the time requirements, the handicapped child himself, all put a strain on relations between parents and other children. Again, mother and father can't do as they did before the handicapped child came home. The other children react in a variety of ways. First of all they probably miss the attention and the amount of time parents did spend with them. Second, because of the crisis and the emphasis on solving some of the problems with the handicapped child, the other children probably suffer from feeling less important than their handicapped sibling. The stress, short tempers, the put-offs, all begin to take their toll on the other children.

Some parents report that their children who are young try to mimic the handicap of their brother or sister, thinking perhaps, "If he gets such attention from my parents and everyone else that way, so can I." This is not a surprising reaction. Many small children react this way when a new baby comes home from the hospital.

Older children sometimes experience embarrassment from their sibling's handicap. Often they do not understand what the handicap is or what it means, and they

^(v)See 14, 15, 16, 18, 19, 28, 44, 63.

are asked many questions as the news gets around the neighborhood. Neighborhood children can tease and even exclude children because of their brother's or sister's handicap.

Sometimes parents require the other children to share a large portion of the care of the handicapped child. Resentment, negative feelings, even aggression toward the handicapped child results.

Feelings of injustice begin to crop up in the "other" children. "Why did this happen to us? To me?" "It isn't fair that I can't have a new bike because Johnny needs a new brace." "It isn't fair that we can't go to the beach because Mary Lee can't go."

Relatives (w)

Relatives can cause a lot of problems. Grandparents, for example, may not accept the idea that "their" grandchild could have a handicap. Sometimes grandparents will try to pass the buck to the other side of the family if the handicap is genetic. Sometimes mothers-in-law or fathers-in-law blame the daughter-in-law, or son-in-law for the handicap.

Relatives can create guilt feelings in the parents. One young mother, for example, reported that her inlaws insisted that the reason their son was born without

(w) See 4, 6.

one eye was because the young couple had shared an apartment prior to their marriage.

There can be disagreements concerning how the parents are taking care of the handicapped child. Often relatives find fault with what parents are doing, thinking they are doing either too little or too much. Some relatives try to overcompensate as some parents do and set out to do everything for the child, upsetting the routine and scheme the parents have worked out.

Still other relatives reject the child, refuse to baby sit, or contemplate the idea that their grandchild is handicapped.

All of these things only compound the problems parents face.

Audience ^(x)

The family also has problems of interacting with the members of the audience who watch what happens on the family stage and often judge what is seen.^(y) Friends and acquaintances create problems for the family, and the family creates problems for friends and acquaintances. Under the new circumstances nobody knows how to act toward one another. Whenever they meet, the situation becomes strained. Friends and neighbors, in their attempt to help, offer unreliable or unrealistic advice, fail to understand the problems, and may offer suggestions that

^(x) See 4, 6, 39, 63.

^(y) See 2, 4, 5, 30.

make family members uncomfortable. Members of the family may tend to withdraw from friends and neighbors due to lack of time, as reactions to stress, or because they are now uncomfortable around certain people.

One mother told how some people made her feel. She said, "There are some people who make you feel terrible. They look down their nose at you, almost indicating that they can't understand how you could let something like having a retarded child happen to you. They act like they are so in control of their lives that this would never happen to them".

Professionals (z)

Professionals in the health field, counselors, and teachers often create problems for parents. Sometimes they offer conflicting advice, suggest different procedures and schedules, expect different things of parents, and in a variety of ways tend to confuse the parents. For example, some professionals feel that a deaf child should learn to sign, while others feel they should all be taught to read lips and to speak. Some doctors are reluctant to or cannot make positive judgments and diagnoses of handicapping conditions, and use such phrases as, "It might be retardation; then again the child may just be a slow developer."

Such conflicting opinions and styles in professionals are often a source of real stress as parents look toward people who are "experts" and hope for something

(z) See 3, 43.

concrete to rely on. Often, however, the condition of handicapped children is not clear cut, and they are expecting too much. As Hammer (no date) points out, "Parents are responsible for their children. Even though professionals may feel that they know what is best for the child, the parents' responsibility cannot be denied" (p. 5).

Strangers (aa)

During Act II and even thereafter, parents, the handicapped child, and other members of the family may encounter problems with strangers. If the handicap is apparent and noticeable, people tend to stare, ask embarrassing questions or ignore the child. The problem, of course, is that these strangers feel awkward and embarrassed in the presence of the handicapped child. They do not know how to behave. But this, especially in the beginning, does not make family members feel better. As Richardson (1971) pointed out "some (parents) will withdraw or avoid such meetings and pattern their family activities so as to reduce outside social relationships" (p. 1052). (bb)

This is the time when parents have not yet learned how to manage the reactions of strangers and have not yet developed skills for putting people at ease. Nor have they learned how to furnish guidelines or to serve as models that will help other people learn how to act around a handicapped child. It is a trying and often discouraging situation.

(aa) See 31.

(bb) See 53 in agreement on this point.

FACING UP (cc)

During Act II most parents try to use their old parent script: the ideas they had about children, themselves as parents, and the models set by their own parents. They also try to follow similar schedules and routines, and seek to do things in ways they did them before. As Kelman (1957) points out, "most families have little or no prior experience in living with and having to restructure their lives to the varied demands and unique needs of a chronically disabled individual" (p. 596). Winterbourn (1971) says,

"Parents...should be comforted by the knowledge that they are not alone in their feelings and frustrations, which are normal human reactions to a difficult situation. It is hoped that they may go a step further...(to) an intelligent facing up to their own particular problems" ... (p.38). (dd)

Sooner or later most parents do "face up" to the fact that things can't be done in old ways.

ACT III - THE RESOLUTION

This facing up leads most families into Act III. It is at this time that resolutions to many of the problems begin to be worked out as family members change and adjust to the new scene.

(cc) See 8.

(dd) See 57 in agreement on this point.

Sad as it may seem, not all families reach what could be judged a "satisfactory" resolution to their problems. That is, a satisfactory resolution in terms of being balanced and just for all members of the family.

Clinging to Old Scripts

Generally, "poor" resolutions find family members clinging to old scripts in the new situation, where the old scripts will not work. This means that they cling to their childhood dreams, insist on conforming to their life blueprint exactly, and insist on doing things in usual ways. Some parents continue on the guilt treadmill. In such cases, the crisis often continues. The family may stay in Act I.

Some families make ineffective adjustments because they withdraw into a close circle at home and ignore the rest of the world. Often this is because their way of management allows little time for anything other than absolutely essential activities related to food, clothing, shelter, and caring for physical needs. It can also relate to one or both parents' feelings of shame concerning their child and their wish to "hide" the child. This frequently occurred in the past in our culture.

In some families, everyone else clings to their old way of doing things, and one family member assumes the total burden of caring for the handicapped child. In such cases this one family member may not have been pushed into assuming this role, but due to personal feelings believes this is their responsibility. Here, other family members go on as usual; however, marriages often fail under this solution.

Develop New Scripts

In many families changes begin to occur. Parents and other family members begin to realize that they must have new scripts in order to manage their new situation. These parents redefine their roles and create new scripts that maintain a balance between the needs of other family members and the needs of their handicapped child.

The remaining chapters in the text are concerned with developing insights and skills which will be useful in developing an effective parent script.

SUMMARY

1. For purposes of analysis, the events which happen in most families where there is a handicapped child can be thought of as occurring in three acts: Act I is the crisis; Act II is the puzzle, and Act III is the resolution.
2. In Act I, parents and other family members face a crisis upon learning of the child's handicap.
3. The more common reactions during the crisis of Act I are:
 - a. Tremendous shock and disbelief
 - b. Fear for the future - for oneself and for the child
 - c. Mourning for lost dreams of a perfect child, and what might have been.
 - d. Guilt feelings which are usually one of three kinds:

- (1) Feeling that somehow, something the parent did or failed to do actually caused the handicap in the child. This, of course, is usually unfounded and unjustified.
 - (2) Feelings that the parent is being punished through his child's handicap for some wrong he did in the past: a sad and unjustified method of thinking, where parents are reacting to childhood beliefs that for wrong thoughts and acts they are sure to be punished.
 - (3) Guilt about negative feelings toward the handicapped child, which parents fail to recognize as common reactions among parents of handicapped children.
4. Anxiety results from fear, absence of predictability, and lack of knowledge. Parents often feel they cannot cope, that they will never be able to manage.
5. Some parents during Act I overreact to the situation and get into pitfalls.
- a. Denying the handicap is a very common reaction. Here parents fail to face the facts, and keep thinking their child will outgrow the handicap, that it is only temporary. At this point they cannot face the handicap head on.
 - b. Searching for a magic cure is another version of failing to

accept the fact that a child has a permanent handicapping condition.

Many parents go to extremes in searching for a magic cure.

c. Other parents go to the extreme in overcompensating in order to "make it up" to the child.

d. Still other parents reject the child, reject the whole situation, and cannot mentally come to terms with their child's handicap.

6. Most parents climb out of the pitfalls and crisis of Act I, and Act II begins.

There is no set time for Act II. It depends on the parents and the nature of the child's handicap. It is a very personal thing.

7. In Act II, when families begin to try to carry out the day-to-day activities of life with a handicapped child, they run into problems. Husbands and wives begin to have problems. There are problems with the other children. There are problems with professionals. There are problems with co-workers, friends, and neighbors. Even strangers may cause problems. Act II is the puzzle, because suddenly parents face the fact that things are not as they were that old scripts aren't working, that something has to change.

8. In Act III, the Resolution, families seek to solve some of the problems.

Resolutions can be satisfactory for everyone in the family, for some members of the family, or for no one. When old scripts, old ideas, old methods are clung to, more problems develop. When no one is willing to compromise, to

change and try out new things, Act III can create more crisis, heartache and problems. When new scripts are followed, when there are people willing to change, resolutions can be good for everyone - not only the handicapped child, but for all family members.

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