no girls
no handicaps

SELF INSTRUCTION

INTRODUCTION

UNIT 1

PARENTAL SKILLS PROGRAM HANDICAPPED CHILDREN

TVRR

SELF-INSTRUCTION WORKBOOK

UNIT I

INTRODUCTION

PARENTAL SKILLS FOR PARENTS OF

HANDICAPPED CHILDREN

INTRODUCTION

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 1

THIS IS UNIT ONE, AN INTRODUCTION TO: A PARENTAL SKILLS PROGRAM DEVELOPED SPECIFICALLY FOR PARENTS OF HANDICAPPED CHILDREN. IT IS DESIGNED TO PROVIDE PARENTS OF HANDICAPPED CHILDREN WITH INSIGHTS AND SKILLS FOR DEVELOPING THEIR HANDICAPPED CHILD.

D.H.E.W.
BUREAU OF
EDUCATION
FOR THE
HANDICAPPED

THE FUNDS FOR THIS PROGRAM WERE PROVIDED BY THE DEPARTMENT OF HEALTH, EDUCATION AND WELFARE THROUGH ITS BUREAU OF EDUCATION FOR THE HANDICAPPED. THIS PROGRAM RESULTS FROM A BROAD RANGE OF RESEARCH INTO PROBLEMS EXISTING IN FAMILIES WITH HANDICAPPED CHILDREN.

- PARENTS
- HANDICAPPED YOUTH

THIS RESEARCH INCLUDED INTERVIEWS WITH THE PARENTS OF HANDICAPPED CHILDREN TO DETERMINE THE KINDS OF PROBLEMS PARENTS FACE AND THE KINDS OF PARENTAL SKILLS THEY HAVE DEVELOPED. HANDICAPPED YOUTH IN THEIR LATE TEENS OR EARLY TWENTIES WERE INTERVIEWED. THEY POINTED OUT AREAS THEY FELT WERE ESSENTIAL TO COVER IN THE PROGRAM.

- COUNSELORS
- PUBLISHED RESEARCH

MEETINGS WERE ALSO HELD WITH COUNSELORS, SPECIAL EDUCATION TEACHERS AND SOCIAL WORKERS WHO WERE FAMILIAR WITH THE PROBLEMS OF HANDICAPPED CHILDREN AND THEIR PARENTS. THESE PEOPLE PROVIDED VALUABLE INSIGHTS AND OFFERED MANY USEFUL SUGGESTIONS CONCERNING PROGRAM CONTENT. FINALLY, RESEARCH REPORTS AND LITERATURE RELATED TO HANDICAPPED CHILDREN AND THEIR FAMILIES WERE REVIEWED. DATA FROM THIS REVIEW WERE UTILIZED IN DEVELOPING THE CONCEPTS UPON WHICH THIS PROGRAM IS BASED.

Check (✓) the answer below which you think is correct: The Parental Skills Program for Parents of Handicapped Children is:

____ 1. Designed to provide parents with insights and skills for developing their handicapped child.

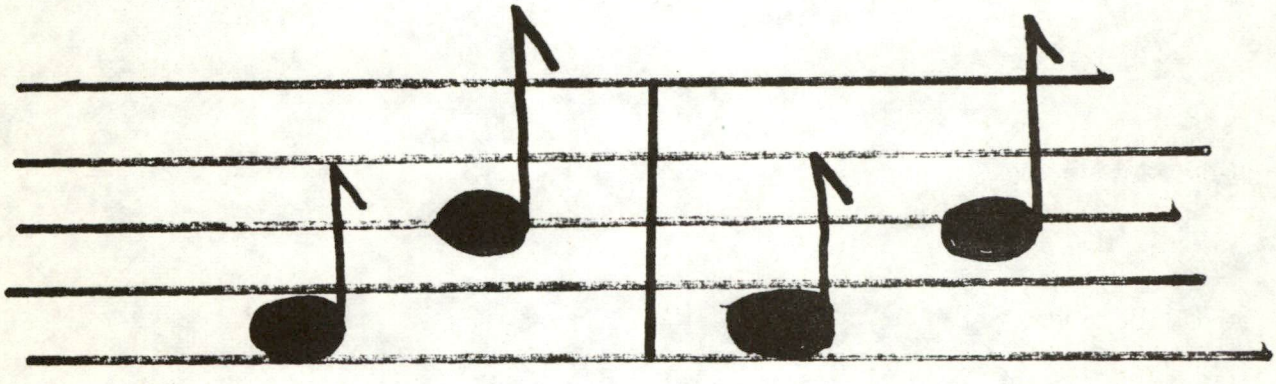
____ 2. Funded through the Department of Health, Education and Welfare.

____ 3. Based on Research.

____ 4. Based on interviews with parents of handicapped children.

____ 5. Based on interviews with handicapped youth and counselors and teachers who work with handicapped children.

(Every statement above is correct. You should have put a check (✓) in each blank.)



RECURRING THEME

IN THE INTERVIEWS WITH PARENTS, COUNSELORS AND HANDICAPPED CHILDREN, AND IN THE RESEARCH REVIEW AS WELL, THERE WAS ONE RECURRING THEME. THERE IS A LACK OF KNOWLEDGE ON THE PART OF PARENTS ABOUT HOW TO FUNCTION AS PARENTS AND HOW TO OPERATE AS A FAMILY WHEN ONE OF THE CHILDREN HAS A HANDICAP.

YOUNG PARENTS

YOUNG PARENTS OF NORMAL CHILDREN TODAY HAVE SOME GENERAL IDEAS ABOUT PARENTING CHILDREN. ALTHOUGH THESE PARENTS EXPERIENCE ADJUSTMENT PROBLEMS AT THEIR CHILD'S BIRTH AND THROUGHOUT HIS DEVELOPMENT, THEY HAVE SOME BASIC IMAGES CONCERNING WHAT TO DO AND HOW TO OPERATE.

Before you had a child, what were some general ideas about parenting that you had? For example, what did you think a parent had to do for a new born infant?

_____

_____

_____

(Many parents say that they knew that their baby would cry a great deal and keep them up at night. They felt the first few months would be a question of feeding, changing diapers, letting him sleep and playing with the baby when he was awake. You might not have listed these same ideas about parenting...the point is that you **did** have some general ideas about how to parent before you had your child.)

TRADITIONS

MEMORIES

FOR ONE THING, PARENTS OF NORMAL CHILDREN HAVE TRADITIONS OF PARENTING AND WAYS OF DOING THINGS THAT ARE PASSED ON FROM FAMILY TO FAMILY AND NEIGHBOR TO NEIGHBOR. SECONDLY, IN PARENTING NORMAL CHILDREN, PARENTS HAVE THEIR OWN CHILDHOOD MEMORIES TO REFER TO FOR GUIDANCE.

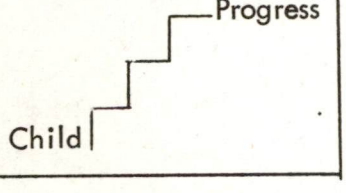
MODELS

THIRDLY, PARENTS OF NORMAL CHILDREN CAN MODEL THEMSELVES AFTER THEIR OWN PARENTS IN DEALING WITH THEIR CHILDREN.

TELEVISION

FINALLY, OUR SOCIETY PROVIDES PARENTS OF NORMAL CHILDREN WITH INFORMATION ON FAMILY LIFE AND "HOW TO REAR KIDS". WE SEE NORMAL CHILDREN ON TELEVISION AND READ ABOUT NORMAL FAMILIES IN NEWSPAPERS AND BOOKS. THIS INFORMATION EXPOSURE HELPS PROVIDE A BASIC SCRIPT TO FOLLOW IN PARENTING NORMAL CHILDREN.

CULTURAL TIMETABLE



PARENTS OF NORMAL CHILDREN ALSO HAVE A CULTURAL TIMETABLE WHICH INDICATES THE PROGRESS A NORMAL CHILD SHOULD MAKE AT DIFFERENT STAGES OF CHILDHOOD, ADOLESCENCE AND YOUNG ADULTHOOD. IN NORMAL PARENTING, ONE CAN APPROXIMATE HOW WELL A CHILD IS DOING AND ABOUT WHERE HE OUGHT TO BE AT GIVEN STAGES BY REFERRING TO THE CULTURAL TIMETABLE.

Below is a list of events related to our cultural timetable. Number the events in the order in which they usually occur. That is, put a "1" beside the event which you think usually occurs first in the development of a child, and so on.

_____ Graduates high school
_____ Learns to ride a bicycle
_____ Begins to walk
_____ Cuts first tooth
_____ First date
_____ Can give name and address
_____ Gets married

(Going down the column the numbers should be 6, 4, 2, 1, 5, 3, and 7. The order of these events are part of our cultural timetable.)

"ACTING OUT"

IN GENERAL ONE CAN SAY THAT PARENTS OF NORMAL CHILDREN HAVE GENERAL GUIDELINES FOR "ACTING OUT" THEIR PARENTAL ROLES. EVEN WITH THESE GUIDELINES THEY OFTEN ENCOUNTER PROBLEMS AS PARENTS IN OUR COMPLEX WORLD.

Put a check (✓) by the statements below which describe where most young parents get their knowledge and ideas about how to operate as parents:

_____ 1. Instincts
_____ 2. Cultural timetable
_____ 3. Their own childhood memories
_____ 4. By copying their own parents
_____ 5. Television, books, magazines
_____ 6. Neighbors, friends
_____ 7. Traditions passed from generation to generation
_____ 8. They must learn how to be parents

(You should have a check (✓) in every blank except #1. There is little evidence to indicate that human beings know beforehand by instinct how to parent a child. Parental behaviors must be learned just as other behaviors are.)

HANDICAPPED

CHILDREN

PARENTS OF HANDICAPPED CHILDREN, ON THE OTHER HAND, HAVE EVEN FEWER GUIDELINES, AND EXPERIENCE AN EVEN GREATER NUMBER OF PROBLEMS THAN PARENTS OF NORMAL CHILDREN.

DO NOT HAVE:

- TRADITIONS
- MODELS
- MEMORIES
- INFORMATION

MOST OFTEN, PARENTS OF HANDICAPPED CHILDREN HAVE NO TRADITIONS, MODELS, MEMORIES AND INFORMATION PASSED ON TO THEM FOR PARENTING THEIR HANDICAPPED CHILDREN. THESE PARENTS ARE FORCED TO FACE THEIR PARENT ROLE WITH LITTLE KNOWLEDGE CONCERNING THE HANDICAP AND FEW SKILLS FOR PARENTING A HANDICAPPED CHILD.

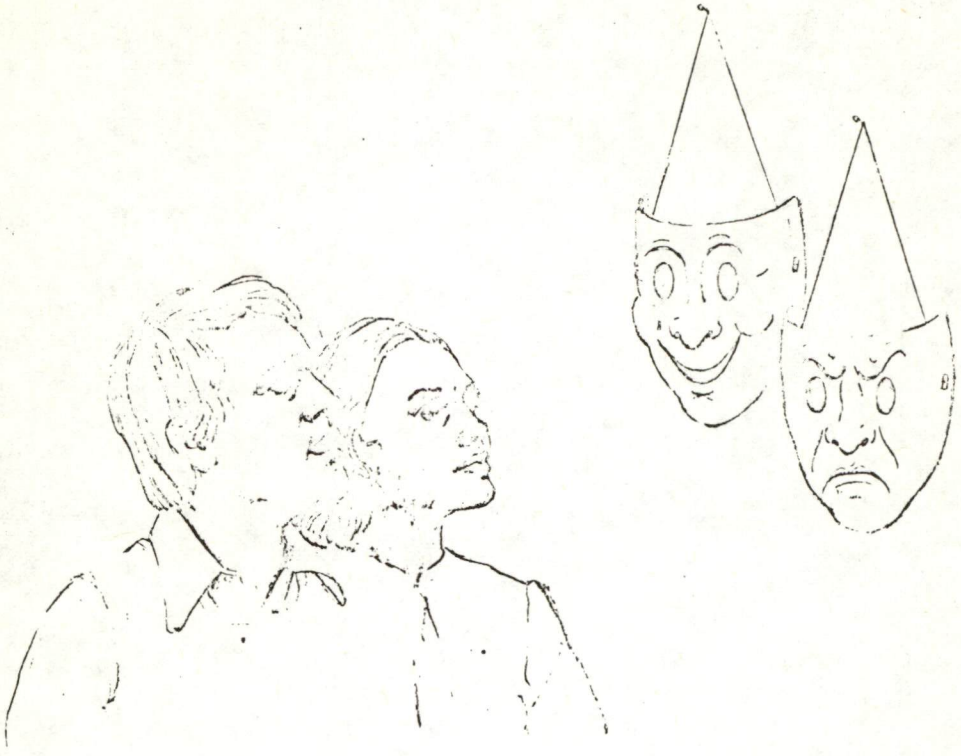
NO
CULTURAL
TIMETABLE

THEY ALSO HAVE NO TIMETABLE TO TELL THEM ABOUT THE PROGRESS THEIR CHILD SHOULD BE MAKING AT DIFFERENT STAGES IN HIS OR HER LIFE.

Check the events in our cultural timetable that did not occur for your child at the same time as for most other children.

_____ Walked
_____ Talked
_____ Started school
_____ Rode a tricycle
_____ Learned to write
_____ Learned to read
_____ Went on a date
_____ Drove a car

(Of course, the events that you checked will depend on the disability of your child. You might have checked some events because they occurred earlier for your child, while other events may have occurred later. Some events may not have yet occurred.



NO
PARENT
SCRIPTS

IN GENERAL ONE CAN SAY THEY HAVE NO CLEAR PARENT SCRIPTS TO FOLLOW AND VERY FEW GUIDE-LINES FOR "ACTING OUT" THEIR PARENTAL ROLE.

Very often parents of handicapped children have limited information and few guidelines to follow in parenting a handicapped child.

Put a check (✓) by all of the following statements which tell why this is true.

_____ 1. No traditions passed on to them on how to parent a handicapped child

_____ 2. Usually have very little prior knowledge or information about their child's handicap

_____ 3. Their childhood memories don't really prepare them

_____ 4. There is no cultural timetable to tell them about how handicapped children grow and develop

_____ 5. Often if they try to follow the model set by their own parents it doesn't work

(All of the statements are correct. You should have put a check (✓) in every blank.

RESULT:

- GUILT
- ANXIETY
- INADEQUACY

AS A RESULT, MANY PARENTS OF HANDICAPPED CHILDREN EXPERIENCE MORE GUILT, ANXIETY AND FEELINGS OF INADEQUACY IN "ACTING OUT" THEIR PARENTAL ROLE THAN PARENTS OF NORMAL CHILDREN.

Write in the three blanks below, the most common feelings that parents of handicapped children experience in the early days after learning of their child's handicap.

1. _____

2. _____

3. _____

(The answer are: (1) Anxiety - because they have such little information and don't know what to expect. (2) Guilt - because they often blame themselves and (3) Feelings of inadequacy because they have never had a chance to learn about how to parent a handicapped child.

PROGRAM PURPOSE

THE PURPOSE OF THIS TRAINING PROGRAM IS TO PROVIDE PARENTS OF HANDICAPPED CHILDREN WITH INSIGHTS AND BEHAVIORAL GUIDELINES TO FOLLOW IN THEIR PARENTAL ROLE.

2 PARTS

THE PARENTAL SKILLS PROGRAM IS DIVIDED INTO TWO PARTS.

PART 1

10 BASIC PARENTING UNITS

PART ONE CONSISTS OF TEN BASIC PARENTING UNITS DESIGNED FOR PARENTS OF ALL HANDICAPPED CHILDREN. EACH PARENT SHOULD COMPLETE THE BASIC PARENTING UNITS.

PART 2

SPECIFIC HANDICAP UNITS

PART TWO CONSIST OF FIVE SPECIFIC HANDICAP UNITS. THIS IS THE SPECIFIC HANDICAP PROGRAM. EACH PARENT WILL COMPLETE THE HANDICAP UNITS RELATED TO HIS OR HER CHILD'S HANDICAP.

10 BASIC PARENTING UNITS

THE FIRST OF THE TEN UNITS IN THE BASIC PROGRAM IS THE INTRODUCTION WHICH YOU ARE PARTICIPATING IN RIGHT NOW.

FAMILY STAGE

THE SECOND UNIT DEALS WITH WHAT HAPPENS ON THE FAMILY STAGE WHEN A HANDICAPPED CHILD APPEARS. THIS UNIT EXPLORES THE IMPACT THE HANDICAPPED CHILD HAS ON PARENTS AND OTHER FAMILY MEMBERS AND THE PROBLEMS PARENTS FACE IN REARING HANDICAPPED CHILDREN.

PARENTAL SCRIPTS

THE THIRD UNIT DEALS WITH THE DIFFERENT SCRIPTS PARENTS TEND TO FOLLOW WHEN REARING A HANDICAPPED CHILD. SOME SCRIPTS ARE FOUND TO BE DAMAGING TO THE CHILD, WHILE ONE STANDS OUT AS BEING MOST BENEFICIAL TO THE CHILD AND WORKABLE FOR THE PARENT.

ACTIVATOR PARENT

THE FOURTH UNIT DEALS WITH DEVELOPING A SUCCESSFUL SCRIPT FOR PARENTING A HANDICAPPED CHILD. THIS SCRIPT IS CALLED THE ACTIVATOR PARENT. THIS UNIT PROVIDES A FRAMEWORK FOR ESTABLISHING REALISTIC EXPECTATIONS AND GOALS FOR HANDICAPPED CHILDREN AND THE ROLE PARENTS NEED TO PLAY IN DEVELOPING THE POTENTIAL OF THEIR HANDICAPPED CHILD.

MOTIVATION

THE FIFTH UNIT DEALS WITH MOTIVATION. IT IS CONCERNED WITH WHY CHILDREN FAIL TO TRY. THIS UNIT PROVIDES GUIDELINES AND BEHAVIORAL STEPS FOR PARENTS TO FOLLOW IN ORDER TO GET CHILDREN TO ATTEMPT NEW THINGS AND TO BUILD SELF MOTIVATION IN THEIR CHILD.

COMMUNICATION

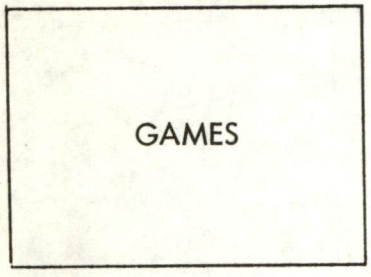
THE SIXTH UNIT DEALS WITH COMMUNICATION. THIS UNIT IS CONCERNED WITH DEVELOPING EFFECTIVE PARENTAL COMMUNICATION SKILLS. IN THIS UNIT YOU WILL LEARN AND HAVE AN OPPORTUNITY TO PRACTICE PARENTAL COMMUNICATION SKILLS WHICH TEND TO GENERATE GROWTH AND MENTAL HEALTH IN A CHILD.

STRESS

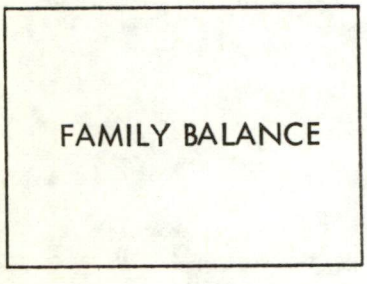
THE SEVENTH UNIT DEALS WITH STRESS. IT EXPLORES THE NATURE OF STRESS, WHAT CAUSES STRESS AND HOW PEOPLE REACT TO IT. GUIDELINES TO HELP PARENTS MANAGE THEIR OWN STRESS ARE PROVIDED, AS WELL AS STEPS PARENTS CAN TAKE TO HELP THEIR HANDICAPPED CHILD MANAGE STRESS SUCCESSFULLY.

RISK TAKING

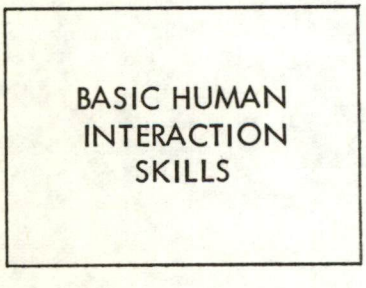
THE EIGHTH UNIT DEALS WITH RISK TAKING. THIS UNIT IS CONCERNED WITH THE EFFECT DIFFERENT TYPES OF PARENTAL RISK TAKING BEHAVIORS HAVE ON EITHER LIMITING OR ENCOURAGING THE GROWTH OF THEIR CHILD. THIS RISK TAKING BEHAVIOR RANGES FROM THE PARENT WHO OVERPROTECTS TO THE PARENT WHO ENDANGERS SAFETY. METHODS ARE OUTLINED FOR ESTABLISHING DESIRABLE RISK TAKING BEHAVIOR SKILLS.



THE NINTH UNIT DEALS WITH GAMES. THESE ARE TRANSACTIONS THAT OCCUR BETWEEN FAMILY MEMBERS IN WHICH SOMEONE RECEIVES A PAY-OFF OR "HIDDEN BENEFIT" AND SOMEONE IS A "VICTIM". THIS UNIT EXPLORES THE DIFFERENT TYPES OF GAMES THAT ARE PLAYED IN FAMILIES HAVING HANDICAPPED CHILDREN.



THE TENTH UNIT DEALS WITH DEVELOPING FAMILY BALANCE IN FAMILIES WHERE THERE IS A HANDICAPPED CHILD. THIS UNIT EXPLORES THE TENDENCY FOR FAMILIES TO BECOME HANDICAP CENTERED AND THE IMPACT THIS ONESIDED SITUATION HAS ON THE TOTAL FAMILY. THE UNIT PROVIDES SOME STEPS FOR PARENTS TO TAKE IN ORDER TO MAINTAIN BALANCE.



SINCE MANY OF THE SKILLS COVERED IN THE BASIC PROGRAM ARE HUMAN INTERACTION SKILLS, THEY WILL NOT ONLY HELP IN PARENTS' RELATIONSHIPS WITH THEIR HANDICAPPED CHILD, BUT ALSO WILL BENEFIT RELATIONSHIPS WITH THEIR SPOUSES, THEIR OTHER CHILDREN AND OTHER PEOPLE.

In completing this program, parents will take the 10 Basic Parenting Units.

In the blanks below, write the names of the ten Basic Parenting Units:

1. _____ 6. _____

2. _____ 7. _____

3. _____ 8. _____

4. _____ 9. _____

5. _____ 10. _____

(You should have written, 1. Introduction, 2. Family Stage, 3. Parental Scripts, 4. Activator Parent, 5. Motivation, 6. Communication, 7. Stress, 8. Risk Taking, 9. Games and 10. Family Balance. You are now working on Unit 1. The Introduction.)

5
SPECIFIC
HANDICAP
UNITS

IN PART TWO, PARENTS WILL COMPLETE ONE OF FIVE SPECIFIC UNITS. THE UNITS ARE DESIGNED TO PROVIDE PARENTS WITH UNIQUE PARENTAL SKILL INFORMATION RELATED TO THE SPECIFIC TYPE OF HANDICAP OF THEIR CHILD.

- PHYSICAL
- RETARDED
- BLIND
- SPEECH
- DEAF

THERE IS A UNIT RELATED TO CHILDREN WHO ARE PHYSICALLY HANDICAPPED, WHO ARE RETARDED, WHO ARE BLIND, WHO HAVE SPEECH HANDICAPS AND CHILDREN WHO ARE DEAF.

Parents will also complete the unit or units which relates specifically to their child's handicap. In the spaces below, write the names of the Specific Handicap Units:

1. _____ 4. _____

2. _____ 5. _____

3. _____

(There is a specific handicap unit for each of the following: (1) Blind Children, (2) Deaf or Hearing Impaired Children, (3) Mentally Retarded Children, (4) Speech Impaired Children, (5) Physically Disabled Children -- for example, wheelchair bound, Ceberal Palsy, Spina Bifida, Cystic Fibrosis and others.)

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.

"I'M DIFFERENT"

THIS CASE HISTORY WILL HELP YOU RECOGNIZE THE DIFFERENCES AND THE SIMILARITIES BETWEEN PARENTS OF HANDICAPPED CHILDREN AND PARENTS OF NORMAL CHILDREN.

The following conversation shows the reaction of a mother of a handicapped child when her friend suggested that being a parent of a handicapped child isn't so very different from being a parent of a normal child.

> "What do you mean? How can you say it's no different? My child and my life and my situation are very different! Can't you see that many things are different in having a handicapped child? How can you possibly understand what it's like to parent a handicapped child? You just haven't been in my shoes. You just don't understand. You could never understand unless you've been through it."
>
> Her friend replied:
>
> "I know some things are different, but you can't tell me there is such a big difference. Not everything is that different for you."

In order to see the differences and similarities you should develop two lists on the next page. On one list include all the things you can think of that make parenting a handicapped child different from parenting a non-handicapped child. Include such areas as time, parent's feelings, etc.

On the other list write down as many things as you can think of which are not different for a handicapped child and a non-handicapped child. For example, both children have to eat, be bathed, get their immunizations, etc.

THINGS THAT I FEEL ARE DIFFERENT AND THINGS THAT I THINK ARE NOT DIFFERENT IN PARENTING A HANDICAPPED CHILD. YOUR LIST WILL DEPEND ON THE NATURE OF YOUR CHILD'S HANDICAP.

DIFFERENT	NOT DIFFERENT

We have asked other parents of handicapped children to make similar lists of what they thought were different and not different. On the next page are examples of their suggestions about the differences and similarities.

OTHER PARENTS

DIFFERENT	NOT DIFFERENT
1. A handicapped child needs more time for bathing.	1. Love
2. Feeding takes more time.	2. Food
3. Potty training is more difficult and takes more time.	3. Shelter
4. It's more difficult to find baby sitters who are willing and qualified.	4. Physical care
5. It may be more difficult in social situations because of the negative reactions to your child.	5. Medical care
6. It's more difficult to find and take your child to special education.	6. Education
7. A parent worries about what will happen to their handicapped child when they get old or die.	7. Understanding
8. Parents experience more guilt, may be more protective and experience more frustration with their handicapped child.	8. Patience
9. Medical care can be more expensive and difficult to find.	9. To be treated as a person
	10. To develop their potential
	11. To have fulfilling social contacts.

TEXT

INTRODUCTION

UNIT 1

PARENTAL SKILLS PROGRAM HANDICAPPED CHILDREN

TRRI

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FIRST DRAFT

TEXT

UNIT I - INTRODUCTION

PARENTAL SKILLS FOR PARENTS OF HANDICAPPED CHILDREN PROGRAM

By

Charlotte A. Clifford

ACKNOWLEDGMENTS

This text is the result of a joint effort by the entire staff of the Parental Skills for Parents of Handicapped Children project.

Wm. A. Spencer, M.D., Chairman, Department of Rehabilitation, Baylor College of Medicine and Director, Texas Institute for Rehabilitation and Research provided guidance and reviewed the program's content.

Shalom E. Vineberg, Ph.D., Professor, Department of Psychology, University of Houston and Clinical Professor in Rehabilitation, Baylor College of Medicine, devoted long hours in reviewing the program's content and this text.

Marcus Furhur, Ph.D., Professor, Departments of Rehabilitation and Psychiatry, Baylor College of Medicine and Co-Chief of Research and Development, Texas Institute for Rehabilitation and Research, contributed to the program's content and reviewed the text.

Kenneth E. Ware, Ph.D., Asst. Professor of Rehabilitation and Psychiatry, Baylor College of Medicine contributed many hours to program development and to this text.

Muriel Meicler, Ph.D. (abd), Psychologist and Helen Matthews, Ph.D. (abd), Sociologist, did a majority of the research and literature review for the program and for this text, while Lex Freedan did a portion of the research for the Stress Chapter.

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Many of the original concepts in the chapters on Parental Scripts, Motivation, Stress, Communication and Games were developed previously by Roy A. Clifford, President, Interaction, Inc., and are referred to in texts previously written by him.

Toni Anderson devoted many long hours in typing this manuscript.

Special appreciation is expressed by the staff to the parents, handicapped youth and to staff members of the Houston Speech and Hearing Clinic, Lighthouse for the Blind, Center for Multiple Handicaps, and Houston School for the Deaf who provided input and suggestions concerning the content of this program.

PREFACE

Parents of handicapped children face unique parenting situations. Many people have recognized the problems these parents face and pointed out the need for a program to aid them in managing their situation. (a)

The Parental Skills Program for Parents of the Handicapped is designed to provide insights into some of the problems parents encounter when their child is handicapped and they seek to fulfill their role of parent. It also seeks to present some of the ideas and theories which social science research indicate will create more meaningful relationships between parents and their handicapped children. In addition, the program presents ways in which parents of handicapped children can develop new skills to more successfully develop the potential of their handicapped child.

The program was made possible through funds provided by the Department of Health, Education and Welfare, Bureau of Education for the Handicapped. It is the result of a two-year effort by members of the staffs of Texas Institute for Rehabilitation and Research and Interaction, Inc., both located in Houston, Texas.

In developing the program and its materials the project staff talked with parents of the blind, deaf, mentally retarded, speech impaired and physically disabled.

(a) See 1-12.

The children of some parents were multiply handicapped. The parents were asked to describe their most common problems and concerns related to parenting a handicapped child. These parents provided valuable input and their suggestions guided the staff in developing the program. A number of handicapped young adults who were blind, deaf, speech impaired and physically disabled also talked with staff members and made valuable suggestions concerning areas to be covered in the program. Counselors, social workers and teachers, each with extensive experience working with handicapped children and their parents, also participated with the staff in determining the content of this program.

Prior to developing the program, the project staff also conducted an extensive review of the literature and research related to handicapped children, their parents and their families. Much of the program is based upon the research findings.

The Parental Skills program for parents of the Handicapped Program consists of ten units. covering basic parenting skills and five units covering specific handicaps. You will participate in the ten basic units and the specific unit or units related to your child's handicap.

The program was developed in three different formats in order to reach as many parents as possible. You may be attending sessions where an instructor makes lecturettes using slides and where parents form teams to share ideas, role play, watch demonstrations or work on case histories. Or you may be attending sessions in which

there is no instructor and the lecturettes are on cassette tapes and slides, and the parents form teams to participate in team activities. Perhaps you were unable to attend group sessions and you are using the individual version where you listen to cassette tapes and work through a self-instructional workbook.

Regardless of the version of the program in which you are participating, THE TEXT PLAYS AN IMPORTANT PART IN PROVIDING ADDITIONAL INFORMATION, EXAMPLES AND EXPLANATIONS. It is designed to supplement the information provided on cassette tapes, lecturettes, slides and in workbooks and team activities. It covers the ten units on basic parenting. A separate booklet covers the special unit on your child's handicap.

It is suggested that you read the text one unit at a time after attending sessions or completing the workbook. The text will familiarize you with concepts and ideas covered in the unit and with labels and terms, some of which may be unfamiliar to you.

In the brief period you attend sessions or participate in the program, it will be impossible to go extensively into all areas which are of concern to you. Instead, the program is designed to provide you with some general insights and to leave you with some new ideas and some alternative approaches to your role as a parent of a handicapped child.

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UNIT I

INTRODUCTION

Let's face it, parents are people. In their relationships with their children just as in their relationships with others, they often face difficulties. Parenting a child isn't easy. It's a hard job.

All the things that are happening in our culture don't make being a parent any easier. Uncertainties brought about by the changing role of the male and female, the changing economic scene, along with the changing role of children have made parenting difficult.

Parents today face many problems in parenting their children. Often parents have never been around children and know little about them. The mobility of many families has created few opportunities for learning about parenting from grandparents, aunts and uncles and other family members. The decrease in the number of children in a family also has afforded fewer opportunities for potential parents to experience being around babies or young children. Consequently, young parents today often romanticize parenthood. They are unrealistic about what being a parent means. They have unrealistic expectations concerning what babies are like and what their life will be like with the introduction of a child into their family.

PARENTS OF NORMAL CHILDREN FACE CRISIS

Research conducted by LeMasters (1968) indicates that the birth of a child constitutes a crisis, sometimes quite a profound one, for most couples.

> A child coming into the life of a couple upsets the normal routines of interaction and requires adjustments that often are painful and stressful ...Parenthood as contrasted with the simple husband-wife relationship requires greater readjustment than formerly believed. (p.459)

The adjustments they must make in their relationships to one another, the changes occuring in their lifestyle, the economic demands which were unexpected create strains on their relationship. The unrealistic expectations they had concerning parenthood and the nature of children often create quite an adjustment for many young couples.

IMPACT OF HANDICAPPED CHILD

If the birth of a normal child creates a crisis for parents, imagine the crisis created by the birth of a handicapped child. Not only do parents of a handicapped child face the crisis of having a child, but the handicap tremendously compounds the problems they must deal with. (a)

It doesn't matter if the parents find out at the birth of their child, or when the child is two, or if they get a call from an emergency room that their child has been injured. Whenever parents learn that their child is "handicapped" everything changes. The degree of change depends upon the nature and severity of

(a) See 12, 13, 14, 15, 16, 22, 32, 34.

the handicap, and it depends on the parents and how they manage their changed life.

RECURRING THEME - LACK OF KNOWLEDGE

When reviewing the literature and research on handicapped children and their parents, or when talking to parents themselves, one notices a recurring theme. This theme is the lack of knowledge parents have concerning how to operate as parents of a handicapped child. (b)

Let's take a look at why parents of handicapped children feel they lack knowledge concerning how to parent their handicapped child and why they often face such a profound crisis upon learning of their child's handicap.

LIFE SCRIPT

All of us follow a mental blueprint to some degree or other in our lives. We all have plans for the future. These plans are not often very detailed; rather, they are vague ideas we have about the things we want and expect to happen to us during our life. This blueprint contains a general idea about the times in our life when we will do different things. For example, most of us expect to go to school until we are seventeen or eighteen, perhaps graduate from high school. Some of us expect to go to college, and have an idea of what we "want to be" when we are grown. We have general ideas about when we will get married, though some of

(b) See 8, 9, 13, 16, 17, 19, 20, 21, 22, 25, 28, 29, 34, 38, 39.

us don't plan to. We have ideas about when we will have children, get a place of our own, etc. We even have a vague idea about the age when we will retire, though we think little about it when we are young. In our society there are times to do things and many people conform to this blueprint. We can call this a LIFE SCRIPT. Each life script is different, but in many ways these scripts are similar. They contain our dreams and expectations.

WE PLAY MANY PARTS

In following our life script, we play many parts. We play the part of "child" when we are young, the part of "teenager," then "young adult." We play the part of bachelor or liberated woman, perhaps; and when and if we marry, we play the part of "husband" or "wife". If we become parents, we then also have the part of "parent" to play.

In each of these parts we follow a script. Our script relates to what we think we are supposed to do and how we think we should behave. Our scripts for these various parts are not the same. For example, we don't think our part as husband or wife is the same as our part of parent. Thus, we tend to behave differently for each part we play.

People have their own ideas concerning how they are to play their part and what the part involves. Therefore, one person may have ideas quite different from how another person thinks the part should be played. For example,

when a couple marries they may have completely different ideas about how husbands and wives are supposed to behave. This can often cause serious problems, as they tend to disagree and disappoint each other. They may be thinking, "you aren't acting like a husband is supposed to act", or "that isn't the way a wife should treat a husband."

Different expectations concerning the script a person should follow in a particular part causes many of the problems people have with each other. Yet who is to say which one of them is "right"? The problem is that we tend to believe that the way we think concerning a part and the way we act is the right way to do it. Sometimes this isn't necessarily so - it is simply that this is the way we have learned to act out that particular part.

If children are in our overall life script, we have ideas about what our child will be like. We expect the perfect child, whole, beautiful and bright. We expect he will grow through the typical stages of babyhood, childhood, adolesence and become a successful adult, hopefully more successful than we are. We have general ideas about when to expect him to sit, stand, walk, talk, go to school, etc. We plan on our child following the typical timetable for child development, and we plan, in general, that he will do what most other children do at certain stages.

PARENT SCRIPT

In addition to these expectations concerning the child we plan to have, we have ideas about how to parent this perfect child. As Schaefer and Bell (1955) have said, "young unmarried women have well-structured attitudes toward child rearing and the family prior to actually assuming the role of a mother" (p.320). Young unmarried men also have fairly specific ideas related to being a father. Consequently, even before a child is born prospective parents have a script they will follow in parenting their child. (c)

Where do these parental scripts come from? Where do we learn how to be parents? Have you ever questioned the parent script you follow? Let's take a look at how most people learn the script they follow when they are parents. (d)

Influence of Traditions

Our society has some traditions concerning parenthood. We expect parents to take care of their children. We expect them to feed them, shelter them, tend to their health and their education. We also expect parents to "love" their children and to do what is best for their child. Our traditions say: Keep your child with you until he can manage on his own; teach him, make him safe, and MAKE HIM HAPPY. A tall order for two parents who sometimes find it difficult to manage themselves. But this is what traditions say we are to do.

(c) See 5, 6, 23, 34, 37.

(d) See 8, 13, 28, 33, 34, 36.

This wasn't such a hard job when we didn't move so often, when we had large families who could help each other out. It wasn't so hard when things weren't so complex, so technical and competitive; but today it is difficult. It takes such a long time for a child to develop all the skills he needs in our complex world that children must stay with their parents many years.

Nonetheless, we tend to follow these traditions when we act out our parent script. We expect to do these things more or less. If our child is normal we can with effort perhaps manage most of it. However, many parents feel it sure would be nice to have some help once in a while.

Influence of Parents as Models [e]

Other ideas concerning parenting come from our own parents. We learn about parenting from them. We tend to copy their style. Men tend to follow their father's style; women their mother's. If our parents watched every move we made, we tend to do that with our children. If they gave up a lot for us, we tend to follow that pattern. If they never showed how they felt, we tend to believe parents don't show their children how they feel. If our parent overprotected us, we tend to do the same with our children.

No matter the style our parents had, we tend to follow that style because this is often the only first-hand knowledge we have about what parents are supposed to do and how they are supposed to act. The fact that our parents may have had

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(e) See 1, 2, 3, 7, 9, 11, 13, 28, 33.

rather bad parental skills, often isn't apparent to us. We merely believe that is the way parents are; that's how you parent a child. We tend to follow the model our parents set for us even if they were ineffective parents.

Influence of Memories [f]

In some specific circumstances, we do not follow our parents' style because of our childhood memories. How often have you said, "I'll never treat a child of mine like my father treated me when I did wrong", because you remember how awful he made you feel. Our past tends to help us alter our parental style somewhat from that of our parents. Yet overall, we do tend to use a script quite similar to theirs.

Influence of Television, Books, Magazines and Neighbors

We also get ideas about being a parent from watching families on television, from reading books on parenting and from magazine articles. Of course, we often encounter conflicting points of view about parenting which only tend to confuse us. Yet, we do alter our parental scripts by learning new ideas and behaviors. Our neighbors and friends also serve as models as they parent their children who may be a bit older than ours. They pass on helpful hints and examples we can follow.

"DEVELOPED" VS "UNDEVELOPED" PARENT SCRIPTS

In copying our parents, relying on memories, reading books, watching other

(f) See 33.

parents and through trial and error we obtain the script we follow as a parent. It contains our ideas about our job as a parent. It also contains the behaviors we act out.

Sometimes parents do not have opportunities to learn how to be effective parents. When parents have had ineffective models and have had little exposure to children or parenting by others, they can actually be "undeveloped" parents. Such parents tend to follow a parent script which is inappropriate and detrimental to their child. They do not know how to parent effectively.

People who have "undeveloped" parent scripts may have very effective scripts for the other parts they play. For example, just because a person has "undeveloped" parent skills doesn't mean that he doesn't have excellent skills for his work or his husband role. People tend to be "developed" in some parts they play, and "undeveloped" in others. It usually depends on the models set for them and their experiences.

Some people are lucky and have "developed" parent scripts. This makes their parenting job much easier and more effective. Such parents usually have a wide range of parental skills which they learn through parenting a number of children, by exposure to others while they are parenting, by having effective models set by their parents, through reading and perhaps through parent education programs.

Considering how ill-prepared many people are for parenting, is it any wonder that so many parents encounter problems as they try to care for, educate, develop and love their children? Most parents' intentions are excellent, but many of them have never had an opportunity to learn parent skills that will enable them to do what they really wish they could as parents.

PARENTS OF HANDICAPPED CHILDREN

If many parents whose children are not handicapped face a crisis and are really ill-prepared to be parents, no wonder parents of handicapped children encounter crisis and often feel so ill-prepared to parent a child with a handicap.

We talked about the parent script most prospective parents have even before they have a child. Although that script may not be the best way to parent a child, it gives them a few guidelines to follow. They do not enter parenthood completely without ideas about what to expect and how to behave.

This is not so with parents of handicapped children. Whenever it occurs, whether it be at birth or later on, when a parent hears "your child is handicapped", everything changes.

Suddenly they have no scripts to follow for being a parent of a handicapped

(g) See 16, 18.

child. [g] They have limited information, few models and few traditions to follow. They do not know how to deal with their child's handicap. [h]

Limited Information

Most parents have never heard of the handicap or have very limited knowledge concerning it prior to learning of their child's disability. They don't know what it is, what it involves or what it means to their child or them. This lack of knowledge and not knowing what to expect of their child or when to expect it makes parenting difficult. [i]

Few Traditions

Parents of handicapped children have few traditions to follow in parenting their handicapped child. Until a few years ago, parents hid handicapped children away. Other people rarely saw them. Until recently, many handicapped people did not assume an active and participating role in our society. Many of them did not go to school, did not work and were dependent upon their parents throughout their lives. They were viewed as tragic and as being incapable of actively participating and contributing.

This is now rapidly changing. Medical science has improved the chances for children with handicaps to survive and lead relatively long lives. Our society

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(h) See 20.

(i) See 16, 18: reference to a "role organization ".

is more tolerant of differences in people and our culture is redefining the role that handicapped persons will take in our society. This new role calls for them to be active and to participate and contribute to the extent of their capabilities and to be as self-sufficient as possible. This means that old ideas concerning the handicapped as dependent, inadequate, non-contributing members of society are becoming obsolete.

In years past parents did not perceive of their job as one of developing the skills and capabilities of their child so that he could become an active member of society; instead they saw their job as provider and caretaker. They knew their child would grow up into a handicapped adult who would likely never be independent.

This is now all changing. It has become apparent that people with handicaps can participate and contribute in their community. This calls for a different role for parents of handicapped children. This means that old ideas concerning the handicapped as dependent, inadequate, and non-contributing are being replaced by expectations that parents and our society develop the skills and capabilities of handicapped children so they can take their place as active citizens.

Consequently, the few traditions we did have concerning the role of the parent of a handicapped child have changed dramatically within the past few years. Parents therefore can't look back to what the society has done and

try to assume a traditional role of parent of a handicapped child. That traditional role is no longer an acceptable one for parents of handicapped children.

In some ways this means that the role of the parent of a handicapped child becomes somewhat similar to the parent of a non-handicapped child. Both roles involve developing the child, educating him, and helping him become independent to the extent possible. The problem is that the task is often much more difficult for parents of handicapped children and it requires new insights, know-how and skills.

Few Models to Follow

Parents of handicapped children have few models to follow in parenting their handicapped child. They, like other parents, merely tend to copy their parents' style and behaviors. Often, these are extremely inappropriate. This is understandable as Leichman and Willenberg (1962) have pointed out, "where would normal parents of a mentally retarded child develop the reservoir of memories to fit the rearing of a mentally retarded child?"

Furthermore, there are unique skills for teaching a blind child, a deaf child, a child with a physical disability or a mental one. A great deal of research has been conducted concerning ways to teach children with specific handicaps. Most parents of handicapped children, in the beginning, do not know other parents whose children have a similar handicap. They are most often completely unfamiliar with the skills and techniques for developing their child.

Parents of handicapped children could model themselves after other parents with whose child has a similar handicap, but often they have never been around such a parent. Sadly, parents of handicapped children have few or no models to follow in parenting their child.

No Timetable

Each handicapped child is unique and his development individualized. Often handicapped children do not follow the cultural timetable in their development. Parents are often confused by this and do not know how to judge the child's progress and therefore have problems planning.

Television, Books, Friends, Neighbors

You don't see handicapped children and their parents on television very often; magazines and books are rarely about parenting handicapped children; and few of our friends and neighbors have children with handicaps. Consequently, parents of handicapped children begin with few sources of information and few examples of how they should parent their child.

PARENTS WITHOUT A SCRIPT

Parents of handicapped children are actually parents without a script. They really do not know how to parent their child. They do not know what to do or how to do it. This results in feelings of inadequacy, (j) anxiety (k) and guilt. (l) As

(j) See 10, 12, 21, 24, 28, 31, 34.

(k) See r, 10, 26, 28, 30.

(l) See 4, 24, 26, 28, 30.

Leichman and Willenberg (1962) have noted, "many parents of mentally retarded children might feel quite inadequate as child rearers and develop feelings of guilt and anxiety" (p.2). Their feelings of inadequacy are unjustified. They are not inadequate. They merely have not had a chance to learn the unique skills for such a unique parenting situation. Their anxiety in not knowing what to do is so common a reaction that it helps to know that in time this anxiety passes. The guilt is unfounded. Parents who feel guilty because they don't know how to parent their handicapped child are blaming themselves for failing to live up to expectations which may be unrealistic. How could a parent of a handicapped child really expect to know how to parent the child? After all, we aren't born with parenting skills. Such skills must be learned.

SUMMARY

The following major points were covered in Unit I.

1. People tend to follow a "life script" or blueprint in their lives. It is not detailed, but they do tend to have expectations concerning what they will be doing at different stages of their life.

2. In following their life script, people play many different parts. They play the part of child, teenager, young adult, spouse, perhaps parent and many others.

3. For all the parts they play they follow a script which is their mental idea of what they are supposed to do and how they are supposed to behave.

4. Most people have a generalized parent script even before they become parents. This script generally follows society's traditions concerning parenting a child, and in many ways specifically follows the model a person's parents set of how parents behave. Scripts are also influenced by personal experiences and by other people. Parent scripts may involve effective or ineffective parent behavior and concepts.

5. Some people have undeveloped parent scripts because they have had few opportunities to be around children, have had inadequate models set by their parents, and have in general had limited opportunities to learn how to be a parent.

6. Other parents have developed parent scripts because they have had good models set by their parents, because they have had opportunities to parent other children, they have been around other people who are adequate parents and copied them. Some have attended parent education programs.

7. Just because a person has undeveloped parent scripts doesn't mean that he is undeveloped as a person. People may have very developed scripts for one part they play and undeveloped for others.

8. Parents of handicapped children are often parents without a script. Often they have little information concerning their child's handicap, and

have had no models to follow in parenting a child with handicap. Our society has few traditions to follow in parenting a handicapped child.

9. The lack of a parent script for parenting a handicapped child creates feelings of inadequacy, anxiety and guilt on the part of parents. Such parents are not inadequate and their guilt is unrealistic. They could not expect to know how to parent a handicapped child. We aren't born with such parenting skills. These skills must be learned and few people have the opportunity to learn skills for parenting handicapped children ahead of time.

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