



## PARENTING CHILDREN WITH SPECIAL NEEDS

(Note: Viewers interested in this video may also appreciate the video entitled PARENTS' VIEWS OF LIVING WITH A CHILD WITH DISABILITIES)

### PROGRAM SUMMARY

This program reviews some very important basic information for parents of children who have various kinds of disabilities. Today, such children are referred to as "children with special needs." The program presents suggestions about ways parents can adjust to the problems of life with a special needs child.

Information on important services available by law to both the child and the parents is also provided. Parents who have a special needs child should seek out such assistance and use the help wisely, as often as necessary.

### MAJOR MESSAGE

Every year, many children are born with a variety of seriously disabling problems. While some are minor and relatively easy to remedy, others are major and involve years of special treatment before significant improvement occurs. Still others represent a lifelong disability which might improve only slightly through appropriate interventions, or which may be irremediable ("cannot be improved by any known treatment").

Parents whose newborn child is disabled suffer a severe shock. They need help to work through the trauma. Their feelings often include anger ("Why me?" they ask). However, they must make many quick decisions even though they are feeling confused, overwhelmed, guilty, and anxious. They tend to **deny** that this could be happening to them! Hopefully, one parent will help the other through the first bad days and onward. This is a time when family, friends, and professionals may be the source of needed help, as well as hope for the future. The hospital will alert appropriate personnel to work with the parents and the child.

Federal regulations require a team of professionals to develop a plan that indicates the services that must be provided for this child. The parents are to be involved in developing this plan. Each family in such a situation must, by law, be assigned a Service Coordinator. This person must be someone appropriate to each particular child's need. Parents should become willing participants with the Service Team, working together as partners for the benefit of the child.

### KEY POINTS

- Often, babies born with serious problems survive, though many survivors die during the first year.
- Marriages have a hard time surviving after the birth of a disabled child; 70% are dissolved within five years.
- Staying together requires problem-solving together, in a deliberate, dedicated way, despite overwhelming frustrations, feelings of despair, prejudices (of the parents themselves, and of others), constant anxiety, and severe, unremitting stress.
- Parents should give themselves time to grieve: grieving allows people to separate from a lost dream - a necessity upon the birth of an afflicted child.
- All the negative feelings associated with the birth of an afflicted child are entirely understandable, but the parents **must** set them aside and become **matter-of-fact** and **realistic**.

Steps to alleviate pain and face facts:

- Involve extended family members.
- Involve professional personnel.
- Realize that, though afflicted, the child has normal feelings, needs, and hopes.
- Involve as many supporters as possible in major decision-making.
- Try not to feel alone, neglected, abandoned, hopeless (as the child's **mother** or the child's **father**).
- Try counseling; learn to express your feelings (both negative and positive), and try to stay calm. As parents, communicate your feelings and frustrations to one another: remember: you're both desperately needed by the child. Treasure one another: become a "trio."



The first plan developed after the birth of a special needs child must be replaced when the child reaches pre-school age. The replacement is called an "IEP" ("Individual Educational Plan"). Parents should contact their local school system before the child is 3 or 4 to learn details of developing their child's IEP. It's probably best to telephone your local school system's Special Education Supervisor to learn about developing an IEP.

### WHILE VIEWING

Several times in this program, comments are made about **parents of special needs children** and their feelings of "**frustration**." Also, statements are made about such **children's** feelings of frustration. Try to notice all remarks about "feeling frustrated." Perhaps you'd like to jot down your thoughts as they occur.

### REFLECTIONS

Sit quietly for a few moments and think about what was said in this video about "feeling frustrated." Be able to tell others some of the points made about frustration. **Also**, think about 3 or 4 **additional points** you might make about "frustration" if you were the little **boy** who has very limited ability to control his **hand movements**. Discuss your points with a friend or a group.

Do you know a handicapped person? Why do you think that person feels frustrated at times? Be specific.

