



Practical Parenting

110

PARENTS' VIEWS OF LIVING WITH A CHILD WITH DISABILITIES

(Note: Viewers interested in this video may also appreciate the video entitled
PARENTING CHILDREN WITH SPECIAL NEEDS)

PROGRAM SUMMARY

In this video, three sets of parents speak about their experiences and feelings right after the birth of their disabled child. They continue with discussions of the continuing years of adjusting to their situation. They review specific problems and critical issues they've encountered.

Their frank discussions about the difficulties of adjusting their lives to the child's need (or to the death of their child) would probably be helpful to other parents with a disabled child as well as to anyone who knows or works with parents who are in similar situations.

MAJOR MESSAGE

Living with a disabled child is a major challenge. If the child survives, it means that you must **redefine your entire existence**, day by day, in new ways.

It is hard to watch a young child struggle with overwhelming problems. However, parents and caretakers must confront and acknowledge all facets of the situation. Lots of couples fall apart during the first few years because of incessant problems, blame, distress and confusion.

If parents can maintain a "united front" and a positive attitude, it's certainly a blessing, given the nature of **any** special child's need. At first, **everything** and **everyone** in the situation is uncertain. As the elements of the situation become clearer, it is important to the parents to do the following three things, above all:

- (1) take time to nurture the marriage;
- (2) take time each day to try to do something that helps reduce and relieve stress (this applies to both the father and the mother); and
- (3) take advantage of any help offered and of any possible source of assistance and support.

KEY POINTS



The interviews with these parents reveal that some of the realities which parents of disabled children face are quite unexpected and unusual, such as the following:

- (1) You learn that you can't plan ahead in the usual way.
- (2) Everything proposed - from the smallest detail to the "big picture" - has to be considered in light of what the disabled child can or can't do.
- (3) Others - even family members, at first - are uncertain about what to say about the child or the situation.
- (4) Even parents are unsure of **what to say**, at first - or **what to feel**, or **what to do**, day by day.

However, as time passes, parents and supportive family members and friends learn ways to adjust and rebuild their lives. Some positive suggestions follow:

- (1) Don't concern yourself with other people's reactions: accept them and go on (**ignore** anything that's **negative** and **cherish** everything that's **positive**).
- (2) Especially within the family, work to gain acceptance and support of the child from all, especially siblings.
- (3) If necessary, adjust your value system. Always consider: what's the highest need now? What steps must we take? A couple might do best to work **together** through adjusting to their "new lifestyle," now that they have a disabled child, keeping in mind the constant thought of "what's best," given the new situation (life with a disabled child).
- (4) Search for all possible sources of assistance. Be aware of the following facts:
 - If disabilities are apparent at birth, most hospitals will help to assemble a team of appropriate persons to plan and administer all possible interventions. This service is required by law. It may be handled in different ways in different states.
 - As the child reaches preschool age, federally-mandated services from Special Education are available through most states and local school systems. Parents should contact Special Education at the state level (call the State Education Agency "**SEA**" or the State Board of Education - substitute the name of **your state** for the word "State"). Also, call your **local** Board of Education and ask for the Special Education Supervisor. If you don't know the name of your local school system, ask a parent who has children in a local school. Also contact your State Department that handles **social services** or handles **health and hospitals** to inquire about advice or services they may offer.

WHILE VIEWING

Viewers will see two disabled children in this program. Apparently both have normal intelligence. Give **especially close attention** to what you see and hear about **either** the little **girl** or the little **boy**. Be able to describe two things:

- (1) the **nature of the child's disability**, and
- (2) **how** you think that **the disability will affect the child** in adult life (from age 18 onward).

REFLECTIONS

Almost everyone knows of **someone** who has a disabling condition that will affect them from a certain moment in time until the end of their life (either from birth, or from the time some accident or situation occurred). Discuss this person's situation with a friend or group. Bring in specific comments on how you think the disablement affected the person's **parents** or **family** or **friends**. Also discuss how **you** would be affected if you were the parent.