PARENTING A CHILD WITH A DISABILITY

When parents first learn that their child has a disability, whether it is physical, emotional, or intellectual, they often experience many different emotions. Denial, grief, anger, fear, guilt, confusion and a sense of powerlessness all are common reactions to the diagnosis.

After parents experience these first reactions, they are ready to move beyond asking “Why?” to determining “What now?”

CONSTRUCTIVE ACTIONS FOR PARENTS OF CHILDREN WITH DISABILITIES

COLLECT INFORMATION

Join a group. Much useful information is held in the hands, heads, and hearts of other parents like you.

Read books written for and by parents of children with special health care needs.

Keep accurate records about conditions that are difficult to diagnose. You may provide information that will be useful to professionals working with your child.

Talk to others for information (nurses, teachers, parents, therapists, etc.)

Research concerns on your own. Your local library may have helpful information. There are also state-wide and national organizations that provide information about many conditions.

SUPPORT AND EMPOWER YOUR FAMILY

Maintain a positive outlook. Focusing on the positives can help diminish the negatives.

Take time to care for yourself. Enjoying yourself helps you to enjoy your children more.

Make time for your loved ones. Pain divided isn’t nearly so hard to bear as pain in isolation.

Don’t be afraid to show emotion. Sorrow, guilt, bitterness and anger are all natural as your hopes and dreams change.

Take one day at a time. Sometimes fears of the future can be immobilizing. Keeping daily routines as normal as possible adds consistency to an unpredictable life.

Decide how to deal with others. Due to a lack of knowledge, some people may not know how to act or what to say. Decide how you want to deal with stares and questions.

Keep the lines of communication open with all your children. Some siblings find having a brother or sister with a disability a positive experience as they learn to accept people for who they are. Other siblings may feel fear, resentment, jealousy, and neglect. Make opportunities for your children to express how they feel.

Expect and encourage your child with special needs to develop his or her capabilities, whatever they may be. Find programs for your child. Assistance is available to help you with whatever problems you are having.
**FORM A PARENT/PROFESSIONAL PARTNERSHIP**

Work together with the professionals involved with your child. As a parent, you have an intimate knowledge of your child, and professionals have a specialized knowledge of your child’s needs. Working together, you can provide your child with the best possible care.

Learn terminology. If someone uses a word you don’t understand, stop the conversation and ask what the unfamiliar word means.

Learn all you can about your child's disability. Ask questions. Don’t be concerned that you are being a bother by asking questions. This is your child. Write down what you learn.

Shop around till you find doctors and other professionals with whom you and your child can work comfortably.

Weigh professional recommendations against your own schedule, finances, values, and commitments. If you don’t agree with a professional's recommendation, say so, and why.

**ORGANIZE YOUR FINANCES**

Keep records of medical bills.

Seek information about any financial assistance programs.

**PLAN FOR THE FUTURE**

Ensure that your child has opportunities to develop skills that will make him or her as independent as possible.

Write a will providing for your child’s care and safeguarding future eligibility for government benefits.

Explore different possibilities for living arrangements once your child is grown.

For more information on parenting a child with special needs or about any parenting topic, call ParentLink at 1-800-552-8522, or en Espanol 1-888-460-0008. Visit us on the web at http://parentlink.missouri.edu.

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