



# CHILDREN'S DISABILITIES INFORMATION COALITION- PARENT RESOURCE CENTER

## Parenting a Child with Special Needs

When parents learn that their child has a disability or a chronic illness, they begin a journey that takes them into a life that is often filled with strong emotion, difficult choices, interactions with many different professionals and specialist, and an ongoing need for information and services. Initially, parents may feel isolated and alone, and not know where to begin their search for information, assistance, understanding, and support. This document has been developed expressly to respond to the information needs of parents –those who have just learned their child has special needs and those who have lived with this reality for some time but who have reached a transition point where they need new information or renewed support. This issue provides a starting point for families in their search for information and resources.

### You Are Not Alone

When parents learn about any difficulty or problem in their child's development, this information comes as a tremendous blow. The day my child was diagnosed as having a disability, I was devastated –and confused that I recall little else about those first days other than the heartbreak. Another parent described this event as a “black sack” being pulled down over her head, clocking her ability to hear, see, and think in normal ways. Another parent described the trauma as “having a knife stuck” in her heart. Perhaps these descriptions seem a bit dramatic, yet it has been my experience that they may not sufficiently describe the many emotions that flood parents' minds and hearts when they receive any bad news about their child.

**Common Reactions:** One of the first reactions is denial -”This cannot be happening to me, to my child, to our family.” Denial rapidly merges with anger, which may be directed toward the medical personnel who were involved in providing the information about the child's problem. Anger can also color communication between husband and wife or with grandparents or significant others in the family. Early on, it seems that the anger is so intense that it touches almost anyone, because it is triggered by the feelings of grief and inexplicable loss that one does not know how to explain or deal with.

Fear is another immediate response. People often fear the unknown more than they fear the know. Having the complete diagnosis and some knowledge of the child's future prospects can be easier than uncertainty. In either case, however, fear of the future is a common emotions: “What is going to happen to this child when he is five years old, when he is twelve, when he is twenty one? What is going to happen to this child when I am gone?”. Other unknowns also inspire fear. Parents fear that the child's condition will be the very worst it possibly could be. Memories return of persons with disabilities one has known. Sometimes there is guilt over some slight committed years before toward a person with a disability. There is also fear of society's rejection, fears about how brothers and sisters will be affected, questions as to whether there will be any more brothers or sisters in this family, and concerns about whether the husband or wife will love this child. These fears can almost immobilize some parents. Then there is guilt and concern about whether the parents themselves have caused the problem:

1101 E. Schuster Ave.  
El Paso, Texas 79902  
(915) 217-2747  
(915) 496-0751 fax  
sandra.pinon@cdicelpaso.org  
patricia.santibanez@cdicelopaso.org





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“Did I do something to cause this? Am I being punished for something I have done? Did I take care of myself when I was pregnant? Did my wife take good enough care of herself when she was pregnant?” *Confusion* also marks this traumatic period. As a result of not fully understanding what is happening and what will happen, confusion reveals itself in sleeplessness, inability to make decisions, and mental overload. In the midst of such trauma, information can seem garbled and distorted. You hear new words that you never heard before, terms that describe something that describe something that you never heard before, terms that describe something that you cannot understand. You want to find out what it is all about, yet it seems that you cannot make sense of all the information you are receiving. Often parents are just not on the same wavelength as the person who is trying to communicate with them about their child's disability. *Powerlessness* to change what is happening is very difficult to accept. You cannot change the fact that your child has a disability, yet parents want to feel competent and capable of handling their own life situations. *Disappointment* that a child is not perfect poses a threat to many parents' egos and a challenge to their value system. This jolt to previous expectations can create reluctance to accept one's child as a valuable, developing person. *Rejection* is another reaction that parents experience. Rejection can be directed toward the child or toward the medical personnel or toward the medical personnel or toward other family members. One of the more serious forms of rejection, and not that uncommon, is a “death wish” for the child—a feeling that many parents report at their deepest points of depression. Not all parents go through these stages, but it is important for parents to identify with all of the potentially troublesome feelings that can arise, so that they will know that they are not alone. There are many constructive actions that you can take immediately, and there are many sources of help, communication, and reassurance.

**Seek the assistance of another parent:** There was a parent who helped me. Twenty-two hours after my own child's diagnosis, he make a statement that I have never forgotten: “You may not realize it today, but there may come a time in your life when you will find that having a daughter with a disability is a blessing.” I can remember being puzzled by these words, which were nonetheless an invaluable gift that lit the first light of hope for me. This parent spoke of hope for the future. He assured me that there would be programs, there would be progress, and there would be help of many kinds and from many sources. And he was the father of a boy with mental retardation.

**Seek information:** Some parents seek virtually “tons” of information; others are not so persistent. The important thing is that you request accurate information. Don't be afraid to ask questions, because asking questions will be your first step in beginning to understand more about your child. Learning how to formulate questions is an art that will make life a lot easier for you in the future. A good method is to write down your questions before entering appointments or meetings, and to write down further questions as you think of them during the meeting. Get written copies of all documentation from physicians, teachers, and therapists regarding your child. It is a good idea to buy a three-ring notebook in which to save all information that is given to you. In the future, there will be

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uses for information that you have recorded and filed; keep it in a safe place. Again, remember always to ask for copies of evaluations, diagnostic reports, and progress reports. If you are not a naturally organized person, just get a box and throw all the paperwork in it. Then when you really need it, it will be there.

**Do Not Be intimidated** by the educational background of this and other personnel who may be involved in treating or helping your child. You do not have to apologize for wanting to know what is occurring. Do not be concerned that you are being a bother or are asking too many questions. Remember, this is your child's future.

**Do Not Be Afraid to Show Emotion.** So many parents, especially dads, repress their emotions because they believe it to be a sign of weakness to let people know how they are feeling. The strongest fathers of children with disabilities whom I know are not afraid to show their emotions. They understand that revealing feelings does not diminish one's strength.

**Learn to Deal with Natural Feelings of Bitterness and Anger.** Feelings of bitterness and anger are inevitable when you realize that you must revise the hopes and dreams you originally had for your child. It is very valuable to recognize your anger and to learn to let go of it. You may need outside help to do this. It may not feel like it, but life will get better and the day will come when you will feel positive again. By acknowledging and working through your negative feelings, you will be better equipped to meet new challenges, and bitterness and anger will no longer drain your energies and initiative.

**Maintain a Positive Outlook.** A positive attitude will be one of your genuinely valuable tools for dealing with problems. There is, truly, always a positive side to whatever is occurring. For example, when my child was found to have a disability, one of the other things pointed out to me was that she was a very healthy child. She still is. The fact that she has had no physical impairments has been a great blessing over the years; she has been the healthiest child I have ever raised. Focusing on the positives diminishes the negatives and makes life easier to deal with.

**Talk with Your Mate, Family, and Significant Others.** Over the years, I have discovered that many parents don't communicate their feelings regarding the problems their children have. One spouse is often concerned about not being a source of strength for the other one. The more couples can communicate and difficult times like these, the greater their collective strength.

**Rely on Positive Sources In Your Life.** One positive source of strength and wisdom might be your minister, priest, or rabbi. Another may be a good friend or a counselor. Go to those who have been a strength before in your life. Find the new sources that you need now. A very fine counselor once gave me a recipe for living through a crisis: "Each morning, when you arise, recognize your powerlessness over the situation at hand, turn this problem over to God, as you understand Him, and begin your day." Sometimes professional counseling is warranted; if

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**Take One Day at a Time.** Worrying about the future will only deplete your limited resources. You have enough to focus on; get through each day, one step at a time.

**Learn the Terminology.** When you are introduced to new terminology, you should not be hesitant to ask what it means. Whenever someone uses a word that you don't understand, stop the conversation for a minute and ask the person to explain the word.

**Keep in Touch with Reality.** To stay in touch with reality is to accept life the way it is. To stay in touch with reality is also to recognize that there are some things that we can change and other things that we cannot change. The task for all of us is learning which things we can change and then set about doing that.

**Remember That Time Is on Your Side.** Time heals many wounds. This does not mean that living with and raising a child who has problems will be easy, but it is fair to say that, as time passes, a great deal can be done to alleviate the problem. Therefore, time does help!

**Decide How to Deal With Others.** During this period, you may feel saddened by or angry about the way people are reacting to you or your child. Many people's reactions to serious problems are caused by a lack of understanding, simply not knowing what to say. Or fear of the unknown. Understand that many people don't know how to behave when they see a child with differences, and they may react inappropriately. Think about and decide how you want to deal with stares or questions. Try not to use too much energy being concerned about people who are not able to respond in ways you might prefer.

**Remember That This is Your Child.** This person is your child, first and foremost. Granted, your child's development may be different from that of other children, but this does not make your child less valuable, less human, less important, or in less need of your love and parenting. Love and enjoy your child. The child comes first; the disability comes second. If you can relax and take the positive steps just outlined, one at a time, you will do the best you can, your child will benefit, and you can look forward to the future with hope.

**Access Information and Services.** One of the first things you can do that may prove enormously helpful, now and in the future, is to collect information – information about your child's disability, about the services that are available, and about the specific things you can do to help your child develop to the fullest extent possible.

**Join a Group.** Much of the information that will be helpful to you is in the hands, heads, and hearts of other parents like yourself. For this reason, it is worthwhile to join a parent's group. Some groups are organized around one particular disability (e.g. cerebral palsy, Tourette syndrome, Down syndrome) while other groups draw together parents who, irrespective of the disabilities of their children, have similar concerns, such as daycare, transportation, coping, or finding out about and supporting special education in their community.

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