

# A Guide to Developmental Disorders of Children

## Part 1 Introduction

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### 1. Introduction

Though not common, from time to time we come across children with some disability, disorder, or handicap. Previously all non physical disabilities were lumped together as mental illnesses or mental retardation. Now there has been a concentrated effort to categorize, and define different set of symptoms and several new disorders have been identified.

As I understand , broadly we can make distinction between

1. [Purely Physical Disorders](#)
2. [Genetic and Injuries to brain at or after Birth](#)
3. [Pervasive Developmental Disorders \(PDD\)](#)
4. [Learning and Behavioral](#)

Most of the disorders are still under investigation and no clear treatment is available. A mixture of medicines and therapies are suggested .

It is imperative that pregnant mothers take extra care to protect against potential disorders. Then there are specific tests to diagnose many problems before the birth. At “Prenatal Tests “ you will find a lot of information about these tests.

Still sometime even with all the precautions things go awry, but now help is available at an unprecedented level thanks to the Internet.

A lot of research is going onto identify the disorders, their causes, treatments, education options, and obtaining skills for as independent a style as possible. Now a days it is possible to identify a problem at a really early stage and get help.

*Parents of special need children are banding together to form support groups . they are more established in the west, especially in UK and USA. Government and other medical personnel, Pharma companies are*

*all doing their bit to promote research and support. There may be some groups here in India also, but probably they are not on the net yet. I found one for Spina Bifida. I will next do the search of Indian support system.*

This help is needed by the child and even more by the parents and the family. It is truly traumatic for parents to know that they have a special need child.

The following is a very compassionate article by a mother who herself has a special need child. I have put it in almost entirely. Anyone who learns first time about their child's problem will find this empathic.

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## **2. You Are Not Alone: For Parents When They Learn That Their Child Has a Disability**

*by Patricia McGill Smith*

*From : <http://www.nichcy.org/pubs/newsdig/nd20txt.htm>*

### **Common Reactions of Parents**

On learning that their child may have a disability, one of the first reactions is **denial**—"This cannot be happening to me, to my child, to our family." Denial quickly becomes **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 known. 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 emotion: "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?" Then other questions arise: "Will he ever learn? Will he ever go to college? Will he or she have the capability of loving and living and laughing and doing all the things that we had planned?"

Then there is **guilt**—guilt and concern about whether the parents themselves have caused the problem: "Did I do something to cause this? Am I being punished for

something I have done? “Much self-reproach and remorse can stem from questioning the causes of the disability.

Guilt feelings may also be manifested in spiritual and religious interpretations of blame and punishment. When they cry, “Why me?” or “Why my child?”, many parents are also saying, “Why has God done this to me?” How often have we raised our eyes to heaven and asked: “What did I ever do to deserve this?” One young mother said, “I feel so guilty because all my life I had never had a hardship and now God has decided to give me a hardship.”

**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 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. It is extremely hard to be forced to rely on the judgments, opinions, and recommendations of others. Compounding the problem is that these others are often strangers with whom no bond of trust has yet been established.

**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 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 everyone goes through all 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 made 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.

My first recommendation is to try to find another parent of a child with a disability, preferably one who has chosen to be a parent helper, and seek his or her assistance. All over the United States and over the world, there are Parent to Parent Programs. The National Information Center for Children and Youth with Disabilities (NICHCY) has listings of parent groups that will reach out and help you. If you cannot find your local parent organization, write to NICHCY to get that local information

### **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 mate. The more couples can communicate at difficult times like these, the greater their collective strength. Understand that you each approach your roles as parents differently. How you will feel and respond to this new challenge may not be the same. Try to explain to each other how you feel; try to understand when you don't see things the same way.

If there are other children, talk with them, too. Be aware of their needs. If you are not emotionally capable of talking with your children or seeing to their emotional needs at this time, identify others within your family structure who can establish a special communicative bond with them. Talk with significant others in your life—your best friend, your own parents. For many people, the temptation to close up emotionally is great at this point, but it can be so beneficial to have reliable friends and relatives who can help to carry the emotional burden.

### **Rely on Positive Sources in Your Life**

One positive source of strength and wisdom might be your minister, priest, rabbi, a good friend, a family member 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.”

### **Take One Day at a Time**

Fears of the future can immobilize one. Even though it may not seem possible, good things will continue to happen each day. 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.

### **Seek Information**

You must 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 many 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**

Many parents feel inadequate in the presence of people from the medical or educational professions because of their credentials and, sometimes, because of their professional manner. Do not be intimidated by the educational backgrounds of these 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, and the situation has a profound effect on your life and on your child's future. Therefore, it is important that you learn as much as you can about your situation.

### **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.

### **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!

### **Find Programs for Your Child**

Even for those living in isolated areas of the country, assistance is available to help you with whatever problems you are having. NICHCY's [\*State Resource Sheets\*](#) list contact persons who can help you get started in gaining the information

and assistance you need. While finding programs for your child with a disability, keep in mind that programs are also available for the rest of your family.

### **Take Care of Yourself**

In times of stress, each person reacts in his or her own way. A few universal recommendations may help: Get sufficient rest; eat as well as you can; take time for yourself; reach out to others for emotional support.

### **Avoid Pity**

Self-pity, the experience of pity from others, or pity for your child is actually disabling. Pity is not what is needed. Empathy, which is the ability to feel with another person, is the attitude to be encouraged.

### **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.

### **Keep Daily Routines as Normal as Possible**

My mother once told me, "When a problem arises and you don't know what to do, then you do whatever it was that you were going to do anyway." Practicing this habit seems to produce some normalcy and consistency when life becomes hectic.

### **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.

## **Recognize That You Are Not Alone**

The feeling of isolation at the time of diagnosis is almost universal among parents. In this article, there are many recommendations to help you handle feelings of separateness and isolation. It helps to know that these feelings have been experienced by many, many others, that understanding and constructive help are available to you and your child, and that you are not alone.

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### **Information from NICHCY**

- [Parent's Guide to Accessing Programs for Infants, Toddlers, and Preschoolers with Disabilities\\*](#)
- [Your Child's Evaluation\\*](#)
- [Parent to Parent Support](#)
- [Related Services\\*](#)

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## **3.Prenatal Tests**

Everyone hopes to have a healthy baby. But these hopes are also mingled with occasional worry whether everything will be all right. Today there are a variety of prenatal tests to determine the size, sex, position in uterus, and many birth defects.

Some of these tests are screening tests and only imply that a problem may exist.

Some of these tests are Diagnostic and can determine fairly accurately the nature and maybe the extent of the problem.

Currently through prenatal testing nearly 250 birth defects can be diagnosed in a fetus – but they all cannot be can be treated or cured.

### **What do they Find ?**

Routine prenatal tests are anyway performed to find out key things about the mother's health . They are done to establish her blood group and type, to rule out diabetes, anemia ,cancer and sexually transmitted diseases, because all these affect the fetus.

The diagnostic tests can find out about Dominant Gene disorder, ( Parents have symptoms - a 50 % chance of inheriting from the parents), recessive Gene Disorders ( Parents have no symptom but are carriers) ,

Chromosomal disorders including X linked, and multifactorial disorders which may be due to a variety of factors.

Down's Syndrome, Spina Bifida, Cleft lip, congenital heart defects are some of the major problems that can be detected through these tests.

Special tests are recommended for women who are older (35+), have history of high blood pressure, diabetes, asthma, seizures, cancer, have already had a premature baby or a baby with some problem, and if there is a history of Mental retardation in either of the parent.

The routine tests are the blood test, urine test , cervical tests and Ultrasound or sonography.

Some specific tests for genetic and chromosomal problems are Glucose screening for gestational diabetes, Chorionic Villus Sampling (CVS) for chromosomal abnormalities, Amniocentesis for Down's syndrome , Spina bifida etc. . There are some more and they are advised as needed by the doctor.

### **Preventing Birth Defects**

A lot of birth defects can be avoided if the mother takes care of her body during pregnancy by:

- not smoking (and avoiding second-hand smoke)
- avoiding alcohol and Drugs, even most medicines
- eating a healthy diet
- taking prenatal vitamins
- getting exercise
- getting plenty of rest
- getting prenatal care

But sometime even after all the precautions a problem occurs, either because of some infection or unknown genetic presence. A lot of these can now be detected through these prenatal tests.

**For Details on these tests please visit :**

**[http://www.kidshealth.org/parent/system/medical/prenatal\\_tests.html](http://www.kidshealth.org/parent/system/medical/prenatal_tests.html)**

**Here they have described the tests in details , what they are, who needs them ,how they are done, how soon the result is expected.**

In writing and compiling this guide I have depended and gratefully borrowed liberally from NICHCY – the *National Dissemination Center for Children with Disabilities*. *The information provided is up-to-date, and is freely available for all – it is not copyright material.*  
<http://www.nichcy.org/index.html> and Kid's Health

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#### **4.List of Disorders mentioned in this guide**

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1. AD/HD ([Learning Disorders](#))
2. Angelman Syndrome ([Genetic Disorders](#))
3. Apraxia of Speech ([Learning Disorders](#))
4. Asperger's Disorder ([Pervasive Developmental Disorders](#))
5. Asthma ([Physical Disorders](#))
6. Autistic Disorder ([Pervasive Developmental Disorders](#))
7. Bed wetting ([Physical Disorders](#))
8. Bipolar Disorder ([Genetic Disorders](#))
9. Central Auditory Processing Disorders ([Learning Disorders](#))
10. Cerebral Palsy –CP ([Genetic Disorders](#))
11. Childhood Disintegrative Disorder ([Pervasive Developmental Disorders](#))
12. Down's Syndrome ([Genetic Disorders](#))
13. Dyslexia ([Learning Disorders](#))
14. Expressive Language Disorder ([Learning Disorders](#))
15. Fragile X syndrome ([Genetic Disorders](#))
16. IsoDicentric 15 ([Genetic Disorders](#))
17. Landau Kleffner Syndrome ([Learning Disorders](#))
18. Mental Retardation ([Genetic Disorders](#))
19. Obsessive Compulsive Disorder –OCD ([Genetic Disorders](#))
20. Other Birth Defects ([Physical Disorders](#))
21. Phenylketonuria –PKU- ([Genetic Disorders](#))
22. Prader-Willi Syndrome ([Genetic Disorders](#))
23. Rett's Disorder ([Pervasive Developmental Disorders](#))
24. Spina Bifida ([Genetic Disorders](#))
25. Swallowing Disorders ([Physical Disorders](#))
26. Tourette Syndrome ([Learning Disorders](#))
27. Traumatic Brain Injury –TBI ([Genetic Disorders](#))
28. Williams Syndrome ([Genetic Disorders](#))

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