

*Disability is a natural part of the human experience..*

## **We as a family!**

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This is a little effort of mine for all those parents who might have recently learned that your child has a developmental delay or disability may be for you. It is written as to describe what are the hurdles which I personally experienced and think that all the parents go through in one or another way.

When parents learn about any problem in their child's development, this information comes as a tremendous blow. I still remember the day my elder boy was diagnosed as having a disability, was like a trauma as "having a knife stuck" in my heart. Perhaps this description seems a bit dramatic, yet it has been my experience.

Following are the important reactions which one can experience and which I had personally.

## Common Reactions

(DENIAL OF ACCEPTING THE REALITY) *This cannot be happen to us.*

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 between husband and wife or others in the family. Early on, it seems that the anger is so intense that it touches almost anyone.

FEAR FOR FUTURE OF THE CHILD

Is another imp response, "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 school or college? Will he or she have the capability of loving and living and laughing and doing all the things that all other people do". There is also fear of society's rejection and concerns about whether will love him. These fears can almost immobilize some parent

(GUILTY OR FEELING REPOSNSIBLE) *(Being parents we are the one behind all this?)*

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? Did I take care of myself when I was pregnant? .Guilt feelings may also be manifested in religious interpretations of blame and punishment. When we cry, "Why me?" or "Why my child?" I have observed many parents including myself "Why has Allah done this to me?" I often use to raise my hands during prayers and asked Allah: "What did I ever do to deserve this?"

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. 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.

Now the question arises how one can deal with such situations .following are the best ways to deal with

### **Seek the Assistance of another Parent**

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 by a lady I met at a hospital but when she described her experience this became the first light of hope for me. She spooked of hope for the future. She assured me that there would be programs, there would be progress, and there would be help of many kinds and from many sources. And she was the mother of a girl with mental retardation.

My first recommendation is to try to find another parent of a child with a disability.

### **Talk with Your husband, Family, and Significant Others**

Over the years, I have discovered that especially in Pakistan maximum 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 the same. Try to explain to each other how you feel; try to understand when you don't see things the same way.



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

Go to those who have been strength before in your life. Find the new sources that you need now. I found my cousin sister Dr Farzana Siddique and her husband Dr Kamran Siddique .Their role in my life is very important .Moreover I can say Allah doesn't give you the people you want, he gives you the people you need to help you guide you and love you and make you the person you were meant to be. Surely she is the mastermind behind all the success of my children.



## **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**

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 help your child.

### **Do Not Be Afraid to Show Emotion**

So many parents, especially fathers, repress their emotions because they believe it to be a sign of weakness to let people know how they are feeling. But what I believe is that fathers too should show their emotions (I experience this when my husband was trying his level best to convince the board people about our son's problem!)



### **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 children were found to have a disability, one of the other things pointed out to me was that they very healthy children and the fact that they had no physical impairments has been a great blessing to me.

Focusing on the Positive diminish 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. There are some things that we can change and other things that we cannot change but what important is that we can make life enjoyable for our children.



### **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**

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 computer and Google plays a vital role .so be in touch with computer

### **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.



## **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. I read this once "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 they are your children**

They are your children, first and foremost. Their development may be different from that of other children, but this does not make your children less valuable, less human, less important, or in less need of your love and parenting. Love and enjoy your children. They come 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 children will benefit, and you can look forward to the future with hope.

#### **Your child is a person first, always.**

Disability does not define your child's selfhood, any more than the color of his or her eyes does. Individuality grows from the rich soil of personality, experience, health, education, upbringing, and more. Know this for fact, and see it unfold in real time, as your child grows and matures. Having a disability is part of the mix, but so are your child's strengths, humor, talents, and interests.

#### **Don't let the labels get you down.**

We humans like to have a name for things—and that includes disabilities. We use terms like "learning disabilities" or "AD/HD" or "autism." These can seem like labels sometimes, limiting and impersonal. It's not uncommon for parents to resist having a label hung on their son or daughter. Some parents even resist accepting special help for their child because of labeling. Yet—labels are just terms used for a particular purpose. They're a convenient way of referring to something... Use the label when it's

convenient or helpful, like when you're looking for information on your child's disability. Forget the label the rest of the time. Your child's the same person, either way. He or she hasn't changed one bit, label or no label.

**Disability does not mean that your child cannot learn or be educated with peers without disabilities.**

Many wonder and worry that the disability means their child cannot learn or must now be educated in special schools. Not true. My elder son have been going to a main stream school for past seven years and competing with rest of the class .the only thing different was that I was also a part of his studies . I had to make him learn a lot.

Also, keep in mind that everyone learns differently. We all have our own personal style of learning, and so does your child. This includes our strengths and weaknesses, preferences and interests, talents and motivation. All of these factors go into how we, as individuals, learn and grow. Your child *can* learn, *will* learn.

**Learn as much as you can about your child's disability.**

They say knowledge is power, and they're right. It's essential to learn more about your child's disability. How does the disability affect learning, movement, memory, behavior, and so on? What kind of special services help? What type of instruction is effective? These are the kinds of questions to ask. Share relevant information with the professionals working with your child. Also share your insights about your child's learning styles and preferences that only a parent can have.

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