

## WHEN YOUR CHILD RECEIVES A DIAGNOSIS: a parent's perspective

Families have different reactions to getting a diagnosis. Some families might be relieved because they have always known something was wrong whereas other families might be devastated because they didn't think anything was wrong with their child.

It is vital to accept that you will NEVER know what it's like to have a child with a developmental disorder unless you have a child with a developmental disorder. Unless you have children, you can never know what it's like. Once you've accepted this, it's easy not to judge the family whatever his/her feelings are. It is OUR JOB to respect and support whatever the family is feeling. It is NOT our job to judge the family, take away their feelings, or change their feelings.

*You Are Not Alone: For Parents When They Learn That Their Child Has a Disability Patricia McGill Smith*

If you have recently learned that your child is developmentally delayed or has a disability (which may or may not be completely defined), this message is for you. It is written from a personal perspective of a parent who has shared this experience and all that goes with it.

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 so 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, blocking 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.



Many things can be done to help you through this period of trauma. That is what this paper is all about. In order to talk about some of the good things that can happen to alleviate the anxiety, let us first take a look at some of the reactions that occur.

### COMMON REACTIONS

Upon learning that their child may have a disability, most parents react in ways that have been shared by all parents before them who have also been faced with this disappointment and with this enormous challenge. One of the first reactions is that of *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 known. Having the complete diagnosis and some knowledge of the child's future prospects can be easier than uncertainly. 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 she ever learn? Will she ever go to college? Will she have the capability of loving and living and laughing and doing all the things that we had planned?"

Other unknowns also inspire fear. Parents fear that the child's condition will be the very worst it possibly could be. Over the years, I have spoken with so many parents who said that their first thoughts were totally bleak. One expects the worst. 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* - 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? Did my wife take good enough care of herself when she was pregnant?" For myself, I remember thinking that surely my daughter had slipped from the bed when she was very young and hit her head, or that perhaps one of her brothers or sisters had inadvertently let her drop and didn't tell me. Much self-reproach and remorse can stem from questioning the causes of the disability.

Guilty 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 many 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.

During this period of time when so many different feelings can flood the mind and heart, there is no way to measure how intensely a parent may experience this constellation of emotions. 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.

## WHAT DO YOU GAIN/LOSE WHEN A CHILD HAS A DISABILITY?

*"It's my second child, Brian, who has PDD. With my first child, Ellie, we were part of the neighborhood community. Kids were always at our house and we were always invited to theirs. By all standards, we had a "normal" life. By the time Brian was 1 ½ we had lost all sense of normalcy. Brian threw tantrums over the slightest little changes. He was fixated on numbers and didn't want to interact with anyone. He rarely slept and barely ate. Brian was also very aggressive and would bite, pinch, scratch, and hit anyone without warning.*

*By all accounts, our lives had changed forever. We couldn't go out to dinner anymore because Brian would scream and was unable to sit for even a minute. Our friends were conveniently busy all the time because they didn't want to be around Brian. When we would come outside to play, our next-door neighbor would grab her child (who is the same age as Brian) and pull him very close. At the neighborhood Christmas party, Brian sat in the corner by himself and didn't even notice when the tree was lit. Even at the grocery store, I constantly get unwanted advice by people who think my child is just being a brat. My daughter keeps asking me, "Mommy, why can't my friend Grace come over?" and I don't have the heart to tell her that last week when I invited her friend Grace over, Grace's mother said that she doesn't feel comfortable around my son. How do you tell a 5 year old that people are afraid of your brother so you need to lose your friend? Brian may have a lot of behaviors, but he's still my little baby. These outside people don't see the other side to him. Our lives will never be the same."*

### Gain:

- New perspective on children
- Sense of openness
- Increased empathy

### Lose:

- Privacy (your life becomes an open book. Every time the therapist is at your door, it's a reminder that your child is not normal).
- Friends (old friends often don't want to be around you anymore because your child isn't "like" their child).

- Sense of normality (going out to dinner, having a typical babysitter, having a sibling's friends over to play, traveling, etc. None of these are ever "normal" again).
- Family (many times family members don't want to have you over)
- Financial resources (average out of pocket expenses for kids with disabilities range from \$5,000 - \$100,000 per year )
- Loss of what could be (fantasies of your child's graduation, wedding, having children, etc.)
- Fear and Anxiety (what if I died, what would happen to my child)

## STAGES OF GRIEF

Grief isn't linear, it's cyclical. Parents pass through stages of grief at different times in their child's life. Anytime there is a major event (child was supposed to hit a milestone, starting school, first friend, holiday times, etc.) the grief process will kick up.

- 1. Denial:** We deny that the loss event has occurred. We ignore the signs of the loss event. We begin to use magical thinking, excessive fantasy, regression, withdrawal, and rejection.
- 2. Bargaining:** We bargain or strike a deal with God, others, or ourselves to make the loss go away. We promise to do anything it takes to make this loss go away. We agree to take whatever extreme measures are needed in order to make this loss disappear. We begin to shop around, gamble, take risks, sacrifice. We lack confidence in our efforts to deal with the loss and look elsewhere for answers.
- 3. Anger:** We become angry with God, others, or ourselves over our loss. We become outraged and incensed over the steps that must be taken to overcome our loss. We pick out "scape-goats" upon whom to vent our anger, e.g., the doctors, hospitals, clerks, helping agencies, and rehabilitation specialists. We begin to use self-blaming, switching blame, blaming the victim, aggressive anger, and resentment. Anger is a normal stage. It must be expressed and resolved. If it is suppressed and held in it will become "ANGER-IN," leading to a maladaptive condition of depression that drains our emotional energy.
- 4. Despair:** We become overwhelmed by the anguish, pain, and hurt of our loss. We can begin to have uncontrollable crying, sobbing, and weeping spells. We can begin to go into spells of deep silence, morose thinking, and deep melancholy. We begin to experience guilt, remorse, loss of hope, and loss of faith and trust. We need support to assist us in gaining the objectivity to re-frame and re-group our lives after this loss event. If we are not able to work through our despair, we risk experiencing events in our life such as mental illness, divorce/separation, suicide ideation or attempts, an inability to cope with the aftermath of our loss event, rejection of the family member who has experienced the "loss" event, detachment, poor bonding, and/or unhealthy interaction with the parties involved in our loss event.
- 5. Acceptance:** We begin to reach a level of awareness and understanding of the nature of our "loss" event. We can now describe the terms and conditions involved in our loss, fully describe the risks and limitations involved in treating or rehabilitating the "loss" feelings involved, problem solve the issues involved in coping with our "loss," test the concepts and alternatives available to us in dealing with this loss, and handle the information surrounding this loss event in a more appropriate way. We begin to use rational thinking, adaptive behavior patterns, appropriate emotional responses, patience and self-confidence. We can be growing in acceptance and still be experiencing denial, bargaining, anger, and despair. We need support from others to gain objectivity and clarity of thinking in order to come to full acceptance. Those who have experienced similar losses form effective support groups.