



Texas Parent to Parent

# Four stages of adaptations

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**SURVIVING:** what you do to keep going when you are feeling completely overwhelmed because something totally out of your control has taken away your child's equal chance at life.

**SEARCHING:** what you do when you are looking for answers for your child. You will probably have periods of Searching during your whole life with your child. There are two kinds of Searching:

- Outer Searching: looking for a diagnosis or services
- Inner Searching: trying to find your identity as the parent of a child with special needs.

**SETTLING IN:** what you do when the frantic pace of Searching lets up. You begin to choose your battles and balance your child's schedule and your family life. Not only has your Outer Searching subsided for a while, but more important, your attitude about it settles down.

**SEPARATING:** what you do as a normal, gradual process that occurs in tiny steps throughout childhood. When a child has special needs, the process may need to be altered or slowed down. Extra parenting may be required - you may have to initiate separation, plan it, find it and make it happen. Letting go on your part is also necessary.

Everyone passes through these periods in their own way and at their own time. There is no "right way" to adapt. The tasks in each stage may overlap. They actually have more of a circular quality than a linear one.

## **SURVIVING**

SURVIVING is what you do to keep going when you are feeling completely overwhelmed because something totally out of your control has taken away your child's equal chance at life.

You have something new and frightening to deal with, and you have to begin adapting to an uncertain future. The nature of your child's special needs and their severity does not make them any easier or harder to deal with. When you become aware that your child has a problem, is developing a problem, or is at risk for a problem, you begin to deal with this information in two ways - you cope and you react.

Coping is doing what you have to do one problem at a time, getting by. Coping always feels like you are just keeping up with what you have to do, with little energy for getting ahead of your problems. This is because you are using most of your energy to deal with your emotional reactions to your situation.

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Reacting drains your energy and diminishes your feelings of control over your life. You have no sense of direction. There are so many aspects of this experience that you may not have expected and that may frustrate and disappoint you.

Typical Reactions to Surviving:

- Shock
- Bodily Stress & Symptoms: Fatigue; physical symptoms (headaches, stomachaches, chest pains, loss of appetite, lack of sexual interest, etc.); feelings of weakness, fragility, and vulnerability
- Grief and Loss: grief; feelings of helplessness & aloneness; sadness; depression
- Confusion and Fear: confusion & chaos; uncertainty & ambiguity; fear; preoccupation with your child; worrying; asking questions that appear to have no answers
- Guilt and Self-Doubt: guilt; self-absorption, self-pity, & self-doubt; shame and embarrassment
- Anger: resentment & envy; blaming; feelings of betrayal
- Denial: chosen denial; unconscious denial

These reactions are the way many people feel upon hearing sad or frightening news. Anyone who tells you that you "should not" have any of these reactions has not been where you are. No one has the right to judge how you feel. The reactions are temporary, although some stick around longer than you would like. Most of the feelings get resolved or fade as you find you are ready to move on and as you begin to feel you have control of your life once again.

Easing the Surviving Process:

- Understand that your feelings are normal.
- Try to make time for yourself.
- Create/use your support system.

“Being in a state of Surviving doesn’t last forever. It just seems that way at the time.”

## SEARCHING

SEARCHING is a time of acting, of moving forward from your reactive stage of Surviving. It is the awakening of a sense of control over your emotions and your life, and a time for seeking understanding about your child, your family, and yourself.

Searching is divided into two types - Outer Searching for answers about your child's problems and Inner Searching for understanding what the problems mean in your life. Searching issues may dominate your life for a while; some may never go away. You will find yourself gaining competence and self-confidence in your parenting role and a new sensitivity as you find your life values and priorities beginning to shift. Searching is a time of active growth and expansion and of gaining a new kind of strength as you seek services to meet your child's special needs. You will soon discover that you have more strength than you ever imagined and you have more potential support than you ever could have dreamed.

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### Outer Searching:

- Gives you knowledge through the quest for a diagnosis and the search for a label.
- Gives you a new perspective about disabilities through contact with other families and a new awareness.
- Gives you strength through a sense of competence & control, and empowerment.

### Obstacles to success in Outer Searching can be:

- child-related issues: your child may not improve as much as you hoped or may lack the stamina or skills required or hates the program you selected or unpredictable medical crises may prevent regular involvement in a program
- parent-related issues: feelings of powerlessness when bucking systems over inflexible rules; frustration or anger if funds are cut or your child doesn't qualify; exhaustion from carting kids to therapy, driving, waiting, etc.; or you may be using Searching as a distraction to keep from dealing with other feelings
- program-related issues: services may be unavailable or too expensive; doctors without answers or who misdiagnose; confusing choices and tough decisions.

There are no perfect programs, infallible interventions, or quick cures. You will learn to balance the benefits of an intervention against the costs to both your child and your family. If you find yourself "stuck" in Searching, you may want to seek help in getting some new ideas about how to move forward.

### Inner Searching:

- Involves asking life questions: Some of these questions are the same questions all parents face, but maybe not to the same extent that parents with children with special needs have to. The questions are about being a good enough parent to your child or children, what about the other children, what about the marriage, job, etc. These answers evolve over time, but in the meantime, you may feel anxious, depressed and incompetent because you cannot answer them.
- Involves self-questions: These questions help you know what you can do today to understand yourself better, to identify your own strengths and limitations, and to find new ways to grow. You will learn to recognize what you can control, focus on those things, and work to change them AND learn to take the things you cannot control and let them go or work around them.

Your Inner Search is a journey of self-discovery that begins with the realization that life is going to be different than you had planned. It is looking for a new identity that includes being the parent of a child with special needs. It is the struggle to understand your own attitudes and values about human imperfections, and it is a re-evaluation of your life's goals and priorities beyond your parenting role.

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### Things You May Become Aware of During Your Inner Search:

- Life is not fair.
- Nobody cares about your problem as much as you do, and no one else can ever really understand what it's like for you.
- No one is going to rescue you and make it okay.
- If you devote all of your time, energy, and thoughts to your child, someone will pay the price, and that someone may be your child.
- Being realistic about your child's abilities and limitations does not mean giving up hope.
- Even if your child does not progress in ways important to you, it does not mean you are a failure.
- Your child and your child's disability have nothing to do with your self-esteem.
- How your child feels about his abilities and limitations is more important than what he can or cannot do.
- Things will change. Some will become harder and some will become easier, but they become different. How you deal with them is what matters.
- Somewhere along the way you are going to make mistakes. Nobody is perfect, so why should you expect it yourself?
- You are not the same person you would have been if your child did not have special needs. You can see that as a disappointment, a challenge, or a blessing.

### SETTLING IN

SETTLING IN is seeing the world for what it is and seeing yourself for who you are. It is moving beyond the intense emotions of Surviving, feeling less of the sense of urgency of Searching, and gaining a greater sense of control and balance in your daily life.

Settling In is a time of more predictable, settled-in living. Settling In is a time of integrating your child's special needs into the rest of your life and working to establish a new sense of stability and harmony for yourself and your entire family.

Settling In:

- A shift in your attitudes becomes apparent. Your definition of "normal" changes - you develop a new normalcy within your family. You don't feel as much of a sense of urgency - you realize you don't have to spend every available minute "teaching" your child and that more isn't always better. You find yourself letting go of unrealistic expectations - you do not expect to never feel sad, guilty, or frightened again; you know that Searching will be reactivated from time to time; you begin to come to terms with "what is". You do not worry as much. Settling In is a time of shifting perspective about your child's needs - you shift your focus to finding ways to help your child do whatever is possible by using whatever means are available.

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- A shift in your balance becomes apparent. You establish some new priorities for your life and your child's life - you are better able to select what is important now. Your child's total needs have become your focus, not just the disability. You are getting on with the rest of your life - you learn to juggle the daily requirements and try to make some time for yourself. Your daily life may be more predictable. You learn that the balance changes as some things get easier, some things get harder, and many things just get different.
- A shift in control becomes apparent. You no longer feel helpless, incompetent, frightened or confused - you no longer just react. You have a lot more information than you did when you learned your child had special needs and you know who to ask when you have questions. You have new skills for Searching - you are more assertive and knowledgeable, and the professionals you deal with recognize this. You are moving forward with a sense of vitality and purpose - you work on making your life and your family's life as stable and cohesive as possible. You are finding what works for you - you are better able to make choices about your life. You have a network of people. You are a lot more flexible than you used to be - you are more able to control your emotions and are able to relax and be more flexible about the daily ups and downs of life.

Some families are not able to enjoy the normality of feeling Settled In or this stage may be delayed, due to the following obstacles:

- continued medical crises or aggressive/self-destructive behaviors or the physical or mental health of any family member
- lack of financial resources or insurance or adequate insurance
- severe medical, learning, emotional, or behavior problems that families are not able to meet at home
- a marriage or relationship that cannot weather the storm
- single parenting resulting in juggling all the responsibilities
- old Surviving or Searching issues that come back into the foreground

## SEPARATING

SEPARATING is a normal, necessary process in development, which occurs in tiny steps throughout childhood. Each step of separation is a step toward independence as your child grows up and away from you and as you let go - one safe step at a time.

The process of Separating includes both emotional separateness between you and your child, and physical separation, which may occur earlier or later than typical when a child has special needs. When Separating issues move into the foreground, there is an increased emphasis on teaching your child skills for community living and on preparing yourself to let go.

Separation for children with special needs often has to be initiated, planned, or supervised by parents. This is not part of the natural order of things, as children and parents typically are both actively engaged

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in Separating activities. But in the natural order of things, parents and children do separate, and there is a time for parents to expand in new directions. Separating is one more step in your personal growth.

A parent must often make a special effort for the child to have experiences that allow for feelings of independence and growth. Your child may need extra time or intensive training to acquire the knowledge and learn the skills that will increase their future choices of living, working, and socializing in the community.

What Your Child Needs To Separate from You Successfully:

- Self-esteem, persistence, and a sense of humor
- Daily living skills
- Pride in physical appearance
- Living skills practice
- Self-discipline
- Understanding and living with a disability
- Learning to meet challenges

Letting Go: A Parent's Role in the Separating Process:

- Letting go is getting tough on certain issues
- Letting go is an affirmation of your efforts - a sense of freedom from parenting
- Letting Go means giving up some control - allowing others to share in caregiving and teaching
- Letting Go is admitting you can't make your child's disability go away - accepting what your child cannot do is an important step in letting go
- Letting Go feels like you are losing something, and you are - it is going to leave an empty space in your life
- Letting Go means reactivating some Surviving and Searching issues

Obstacles to Separating:

- Child-Related Obstacles: special communication needs, social skill or safety issues
- Parent-Related Obstacles: concerns about how much to protect or pull back, time or support team issues
- Community Obstacles: lack of programs, lack of services or resources - funding, lack of transportation or scheduling problems, negative or hesitant attitudes in community.

(Taken from "Nobody's Perfect - Living & Growing with Children Who Have Special Needs" by Nancy B. Miller, Ph.D., M.S.W., adapted by Laura J. Warren, Pilot Parent Family Resource Center, The Arc of the Capital Area, 1/96)

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