

CHAPTER 2 MEET THE SPECIAL NEEDS FAMILY

Introduction Where Are The Parents?

A great barrier to the empowerment of special needs families might be the lack of understanding toward them. Piled high on the mountain of struggles that special needs families face is misunderstanding. Likely, at the root of this problem is the tendency for these families to be measured and evaluated by the standards of other families. This is a potent breeding ground for frustration. One such mother struggling with the disability of her nine-year-old daughter¹ could not resist reacting to a “nit wit PTA official’s” question regarding why she was not attending the meetings. I include her candid reaction in its entirety:

Where are the parents?

They are on the phone to doctors and hospitals and fighting with insurance companies, wading through the red tape in order that their child's medical needs can be properly addressed.

They are buried under a mountain of paperwork and medical bills, trying to make sense of a system that seems designed to confuse and intimidate all but the very savvy.

Where are the parents?

They are at home, diapering their 15 year old son, or trying to lift their 100 lb. daughter onto the toilet.

They are spending an hour at each meal to feed a child who cannot chew, or laboriously and carefully feeding their child through a g-tube.

They are administering medications, changing catheters and switching oxygen tanks.

Where are the parents?

They are sitting, bleary eyed and exhausted, in hospital emergency rooms, waiting for tests results to come back and wondering: is this the time when my child doesn't pull through?

They are sitting patiently, in hospital rooms as their child recovers from yet another surgery to lengthen hamstrings or straighten backs or repair a faulty

¹ She describes her daughter as “[microencephalic], athetoid/spastic CP, Cortical Visual Impairment, Seizure disorder -- and CUTE!”

internal organ.

They are waiting in long lines in county clinics because no insurance company will touch their child.

Where are the parents?

They are sleeping in shifts because their child won't sleep more than 2 or 3 hours a night, and must constantly be watched, lest he do himself, or another member of the family, harm.

They are sitting at home with their child because family and friends are either too intimidated or too unwilling to help with child care and the state agencies that are designed to help are suffering cut backs of [their] own.

Where are the parents?

They are trying to spend time with their non-disabled children, as they try to make up for the extra time and effort that is critical to keeping their disabled child alive.

They are struggling to keep a marriage together, because adversity does not always bring you closer.

They are working 2 and sometime 3 jobs in order to keep up with the extra expenses.

And sometimes they are a single parent struggling to do it all by themselves.

Where are the parents?

They are trying to survive in a society that pays lip service to helping those in need, as long as it doesn't cost them anything.

They are trying to patch their broken dreams together so that they might have some sort of normal life for their children and their families.

They are busy, trying to survive.²

A Whirlpool of Emotions

The Pearson family, like most any family, possessed hopes, dreams, and expectations. But unlike many families, Matthew and Ruth Pearson were reaching far beyond themselves, aiming for the mission field. Then, one day, life began to take a drastic turn.³

While Matthew was in seminary, David was born, nineteen months after their first son, Alex. Sudden Infant Death Syndrome almost claimed David and from there he succumbed to continuous sub-clinical seizures. Before reaching his first birthday, he was started on anti-convulsant medications. The Pearsons were told, however, that by age six

² Sue Stuyvesant, "Where are the Parents?" at www.ourkids.org/archives 1996.

³³ The Pearson family is a personal friend of the author. Family names have been changed to protect the family's privacy.

David would be up to speed and in school with other kids his age. The family was faithful with physical therapy and eventually David was feeding himself, walking with support, and starting to communicate through sounds. But at age four he began to decline, and by the time he was five years old, he was like a “limp spaghetti noodle,” unable to lift his own head or even swallow. He merely lay in whatever position he was placed.

David was diagnosed with NCL (Neuronal Ceroid Lipofuscinosis), also called Batten Disease, a genetic metabolic disorder that is degenerative. Symptoms of the disease are horrific, leaving a child blind, bedridden, unable to communicate, and guaranteeing an early death. Most children die by the age of ten, but David is now nineteen. However, David only functions at the level of a 6-9 month old infant. He is fed through a stomach tube five times a day, and continues to wear diapers. When Ruth was contacted about sharing her story, she was on her back with a fractured disk, the result of lifting her teenage son.

The family also has another member. Aria is sixteen years old, and has no memory of David before his incapacitation, or of her family outside of its special needs status. Amazingly, the family lives in Asia to minister, despite the great inconveniences they face, both with regard to accessibility for wheelchairs, and the inclusion of special needs families in society.

For nineteen years now the Pearson family has struggled with the huge implications of disability within their own family. Ruth describes the impact this disability has had on the family as follows:

It's affected just about every part of our lives, both the major and the mundane: the number of children we had, choosing the city we live in, the kind of car we drive, the public transportation we take, the recreation we do, the amount of life insurance we bought, the kind of clothes and jewelry I wear, the furniture we

have, the flooring in our downstairs, where we vacation, where we attend church, the type of friends we have, how people view us, where we get seated in restaurants, the books on our bookshelves, how much and what we pack when we travel, how much laundry we do, the equipment we keep in the house (outside wheelchair, toilet/shower wheelchair, hooyer lift), how often we get up during the night, the physical toll on our bodies, what we pray for. . . There is very little that is not affected by having David in our family.⁴

Life with a disabled child is tough. Such a life results in an intensification of many emotions. This may be seen as a process akin to Elisabeth Kübler-Ross's classic description of the stages of grief: denial, bargaining, anger, depression, and finally acceptance.⁵ However, there are drawbacks to viewing the process in such a linear fashion. Helen Featherstone has doubts about classifying experiences solely through stage models, asserting that they "oversimplify a complex and diverse process,"⁶ particularly in trying to define the experiences of special needs families. Rosemarie Cook states that "no model of family development, stress, and crisis, fully describes the family of a child with a disability."⁷ Controversy regarding the number and character of stages continues to this day. Both Featherstone and Cook speak from experience; each of them has a child with disability. Featherstone, however, does discuss inevitable emotions that the family will encounter. These include fear, anger, loneliness, guilt and self-doubt.⁸ For the purpose of this study we examine Featherstone's list and also add the emotions grief and sorrow, as research indicates the prevalence of these other emotions at work.

When disability strikes a home it is not through a well-ordered process; rather, it is through a messy process, with many digressions. The shock alone sets in motion a

⁴ All quotes of Pearson family from interview with author.

⁵ Elisabeth Kübler-Ross, *On Death and Dying* (New York: Macmillan, 1969).

⁶ Helen Featherstone, *A Difference in the Family* (New York: Basic Books, 1980), 10.

⁷ Rosemarie S. Cook, *Counseling Families of Children with Disabilities* (Dallas: Word Publishing, 1990), 16.

⁸ Featherstone, *Difference*, 10.

whirlpool of emotions that sends one reeling.⁹ It is something for which no one can be prepared, and which no one can fathom. One mother of a baby with disability gives a forceful description of her disorientation in the poem “Immersion”:

Seduced by myths
of the effortless life
I float, footless, into adulthood,
down streets of dreams-
love,
marriage,
motherhood,
happily ever after

Until a broken boy
lays waste to legends.
Dear God, the shock of it,
the plunge, the headlong speed of it,
the darkness,
the fear,
wind whistling in ears,
and louder still
the roar of a river,
rising to meet my fall.

The impact rude, cold.
The unimaginable strength of it,
the mighty, weighty pull of it!
I flail for bearings,
for surface, for breath...¹⁰

Fear

Any new special needs parent who is reasonably informed of the challenges that lie ahead will encounter fear. There will be fear that the child will face discrimination and exclusion. There will be fear of the possible effects on siblings, including bitterness and

⁹ These statements based on personal observation of author while participating in numerous special needs family support groups over a four year period.

¹⁰ Kathleen Deyer Bolduc, “Embracing Our Brokenness: Poems and Reflections on Disability and the Kingdom,” *Journal of Religion, Disability, and Health* 4, no.4 (2001): 67.

neglect.¹¹ There will be fear of the instability of one's home, of one's faith, of one's future sanity. Fear begins to rise from the internal depths, often even before the official label has been affixed on the child. Fear may prompt parents to deny that a problem exists, as they seek to recoup themselves before they face the overwhelming truth.¹²

The mother of a son with multiple disabilities writes:

Fear is my unexpected companion. He comes to me in the darkest part of the night and in the brightest sunlight. He cannot be controlled, tamed. Something as minor as a cough, a twitch, unleashes Fear through my very soul. What if I miss something? What if I'm not there? What if I am there, but can do nothing?¹³

Over time, fear may change in quality and quantity, but it can rear its head, as illustrated above, even on a sunny day. After all, a family may feel they face a future of no relief; instead of being able to look forward to "independence, growth, and differentiation, a family may see only despair, dependence, and social isolation."¹⁴

Anger

Anger has the potential to consume a person and family. Anger can be a substitute for hurting, and a camouflage for an assortment of other emotions.¹⁵ There can be anger at families who fuss over trivial matters, anger at oneself for personal failings, and anger at society's hypocrisies and cruelties. Disability rubs raw and exposes nerves. Aria, the youngest member of the Pearson family, voices one such frustration:

My biggest pet peeve is when they [other kids] say something about being a "retard" (before they have met the rest of my family) and I feel like slapping them and saying, "What do you know? That is not retarded! You want to see retarded? I'll show you my brother!"

¹¹ Elise H. Wentworth, *Listen to Your Heart: A Message to Parents of Handicapped Children* (Boston, Mass.: Houghton Mifflin, 1974), 98-99.

¹² Evidenced not only from personal family experience, but in friendship with other special needs families.

¹³ Sue, mother of a child with cerebral palsy, "Fear," (1997), at <http://www.our-kids.org/archives>.

¹⁴ Milton Seligman and Rosalyn Benjamin Darling, *Ordinary Families, Special Children: A Systems Approach to Childhood Disability* (New York: Guilford Press, 1997), 88.

¹⁵ *Ibid.*, 160-161.

Anger often has its source in financial strain. Insurance does not pay for everything and even a five percent deductible, when applied to a half million dollar medical bill, can clean out almost any family, leaving its members in reeling debt. They may start to tell themselves, “I’ve been ripped off! I deserve better!” With so many dreams dashed, one may burn with anger toward God. “After all,” one reasons, “He is the sovereign cause of my pain, this supposedly loving God.” But a prolonged anger toward God only increases the suffering. “By rejecting God you are truly alone, and you are afraid now in your depth of despair at the bottom of a black pit of aloneness and hopelessness. There is nothing left with which to fight, nothing for you to hold on to...”¹⁶

Mothers seem to carry most of the anger, not only because they are often the dominant caregivers, but also because they have so few escapes.¹⁷ Yet fathers are not excluded from this emotion, either. In especially stressful seasons, anger that has been controlled can flare up unexpectedly. Matthew Pearson shares about the frustration of trying to manage a crisis which pushed his family even beyond the usual struggle to manage life.

When I first started doing all of David’s care due to Ruth’s bad back, anger was a big deal. Frustrated by my inability to control my life. Angry that I was so angry. I mean, how can you really be angry at a child whose only claim on your anger is the ability to do pretty much nothing? You can hardly claim that it’s intentional. But there were times when it was all I could do to keep from shaking the kid, times when I would have to make sure Ruth, or someone, was with me watching, and even still, times when any fair referee, had they been there, would have called me for “unnecessary roughness.” (Well, the Holy Spirit was there, and did make the call, actually.) The line you cross to get to child abuse gets pretty thin sometimes. People sometimes wonder how anyone could do such a thing. I have no trouble at all understanding it.

¹⁶ Elise H. Wentworth, *Listen to Your Heart: A Message to Parents of Handicapped Children* (Boston: Houghton Mifflin, 1974), 124.

¹⁷ Hillary Schofield, ed., *Family Caregivers: Disability, Illness, and Aging* (St. Leonards, N.S.W.: Allen and Unwin, VicHealth, 1998), 78.

Loneliness

Another emotion voiced by many with disability is loneliness. People with disability are generally noticeably different than the able-bodied, this difference can create walls that isolate those with disability from inclusion. The following lines convey this solitude.

I'm handicapped and wheelchair bound
 Expected to sit and not make a sound
 Just to smile and let the World go by
 With Sainly patience and never sigh.

Inside my head thoughts come and go
 Ideas are born which long to flow
 Flow from my lips and link me with others
 But my words sound strange so no one bothers.¹⁸

A child with disability may never, in a lifetime, meet another child with the same challenge. For a child, this being different, this never “fitting,” can be a lonely trail to trek. The child has a fundamental difference, even from his/her own family, and in some cases may be emotionally or socially severed from his/her family. One sad example of this is found in the entire generation of deaf children whose parents were advised not to use sign language for fear that it would inhibit their children’s development of speech. However, most deaf children never learn to read lips. The tragic result has been an inability for parent and child to adequately communicate with each other. Deafness isolates in many ways, as Mary Elford describes in “What is Deafness?” “It is pain. It is frustration when

¹⁸ Anonymous, “The Outsider,” sourced at <http://www.our-kids.org/archives>.

someone refuses to repeat something for you. It is withdrawing into silence, pretending that it doesn't matter that conversation is flowing over you."¹⁹

This description seems akin to the loneliness in other disabilities, as well. There is pain and there is withdrawal. Life becomes too painful when family members associate with people who say stupid and hurtful things, as Aria explains, "I suppose the most difficult thing is how other people react to us as a family when David is around. Everyone knows us, 'Oh, you are the one with the, the...brother.' My response, 'Yeah, I have two. (BIG DEAL).'" Siblings abhor being known as the one with the "weird" family member, as though they were part of the Adams Family with a "Thing," or "Cousin It." Family members may feel unable to share their lives with others for fear of being wounded. Consider the hurt of Rosalyn, a mother who poured out her anxieties about her little girl to a friend; the friend urged her to quiet down and then dropped the bomb: "These children don't generally live very long anyway." Rosalyn froze, unable to speak. She later wrote, "I never poured out my heart to anyone again."²⁰ Even doctors have been known to blunder with phrases like, "Don't get too attached to this child or it will break your heart."²¹

There are two paths to isolation. On the first path, the family may be cut off by others who cannot bear to endure the pain or inconvenience of unpleasant sounds, smells, and situations. On the second path, the weary and smarting family may, of necessity, drift away themselves. Special needs families struggle with limited resources and lack the energy necessary to weather hurtful comments.

¹⁹ Mary Elford, "Part of Who I Am," in *Not All Violins: Spiritual Resources by Women with Disabilities and Chronic Illnesses*, ed. Charlotte Caron (Toronto: United Church Publishing, 1997), 39.

²⁰ Featherstone, "Difference," 58.

²¹ Dick Sobsey, letter to Joan, "Coping with Loss of Support and Hurtful Comments," at <http://www.our-kids.org>, 1995.

Guilt and Self Doubt

Who is ultimately responsible for a child's disability? Physicians, in-laws, and even spouses may inadvertently, or even blatantly, speak in a way that assigns blame, and blame can be a gargantuan burden to carry. In the case where the disability is caused by some failure, the person responsible has the continual reminder, day after day, of his/her guilt; the child becomes a symbol of the guilt. Continuous and unaddressed blame in a family may continue to work its poison, working deeper and deeper to disintegrate the family.²²

But blame is not usually limited to one family member. Each member can carry a measure of guilty feeling. Children with disability may feel guilty about the struggle their disability brings to the family, and they will likely blame themselves in the event of a divorce. Siblings might feel guilty for thinking about how the death of a disabled brother or sister might better their lives and the life of the family. Parents can feel guilty for wishing malady upon a friend's child, so as to have a friend with whom they could share their heartache. Family members may secretly hope for the misfortune of others, toying with thoughts that are actually abhorrent to them, and then feel guilty for having stooped so low. Then there are always the "lesser guilts" of neglecting other family members, social functions, extended family needs, and church duties, that pile guilt on top of guilt. Matthew Pearson explains his struggle in trying to care for his son and his own life adequately:

Guilt is a big one. All the billion things you could have done and didn't, are always lining up leering at you at the end of the day. Sometimes you have the presence of mind to remember who you are, and tell them to get lost. You're not

²² Elise H. Wentworth, *Listen to Your Heart: A Message to Parents of Handicapped Children* (Boston, Mass.: Houghton Mifflin, 1974), 43.

God, after all, and have to choose from a finite, time-bound list of possibilities that you are going to do. Sometimes you just get depressed.

Grief and Sorrow

Similar to the death of someone dear, there is a lingering sorrow even after many years have passed, but for those affected by disability, it is the uncertain sorrow of many undefined and precious things lost. Something seems morally wrong with babies and small children having to suffer, and experiencing this situation firsthand can be an agonizing grief itself. Likely, this grief and sorrow never completely subsides, but is revived repeatedly during different life situations and life stages. Sorrow is revived when the parent of an autistic boy sees another child smile and make a friend. It is revived when the mother of a deaf girl hears another little girl sing a song or play the piano. It is revived when the father of a wheelchair-bound boy watches another boy score a touchdown.²³

A mother named Rhonda speaks of her son, Tom, who is affected by spina bifida:

Seeing other normal healthy babies sometimes hurt. I remember crying for hours after a family get-together when Tom was three. I watched him clapping and celebrating along with everyone else as his one-year old cousin took her first steps. Tom should have been running and jumping and playing with other children. It broke my heart to see him so incapacitated, yet he was happy for her.”²⁴

Another great source of sorrow is found in the misunderstanding and hurtful words that seem to bump the scabs off of healing wounds. Ruth, of the Pearson family, explains that the most difficult issue is:

²³ The essence of this dynamic has been distilled through the author experiencing the testimony of many other special needs families.

²⁴ Delores Kuenning, *Helping People Through Grief* (Minneapolis, Minnesota: Bethany House, 1987), 33.

How other people respond (or don't respond)... The people who I thought would be most supportive and helpful have been the most hurtful. Often it's been the non-Christian who has been the most helpful (no pat answers and no preaching). One of our closest friends talked to me of how it's too bad Daniel won't be in heaven as he "Can't confess with his mouth, Jesus as Lord, which the Bible clearly states is necessary for salvation."

Grief can easily grow into chronic sorrow, as well. The mixture of sorrow and fatigue can brew depression into a swampy, colorless, gray world where nothing seems to bring enjoyment. Even small things become unbearable, and a trip to the grocery store exhausts what little energy has been mustered up for the day.

At Wits End

What happens when the whirlpool of emotions sucks one into its depths? On the negative side, there are many horrible stories. There are stories of desertion, where a spouse gives in to fantasies about falling in love with someone else and starting a whole new life in another place. There are stories of abuse, where helpless children are stuffed away in dark closets for years. There are stories of murder and suicide, where parents strangle or knife children, and then destroy themselves, as well. They are all hellish stories of unimaginable horror, yet they do happen.

The horrible, climactic events of special needs family members who have gone over the edge get most of the publicity. There are, however, many unpublicized stories of silent suffering and isolation where people have come to the end of their rope, then dangled there for years. Where people have exhausted all their resources and still hang on, continuing to face the onslaught:

I prayed. Over and over, I prayed, "God, please give me the grace to withstand this." And my other prayer, long night after long night, was "God, I know you never give a person a greater burden than they can bear. Your math is wrong here: I've had all I can take. I've searched the deepest pockets of my soul, and

then of my entire being, and I've found wellspring after wellspring that I never knew was there. But now I'm all out. It's time for a break. Are you listening?"²⁵

Despite the struggle, some families find the means to move ahead, even if for just one more day, and find firm enough ground to get footing for just one more step. Ruth, of the Pearson family, speaks about this experience, "There are instances where we were totally thrown on God's mercy, and we have seen God provide exactly what we needed at the perfect time. In other instances God has given grace to get through hellish days sane, and that in itself is a miracle."

In a world saturated with broken lives and broken homes, there is a longing to hear stories of hope. Each person clings to the hope that in the end, all injustice will be righted and all suffering will have been meaningful. Such a hope is captured in the lines of:

"Grace Alone"

Terrorized in the face
of her son's Furies
she calls on a God
whose name is Love
before slipping into sleep
muddied with truth
too awful to bear

While drops of pain
which cannot forget
build night by night
moon by moon
upon her heart
until, in her despair
against her will
comes wisdom
through the awful grace
of God²⁶

²⁵ Helen Betenbaugh, "Disability: A Lived Theology," *Theology Today* 57, no.2 (July 2000): 206.

²⁶ Kathleen Deyer Bolduc, "Embracing Our Brokenness: Poems and Reflections on Disability and the Kingdom," *Journal of Religion, Disability, and Health* 4, no.4 (2001): 72.

Understanding Family Cohesion and Control

In beginning to understand a family system, it is helpful to engage a model for evaluating its health. Numerous tools are available to help place a family on some scale of vitality and functionality. There is, however, a danger in giving a family a label or finding some psychopathological definition of a family that can lock its members into a pattern of behavior. One useful tool for evaluation is Robert Beaver's Systems Model, which consists of five developmental levels any given family can fit into.²⁷ Family functioning is rated from 1, the highest, to 5, the lowest. The most densely populated cluster, consisting of 60 percent of families, tends to occur midrange, at Level 3.

A Level 5 family is termed the "family in pain" and is considered... severely disturbed. In this type of family, nobody seems to have authority and leadership is absent. If someone tries to rise up and initiate an idea, he/she is likely to be automatically negated by the others. These families are haunted by the ghosts of many unresolved past hurts. They also cannot face any potential losses the future might hold. Developmentally, this family never progresses but continues in its perpetuation of a lose-lose scenario. Though this family desperately longs for cohesion, or intimacy, it continually fails at fostering it.

A Level 4 family is a "polarized family," and is also considered a "borderline" family. In this family, there is a desperate effort to conquer disorder and bring control. This is a pendulum swing from the Level 5 family. Here, family members see everything in black and white, and each action is considered either wonderful or atrocious. Though it is hard to believe, this family is an improvement over the Level 5 family. It can be

²⁷ Maggie Scarf, *Intimate Worlds: Life Inside the Family* (New York: Random House, 1995), 24-29.

compared to a nation that has a tyrannical autocrat who institutes boundaries and laws, as opposed to a nation without any government or justice system whatsoever. In this family, one member works to control what everyone thinks and does, and though this is effective for the short term, it will eventually fail. Level 4 families solve the problem of cohesion, but the emotional price is great: there is resentment and spirits are crushed.

The Level 3 family is the “rule bound family,” the family classified as midrange. In such families, the influence of family members’ close relationships are the source of order. Each member of this level of family lives by the underlying premise that “if you love me then you will do what you know I like.” However, rules are still more important than people. In this legalistic style of relating, family members can become resentful of the constant sense of guilt they carry. In the words of Robert Beavers, an “invisible referee” is always keeping watch. Family members feel basically un-trusted and obligated to do things because they “ought” to, not because they would like to. Unfortunately, besides being a depressing environment, the Level 3 family does not allow people to get in touch with themselves, and worse, it can keep family members from ever finding true intimacy.

Level 2 is the “adequate family” and Level 1 is the “optimal family.” Characteristics of both are similar, and an increase in the quality of these characteristics differentiates Level 1 from Level 2. These families are able to deal comfortably with both loving feelings and feelings of frustration with each other. They can deal flexibly with change and keep a clear sense of direction. There is a deep sense of dependability and

trust among family members and a secure feeling that no matter what happens, “we can work it out.”²⁸

One can now begin to imagine the varied impact that disability will have on different family types. The Pearson family has matured through many difficult years to become a family that can express love and frustration, and can be flexible while maintaining direction. This places it in the vicinity of a Level 1 family. Unfortunately, the nineteen years experience of the Pearson family’s special need status is a long time to evaluate. What the family looked like when the crisis initially occurred is unknown. Of course, some families are better prepared than others. Certain families are struggling already with poor cohesion and control mechanisms. These poorly prepared families may be tragic examples of the metaphorical “sitting duck.”

Understanding Stress and Coping

Another relevant measurement for the special needs family is its ability to cope with stress. Family functioning is often described in terms of the relationship between stress and adaptation.²⁹ The degree of stress experienced by a family has much less to do with an event than with the factors that define the family’s stress hardiness, such as child/parent interactions, family resources, and coping strategies. The same event can be for one family as mild as a bat flying around the house, but for another family, as severe as a holocaust, depending on each family’s coping abilities. Which families will succeed

²⁸ Scarf, *Intimate Worlds*, abbreviation of Beaver’s System, 24-33.

²⁹ P. Minnes, “Family Stress Associated With a Developmentally Handicapped Child,” *International Review of Research in Mental Retardation* 15 (1988):195-224, in “Effects of Stressors, Internal Resources, and Coping Strategies on the Adaptation of Families of Children With a Mental Handicap,” Doris Paez, (Ph.D. diss., University of Florida, 1992), 2.

depends on whether their vulnerabilities will be counter-balanced by their coping strengths.³⁰

Empowering families is about identifying strengths and building upon those qualities. A study by D. Abbott and W. Meredith indicates that adjustment to stress is strongly related to several factors: each family member's self view, the strength of the marital relationship, and the family's ability to reframe stressors in positive ways.³¹ Later chapters will discuss means to help a families build upon the strengths of self-view and reframing of stressors.

Models predicting stress adjustment are useful in understanding the effect of stress on families. The most prominent model, the ABC-X, was devised by Reuben Hill in 1949. Today, most models are some variant of Hill's approach. The majority of empirical support for this model comes from studies involving families with children who have severe illnesses or disabilities.³² In 1989, Gallagher and Bristol suggested this model as an accurate representation of what occurs within special needs families.³³ In this model, the "A" represents the characteristics of the stressor event, the "B" represents the family's internal resources, and the "C" stands for represents the family's definition of the event. The interaction of these three factors then contributes to the preventing or precipitation of "X", which is the crisis.

The Severity of the stressor, or disability, usually increases the stress on a family to the point of crisis. Stress was originally described by Selye in 1956 as a "noxious

³⁰ Pauline Boss, "Family Stress," in *Handbook of Marriage and the Family*, ed. M. B. Sussman and S. K. Steinmetz (New York: Plenum Press, 1988), 695.

³¹ D. Abbott and W. Meredith, "Strengths of Parents With Retarded Children," *Family Relations* 35 (1986): 371-375, in Paez, "Coping Strategies," 4-5.

³² Paez, "Coping Strategies," 26.

³³ *Ibid.*, 6.

stimulus.”³⁴ By 1974, it had been redefined and interpreted more neutrally, leading Lazarus to term it a mere “threat.”³⁵ Central to the occurrence of stress is a change or a stimulus that threatens the present equilibrium. In this disruption of the equilibrium, the system is pushed off balance and strained. Crisis, on the other hand, is change that is so severe that the system is immobilized and incapacitated. Crisis is acute dis-equilibrium as opposed to stress that has merely disturbed the equilibrium.³⁶

The severity of a disability often has a strange inverse effect on a family, which may actually decrease its severity on the system. The likely cause is that with severe disability, a family tends to face the difficulty straight on; unrealistic expectations are reduced, denial is impossible, and a family is pushed to make the needed adjustments immediately.³⁷

One hugely significant element related to the severity of disability is the status of the disability itself. Is the child educable or trainable? Is the disability something that may improve, as is the case of a child with hearing loss who may benefit from the use of a cochlear implant for communicating, or a child with incapacities who may learn to walk with the use of a prosthesis? Will the situation continue to increase in severity, as is the case with a child whose cerebral palsy may progressively worsen, or one whose cystic fibrosis will end the young life prematurely?

³⁴ Boss, “Family Stress,” 698.

³⁵ Ibid.

³⁶ Ibid., 700.

³⁷ M. Bristol, “Family Resources and Successful Adaptation to Autistic Children,” in *The Effects of Autism on the Family*, ed. E. Schopler and G. Mesibov (New York: Plenum, 1984), 289-309, in Paez, “Coping Strategies,” 30.

The following classic diagram traces the progression from stressor to outcome:

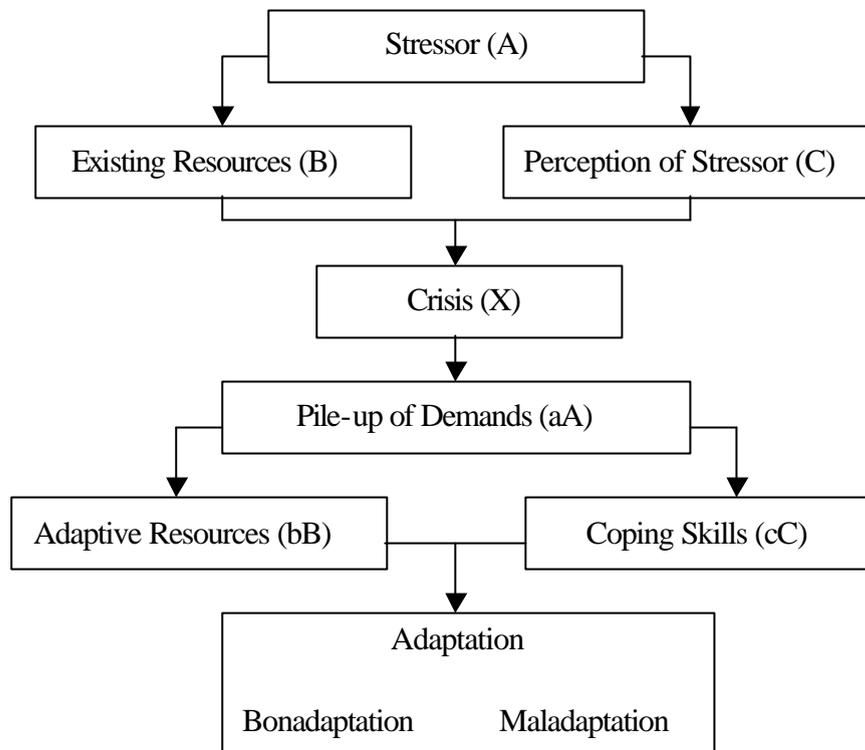


Figure 2.1. The Double ABC-X Model (McCubbin & Patterson).³⁸

The Double ABC-X model builds off of Hill's classic rendering of the factors relating to stress and crisis. However, it also makes some additions to the equation: the pile-up of demands, the adaptive resources, and the coping skills. Another model that gives insight into the dynamics of dealing with stress is the Five-Factor Model. The Five-Factor Model is comprised of Hill's stressor event, family resources, and definition of the event, and two additional factors: family residual past and family readiness. Residual past refers to the family's past problem solving experience, unresolved conflicts, and leftover

³⁸ H. McCubbin and J. Patterson, "The Family Stress Process: The Double ABCX Model of Adjustment and Adaptation," in *Advances and Developments in Family Stress Theory and Research*, ed. H. McCubbin, M. Sussman, and J. Patterson (New York: Haworth, 1983), 21-35, in Paez, "Coping Strategies," 25.

compromises. Readiness has to do with the issues of preparedness and predictability for crisis.³⁹

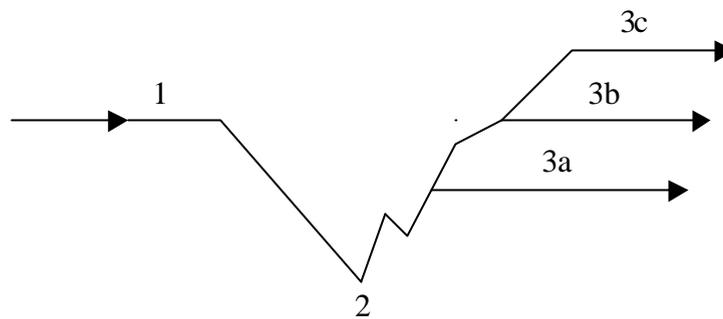
It is also beneficial to gain more insight into coping strategies. Coping strategies are cognitions or behaviors aimed at decreasing the impact of stressors. Of course, there are both helpful and unhelpful types of coping strategies which Ann Bailey and Stephen Smith describe as either “adaptive,” which is actional and involves changing the self or source of stress, or “palliative,” which is emotional and involves engaging in activities such as avoidance, denial, blame, and wishful thinking.⁴⁰ Coping strategies can also be seen as either external or internal.⁴¹ External strategies may be social, as in support groups, or spiritual, as in church help. Internal strategies may also be spiritual, as in one’s reliance on God, or mental, as in reframing the situation to see it differently.

The following diagram shows the potential outcome of crisis events. There are three possible results: worse off, back to normal, and better off.

³⁹ Cook, *Counseling Families*, 21.

⁴⁰ Ann Bingham Bailey and Stephen W. Smith, “Providing Effective Coping Strategies and Supports for Families with Children with Disabilities,” *Intervention in School & Clinic* 35, no. 5 (May 2000): 294.

⁴¹ R. Fewell, “The Measurement of Family Functioning,” in *Evaluating Early Intervention Programs for Severely Handicapped Children and Their Families*, ed. L. Bickman and D. L. Weatherford (Austin, Texas: Pro-Ed, 1986), in Paez, “Coping Strategies,” 46.



- 1= Level of family functioning before event
 2= Low point in disorganization
 3= Level of reorganization
 a. below previous level of functioning
 b. equal to previous level of functioning
 c. higher than previous level of functioning

Figure 2.2. Diagram of family crisis model.⁴²

In considering the stress and crisis experienced by the Pearson family, one marvels at how well they have coped. One may hypothesize that the history of Matthew Pearson's family of origin has contributed significantly to the family's success. Matthew's parents ministered in the deaf community; thus Matthew and his family of origin lived intimately in a culture of disability. This history has likely had a powerful influence on factors within the Five-Factor Model, such as family resources, definition of event, family residual past, and family readiness. Not only Matthew, but even his family of origin were partially prepared for the birth of a family member with disability. Because of this family history, David's paternal relatives would be able to define the event more readily and positively. Much of their social life had already involved people with disability, and spiritually, they had likely already dealt with some of the crucial

⁴² R. Hill, *Families Under Stress* (New York: Harper & Row, 1949) and E. L. Koos, *Families in Trouble* (New York: King's Crown Press, 1946) in Boss, "Family Stress," 697.

questions that challenge faith. They had a rare advantage over the average family facing an occurrence of disability.

Positive Outcomes Despite Crisis

Without a doubt, most literature and studies focus on the dangers and problems associated with having a child with disability. However, all is not negative. Many families seem to thrive on the challenge,⁴³ some marriages are strengthened,⁴⁴ and some families grow in cohesiveness and adaptability.⁴⁵ When families are undergoing stress, there seems to be an intensification of strength, as well as an intensification of strength weakness. Both the best and the worst will be magnified in the situation of life with a child who has disability.

Though empirical studies that document the positive sides are few, much evidence for the positive contribution of having a child with disability comes from the narratives of parents themselves. Murray gave testimony to this as far back as 1959:

It has been my privilege to have talked with hundreds of parents of retarded children. One of the favorite themes which permeates our conversation is how much our children have meant to us. This thought runs like a bright golden thread through the dark tapestry of our sorrow. We learn so much from our children. . . in patience, in humility, in gratitude for other blessings we had accepted before was a matter of course; so much in tolerance; so much in faith—believing and trusting where we cannot see; so much in compassion for our fellow man; and yes, even so much in wisdom about the eternal values of life.⁴⁶

⁴³ H. I. McCubbin, M. B. Sussman, and J. M. Patterson, *Social Stress and the Family* (New York: Howarth Press, 1983), in *Support for Caregiving Families: Enabling Positive Adaptation to Disability*, ed. George H. S. Singer, and Larry K. Irvin (Baltimore: Paul H. Brookes Publishing, 1989), 12.

⁴⁴ Kazak & Marvin in Singer, "Support for Caregiving Families," 12.

⁴⁵ H.L. McCubbin, in Singer, "Support for Caregiving Families," 12.

⁴⁶ M. A. Murray, "Needs of Parents of Mentally Retarded Children," *American Journal of Mental Deficiency* 63 (1959): 1087-1088, in "Positive Adaptation and Coping Strengths of Families Who Have Children with Disabilities," Jean Ann Summers, Shirley K. Behr, and Ann P. Turnbull, in Singer, "Support for Caregiving Families," 28.

Mullins evaluated 60 books written by parents of children with disabilities, and distilled the common principles contained in all the writings. The result was four prevalent themes:

- A realistic appraisal of the disability
- Extraordinary demands on the family
- Extraordinary emotional stress
- Resolution and growth⁴⁷

In spite of all the extraordinary demands and stresses, the majority of writers felt their lives had been enriched and made more meaningful. Many families vouch for the fact that they have entered into life on a different level, and it is something that they would not trade or have otherwise.

Alex Pearson shares about his “baby brother”:

Although it is a world that is full of pain and sorrow, one of David’s smiles brings infinitely more joy. It is not really that the smile erases the pain, but it somehow makes the pain bearable. I can’t really explain it except to say that my brother’s smile is so beautiful that it makes you forget about the pain, the way looking at a rose makes you forget about its thorns.

Alex, now a student at UC Berkeley, seeks to function in a world of skewed values, but is reminded, by David, of what really matters:

The most important lessons I have learned through him (David) are about perspective. Another vivid memory is before going up to study after coming home from high school, I tousled his hair for half a second longer than normal when I said “Hi” to him. He looked up at me and I was looking down at him, and I held his gaze instead of going off to do homework, and he started laughing and laughing and laughing. And I thought, “Why do I spend so much time studying for Advanced Placement tests when with 5 seconds I can bring this much happiness?”

Turnbull and her associates identified a list of benefits, experienced by many special needs families, that is quite impressive:

⁴⁷ J. B. Mullins, “Authentic Voices From Parents of Exceptional Children,” *Family Relations* 36(1987): 30-33, in Summers, Behr, and Turnbull, “Positive Adaptation,” 28.

Increased happiness	Greater love
Strengthened family ties	Strengthened religious faith
Expanded social network	Greater pride and accomplishment
Greater knowledge about disabilities	Learning not to take things for granted
Learning tolerance and sensitivity	Learning to be patient
Expanding career development	Increased personal growth
Assuming personal control	Living life more slowly ⁴⁸

The familiar prayer of an unknown Confederate soldier may partially explain what these families are experiencing.

A Prayer

I asked God for strength that I might achieve,
 I was made weak, that I might learn humbly to obey.
 I asked for health, that I might do greater things,
 I was given infirmity that I might do better things.
 I asked for riches, that I might be happy,
 I was given poverty, that I might be wise.
 I asked for power, that I might have the praise of men,
 I was given weakness, that I might feel the need of God.
 I asked for all things, that I might enjoy life,
 I was given life, that I might enjoy all things.
 I got nothing I asked for—
 but everything I had hoped for.
 Almost despite myself,
 my unspoken prayers were answered.⁴⁹

⁴⁸ A. P. Turnbull, S. K. Behr, and N. Tollefson, "Positive Contributions That People With Mental Retardation Make to Their Families" (Paper delivered at the Association on Mental Deficiency, Denver, CO, May 1986), in Summers, Behr, and Turnbull, "Positive Adaptation," 29.

⁴⁹ M. Cleland, *Strong at the Broken Places*, in "Life's Challenges: Curse or Opportunity? Counseling Families of Persons With Disabilities," Mary R. Hulnick and H. Ronald Hulnick, in *The Psychological and Social Impact of Disability*, 3rd edition, ed. Robert P. Marinelli and Arthur E. Dell Orto (New York: Springer Publishing, 1991), 267.