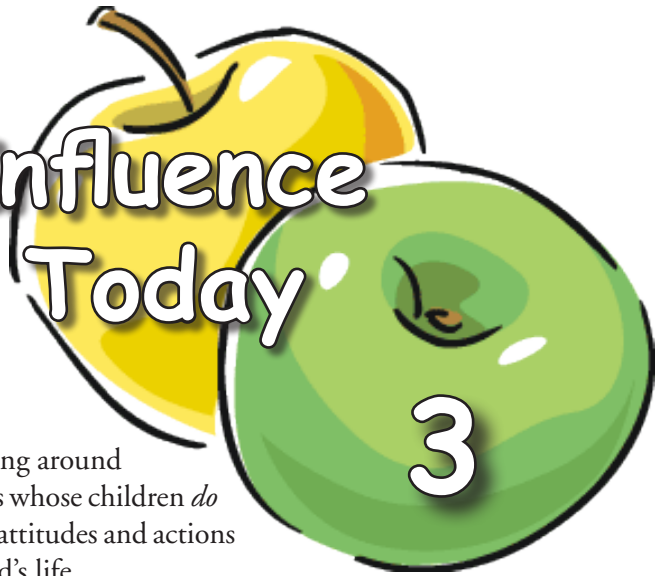


Yesterday's Influence on Your Child Today



Is the past clouding your child's life? While traveling around the country doing presentations, I've met many parents whose children *do* seem to be living in another century—the result of the attitudes and actions of people who have power and influence over the child's life.

Are you ready to stop history in its tracks? Grab a pencil, get comfy, put on your thinking cap, and answer a few questions about your family's life. Don't worry: it's pretty easy—you're an expert on this subject (but I do want you to think hard). Don't skip it: the questions asked, the situations discussed, and the thinking you'll do can give you a deep perspective and wisdom that can help you create a better life for your child and family. When my son was younger, positive change occurred only after I spent some time thinking about *what* we were doing, *why* we were doing it, and *what impact* it was having on all our lives. Before you start, here are some guidelines:

1. There are no right or wrong answers, so there's no need to try to "cheat" or give the "best" answer! This survey can help you better understand the historical dynamics which may be having a profound (and negative) influence on your child and family today.
2. Some of the questions say, "Have you and/or others . . ." You, *personally*, may not be doing the actions described. But others—family members, professionals of any kind, educators, etc.—might be. And their influence on your child's life may be substantial.
3. Read each question carefully, give each some thought, then circle the answer. Don't worry about the number, focus on the answer ("yes, sometimes, no").
4. These questions may cause sad, angry, or fearful emotions. If so, that's OK. The questions and discussion points can help you gain a clearer picture of your child's life today and help you move to a better place! Just like in a garden, we've got to pull the weeds before planting new seeds. Solutions to the dilemmas presented here are detailed in later chapters, so fear not—bushels of positive change are coming your way!

There's space after each set of questions to write down your thoughts—this can help clarify them. You might also want to begin keeping a journal; I'm going to ask you to write other thoughts throughout the rest of the book. Writing has a way of crystallizing what's in our hearts and minds, and can help us move beyond the status quo. Here we go!

REALITY CAN
DESTROY THE
DREAM, WHY
SHOULDN'T
THE DREAM
DESTROY
REALITY?

George Moore

Your Child's Diagnosis and Prognosis

- A. At the time your child was diagnosed and since that time, have doctors, educators, therapists, and/or professionals of any kind (1) described your child's "problems" and/or (2) told you what your child would not be able to do? (Since many of us have had to deal with numerous people in this situation, circle the answer that best represents an average of these experiences.) Yes/3 SOMETIMES/2 No/1

- B. Have professionals (doctors, therapists, educators, etc.) recommended treatments, interventions, therapies, and/or services to help these "problems" or remedy these "deficits"? Yes/3 SOMETIMES/2 No/1

- C. Do you and/or others believe your child's diagnosis and/or "problems" are, or will be, barriers to his overall success now and in the future? Yes/3 SOMETIMES/2 No/1

- D. Based on what you personally know about your child today, do you feel the prognoses (the predictions) about your child, delivered by professionals of any kind, were accurate? Yes/3 SOMETIMES/2 No/1

- E. *Instead* of treatments, therapies, services, etc., have professionals recommended assistive technology devices, adaptations and/or accommodations to enable your child to be successful? Yes/3 SOMETIMES/2 No/1

- F. Do you and/or others (family members, friends, professionals of any kind, etc.) routinely discuss your child in terms of his strengths, abilities, talents, hopes, and dreams? Yes/3 SOMETIMES/2 No/1

A *YES* or *SOMETIMES* answer to Questions A-C indicates the influence of the *MEDICAL MODEL*: individuals with disabilities are thought of in terms of their "problems/deficits" which need to be "fixed." And these "problems/deficits" are thought to constitute significant barriers to success. (The *MEDICAL MODEL* will be discussed further in the next chapter, and new ways of thinking about disability will also be detailed.)

A *NO* answer to Question D reflects what many parents have learned: "expert advice" is often simply an opinion based on antiquated attitudes, personal bias, or other factors. A *YES* answer to Questions E and F means your child is living in the 21st century, and this is cause for celebration!

In the space below, or in your journal, write your thoughts about these issues (what you're feeling, what you'd like to change, etc.).

Your Child's Responsibilities and Opportunities

- A. When an IFSP, IEP, IHP, or other Individualized Planning meeting has been held for your child, had everyone in attendance *actually met and/or spent some time with your child* before making decisions about him during the meeting?
- B. Does your school-aged child *attend and participate* in his IEP meeting (or IHP meeting if your child is a young adult)?
- C. Does your school-aged child *contribute to writing his IEP (or IHP) goals*?
- D. If your child does *not* help write his goals, do you and/or others tell him what his goals are?
- E. Do you and/or others ask your child with a disability (at any age) to share her thoughts and feelings about services, treatments, and/or interventions she receives?
- G. Does your child (age two and above) have opportunities to learn responsibility at home (such as doing chores, taking care of his own room, helping around the house, and so forth)?
- H. If the other children in your family receive an allowance or other “perks,” does your child with a disability receive those, too?

YES/3	SOMETIMES/2	NO/1
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YES/3	SOMETIMES/2	NO/1
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YES/3	SOMETIMES/2	NO/1
-------	-------------	------

YES/3	SOMETIMES/2	NO/1
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YES/3	SOMETIMES/2	NO/1
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YES/3	SOMETIMES/2	NO/1
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If you answered *SOMETIMES* or *NO* to any of these questions, a pervasive and long-standing assumption is a powerful influence in your child's life: people with disabilities are incompetent to make decisions about and/or take responsibility for themselves, so

others must do it for them. Strategies to change these practices are included in Chapters 6-9.

In the space below, or in your journal, write your thoughts about these issues (what you're feeling, what you'd like to change, etc.).

Your Child's Future and Potential

- A. Do you and/or others anticipate your child will need to be a recipient of Adult Services (for example, live in a group home, work in a sheltered workshop or be in a day program, etc.) when he's grown? YES/3 SOMETIMES/2 NO/1

- B. Do you and/or others anticipate that your child will go to college, trade school, and/or successfully enter the workforce as a young adult? YES/3 SOMETIMES/2 NO/1

- C. Do you and/or others anticipate that your child will become a self-supporting, contributing adult member of society? YES/3 SOMETIMES/2 NO/1

- D. Do you and/or others believe your child will be able to live in the place of her choice in the community, with supports, if necessary, when she's an adult? YES/3 SOMETIMES/2 NO/1

- E. Do you and/or others believe your child would benefit from an *academic* education (the same type of education children without disabilities receive) and other opportunities for typical growth and development? YES/3 SOMETIMES/2 NO/1

- F. Do you and/or others routinely talk to your child about his future, and ask him about his opinions, ideas, hopes, and dreams? YES/3 SOMETIMES/2 NO/1

- G. Do you routinely dream Big Dreams with and for your child? YES/3 SOMETIMES/2 NO/1

If you circled *YES* for Question A, and *NO* for Questions B-G, many old ways of thinking are still surrounding your child, including 16th Century Malthusian theories—that only those who contribute to society should benefit from what society has to offer. People with disabilities and/or other differences are victimized by this destructive paradigm which creates a self-fulfilling prophecy: if we don't believe a person can be successful, we see no reason to invest time and energy in him, and then the person is not successful because we haven't invested anything in him, and then we say, "See, we knew he couldn't be

successful." Your child, like all children, deserves the best and the most—the best education and the most opportunities—to live the life of her dreams. This cannot happen unless we believe in her unlimited potential. Strategies to address these issues are included in several different chapters. If you circled *YES* or *SOMETIMES* to Questions B-G, you're on the right track!

In the space below, or in your journal, write your thoughts about these issues (what you're feeling, what you'd like to change, etc.).

And last but not least: Grief

- A. Has your child's disability diagnosis and the prognoses about your child's future from physicians, educators, and others, caused emotional pain in yourself and/or others?
- B. Have you asked yourself, "Why did this happen to me?"
- C. Have you ever felt anguish, that having a child with a disability was not "what you had planned" for your life?
- D. Do you/have you felt hopeless about your child's future?
- E. Have you questioned your child's ability to be a parent when he/she is grown, and wondered if he/she should be sterilized to prevent a pregnancy?

Yes/3	SOMETIMES/2	No/1
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Yes/3	SOMETIMES/2	No/1
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Yes/3	SOMETIMES/2	No/1
-------	-------------	------

Yes/3	SOMETIMES/2	No/1
-------	-------------	------

Yes/3	SOMETIMES/2	No/1
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If you circled *YES* for any of these questions, the Eugenics Era influence is again present, but it's taken on a new, more respectable name and appearance: genetics. And this influence, along with religious and cultural beliefs, can generate grief.

As you recall from the previous chapter, eugenicists in 20th century America, attempted to "improve society" through breeding, extermination, and other methods (which later influenced Nazi Germany). This led society to make conclusions about:

- who *should not* be allowed to become parents, and "make more like themselves;"
- what makes a "good" or "healthy," and therefore, *desirable*, individual;
- who will/will not have a good quality of life;
- what type of people will contribute to the overall good of society, and what type will lead to the decline of society, and much more.

As discussed in the previous chapter, the Eugenics Movement in the U.S. eventually died a slow death, as its "research" was proven to be fraudulent. But a tentacle lay dormant for decades, to be reborn in our time as the science of genetics. Like many controversial sciences, much good can come out of the genetics field, if its research is accurate, truthful, and applied ethically. Perhaps a cure for cancer and other diseases that *kill* will be found.

But genetics—like its mother, eugenics—sits precariously on a slippery slope. For with the advances in medical science and technology, genetics

can do far more—for good and ill—than eugenics ever could. With the advent of prenatal testing, DNA research, and more, the potential to create a "master race" or a "superior society" once again exists, if scientists, doctors, bureaucrats, couples planning on having children, and/or others have the power and the capability to decide that some individuals:

- are not "healthy," wanted, or desirable;
- do not/will not/can not have good lives, so they should not be "allowed" to be born, *or* they should be "allowed" to die;
- will be a burden to themselves, their families, or society;
- are inherently incapable of, or should not be allowed to, have children of their own.

These questions don't fall only under the mantle of "science" (eugenics and genetics). They also involve religious, cultural, moral, and ethical domains. These domains often merge—whipped together in a social blender—and what pours out are negative and pessimistic attitudes; scorn and rejection; ignorance, pity, and fear; and so much more, as demonstrated by comments we hear on a regular basis, said by people from all walks of life:

Someone is asked, "Do you want a boy or a girl?" and the response is, "I don't care, as long as it's healthy." (Meaning as long as the baby doesn't have a disability or other difference.)

In response to thinking about the possibility of having a disability and/or after seeing someone with a significant visible disability, someone says: “I’d rather be *dead* than be like that.”

These statements reflect our society’s devaluation and marginalization of individuals with disabilities—based on the assumption that people with disabilities live such pitiful, unfulfilled lives, they’d be better off *if they were dead or had never been born!*

What does this have to do with you? Any grief, guilt, angst, or hopelessness you feel about having a child with a disability is not just the result of your *personal* beliefs. We have been set-up—*brain-washed*—to grieve. We have grown up with the belief that the “normal” parental response to a disability diagnosis in a child is grief. Let’s take a slight detour to look at the bigger issue.

We seem to be a society at war with ourselves: we “fight” cancer, baldness, wrinkles, gray hair, and more! (Yes, as I already mentioned, I hope we find a cure for cancer and other diseases that kill, but when that happens, “new” diseases will come along—we’ll always have *something* to fight.) So when we, as a society, have difficulty accepting “little” differences in *ourselves*—gray hair, wrinkles, a big belly, a bald head—is it any wonder we have difficulty accepting more significant differences, like a disability?

Is today’s society substantially different from the Ancient Greeks, whose goal was “human perfection”? (Isn’t *that* the ultimate goal of today’s genetics?)

In order to deal with one of these significant differences (a child’s disability diagnosis), we’re expected to grieve the “loss.” Yes, we have been programmed to grieve (and you can call me the “Deprogrammer”).

Here’s what you must know: *your child does not want you to grieve for him. He did not die; the dream of a “perfect child” or a “normal child” may have died.* (But, of course, there *is* no such thing as a “perfect” or “normal” child!)

But let’s get down to the nitty-gritty: feelings of grief are not really about your *child*; they’re about *your* hopes and dreams—for yourself, your child, and your family. I believe, with all my heart, that you can

rekindle the dreams you once had—the dreams that were present before your child was diagnosed. Now, your child may never walk or talk or do something else. But were *those specific things* really part of your hopes and dreams? No! Your dreams were bigger than that, weren’t they?

In this book, you’ll learn that your child doesn’t have to walk, talk, feed himself, achieve a certain level of behavior/social skills, or do anything similar in order to live a wonderful life. Isn’t *that* what you dreamed? That your precious son or daughter will have *a wonderful life*? He or she can!

Every hour, every minute, every *second* spent grieving is *time wasted!* It’s time you could have spent feeling happy, proud, hopeful, delighted, and so much more! If you want to have a happy, successful child who believes in himself (*because you believe in him*), I have this advice about grief:

get over it for your child’s sake!

Your grief will do nothing but hurt your child, one way or another. And don’t think your child doesn’t know what you’re feeling, even if you think you’re good at hiding it! Children are very intuitive. Please remember the words of the adults with disabilities who told me, “I wish my parents could have loved me just the way I am.” *Those are your child’s words, too.*

Frankly, our children have enough to deal with, without us burdening them with *our* issues! Aren’t we grown-ups? Let’s shape up!

If grief still lives in your heart, let it go, now! And I don’t think you need a “grief counselor.” (Frankly, I am appalled and disgusted by “grief sermons” for parents like us, that focus on *our* feelings, while never considering the effect our feelings, and our actions based on those feelings, *have on our children!*) Like I said, I’m the Deprogrammer, and the strategies in this book are grief-eliminators. You are not alone. If you ever need to ventilate, write me (kathie@disabilityisnatural.com). I’m a good listener and I’ll write you back. (*I will, too*, so don’t write if you don’t want a reply!)

One antidote to grief is thought to be action: we’ll fight the grief. (Here we go, fighting again!) So,

instead of sitting around feeling sorry for themselves and/or their child, many parents get moving. And the direction many move toward is a “cure” via therapies, services, interventions, rehab, and more. This, Dear Reader, is not the best direction (and I’ll show you a better direction in other chapters). But let’s explore this further.

Right now, you may believe a “cure” for your child’s condition would be a miraculous wonder, which could restore a sense of wholeness to your hopes, dreams, and family life. But there are several things to consider about this way of thinking.

First, how would your child feel if he knew you felt this way? Can you put yourself in your child’s place for a moment and try to imagine what this would feel like? You’re a child, and the people who are supposed to love you the most want you to be different, want you to be some other way, want you to be some other child—but *there’s nothing you, as the child, can do about it!* You can’t make your condition go away. You can’t take a magic pill, nor can you wish it or pray it away. How would this make you feel?

What might it feel like (remember, think like a child) if you thought your parents didn’t love you the way you are? What can you do to make them love you? How can you please them? And perhaps most importantly, how can you live with yourself, and how

Grief is the agony of an instant;
the indulgence of grief
the blunder of a life.

Benjamin Disraeli

can you love yourself, under these circumstances? As painful as it might be, I urge you to give this serious thought. And it’s okay if you’re uncomfortable. I’ve learned that most of us change only when we *are* uncomfortable!

Second, I’ve never met an adult with a developmental disability who has wished for a cure! On the contrary, they love who they are, they want to be loved for who they are, just the way they are, and the idea of a “cure” insults, demeans, and marginalizes these men and women.

Third, what message does the “cure/prevention” mentality send to individuals with disabilities? It’s this: “We don’t want people like you in the world.” Now, you may be thinking, “No, that’s not it. We just don’t want people having those conditions (disabilities).” If you think this is a rational, respectful statement, say it to an adult with a developmental disability and see what response you get. If she’s a self-confident person, she may tell you to go jump in the lake (or something that couldn’t be printed in this book)—“*Who are you,*” she thinks, to tell *her* you wish she wasn’t the way she is? If, however, she’s a person *lacking* in self-confidence, she’ll interpret your words as pity or revulsion, reinforcing her existing belief that she is not OK the way she is.

Finally, here’s another perspective for you to consider. If there was a magic pill that could make my son’s cerebral palsy go away, I would not give it to him. And, at age 18, he has told me he wouldn’t take it (we’ve talked about this). *Benjamin having cerebral palsy has enriched our lives—mine, Mark’s, Emily’s, and Benjamin’s.* The experiences we’ve had have taught us so very much, helped us see what’s really important in life, and given us a deep understanding of so many other issues.

When Benjamin was 17, an interesting incident occurred while we were visiting my dad and step-mom in another city. We were going out to dinner, and my 84-year-old dad, Benj, and I were chatting in the living room, waiting for my step-mom, daughter, and husband to finish getting ready. Out of the blue, my father said, “You know we pray for all of you every night. Kathie, we pray that your book sells, and we pray for Mark and Emily. And, Benji-Boy, we pray every night that one day you’ll get up out of that wheelchair and walk.”

In a sense, we were “saved by the bell.” My husband, daughter, and step-mom came in at that moment, and it was time to go. On the way to the restaurant, Benjamin and I talked about what my dad said and how he wanted to respond (we were in our van, my dad and step-mom were in their car). We had a nice dinner at the restaurant; Benj didn’t want to bring this up during the meal. When we got back to my dad’s house, Benjamin wheeled up to my dad and said, “Papa, what you said earlier about praying I

would walk—that hurt my feelings. I'm fine the way I am. I don't need to walk; I get around fine in my power chair. I know you love me, but I don't want you to pray for me like that anymore, OK?"

I was hoping my son's words would lead to an important discussion. Instead, my dad grabbed the TV remote and said, "Let's see what's on the boob tube." He didn't know how to respond. I gave Benj a look to indicate, "Let it go..." Later, Benj and I talked again. I explained that just as he wants to be loved the way *he* is, we needed to love Papa the way *he* is. Benj got it. (You might be wondering why I didn't pursue the matter with my dad. Part of me wanted to, but I know my dad, and know some people may *not* ever change. I've learned to pick my battles.)

In many ways, I shouldn't have been surprised by my father's words. Several years before, while visiting at *our* home, he told me about several of his bowling buddies who recently had strokes and/or heart attacks and were now using wheelchairs. With sadness, he said these friends had moved into nursing homes or assisted living centers, and added that he didn't ever want to have to go through that. I hugged my dad and told him not to worry, that if he ever needed to use a wheelchair and his own place wouldn't work, he could move in with us since our home is accessible! He replied, "I didn't mean it like *that*. What I meant was that if I ever get to that point, I hope someone will just *shoot me!*" I pulled him toward the living room, pointed to Benjamin playing a game on the computer and asked, "So you're telling me that because your grandson uses a wheelchair, his life is not worth living?" "Oh, no," he sputtered, "that's not what I meant." "Yes, Dad," I said. "That *is* what you meant." And then he mumbled and muttered, trying to clarify. Part of his attitude, I feel, is a "generational thing"—he's a World War II veteran of Pearl Harbor—and to him and many others, disability represents weakness, being "unable," and worse. (But who's really the "stronger" person here: my dad or my son?)

I've shared a couple of stories to illustrate instances when we've been on the receiving end of ignorance, misunderstanding, pity, sorrow, and negative attitudes. I wish those who are on the *giving end* of these attitudes had opportunities to have

personal and intimate experience with a person with a disability, so they could learn and experience what we have! If Benjamin didn't have a disability, we would have never learned what we've learned, never met the people we've met, and never had the experiences we've had, individually and as a family. I wouldn't change one thing about my son, his life, or our family's life. Our lives are enriched! If you don't already feel this way, I hope you will by the time you get to the last page of this book.

And one more thing: I do not feel like I'm a "chosen" parent, that my husband and I must be "special" or "worthy" or somehow "saint-like" (*Gag!*) because we have a child with a disability. My husband and I are ordinary people, just trying to get along in the world like everyone else. We're human, we try to do good, we make mistakes, we want to be happy, and we want to raise happy, successful, kind

I wish they could only take me as I am.

Vincent Van Gogh

children. We've done no more or no less than millions of other parents. We've just done many things differently, based on our belief that we didn't want our son's disability—a medical diagnosis—to run his life or be the most important thing about him.

It's all about our attitude! And for all of us, the attitudes we hold are *a choice!* Every minute of every day, we make choices about how we'll think and feel about everything! *We can choose how to see our children!*

Let's go back to the attitudes of others for a moment. I'm an eternal optimist, and I believe that most people are basically good. So I don't believe the negative attitudes held by our society regarding disability are the result of people being intentionally cruel or discriminatory (although some are). I think these beliefs stem from gross ignorance and misunderstanding, passed from generation to generation. I also believe that you and I, along with people with disabilities, and others who care about these issues, can help eliminate and/or minimize this ignorance and misunderstanding by educating others (and you'll learn how in other chapters). But

it has to start with a change in *our own* attitudes, beliefs, and language.

Leo Tolstoy said, "Everyone thinks of changing the world, but no one thinks of changing himself." Gandhi said, "Be the change you want to see in the world." Can you change yourself? I believe you can; I've changed myself, many, many times! Can you be the change you want to see in the world? I think you can do that, too.

In the space below, or in your journal, write your thoughts about grief (what you're feeling, what you'd like to change, etc.):

TO BE A GOOD PARENT,
 YOU HAVE TO PUT YOURSELF SECOND,
 TO RECOGNIZE THAT THE CHILD
 HAS FEELINGS AND NEEDS SEPARATE
 FROM YOURS, AND FULFILL THOSE NEEDS
 WITHOUT EXPECTING ANYTHING
 IN RETURN.
Howard Kogan

Flip back through this chapter, add your score, and write it here:_____.

A score between 103-132 indicates ancient histories are having a powerful and most likely, negative, influence on your child's life and your family's life. As a result, you're probably feeling pretty hopeless, angry, and/or frustrated, and your child is most likely not on a path to success as an adult. But this can be changed, so put your fears aside for now!

A score between 73-102 indicates a mixture of old and new influences affecting your child and your family. As a result, you may experience highs, lows, highs, lows, and . . . well, you might feel like you're on a roller coaster; ditto for your child. He may also be in situations in which he takes two steps forward and one step back on a regular basis. This, too, can

be changed: your child can get on the highway to success and move forward!

A score between 44-72 indicates little of the past is affecting your child, but improvements could still be made to ensure you, your child, and your family are all living the lives of your dreams!

If you wrote your thoughts and feelings in the spaces provided and needed to add additional paper of your own, staple those extra pages inside the back cover of this book. We'll come back to them later.

Now it's time to move forward! We've looked at the past, as a whole, and also how it may be affecting your child and your family. Next, we'll focus our attention on today's DISABILITY WORLD to see what's working, what's not, why, and what we can do about it!