

chapter 4

On Belonging

A Place To Stand, A Gift To Give

Janet Vohs

Before I begin, I would like to offer a few words on the definition of cognitive coping and the focus of this chapter.

On the definition of cognitive coping: I have adopted the definition of cognitive coping as presented by the editors of this book and have focused, therefore, specifically on ways of *thinking* that "enhance a sense of well-being." Using that definition, I would say that cognitive coping has been the empowerment strategy par excellence in my life. Interestingly, the very notion of coping is one to which I have given considerable thought. To me, that word has always connoted a sense of putting up with, or enduring, an undesirable situation. I personally decided many years ago that the possibility of a life gauged against a standard of coping as the highest value did not inspire me. So, while I accept the definition and the notion that our thinking about a situation is the ultimate avenue for empowerment, I find the choice of the word *coping* unfortunate. This thought is explored further in my chapter.

On my family: Jessica is my only child, and we have always lived together as a single parent and child. Although we usually have lived with a few housemates, some of whom we have come to consider family, we have lived alone for the past 6 years. Jessica's father and my parents and siblings live quite a distance away. Although they provide a valuable extended-family context, the actual contact is by telephone and annual visits. Therefore, for the purpose of this chapter, I have taken the liberty of focusing on myself and Jessica and the kind of thinking that has empowered us.

BACKGROUND

I sometimes think of my experience of being Jessica's mother as having my own personal guru-or maybe I should say cognitive coping coach-for the past 20 years. Our relationship, in which we have been both student and teacher to each other, has given me a distinct vantage point from which to consider the whole notion of cognitive coping. The coping strategies I have invented, learned, or discovered are, in themselves, of less interest and usefulness in many ways than the vantage point itself. It is that perspective for which I would like readers to have some appreciation before going on to specific strategies.

My decision to devote attention to what I think of as the background or underlying principles was fortified by a story about Tom Peters, the celebrated business management leader, teacher, and author of such books as *Passion for Excellence*, *Pursuit of Excellence*, and *Thriving on Chaos*. There was an investigation into why Peters's ideas, which had proven to be so successful in the companies with which he studied and worked closely, seemed to be having minimal long-term impact on the larger business world. The authors concluded that widespread adoption of Peters's ideas over time was hindered because managers were too eager to pick up these tips and lay them on top of entrenched management structures without adopting the underlying principles of which the tips were merely the most superficial expression.

For myself, I have always viewed tips, even the most benign, as a sort of tyranny imposed from the outside – another piece of advice, which, if I were *really* committed, or good, or cared at all, I would follow. But mostly they occurred for me as an imposition, another burden: "What, now I have to be funny, too!" Or, "Oh, no! Don't tell me I have to be good to myself! I'm all out of energy for taking care of anyone, even if it is me." Without an empowering set of background assumptions, tips might work for awhile, but seldom have the power to make any real difference. When I review my history with Jessica, what I have appreciated most along the way have been those thoughts that have had the power to alter me, the thinker – thoughts that have enabled me to generate my own tips and principles from the opportunity to see the world from a new vantage point. Before I go on to specific thinking strategies, I would like to share a couple of these major shifts in perspective because they do provide the background from which all the rest of my thinking derives its power.

Shift I: The Private World

When Jessica was diagnosed with cerebral palsy at age 1, I knew something bad, really terrible, had happened. I was very confused, upset, and scared. I personally did not have to make up the interpretation about the badness or wrongness of the situation. It was something everyone knew, a given: To be disabled or to have a child with a disability is a tragedy. Of course, by the time she was a year old, I was also *hopelessly* in love with her. And, from early in Jessica's infancy, I was committed to having a life of joy. This new information about Jessica did nothing to diminish my love or my commitment; it meant that now I would just have to be in love and committed in spite of this situation. It was as if the "in spite of" translated into a permanent little dark cloud or shadow under which I would have to live and with which I would have to cope. I can still remember the moment – Jessica was around 2½ – when I became aware of this little cloud and its attendant mood of sadness. Nothing extraordinary was going on, it

was just a quiet afternoon. The immediate justification for the mood was, "Of course I am sad. This is a terrible situation. Jessica has cerebral palsy." Almost simultaneously came a question about what *exactly* was the matter. I asked myself if anyone was in pain or was suffering and instructed myself to observe what actually was happening. I looked at Jessica. I saw a beautiful toddler, happily playing, grinning, and cooing. It was a warm spring day. I checked myself out – I felt good, I had friends, we had food, shelter. We were comfortable. Neither of us was suffering at that moment.

Yet there was the sadness and it was connected to the fact that Jessica had cerebral palsy. Since no one up to that time had been able to give me a coherent description or definition of cerebral palsy and what this condition might really mean for Jessica, I did not have dire predictions of the future to deal with other than a generalized notion that she would be disabled. In looking a little deeper into the cause of the sadness, what I saw was that the disability meant something, and it was the meaning, not the actual disability, that caused me sadness. One of the meanings was that this was a situation that really should not be the way it was, that in and of itself it was wrong.

In the exercise of looking at what actually was going on and separating it from the interpretation I had about what it meant, amazingly the sadness dissolved. Was it possible that suffering was not an inevitable correlate of having a disability or a child with a disability? I did not really believe it, but I was willing to suspend my disbelief long enough to consider and entertain the possibility. At the time, *merely* asking the question, a simple unassuming act of cognition, cracked the solid wall of reality that I had previously accepted as the truth: Disability equals tragedy, a life of sadness and coping as best one can with this terrible reality.

When I reflect on what thoughts made the most difference to me in my own growth with Jessica, what stands out the most was the first occurrence of the notion that maybe the suffering was not necessary. What that thought allowed me to do was to begin to *observe* what was actually going on in the world rather than in my head. While there was not an instantaneous change of behaviors or beliefs, I began to cultivate the view that disability was a natural part of life, that there was nothing inherently wrong with having a disability.

As I was able to define disability as a legitimate part of ordinary life, I became freer to interact with Jessica and her disability separate from the impulse to try to make her better. Suffering over the fact of a disability eventually became totally inconsistent with the idea that Jessica was whole and complete. (Obviously this thinking opened up whole new problems, such as how to motivate myself to continue doing therapies and other exercises that seemed to reinforce the notion that something was wrong. The idea of goals as stemming

from personal visions and values, as a delightful way of participating in life's unfolding, not rooted in the need to adapt to or right a wrong, was a whole other language I had not even begun to hear or invent for myself. More on this subject later.)

The point here is that suffering arose from a background assumption of what it meant to have a disability, namely that something was wrong and should not be the way it was. Learning simply to identify or notice these assumptions as assumptions is a way to pull the presuppositional rug out from under thoughts and interpretations that result in suffering, and is a major cognitive coping strategy. *It allows one to separate the world or whatever is happening from the interpretation or meaning ascribed to it.* It also opens the door to the possibility of inventing or choosing new descriptions and interpretations, ones that may be more personally empowering.

Shift II: Us and the World

The next assumptional axis shift had to do with our place in the larger society, beginning with my own immediate family. I pretty much felt that my acceptance of Jessica was a private matter, and that the world, although I expected it to be "nice," did not necessarily share my view. Therefore, I had two strategies (really two sides of the same strategy): I would try as much as possible to be around only people whom I felt confident shared my view of Jessica. And, I was determined *not* to be around folks who saw us as tragic. Unfortunately, that included my family, most professionals, and just about everyone else I knew. In a valuable piece of coaching, one of my friends offered the suggestion that the world-in particular, my family-would accept Jessica to the extent that I did. An interesting paradox, that a possible measure of my love and acceptance of Jessica could be the degree to which she was accepted by the world. (What made this piece of advice so "listenable" to me, by the way, was that I knew this person absolutely adored Jessica and me and she offered it more as a hint than as advice that I should follow.)

This possibility presented a challenge that I found a bit more daunting. For me, it was one thing to feel some power with regard to my own personal acceptance of Jessica, but quite another to begin asking others for a place in the world. When I asked myself what exactly was so scary, there seemed to be a lot more charge to this little black cloud than to the other one: I was afraid of the shame and embarrassment my family would feel and of their rejection. I did not have those feelings of shame and embarrassment myself (or so I thought), but I assumed and felt that they did.

My own personal history with my family had a crucial impact: As a 1½-year-old, I was hospitalized for 18 months for traction and surgery to correct dislocated hips. My parents were discouraged from visiting because, according to

the nurses, the only time I was distraught was when they came. In order not to hurt me, they stopped visiting. By the time I came back home at age 3, there was my older brother; a new sister half my age whom I had never met (and who, my parents say, played a major role in teaching me to speak once I came home); a new baby due any day; a mother overwhelmed with the stresses of parenthood, and probably broken-hearted over what had happened to me; and a dad in the Air Force who had been transferred to another city. I was essentially going home to a new family that already had its fill of stresses. Once my belonging was broken by being gone for so long and by what I interpreted as a weak welcome home, I never felt as though I belonged. In fact, in my 3-year-old mind, I was convinced there was something *really wrong with me* that made me not "belongable." As I grew up, my outsider stance was reinforced by a family ethos that preached independence; in the family context, there was really nothing wrong with being "unbelongable" except that I was miserable.

In my young adulthood before Jessica, it was obvious to me that I should definitely limit my world to places where I was accepted and, therefore, belonged. Needless to say, I was pretty much off a loner. I would have rather lived isolated than face being rejected or having Jessica be rejected.

Viewing myself as Jessica's primary ambassador to the world, however, meant I had quite a job to do to love and accept myself and deal with my own issues of belonging. I had learned early on to "cope" by becoming deeply re-signed to the fact of my own unworthiness. Being Jessica's ambassador meant reconstituting myself as a valued member of my own family, as a person who belonged in the world. One does not undertake lightly re-creating oneself, nor does one accomplish it without pain. It was the desire and commitment to create a place of belonging in the world for Jessica that made loving and caring for myself a project worth bothering about. I could no longer afford the outsider stance; I had had my fill of coping, and of the misery of not belonging. My commitment, inspired by my love for Jessica, was that we would be happy, dammit.

Although I did not know how to do this, I had heard and read a little about transactional analysis and the idea that we each have a child who is still part of us. I began immediately to take on the role of parenting myself and of telling my "child" self that I loved her, that she was beautiful, that, most of all, she belonged – all the things I wanted to make sure Jessica had as part of her self-image. In the process, I discovered that I longed to hear those words myself. I gave myself the power to love myself. I "pretended" I was big and strong and could do that. And the stand "I belong" gained power in the saying of it, and as the child part of myself believed me and looked up to me, she empowered me even more.

Creating a place for me to stand called "I belong" caused a major shift in the world. Neither my parents nor Jessica changed. My fundamental belief about who I was shifted and *that* altered the way I saw the world. Standing up for Jessica became a natural, although not always easy, extension and expression of my stand, for my own absolute belonging. I have found my family to be deeply feeling, accepting, and loving. I am also much more free to ask that Jessica be included when I feel she is being left behind.

I am convinced that the issue of belonging is at the heart of the considerable pain there is in relation to disability, and is probably close to the heart of what it is to be a human being today. Yet belonging is hardly ever acknowledged as an issue. The urgency of my desire to have a happy life forced me to give myself the gift of belonging. In the process, I discovered that we *do* have the power to bestow that gift on ourselves, and, in the process, to affirm the humanity and belonging of others.

NOW THE WORLD

Lao Tsu is said to have linked courage to love. I believe that it does take great love – of ideas, of people, of life – first, to perceive the possibility of a reality not expressed in the common-sense view of the world, and second, to question the accepted reality with courage. Jessica, has granted me the gift of great love. The common-sense reality would have been for me to "accept" the tragic view: to care for her as a burden, to love her privately, but to accept the world's view of her as a defective little creature. My own early years of questioning and rejecting the common-sense assumptions about disability did require courage. But this was only a hint of the courage I imagine parents 30 or more years ago must have had, who, when advised, even ordered, to institutionalize their babies with disabilities, said, "No."

Obviously, if going into the world with a disability and insisting on a place, on belonging, requires courage, things in the world are not all that wonderful. Once I had arrived at the views that nothing was inherently wrong with Jessica, that the disability did not diminish her worth as a human being, and that nothing was wrong with me and that I was not "unbelongable," the tendency was to view the world as the place where things were wrong. Something had to be wrong, somewhere.

A TV cooking class on making bread supplied an interesting metaphor that I have found useful for thinking about notions of disability in our society and where they come from. In fact, the anecdote has helped me think differently about what there is to cope with. In Europe, years ago, castles and homes were built with a small enclosed room used for making bread. Today, after generations of making bread in these rooms, it is unnecessary to add yeast to the bread dough.

The yeast culture simply lives in the air and leavens any dough that happens to be placed there. For the most part, I have come to see our assumptions and presuppositions as invisible – like the yeast, part of the air we breathe. We do not consciously choose them or invent them; Philosophers. have described them as "inherited." As I envision it, our "culture, instead of little yeast bacteria, is made up of millions of sentences, metaphors, and stories about life that we have learned to call true. And although the conditions that make the sentences and stories seem like the truth frequently change, they usually linger in the cultural atmosphere long after their usefulness has been exhausted.

Many people have traced the fear and hatred of people with disabilities to the eugenics movement, the desire to "perfect" the species through genetic control, that swept the country in the early decades of this century. As such, this prejudice has common roots with racism. I am convinced that the current social institutions, unfortunately, still reflect assumptions from that legacy. Even more insidious are the automatic inherited strains of that kind of thinking that still live in and are given expression in our culture. Others have noted that fear of "difference" is characteristic of primitive societies and that the conditions for tolerance and appreciation of diversity must be generated intentionally and nurtured.

In terms of sheer survival, the automatic interpretation of disability as a tragedy was a reasonable response when gauged against a backdrop of a rugged frontier land or a time before we had the modern conveniences we take for granted now. I shudder to think of what life with Jessica would be like without indoor plumbing, electricity, roads and sidewalks, and health and family supports. But now – and I believe it *is* only a very recent phenomenon-we are lucky enough to live in a society based on democratic values and in a time of technological and material advancement that makes contribution and participation for people with disabilities a real possibility beyond what was previously even thinkable. However, like the rising loaves in the bread room, we also dwell in a cultural environment that has a profound effect on us. The sentences, or assumptions, we inherited about disability are part of an inappropriate and outmoded vocabulary.

An interesting research project reported in the July/August/September 1990 issue of the *Journal of Rehabilitation* illustrated the pervasiveness of the assumptions and how they affect our day-to-day perceptions. Entitled "Stresses as Perceived by Children with Physical Disabilities and their Mothers," the article examined the results of a study that compared the reports from 20 children with physical disabilities (ages 8 to 15) of what stressed them with their mothers' beliefs about what stressed their children. There was a wide gulf between mothers' and children's perceptions of what is stressful. With the exception of

one response from one child, the children did not express concern about "being different" nor did they dwell on things they couldn't do. They were stressed most often by aversive events they *did* experience.

The mothers' concerns were with how their children differed from the norm, and they frequently identified the disability itself as the source of stress. Not surprisingly, this same perspective was shared by many of the professional helpers as the researchers learned that the study was begun:

Similarly, a group of medical and mental health professionals predicted that the research presented here would be a waste of time because "*everyone already knows* [italics added] that the disability itself is what causes the children's stress." Further, they believed that any stresses other than those arising from the physical difficulty itself would be trivial and unimportant. They speculated that the children, in particular, might fail to understand what is their "real" problem. (Tackett, Kerr, & Helmstadter, 1990, pp. 33-34)

I had a similar experience and revelation about Jessica. Not that long ago, I realized that I believe that Jessica must be sad not to be able to walk. So much a part of me was this belief that I didn't even really know I had it lurking there in the background. I just *knew* it was true. Since, like most parents, I hurt when my child hurts, there was an appropriate sadness that went with the thought. Once I became aware of the assumption, I thought I would ask her, but I was afraid to. I was so certain that not walking *must* be a source of pain for her that-I felt it would be a cruelty to ask her, that the asking would call to mind her limitation and thus cause her pain. When I finally did summon the courage to ask, "Jessica, don't you wish you could walk?" her response was a nonchalant "No." When I asked why, she simply said, "I fall down." There was not a shred of suffering about it, or regret, or anything.

CREATING A NEW CULTURE

Going back to the bread room for a moment, it is easy to grasp the pervasiveness and inescapability of the "culture." At the same time, though, there is a hint of a very exciting possibility: Regardless of how much they are presented as true, the assumptions and presuppositions are only sentences. With regard to disability, the children in the study cited earlier seemed to grasp this reality much more profoundly than did the adults in their lives. They did not automatically attach stigma and suffering to the fact of a particular physical condition. Were they wrong not to do so? Were they deluding themselves or in denial? Were they unaware of what was "really wrong" with them, as suggested by the professionals?

Richard Rorty, professor of humanities at the University of Virginia, offered this thought on the relationship between the way things are and what we *say about the way things are* in his book *Contingency, Irony, and Solidarity* (1990): "Only *descriptions* [italics added] of the world can be true or false. The world on its own-unaided by the describing activities of human beings-cannot" (p. 5). Descriptions and interpretations of meaning are really the essence of what we are talking about when we say "cognitive coping." To separate the circumstance from the meaning associated with it is the first step. Next is to realize that the concern with the truth or falseness of what a situation means is not all that important or useful. What is useful is to ask whether the meanings we attach are empowering. Do they offer more freedom? Rorty wrote that "revolutionaries and poets of two centuries ago [began to realize that] ... anything could be made to look good or bad, important or unimportant, useful or useless, by being redescribed" (p. 7). It is the sentences we say to. Ourselves about what things mean that make the difference. And sentences can be replaced with new ones.

Realizing that we have some power to choose interpretations is empowering because it enables us to try on many different personal redcriptions. It also points to a way to have an effect on the kind of sentences that will make up the "bread-room bacteria" for future generations.

The method is to redescribe lots and lots of things in new ways, until you have created a pattern of linguistic behavior which will tempt the rising generation to adopt it, thereby causing them to look for appropriate new forms of non-linguistic behavior, for example, the adoption of new scientific equipment or new social institutions. (Rorty, 1990, p. 9)

There are many to whom it is still most obvious and "commonsensical" that loss and tragedy are inherent in disability, that the people so affected are truly outside the norm of what it is to be a full and complete human being, that they do not belong. To those who hold this view, the parents and others who do not are in what some label *a denial stage*. Or perhaps they are bravely or cleverly coping with this tragedy by concentrating on the so-called positive aspects. (Of course, we all know that the only things needing a positive veneer or attitude are things that are really negative.)

It now seems to me that nothing could be more obvious and self-evident than that people differ from each other, that nature is full of variation, that heterogeneity is the norm, and that chance and contingency could disable any of us at any time, that the vulnerability that comes with disability is a gift. A fundamental belief about the tragic nature of the situation informs one world view. Acceptance of disability as a legitimate part of life informs another.

The view that has disability as a tragedy is not "wrong"; neither is the other view "right." The accuracy or truthfulness of the view – whether it corresponds accurately to the real, inherent meaning – is not as interesting or fruitful a question to pursue as the question of whether the interpretation is useful or empowering. (Especially since, if you take Rorty's [1990] perspective, there is no true inherent meaning!)

If disability is an ordinary part of life, there is no longer a need to *cope* with the obvious and inherent tragedy of disability. But that most certainly is not the vocabulary with which I began my adventure with Jessica, nor do I believe these assumptions are the ones our culture bestows on us simply by virtue of being born in a particular place and time. Not yet, anyway. Families, even if they have managed to invent or discover a new description of the situation for themselves, are still living in a world of inherited meaning.

COPING

Coping can be empowering or disempowering. If the source of the problem is that *the person* is defective, coping, even at its best, can only convey a sense of putting up with a situation that is inherently bad and about which nothing really can be done. What one is left with is to be brave and courageous, or to find humor, or to adopt any number of other strategies to help deal with this unassailable fact. Since, obviously, most people with disabilities are not going to get magically fixed, and the source of the problem is the disability, all there is left to do is cope.

How can coping be empowering? The "cognition" about the possibility that maybe things are not wrong was ultimately empowering to me. It gave me a new freedom to act and participate more fully in actual, as distinct from feared or made-up, scenarios. I prefer to think of that kind of cognition as something other than coping. To be actually empowered, to cope because of a presuppositional shift, is very different from coping by resigning oneself to putting up with or enduring a miserable reality. When sailors and explorers thought the world was flat, they coped with that fact. That knowledge structured everything about how sailors thought and behaved. When word got out that the world was round, this news caused a shift in behavior and in people's perceptions of what was possible. The world did not change, but what was thought to be true about it changed and people went about sailing their boats very differently based on the fact that the world was round. I am interested in giving parents access to the kind of thinking that allows the "world" to change from flat to round.

Current Coping Strategies

1. *Be aware of the power of presuppositional meaning attached to a particular situation.* When I experience distress, I ask myself what meaning and significance I attach to the situation. The degree to which people have access to the assumptions that shape their world view determines the degree to which they are free to interact with varying situations.

2. *Identify what there is that I need to cope with.* What is the source of stress? Have I made a judgment that the situation is simply wrong and should not be the way it is? Is it that Jessica is not able to walk, or is it the flight of stairs that prevents access? If Jessica were already viewed as beautifully and perfectly human, if she really belonged and knew it, even if she had to face physical barriers every day, inside a vision of total belongingness and a commitment to making the world accessible, would that be a tragedy or an opportunity for committed action?

3. *Distinguish Jessica's experience of life from my own assessments of what her life must be like.* In other words, I try not to assume that I know how Jessica feels – instead, I ask her to tell me. This one deserves to be taken on as a discipline, with vigor.

4. *Don't worry so much about being right or wrong.* I trust myself and my instincts. I have substituted my concern for "truth" with a concern for freedom, self-expression, and participation.

5. *Try on a variety of interpretations for a situation.* Taking a victim stance is automatic – I am already familiar with what that perspective allows for. Sometimes I find it empowers me. Often we are victimized by the way society is organized. There are inequities; life is not fair. Given that reality, what is my commitment in the matter? I also like to try on other perspectives. Sometimes I pretend that, if I were God, what might I want to gain from things being the way they are? It's just a silly pretense, but sometimes it empowers me to try on all kinds of different perspectives, all sorts of meanings. If I hit on one that speaks to me, that enables me to act on things in a more powerful way, I keep it.

6. *Ask, "What am I building?"* For me, the answer is always something grand and glorious. My vision takes me back to the bread-room metaphor. If, even through my everyday actions and conversations, I can help change the "culture," if I can add strength and vitality to certain sentences and metaphors such that they replace the ones that make up the current environment, that possibility empowers me. I want to replace our current story about who belongs and who doesn't with a story of increasing willingness to live with plurality. My vision for an inclusive society extends way past my own and Jessica's lifetimes.

7. *In times of upset and stress, remind myself what it is I am committed to.* If I were not committed to belonging and participation as a natural part of Jessica's life, there would be no occasion for me to be upset when she was excluded or not

respected as a valid participant. And so it goes for education, health, employment, and recreation. Seeing the upset as an expression of vision lets me first of all be upset when I am upset, and it provides powerful access to the vision.

8. *Be on the lookout always for ideas, thoughts, stories, and poems that empower me in designing a new view of the world.* The following are some that I have recently collected (Safransky, 1991, p. 40):

One cannot be deeply responsive to the world without being saddened very often. [Seeing people left out, marginalized, or suffering for any reason is painful. Sadness is an appropriate response to that suffering and can be a powerful motivator.] -Erich Fromm

It is slow, painful, and difficult for an adult to reconstruct a radically different way of seeing life, however needlessly miserable his preconceptions make him. -Peter Marris

The greatest and most important problems of life are all fundamentally insoluble. They can never be solved but only outgrown. -Carl Jung

There are only two ways to live your life. One is as though nothing is a miracle. The other is as though everything is a miracle. -Albert Einstein

The reasonable man adapts himself to the world; the unreasonable one persists in trying to adapt the world to himself. Therefore, all progress depends on the unreasonable man. -George Bernard Shaw from "Reason," in *Maxims for Revolutionists*

Most Promising for Other Families

1. *Help families create a vision that empowers them.* These words are from a poem by Darrell Bolender, a father from Iowa (*Looking to the Future II*, 1991):

A Simplified Tale of An Ongoing Story

From family groups to conference gatherings,
Out of our uniqueness,
And unifying experiences
We create visions "Looking to the future."

Toward what future are we moving?
As parents of children with special needs,
We often hear,
Take it one day at a time.
The future, tomorrow,

Is many "one days" added
up to a today.
This day.

Tomorrow, the future,
The whole of what our children,
And families,
Will grow to be,
Is greater than just the sum of many days
Taken "one day at a time."

I love this poem's assertion of a wholeness beyond the constraints of what Shakespeare referred to as the petty, creeping pace of day-to-day living. It wasn't until I began to investigate contemporary management practices a few years ago that I even began to take the notion of vision seriously. I learned that what was characteristic of companies that had achieved incredible success was that they all had a vision from which they operated. I figured if Fortune 500 companies could make big bucks by having an empowering vision, it might be useful to me in generating my own wealth in terms of belonging and a network of support.

I agree with the poet that families of children with disabilities are not allowed – or at least not encouraged – to have a dream or a vision for their children's future. What the past has given as possible outcomes for people with disabilities is far less than inspiring. If all we have to look forward to is an extension of the past, I should think we would want to avoid the pain of that future as long as possible. But I have a motto: *Vision over visibility*. Having a vision is not just planning for a future we already know how to get to. It is daring to dream about what is possible.

It is one's vision that influences every detail. It is the vision that gives the tips. Creating a vision is very different from trying to follow tips. So many people start with the details-the day-to-day. One's intention, or vision, if it is powerful enough, automatically organizes his or her actions accordingly. What has helped me has been people asking me about my vision and encouraging me to talk about it. It can be true that even in the middle of the most dire circumstances, the vision can exist as a full and complete vision, as a possibility to be lived into. It is not something that will suddenly occur one day. It begins now, as a possibility to which one is devoted, and unfolds into the future as one takes action appropriate to the vision. One tip: Be ready for surprises!

2. *Learn to speak differently*. According to Rorty, "Speaking differently as opposed to arguing well is the chief instrument of social change" (1990, p. 9). In the area of disability we do need social change. We need to help create new possibilities for belonging and participation by how we speak about our dreams and visions of what is possible for our children and for society. People with differences have been marginalized in our country's imagination. We have

made tremendous legal advances by focusing on a kind of speaking that emphasizes rights. Considerable grassroots advocacy efforts have helped ensure the right of all children with disabilities to an appropriate education alongside their peers without disabilities, a right that has been protected by federal legislation since the 1970s. With the passage of the Americans with Disabilities Act of 1990, there is now a federal law that guarantees the civil rights of people with disabilities and prohibits discrimination against them in all aspects of society. We are accustomed to encouraging parents to be strong advocates to stand up for their children's rights. Indeed, the conversation to further rights is basic and cannot ever be ignored. However, it does not allow the heart of the tale to be told. Perhaps the next era's unfolding will require parents to be strong poets and storytellers as well, helping to create communities where all belong.

Anticipated Future Stresses

The future is now. Jessica is 21, almost 22. Thanks to a lot of help from our friends, Jessica is no longer in a state school but is living on her own in the community and loving it. I had a meeting with the adult services agencies charged with Jessica's care. Some professionals and agencies are eager to help because they share the same vision of belonging. We are exploring and pushing the boundaries of the current system together. I have learned from the state rehabilitation agency that supported employment as practiced in my state is only available to people who will need it for up to 1 year. Furthermore, they do not consider people with mental retardation or severe disabilities their concern. This too shall change. I am interviewing business owners whom I know and asking them to consider the possibility of employing Jessica, and they have expressed a willingness at least to explore the possibility. The school system is contracting with an outside agency with a good record of success to create a job for Jessica and to support her in the long term. The state mental retardation agency has tentatively agreed to pick up the funding once the school year is complete and her entitlement to an education ends. There is a pervasive element of uncertainty and risk. Clearly we are making the path by walking it. Sometimes we bump into trees and brambles, and sometimes huge vistas open before us.

The sheer physical and mental effort required to make her life happen is enormous and stressful. Jessica has finally gotten an electric wheelchair, but it is impossible for us to get it into the apartment where we live because there are eight steps. It is a major effort simply to get her in and out of the house. Everywhere I turn, there are barriers.

There is no question that without the help of society, the sheer details of providing adequate care are overwhelmingly stressful. While life is

not easy now, it is not more than I can bear. But it is possible that it could become so. The most effective form of cognitive coping with these tough realities is engaging in political and other forms of action that can help change unsuitable social structures. True access to equal opportunity for Jessica and many others must include accommodation and a range of supports. Yet even health care, a basic right in most industrialized countries, is a privilege in the United States of America. Preexisting condition clauses exclude people with disabilities from most health insurance plans. Also, for Jessica and others with severe disabilities, the new world of inclusion made possible by the ADA means nothing without the personal assistance they need simply to get up, get dressed, and get out of the door so that they *can* participate and contribute. Personal assistance of this nature should be part of basic health care. Our country's social policies, however, are designed such that billions of dollars go toward keeping people with disabilities restricted in nursing homes and institutions rather than making attendant services available. The latter would enable people to live and work in their own homes and communities.

People who have been excluded and stigmatized because of their difference need support to belong. They may need to be invited, to be shown hospitality, or simply to be viewed as regular people. Even though students with disabilities have a right to an education, the opportunity for an integrated education, where they can be truly part of their school communities, is still a rarity. People with disabilities generally say it is the attitudinal barriers that are the most oppressive. Unfortunately, I do not see these stresses vanishing any time soon.

FUTURE RESEARCH DIRECTIONS

People with disabilities regularly identify societal attitudes as the most potent and negative stressor in their lives. Yet, we still seem to lack powerful access to what it will take to alter those attitudes, or even much of a sense that they are alterable. There is a need to begin to explore the unknown, almost taboo arena of human relationships and the impact of difference. How do we shift these attitudes? How do we help families gain the tools *they* need to tell (and believe) a different story about disability and empower and ennoble themselves at the same time? How do we learn to speak differently about disability in such a way that our speaking will cause new social structures to take the place of the ones we have now? How do we all learn to tell the kind of stories that will help ameliorate differences and allow for a sense of belongingness? What would it take to equip professionals-in-training with a sense that learning to speak differently about disability is part of their job?

How can people with disabilities themselves play a role in rehabilitating our sense of community? Self-determination and self-definition go hand in hand. A worthwhile inquiry might be to ask what people with disabilities need to define themselves newly. Even more important, we should ask what it would take for everyone else to listen with new ears.

For ideas and stories that can help, we need to gain exposure. Perhaps we should conduct research, for example, on the effectiveness of television as a vehicle for transforming attitudes. What more can we learn by listening to people with disabilities themselves and by using every possible medium and forum for them to tell their own stories?

Even more than new research projects about what people think about disability, we need to give exposure to what we now know and have known for at least 20 years: People without disabilities usually have mistaken notions of what people with disabilities think and feel. We as parents and professionals committed to furthering the rights of citizenship for people with disabilities have a right to expect that the people working for them be aware of research findings that have a direct impact on the most critical issues of their lives.

The professionals who compared the mothers' and the children's perceptions in the research (Tackett et al., 1990) referred to earlier in this chapter thought it was irrelevant to inquire into what it was that caused the children stress—they already knew what the answer must be. One wonders how many questions are not asked because the answer is already supposedly obvious and self-evident. How much of what we "already know" do we know wrong?

CONCLUSION

On belonging, what empowers me every day is that I totally belong to Jessica and she to me. In that total handing over of my life to her, and in claiming her life for me in the utter, complete selfishness of all that, I find that I belong to the world. I find that state of being freeing and exhilarating. There is something about living at risk for one's dreams that, while certainly painful on occasion, is fun. I forget this all the time. Thanks for giving me the opportunity to remember.

ABOUT THE AUTHOR

Janet Vohs In addition to being the full-time mother of Jessica, I am the director of publications for the Federation for Children with Special Needs and editor of *The Coalition Quarterly: The Journal of the TAPP (Technical Assistance for Parent Programs) Project*, and *Newsline*, the Federation's regular newsletter. I am also involved in projects dealing with assistive technology, health care and school reform, transition and supported employment, and, in general, issues related to creating a society that works for everyone with no one left out. Jessica is now 21 years old and is integrated on a full-time basis at her local high school with a heavy focus on community-based supported employment. She also has her own two-bedroom apartment in the neighborhood in which she grew up. She pays rent with her SSI check and with assistance from Section 8, a federal rent subsidy program for people with low incomes. There are surprises – some thrilling, some terrifying – every day. But that's another story!

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