

## Seeing With New Eyes: Metaphors of Family Experience

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“The real voyage of discovery consists not in seeking new lands but in seeing with new eyes” (Proust, 1934)

When I first learned that my son had a significant disability, no way did I think I could be a good mother to him! It was as though all I had ever ridden was a basic street bike, with fat wheels, no gears, and back-pedal brakes, and, suddenly, I was presented with a fancy Italian racing bike, with thin tires, curly-over handlebars, umpteen gears, hand brakes—and on top of it all, it was a tandem! “You’ve got to be kidding!” It was the only vehicle we had to get from there to here, so we rode it. Along the way, I fell a few times, changed riders in the other seat, but also learned to ride better and faster, with far greater skill than I ever dreamed I could.

There was not anything “broken” about my son. He was just far more complex, more sensitive, more responsive, in more unusual ways, than anyone I had ever known before. As I learned from necessity how to interact with him, read his subtle signs, love him, I became better at being a mother. He raised me as much as I raised him, like the small wheel turns the big wheel in a set of gears (Erikson, 1964).

The perception of disability is shifting. The Developmental Disabilities Assistance and Bill of Rights Act of 2000 states:

Congress finds that. . . Disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society.

Although Congress may have reached this finding, this awareness has only begun to filter, slowly, into the perception of most people in America. Why is this important? With cutbacks in services and supports; rationing of medical care (managed care); genetic engineering; and, at the most extreme, assisted suicide and euthanasia, ethical dilemmas confront us daily. Tracy Latimer, the Canadian child killed by her father in 1993, is far from the first person with a disability to be “put out of

her misery.” It matters terribly how we see all of our children, and how we see our own lives as family members.

If our child’s having a disability is seen as a tragedy, then our business is to grieve, cope, and survive. We have had nearly 2 decades of research in positive perceptions of families of children with disabilities (Hastings & Taunt, 2002). We have had new theories of disability, such as social role valorization (Wolfensberger, 2000) and social construction of disability (Biklen & Duchan, 1994). We have had new theories of family adjustment (McCubbin & Patterson, 1983). We have had strengths and assets-based approaches in education and human services. We have had Kingsley’s (1987) landmark popular essay, “Welcome to Holland,” and the book *Disability is Natural* by Snow (2001)—yet the Kubler-Ross (1969) grief model still dominates the popular understanding of both professionals and the families they serve.

Through the network of grants and programs sponsored by the Administration on Developmental Disabilities, a corps of family members/instructors has offered the family-generated training Family Support, Self-Determination and Disability (Yuan, 2001) to more than 2,500 family members, professionals, and people with disabilities in 19 states and territories. This interactive curriculum, developed at Vermont’s Center on Disability and Community Inclusion in 1993, is constantly under revision, in response to changing issues, concerns, and participant feedback. The cultures represented in the workshops have been rich and varied, as the training moved from Vermont to more diverse places—Alaska to Guam, Maine to Georgia, Rhode Island to Arizona. The participants, potential leaders in their states, had opportunities to personalize the concepts in the training through experiential exercises and group discussion in workshops averaging 20 to 25 participants. Among many other topics, we chose to address this fundamental issue of perception. How can we shake loose from our blinders enough to “see with new eyes?” The urgency of this task led us to explore

the power of metaphor. Could people compare their personal experience as parents of children with disabilities to some other image (like the bike-riding example with which I began this discussion)? Would that open up their perspectives in a nonthreatening, supportive, maybe even playful and creative way (Leff, 1984; Parnes, 1992)?

In the training, we introduced the metaphor exercise early, before any presentation or discussion of more academic theories of family adaptation. When we asked participants to identify a model describing the experience of families with a child who has a disability, in the 9 years of the training, almost every single group identified the stages of the grieving model, usually in the correct order! Most groups knew this was the work of Elisabeth Kubler-Ross, famous for her book *On Death and Dying* (1969). Regardless of whether their exposure was through their own reading or contact with professionals, families have felt the domination of this model in their own understanding of their emotional turmoil in response to the unexpected challenge to their hopes and expectations of an “ideal life.” Even as some parents moved to a more positive perception of their own child, most framed this shift as having reached the acceptance stage of the grieving model. Those parents who have completely moved beyond this model, or who never felt a level of comfort within it from the start, still encounter it in their interactions with professionals.

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### Visual Metaphor Exercise

In this exercise, we use simple materials: flipchart paper and markers. An assortment of small workshop toys is also available on all the tables throughout the training, to spark creativity.

In Step 1, we invite participants, particularly the family members within the group, to identify the positive contributions of the Kubler-Ross grief model. They have usually identified such matters as:

It helps me realize I'm not weird for feeling this way; it helps others understand what I'm going through; it helps me know what may come next; it gives me hope that things will get better; it's a way of looking at loss that fits many life experiences; what I am experiencing is a part of life.

In Step 2, we invite participants to identify problems with the grief model. To be fair, most of the concerns do not relate directly to Kubler-Ross'

work, but rather its rigid interpretation. The problems usually identified have been:

It is often overgeneralized by others, and used to label or judge families; it can oversimplify the complexity of emotions a family member may experience: it is often interpreted as linear; the stages are often interpreted as prescriptive; it was created around the single event of death—we are dealing with multiple, ongoing events of life; it is basically incompatible with the disability rights movement; disability is not a tragedy to be grieved.

Following this discussion, in Step 3, the participants go into groups of 5 to 7 people, with a mix of family members represented in each group. We give them flipchart paper and markers and ask them to try to erase from their minds, everything but their own personal experiences as families and supporters of children and adults with disabilities. We ask them to look back on that experience and come up with new and different words and pictures—a visual metaphor of the experience of a family raising a child with a disability.

At first, people often flounder in confusion, followed by family members telling bits and pieces of their individual stories. With urging, groups usually start drawing within the first 10 minutes, followed by one image catching on, with a growing excitement as participants fill in the details in both images and words labeling the experience. The process generally takes about 20 minutes, although we allow more time if necessary. When all groups are satisfied with their pictures, in Step 4 they post them on the wall and present them to one another, with considerable group pride and ownership.

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### Metaphorical Themes

Repeatedly, the same themes have appeared (with a few highly unique “outliers”): the journey, connections, and cycles.

#### *The Journey*

Virtually every workshop had at least one example of the visual metaphor of a journey. Common to all examples was the basic neutrality of the metaphor; it could, and did, include both positive and negative experiences. Some emphasized the “roller-coaster” nature of the experience; others focused on overcoming barriers. Still others identified dead-end routes and important turning points as well as supports that had helped along the way. The “method of transportation” varied with the culture and geographic location of the training. In a group of family

members from the islands of the Pacific Rim, the journey was in an outrigger canoe, going from island to island, weathering storms and finding safe havens. In Alaska, a kayak navigated the length of the Yukon River, encountering ice and bears, but also green islands and caribou herds. One group in Alaska, strongly influenced by a mother who was having a rough time, started and ended their journey in the outhouse, labeling their metaphor, “The Outhouse Model of Coping and Adjustment!” Using the workshop toys as props, one group fitted a dragon on the top of a magic marker and shot him out into space to experience the strangeness of weightlessness, encounter dangers from asteroids and barren moons, and also discover fantastic living planets. Although most were familiar with Kingsley’s (1987) essay “Welcome to Holland,” groups using the journey metaphor did not tend to focus on a destination but rather on the on-going nature of the journey itself.

### Connections

The second most frequent theme was that of strength through connection. One example of this was a spider web. Each strand was very fine and weak and responded to every puff of wind or drop of rain but achieved strength and endurance through interconnection in the web. Some groups went into detail labeling the fabric of supports. A group in Iowa created the metaphor of a braided rug, with each colorful strand representing a different support (e.g., extended family, school, faith community). Each strand was braided together and then sewn into a rug. Participants made the point that threads in the stitching could break, but that the rug would still hold together because of the way the supports were intertwined.

In Georgia, a group used the metaphor of a patchwork quilt, with both the warmth and the patterns created by the combination of a variety of supports. Conspicuously discarded at the side of the quilt were dark patches of the negative emotions of guilt and anger, with the statement that families themselves could choose which patches to include and which to leave out.

### Cycles

The third most frequent theme to emerge was that of the cyclical nature of life. “What goes around comes around—and keeps on coming around!” Although this might be considered part of

the journey metaphor, the emphasis was on the repetitive aspects of the experience. Recurring processes, such as transitions, fit easily into this metaphor.

Organic cyclical metaphors included trees that blossomed and sprouted leaves, bore fruit, lost their leaves and went dormant, only to leaf out again in spring. Along with this metaphor, one group of parents described the seasonal nature of the stresses they experienced, such as the tensions at the beginning of each school year and the difficulty with having to start all over with new personnel, telling the same information, yet again and again. Although most people welcome summer, for a single parent trying to work and arrange care and activities for her child, it can be the most barren season of all.

Some groups drew spirals, which could move either up or down. The metaphor of the Pacific Islands’ journey included within it whirlpools to avoid—those traps in which people could be sucked into repeating the same destructive process over and over. One group used a workshop toy, a miniature Slinky, as a metaphor for the cyclical nature of their experience. They pointed out that although most tended to spin up and down, back and forth within the spiral, they could also play with it, even using it as a jump rope, if they got creative enough to escape the traditional constraints of “reality.”

### Outliers

Although most metaphors fit into one of the three main themes, occasional unique images emerged that illustrate the range of creativity people can use in making sense of their lives. One father, who is a biochemist, came up with a “catalytic” metaphor, in which he said that he and his wife were like inert elements before the birth of their son. Their son served as a catalyst to initiate a chain reaction, which continues to this day, creating a wealth of ever-new compounds (J. Susa, personal communication, 1998).

Another academic participant used the metaphor of overhead transparencies, laid one on top of the other on a projector. The first transparency contained all the raw experience of strong emotions. Over that, additional transparencies were layered that included information and learning, family and social networks of support, so that over time, even though the original emotions could still occasionally penetrate through, they were seen through a

context of experience that softened their impact (C. Evertsbusch, personal communication, 2001). This metaphor was later identified (in the cultural section of the training) as being fundamentally compatible with the Chinese concept of time, which includes the past as part of the present.

Finally, some families already have in place highly personal mythologies that have created a shared understanding within the family. The “woolly-bears” retreat to their den when the winter gets too cold and emerge when spring’s warmth makes it safer and more inviting (A. Johnson, personal communication, 1995). “The Queen of the Penguins” holds court, protecting her young even when ice and snow cover the land (A. Lee, personal communication, 2000).

In the dynamics of the training, this visual metaphor exercise helped the groups come together, bond, develop playfulness, and pride in accomplishment. More important, perspectives changed, and those changes lasted through the remainder of the training. Over and over, participants referred back to their metaphors, even though some of the training extended over months. In addition, as much as 5 years after the initial training, participants still refer to their metaphors when they encounter one another at conferences and meetings. At this point we can only speculate about the impact of the changed perspectives and, indeed, whether the new perspectives continue to evolve.

## Conclusion

Finally, after seeing the metaphorical pictures, Ann Turnbull of the Beach Center on Disability made a perceptive observation (personal communication, December 2001), asking the question, “Where is the disability in these pictures?” Although we had been facilitating this exercise for nearly a decade, we had never actually noticed that the disability had disappeared! In almost all the examples, not only is the disability not a focus, but it can only be inferred from the nature of the supports or barriers. Even more important, the person with a disability is not presented separate from the family in these metaphors but is integrated into the totality of the family experience. This runs counter to interpretations by Hodapp and others (1995) of current theoretical models of family coping and adjustment (McCubbin & Patterson, 1983), who refer to the child or person with a disability as the stress-

or on the family. In the visual metaphors created in our exercise, the child or person with a disability is viewed as part of the family navigating a life journey together, supported by a web of connections, undergoing and sometimes transcending recurring cycles of experience.

In my own life, though I may not be ready for the Tour de France, I have become quite comfortable and capable with my own fancy, complex bicycle, known in the nonmetaphorical world as my son, Andreas. Yes, he has his own unique characteristics, idiosyncrasies, peculiarities—don’t we all? As I enter the 30th year of an incredible journey, I am still tinkering with the gears, appreciating that this bike has a mind of its own, and enjoying the ride.

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