

CHAPTER 5 INTEGRATION FOR EMPOWERMENT

Introduction **The Power of Disability**

At the risk of violating academic or scholastic protocol, I venture to make a shift in voice and transition to the viewpoint of first person. The reason for this shift is that the issues surrounding the special needs family are entirely personal; they are a daily life experience, as I have a daughter who is deaf. The sorrow, the frustration, the stress, and the spiritual journey are all paths that were, and are, being traversed. The insights, the depths, and the joys are also an integral part of this life. I believe that my highest qualification in addressing issues related to disability is not in some diploma, or a degree that may result from this document, but in some wisdom gained through having a girl named Sophia. The text included herein is not merely something gleaned from yellowed pages in a dusty library (they were actually quite beautiful libraries and very potent writings), rather, these words have been sustenance for our empowerment.

Gut-wrenching information regarding the issues surrounding disability has plagued me in my research. My heart weeps as I realize realizing the likely fate of most special needs families, in contrast to their possible destiny. My eyes stream when I see that most children not only suffer greatly from their disability, but also from abuse, broken homes, and isolation—often becoming handicapped emotionally, relationally, and spiritually.

The issues surrounding disability contain a vast, potent power to move hearts and spur volition. Yesterday, I tearfully read Alex Pearson's description of a memorable

Eucharist:

Last Sunday in church I watched as a father and severely handicapped son came up and the father took the sacramental body and blood of our Lord, and after dipping the former in the latter, proceeded to stuff it into his son's mouth, while his son beamed. I cried; for the first time in a while, it wasn't just my eyes tearing up, but tears ran down my face. I was touched by the beauty, and the happiness, mixed with homesickness...

The symbolic presence of this boy at Eucharist opened for me, enlightening me. The broken boy partaking of the broken body became a reminder of the verse where Jesus broke the bread and said, "This is my body given for you."¹

Disability gains entrance to "limited accessibility" places in the heart. Coupled with this capacity for entry is the capability that children have to enter into our hearts. We all have, in the words of Stephen Gilligan, "an indestructible tender spot which exists at the core."² A child struggling with disability has effective means to touch that spot. The following fairytale captures this capacity:

Princess Eleanor always got whatever she wanted. Every one of her whims was fulfilled by order of her father, the king. Consequently, Eleanor never cried.

One day she said to her father, "I want to see God."

"God? But no one has ever seen God," her father said.

"That is exactly why I want to see Him," Eleanor replied with a smile.

"If that is what you want, that is what you shall get," he told her.

The king asked his chief judge to show God to Eleanor. The judge led Eleanor to the royal library where the Great Book of Law was kept.

"This book contains all the law in the kingdom. It is as good as God," he stated.

Eleanor was not impressed. She stamped her foot and insisted that the book was not God.

Next, the king called on the royal treasurer and asked him to show God to Eleanor.

"Very well," he replied as he led the princess off to the royal treasury.

¹ Luke 22:19, New International Version.

² Stephen Gilligan, *The Courage to Love: Principles and Practices of Self-Relations Psychotherapy* (New York: Norton, 1997), 4, in "Collaborative Therapies with Young Children and Their Families: Developmental, Pragmatic, and Procedural Issues," Jeff Chang, *Journal of Systemic Therapies* 18, no. 2 (1999): 60.

The treasurer unlocked and swung open the thick iron doors, and showed Eleanor all the glistening gold.

“But I want to see God, not just a pile of gold,” she screeched.

Wondering how to fulfill Eleanor’s wish, the king took a walk, and noticed an old man planting a tree.

“Do you expect to live long enough to enjoy the fruit from that tree, old man?” the king asked.

“No, but I hope my grandchildren will enjoy it, God willing,” he answered.

“God willing?” the king repeated. Then he asked the old man, “Do you know where to find God?”

The old man answered with a question: “Don’t you?”

“I am not sure,” the king replied. “My daughter wants to see God. Could you show God to her?”

The old man agreed. When Eleanor arrived she demanded to see God and threatened the man with all kinds of dire consequences if he did not fulfill his promise.

“Not so fast,” said the old man. “First you must come with me.”

They walked to a ramshackle hut at the far end of town. The old man knocked on the door and told the princess to go in. She pushed the door open. Never before had she seen such poverty. Sitting at table was a little girl dressed in old and ragged clothing. Eleanor ordered the girl to rise in the “presence of the princess.” But the girl was crippled and unable to stand.

Eleanor’s head began to spin as she backed out of the hut and closed the door behind her. Silently, the two returned to the palace. The princess had completely forgotten about herself and her demand to see God.

Seeing this, the old man smiled and said, “Now you are ready.”

He handed the princess a mirror and asked her to look deep inside her soul. For the first time in her life, the princess who never cried had tears rolling down her cheeks. The old man asked her why she was crying.

“All my life I have been selfish and have thought only of myself. I never realized how selfish I was! Do you think it would help if I brought that girl food and warm clothes to wear?” she asked.

The old man put away the mirror and said, “Now you have seen God.”³

The phenomenon of this story is not uncommon. The mere presence, or even the “inappropriate” behavior, of those with disability can initiate the meltdown of a cold heart, or even a frigid church. A group with mental disabilities from the L’Arche community was making a pilgrimage to the Canterbury Cathedral at Easter. Suddenly, during the service, they began dancing in the aisles and before the altar. Apparently,

³ Adapted from M. Cone, “The Princess Who Wanted to See God,” *Who Knows Ten? Children’s Tales of the Ten Commandments* (New York: Union of American Hebrew Congregations, 1965), in *Flash of Insight: Metaphor and Narrative in Therapy*, Stephen S. Pearce (Boston: Allyn & Bacon, 1996), 157.

never in the history of Canterbury had there been such a display of joy in worship. The Dean of the Cathedral was so deeply moved that he cried. The Archbishop of Canterbury himself was so inspired that, in that great and solemn cathedral in Britain, on the greatest and most solemn of feast days, he rang a bell, much as the Pilgrims to Canterbury have traditionally done.⁴

Disability possesses the potential for immense good. This good is of the variety that comes only through a journey that seems anything but good. Pain becomes a passageway to a much larger and simpler world. In the words of Kahlil Gibran, “Your pain is the breaking of the shell that encloses your understanding.”⁵ This is part of the gift that special needs families have to offer this world. As the trivial distractions of society are exposed, a perspective of what really matters emerges. When I asked Matthew Pearson what his child and his family have to offer others, his reply was stark and simple: “Our presence.”

Presence may be all that is needed, for in the simple act of being, a perplexing and life-changing power is released. The silent world my daughter brought into our family completely revolutionized our view of life. David and Lo-Ann Trembley write about the particular significance of the fruits of the Spirit that are displayed through the lives of several people with disability:

Shy, introverted Minnie greets and takes leave by gently hugging and laying her head on one’s shoulder. Minnie doesn’t say much, but her actions speak volumes about demonstrating *love*. Phyllis can squawk out only a few recognizable syllables, but she claps her hands with *joy* when she is the first person to recognize a plaque of praying hand as the latest addition to the worship space. Billy was kept in a closet for most of his 23 years. During that time his only

⁴ Attributed to Shearer (1974), in Wolf Wolfensberger, “The Prophetic Voice and Presence of Mentally Retarded People in the World Today,” *Journal of Religion, Disability, and Health* 4, no. 2-3 (2001): 27.

⁵ Kahlil Gibran in Kathleen Deyer Bolduc, “Embracing Our Brokenness: Poems and Reflections on Disability and the Kingdom,” *Journal of Religion, Disability, and Health* 4, no. 4 (2001): 66.

comfort was masturbation. Billy has no speech, but he demonstrates *self-control* as he learns to curb his impulses in a public situation.⁶

Two Approaches for Empowerment

In empowering special needs families, numerous needs scream for attention.

Many parents echo that their greatest need is respite.⁷ Certainly this is a valid issue. If family, friends, and church were more present in this ministry, could it purge these people of the ingratitude that possibly fuels a rampant divorce rate, among other things? This document has not touched on the issues of respite, or advocacy, or accessibility—all of which are critically important. Rather, the aim has been focused on how to empower the family as a spiritual entity, an issue that permeates every other aspect of family life. Thayer defines “spiritual” as “conscious of, and relat[ing] to a dimension of power and meaning transcendent to the world of sensory reality.”⁸ Thus, the goal has been to give some insight into enabling special needs families to live within this “transcendent power and meaning,” and to live on a level that is beyond, yet intricately tied to this world. This is a difficult task, for “there is no single model for living with a disability, no single way of ‘handling’ or perceiving it.”⁹ There is no jello mold or rubber stamp intervention for these families. Each family is unique, and all disabilities are not of the same magnitude.

However, I believe the approaches of spiritual direction and narrative therapy carry weighty potential for empowering families affected by disability. Narrative therapy encourages a family to challenge both its own and society’s perspective of disability, and

⁶ David Trembley and Lo-Ann Trembley, “God in the Oven: About the Demonstration of Faith and Gifts of Persons Who Have Developmental Disabilities,” *Journal of Religion, Disability, and Health* 5, no. 1 (September 2001): 79.

⁷ See archives of parents’ inspirational writing at Our Kids website: <http://www.our-kids.org>

⁸ Nelson Thayer, *Spirituality and Pastoral Care* (Philadelphia: Fortress Press, 1985), 55, in “Spirituality and Systems Therapy: Partners in Clinical Practice,” Douglas A. Anderson, in *Religion and the Family: When God Helps*, ed. Laurel Arthur Burton (New York: Haworth Pastoral Press, 1992), 89.

⁹ Helen Betenbaugh and Marjorie Proctor-Smith, “Disabling the Lie: Prayers of Truth and Transformation,” in *Human Disability and the Service of God: Reassessing Religious Practice*, ed. Nancy L. Eiesland and Don E. Saliers (Nashville, Tenn.: Abingdon, 1998), 287.

it frees its members to live by a different story. Spiritual direction is a channel through which a family can find eternal meaning and divine power, even amidst the struggle. Acquiring a new story, eternal meaning, and divine power can be critical, not just in order for the family to thrive, but even for it to merely survive.

Why were these two approaches selected? In recent years, there has been an incredible rise in the postmodern influence (narrative/social-constructionism), as well as in spiritually focused counseling (akin to spiritual direction).¹⁰ There are those who believe that the surge of these two movements in the field of therapeutic counseling is no mere coincidence.¹¹ Together, these approaches balance the responsibility for change and empowerment between the realms of humanity and divinity. Yet, while utilizing both perspectives, there may be balance and benefit in allowing them to maintain their distinctiveness.

Similarities

Both approaches drip with ripeness for today, as they follow an inevitable consequence of our times.¹² Benevolence toward spirituality and antagonism for the scientific view of life pervade much of today's society. The rise of the postmodern worldview has birthed a new openness in the spiritual realm, because "social constructionist theories provide a natural framework for incorporating the religious and spiritual beliefs of clients' lives."¹³

¹⁰ These two interventions have emerging side by side in numerous places. Dorothy Becvar's choice of chapter titles in *Soul Healing: A Spiritual Orientation in Counseling and Therapy* (New York: Basic Books, 1997) is one example. Chapter titles, back to back, read, "Trusting the Universe" and "Creating Realities."

¹¹ Thomas D. Carlson and Martin J. Erickson, "Re-Authoring Spiritual Narratives: God in Persons' Relational Identity Stories," *Journal of Systemic Therapies* 19, no. 2 (2000): 66.

¹² Douglas A. Anderson, "Spirituality and Systems Therapy: Partners in Clinical Practice," *Religion and the Family: When God Helps*, ed. Laurel Arthur Burton (New York: Haworth Pastoral Press, 1992), 92.

¹³ Carlson and Erickson, "Re-Authoring Spiritual Narratives," 67.

But in what ways are the two approaches similar? Although spiritual direction aspires to reach a new connection and narrative therapy aims at a new story, the outcome of each is a new description of reality. In both approaches, this new reality entails a new call and sense of being. This new call refers to a new view for living life, and this new sense of being is a way of existing.

The beauty of each approach is that it is innately simple. This has particular benefit when dealing with families that include children and those with mental disability. Children love playfulness, creativity, imagination, and stories, which are all components of the process in both. When the approaches are combined, the outcome becomes the re-authoring of a spiritual narrative—developing stories with a theme of God’s love, protection, and purpose. Thus, the meaning of experiences relied upon to support the problem would be transformed to support a new story of God’s love despite disability.

The view of knowledge and power is another similarity. Neither approach views the power as resting in the lap of the helper. Both emphasize a “not knowing” position of discovery. Both seek to agitate a greater reality within the directee/client, a reality wherein life is much larger and more creative than presumed before. Neither approach seeks to merely solve problems, but each seeks to deconstruct the power of the lie, whether spiritual or social, and to find entrance into an existence that transcends this world.

Differences

The two approaches are also very different, and in this, they seem to complement each other. The human emphasis in narrative therapy helps to correct the tendency of over-spiritualizing problems. It does this by stressing that our inner experiences are

related to meanings derived from past experiences, and from the discourse in which we live. Many issues in life are not merely spiritual. We are beings of many facets, and utilizing an approach in the field of therapeutic counseling helps to answer questions about our diverse makeup.

Spiritual direction, on the other hand, tends to keep in check potential imbalances in the postmodern mindset. Direction keeps a God focus at the center of the dialogue, thereby avoiding the vacuum of a humanist viewpoint. True self is viewed as having ancient and eternal linkings, and Divine power is needed to find strength, hope, and healing. Self is not the master, but rather, is enveloped in the Mystery. Many believe that “the behavioral sciences can only take us to the gateway of meaning, and spirituality is needed to move through it.”¹⁴ An approach that ignores the spiritual obliterates the Divine encounter, and inhibits Relationship with a capital “R.” It is wise to remember that both approaches are different; in spiritual direction, we have a movement from false self to spiritual child, whereas in narrative therapy, we have a movement from cultural discourse to preferred being.

Special Needs Families and Spiritual Direction

How does spiritual direction benefit the special needs family? Direction provides a special opportunity to deal with two huge barriers. The first is related to connection and the second to meaning. Any family confronted with disability will have to struggle with the perplexity of the existence of both suffering and an omnipotent, benevolent God. Many families get stuck in this struggle and hit a spiritual impasse. Few want be connected to a “hateful God who causes pain” or an “irrelevant God who does not cause

¹⁴ Source of this quote unfortunately lost.

pain but is powerless against the forces who do.”¹⁵ Special needs families will easily arrive at the conclusion that God is either punishing them (resulting in guilt), or that he is unjustly imposing on them (resulting in bitterness). They become blind to the fact that their lives are filled with many blessings, because their focus is overwhelmingly on the sufferings. This results in feeling unloved, abandoned, or even rejected by God.

The great tragedy of this phenomenon is that the special needs family separates itself from God and flounders in its own strength. Tan reminds us, “Christ should also be the answer for the disabled and their families.”¹⁶ Crudely stated, God is the “metaphysical glue” that holds the family together; the source of love, joy, peace, and everything that a family needs to weather the tumult of disability. Spiritual direction puts the issue of connection to God at the center, not as a secondary consideration, but as the most potent relationship in life.

The second barrier that spiritual direction answers is related to meaning. Without a sense of eternal meaning, a sense that everything is part of an ancient plan and purpose, there is little hope for the family that suffers grave loss or colossal frustration. A spiritual view opens a new horizon of meaning. Families have the opportunity to enter life on another level. Quadriplegic Joni Eareckson Tada says, “I think the most blessed benefit of suffering on this earth is to force us to make eternal decisions.”¹⁷ Eternal decisions, not just day-to-day and keeping-the-head-above-water decisions, are easily postponed. Living with disability can effortlessly become the primary focus of a family. Due to the enormous amounts of attention that must be lavished on a disability, family members become distracted from connecting with God, self, and family.

¹⁵ Charles Gourgey, “Disability and Destiny,” *Journal of Religion in Disability and Rehabilitation* 2, no. 1 (1995): 76.

¹⁶ Amanda Shao Tan, “The Disabled Christ,” *Transformation* 15, no. 4 (October-December 1998): 9.

¹⁷ Linda Piepenbrink, “Joni Eareckson Tada’s Secret to Joy,” *Virtue* (October-November 1998): 66.

Spiritual direction helps the family to hear not just words, but the Word coming out of one's "forgotten depths."¹⁸ Through this Divine connection, a family may be able to boldly proclaim:

You don't have the slightest inclination of the depth and breadth of the grace of God that I have experienced, the intimate ways in which I have been touched by the Divine, the powerful ways in which I have encountered the *Mysterium tremendens et fascinans*.¹⁹ Like Job, I have had an experience of God that radically changed my way of looking at things. Like Jacob, I have wrestled with God, have persevered until I received God's blessing, and have received a new name.²⁰

The members of the Pearson family, who were described in Chapter Two, may be empowered by an advocate that will help them to halt and hear the Voice within—not the voice of a distant god but of the One who is entirely present. As the Pearson's learn to hear the Voice, their turmoil can begin to calm. Though David is encumbered by severe mental disability, it is possible that he has the same capacity as the rest of the family to experience God, to hear his voice, and to savor this calm, as well. The family will benefit in re-discovering that it will only flounder in its own strength, and that God is the ultimate source of energies so desperately needed. The family needs a friend who will help it realize the hope of believing that its suffering is not vain, that there is eternal meaning which will bring blessing, though presently life may be shadowed in a dark mystery.

Special Needs Families and Narrative Therapy

How does narrative therapy benefit the special needs family? Quite simply, I believe its greatest benefit is in helping to free a family from the perspective of an anemic culture that disdains disability and adores the things that destroy family, such as

¹⁸ Rubem Alves, *The Poet, The Warrior, The Prophet* (London: SCM Press, 1990), 18.

¹⁹ This phrase describes God as a mystery that both attracts with its fascination and terrifies with its tremendous power. Rudolf Otto, *The Idea of the Holy* (London: Oxford University Press, 1950), 12-30.

²⁰ Helen Betenbaugh, "Disability: A Lived Theology," *Theology Today* 57, no. 2 (July 2000): 209-210.

materialism and the quest for egotistical productivity. The narrative approach gives the family members space to determine whom and how they want to be. This is a critical empowerment for the special needs family that must struggle with the handicapping attitudes, values, and priorities that surround, and often permeate, it. Handicapping attitudes, values, and priorities are statements that infer, “You are incapable. You are insignificant. You are inferior.” Though these families must live in a harsh world, with the help of narrative, they can embellish the text of a separate world. Wood gives a good description of two possible worlds that exist on earth:

“Two Worlds”

For us, there are Two Worlds of Being.
The first World is the outer world we live in,
A shell that encases the body, an attitude
That stifles the mind and pretends
That money is the measure of worth.

The First World is harsh, though comfortable,
Alluring, though vain. It is the popular world
Where everyone longs to be, yet once they arrive,
They dream of a new direction. In this world,
Everything costs something and what is free costs more.

The First World is one of wheels and destinations,
Membership dues and limitations. It is a sanctuary
For those who desire conformity in all things.
Here duplicate people wearing duplicate clothes
Speak a language without meaning, and think thoughts
Without substance in their form.

The First World is where everyone lives, yet
No one actually survives. It is an acceptable address
Where you forfeit all that you are for what
You will never become and what you are not
Is what you want those around you to remember.

The First World has power, but no strength.
It is one of mirrors, but no reflection.
In this world, there is success, but no mystery.

Goals, but no journey. In this world,
Boundaries keep ideas from colliding...

[And then]

The Second World is one of joy and curiosity,
A connecting thread to birds and oceans, plants and animals.
The Second World is one of children's laughter, women's songs,
Men's stories, the essence that remains long after the experience
Has passed on...²¹

At some point, special needs families must make the distinction between the two worlds; otherwise, life is infested with confusion and frustration. Special needs families will not likely survive in the "First World." The futile endeavor to live by those standards will only lead to dissolution of entity and sterility of life; families will tear apart and lives will be shallow. But in the narrative approach, one is emboldened to face the real culprit, a hurtful discourse, and banish it from the home by rewriting the narrative of family life.

As space for new stories opens up, stories can take on a new form:

<u>Not stories of</u>	<u>But stories of</u>
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Fear	Hope
Anger	Compassion
Guilt	Grace
Loneliness	Communion
Grief	Meaning
Sorrow	Depth
Bewilderment	Vision

The members of the Pearson family, like those of any special needs family, can be empowered by an advocate who helps them identify the existence of more than one world and that they may choose which world to embrace. Choosing one's world is synonymous with finding a new story, one that matches the family's identity and call. This story is not based on the cultural sludge in which the family is immersed, but is based on what is

²¹ Nancy Wood, *Spirit Walker* (New York: Delacorte Press, 1993), 54-55, in *Soul Healing: A Spiritual Orientation in Counseling and Therapy*, Dorothy S. Becvar (New York: Basic Books, 1997), 149-150.

helpful for the family's existence. The Pearsons would benefit from realizing that they are distinct and have no need to compare themselves with others or to have unrealistic expectations for themselves. David cannot be expected to fit into the world— that is not possible— rather, the world, or at least David's own family, will have to embrace him as he is. The Pearson family needs assistance to keep off society's merry-go-round and continue the real journey— this is true empowerment for their survival and fulfillment.

Final Consideration of Approach

In summary, I propose that the ultimate outcome of these two approaches, when used together, will be a new story and new connection, resulting in a new reality and a new being. I do not believe empowerment is about a strategy or technique. There are no strict blueprints; the spirit of both approaches is deep and wide, and originates in the pre-modern and the postmodern. What is most empowering to the family seems to be an attitude that models and emphasizes a way of being. This view opens the door to many more possible helpers. Madsen was dumbfounded observing this phenomenon in the narrative realm, stating that, "They were not 'technically proficient' therapists. They had neither an articulated conceptual framework nor a set of techniques from which to draw. And yet, they were doing remarkable work with families."²²

Empowerment may be a very simple matter, for "treating families is not about science and technology (technique)." As Nichols reminds us, "It is an act of love."²³ There is wisdom in remembering that whoever welcomes "a little child," whoever does unto "the least of these," has ministered to a guest of celestial magnitude.

²² William C. Madsen, *Collaborative Therapy with Multi-Stressed Families* (New York: Guilford, 1999), 13.

²³ Michael Nichols, *Family Therapy* (New York: Gardner, 1984), 572, in Anderson, "Spirituality and Systems Therapy," in Burton, *Religion and the Family*, 94.

Divine Destiny

We exist in an age of flux where diversity is cherished, where norms are challenged, and where opportunities abound, especially for those with disability. Technology has opened many avenues for people with disability, creating means for access, communication, and independence. Technology has done much good. Technology has also controversially invaded many sacred realms. Through technology, humanity has invented, produced, and stockpiled numerous modes for eliminating every being on the planet many times over. Catastrophes in nuclear, biologic, genetic, or cybernetic fields could obliterate creator mankind at any moment. Perhaps this is the end result of the deification of progress. Perhaps this is also the age in which God is about to “confound the human intellectual arrogance that tends to replace Him.”²⁴ Until recently, those with disability have been relegated to a marginal role in history, but in another world, a world where human power is conquered by human frailty, they may play a central role. For true strength realizes that “in our weakness, God’s power shows up best.”²⁵

The prophetic voice of those with disability is beginning to be heard more clearly. That “still small voice” comes through here and there. Wolf Wolfensberger spoke of hearing such a voice. At a L’Arche retreat sat a man who would be classified as functioning in the “severely mentally retarded” range. He had lived in institutions all his life, had very little speech, was epileptic, and had a totally inexpressive face. At this retreat he sat all day with everyone, silently praying. Suddenly, about halfway through the day, he looked up, and though his speech was generally unintelligible, he spoke the

²⁴ Wolf Wolfensberger, “The Prophetic Voice and Presence of Mentally Retarded People in the World Today,” *Journal of Religion, Disability, and Health* 4, no. 2-3 (2001): 15.

²⁵ Joni Eareckson Tada in Piepenbrink, “Secret to Joy,” 21.

only thing he said all day. Wolfensberger was almost knocked off his chair by hearing him state slowly, loudly, and clearly, “This is my body.”²⁶ The theological ramifications and prophetic significance of that statement are staggering.

The influence of the community of disability continues to expand. Struggling against huge odds, people with disability are sources of inspiration for life. When Joey Deacon, of Britain, was asked to write his autobiography, it was a challenge of massive proportions. Having lived in an institution for the mentally disabled for 42 years, he suffered from cerebral palsy and was barely able to care for himself in any way. For years, Joey mulled over the idea of writing a book, then at age 50, he put together a team to assist with the task. Ernie was the only person who could understand Joey’s speech. But Ernie could not write, so he interpreted Joey’s speech to Mike, who could only write slowly and laboriously. But Mike could not type, so he dictated to Tom, who could type with one finger, but not spell. Carefully, Mike spelled each word for Tom to type. The four worked for 14 months, averaging five lines a day, until *Tongue Tied* was published. The book merited global attention.²⁷

Since those with disability have been neglected, even disparaged, creating a better environment for them could have astounding results. Hikari Oe was born with a herniated brain. Doctors told his parents that though a risky surgery might save his life, he would be, at best, severely mentally handicapped. They also tried to convince his parents to let him die, because the best they could hope for him was “a kind of vegetable existence.” Though an accomplished writer, baby Hikari’s father was already depressed because of a stagnating career, and wondered how they could endure a “monster baby.” They decided,

²⁶ Wolfensberger, “Prophetic Voice,” 24.

²⁷ *Ibid.*, 19.

however, to try the surgery. Hikari survived. Today he is epileptic, developmentally delayed, and visually and physically impaired. He is also a musical savant. Hikari's CDs have been bestsellers, and he has received one of the top musical awards in Japan.²⁸ But Hikari gave another gift to his father. Through the struggle of raising a son with disability, Kenzaburo Oe's life took on new meaning as he sought to give voice to his son who could not speak. His writing once again flourished. In 1994 he was awarded the Nobel prize for literature.²⁹

Another recent example also comes from Japan. Hirotsada Ototake was born with only stumps for arms and legs, but he was born into an intensely positive home. While a student at Japan's prestigious Waseda University, he published his autobiography. It became Japan's best-seller of the 1990s, and the country's number two book of the last half century.³⁰ Hirotsada has inspired a nation and revolutionized the issues surrounding disability in Japan, a country which formerly kept those with disability in the closet.

Where will the community of disability take this world? What is the message it will convey? It is likely something we need to hear. As Wolfensberger explains, "if God is suddenly elevating retarded people to special and worldwide prominence, we may be witnessing the ultimate instance of God choosing the foolish to confound the wise, and there must be a terribly important message."³¹

All special needs families will not enjoy such grandeur or recognition. For some, the struggle to survive may last a lifetime. Not by any means will all children with

²⁸This fantastic site is a who's who of accomplished people with disability.
http://www.tampagov.net/dept_Mayor/mayors_alliance_for_persons_with_disabilities/famous_persons

²⁹ Dick Sobsey, "Hikari Finds His Voice," at www.chninternational.com

³⁰ Mutsuko Murakami, "Handicap? What Handicap?" at www.asiaweek.com L.W. Milam, book review "No One's Perfect," at www.ralphmag.org

³¹ Wolfensberger, "Prophetic Voice," 31.

disability become world renowned. Many will lie limply wherever they are laid and seem oblivious to this world. But the issue of progress is likely pointless; the foremost issue is that a family follows its call to enter into a higher reality and way of being. For nothing is accidental, but intense meaning can be found in everything. Most special needs families will never change the world in some grand fashion, but they may change their own world, and perhaps change the larger world on a plane that many do not see.

APPENDIX

WARNING TO HELPERS:
PHENOMENON OF THE DIVINE REVERSAL

On a recent trip to Japan, I was reminded of the things that really matter— the same things that Henri Nouwen contrasted, the horrid distortions of what we consider important in ministry as opposed to standing stark and vulnerable with love.³² On my last day in Japan, I decided to heed a long- time, nagging sense that I should visit an old friend. I had first met Shotaro at our small church in an office building in the heart of Tokyo, not long after arriving in Japan with the noble ambition to spiritually impact the lives of future movers and shakers at the Ivy League Universities. But Shotaro was far from that. An adolescent in his early teens, he was not only mentally handicapped, but also blind. One day, church leaders asked if I would take time each Sunday to spiritually mentor Shotaro. Shamefully, I now admit that I was chagrined at the thought of spending my precious energies in such an unpromising endeavor. How little I knew of the spirit of Christ period.

Shotaro immediately attached himself to me. In the months that followed, I began to appreciate his simple trust, his faithful attendance to the Sunday preaching that was far above his capacity to grasp, and even the ghastly way he slurped his food at the noon meal. Shotaro was probably, at best, five years old mentally, and so the Bible stories and songs I taught him were simple and short. And he never forgot them. I heard he would sing songs like “God is so Good” over and over during the week. Shotaro was eventually baptized.

Nearly a dozen years passed. Shotaro was hospitalized, as his condition had continually declined. So before heading for my U.S. bound flight that day, I took a train to a remote part of Tokyo, and then walked a great deal distance to find the facility. Shotaro’s mother met me at the door and escorted me up to where he and his father waited. There lay my poor friend, emaciated like a victim of Auschwitz, with tubes protruding from his frail body. His joints bulged in comparison to his stick-like limbs. The playful personality was gone—he was merely hanging on.

I brought some sweets, which before he would have happily devoured, but his mother told me he could no longer eat. Besides that, he could no longer sit, or stand, or walk. And the mouth that used to laugh and joke could no longer talk. The one thing my little girl lacked was all he had, he could hear, but all else was lost. Inside a broken body, tightly shackled in a prison of darkness, lay a five-year-old little boy. I will never forget the look in his parents’ eyes—that look of indescribable agony. One cannot imagine what it’s like to watch the child you love slowly and painfully disintegrating.

I talked to him, I prayed for him, I felt like I was facing a stone wall. But then his father hoisted him up on the edge of the bed and braced him so we could sit side by side. Taking hold of his stiffened hand, of his permanently clawed outward fingers, I began to slowly sing our old tune, “Shu wa Subaruashii” (God is so good, God is so good, God is so good, He’s so good to me). I almost lost it, but somehow got through singing those

³² Henri Nouwen, *In the Name of Jesus: Reflections of Christian Leadership* (New York: Crossroad, 2000).

seemingly inappropriate words. Later, his parents wheeled him down to the entrance to bid me farewell. And then, as we parted, Shotaro managed to get one stiffened arm up to say good-bye. As I turned to go, I did lose it. My eyes streamed all the way back to the train station that sticky August afternoon. And inside, I cried out to God, “Why, why, why, must they suffer so?”

Originally, years ago, I went to Japan to impact some upcoming prime minister or CEO. However, I ended up touched by the simple and inconspicuous life of a boy struggling with disability. In a situation similar to Nouwen’s, I found myself healed by one “who had few or no words and considered, at best, marginal to the needs of our society.”³³ Who was the real minister in this story? That is humiliatingly obvious. The simple and vulnerable broken boy taught the highly trained, educated, and mistakenly motivated missionary. I am immensely grateful and proud to have been under the tutelage of Shotaro. And last May, Shotaro got a new body.

When asked to write words for his memorial service, I penned the following lines:

Inspiration

Your body bore the stain
Of a world soiled with pain
You carried the greater share
Of suffering others might not bear

Reminder of an innocent Son
Hanging on jagged wood
Drained of precious blood

Your body carried the light
Of a world filled with delight
Relishing the smallest joy
Grateful sermon in a little boy

Reminder of a realm to come
Finally seeing all will know
The gift of life above, below.

Thank you my friend.

³³ Nouwen, *In the Name of Jesus*, 11.

AUTHOR PROFILE

Andrew Leon Meeko is the father of a special needs child—his daughter Sophia was born profoundly deaf. Andrew and his wife, Junko, along with their four children, fellowship in a deaf church in Japan. Andrew is a second-generation missionary to that country. Part of the family's ministry has centered on pioneering Campus Crusade for Christ's FamilyLife Japan, which specializes in strengthening marriages and homes. Besides speaking on family issues nationwide, Andrew has written for numerous publications. His writing includes the book *Shorai no Tamashii: Atarashii Jidai no Tame no Kosodate* (Souls of the Future: Parenting for a New Era). He has a B.A. in Geology and a B.A. in Japanese Language from the University of Hawaii, and a M.Div. from Western Seminary in Portland, Oregon.

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