



Rethinking Disability: A Pathway for Parents, Providers, and Policymakers

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Abstract:

Societal attitudes shaped by historically prejudicial perceptions of persons who have disabilities still act as unnecessary barriers for those individuals. This essay explores the roots of injurious attitudes found in literature, religion, cultural practices, education, and government policy. Often because of unfamiliarity with persons who have unique needs related to disabilities, it's common for parents to have deeply emotional reactions to the identification of a disability in their child. The essay explores the basis of those emotions and their implications for family members, service providers, and policymakers. With the conviction that greater understanding of our fellow humans who have physical, sensory, intellectual, processing, or emotional disorders, the author asks readers to consider the profound lessons for living by having unconditional positive regard for those who may be our greatest teachers.

Purposes:

- To promote a fresh, more humane understanding of disability;
- To express a more inclusive level of support for humans who have disabilities;
- To promote understanding of differing perspectives among parents, service providers, and policymakers;
- To provide a broader context for experiencing emotions surrounding disabilities, and emotional support for parents and family members;
- To assist present and future policymakers in considering improved services on behalf of people who have disabilities;
- To enhance empathy and improve human behavior regarding persons who have differences as a result of a disability.

“The greater danger for most of us lies not in setting our aim too high and falling short; but in setting our aim too low, and achieving our mark.” (Michelangelo)

“A man’s actions follow from his innate character and the motives acting on him. What is conscience and the sense of right and wrong in action that follows from the consciousness of freedom? That is the question of ethics.”
(Leo Tolstoy, *War and Peace*)

You and Your Connection to Disability

Who are you? Are you a person who has a disability? Are you a parent of a child who has a disability? Are you a brother, sister, grandparent, or other relative of a person who has a disability? Are you a teacher, therapist, paraprofessional, school administrator, or medical provider involved with the education and care of students who have disabilities? Are you a policymaker at some level of our society whose decisions affect the lives of persons among us who have special needs as a result of disabilities? Do you see yourself in more than one of these categorical descriptions?

Often writing related to disabilities is targeted toward one of these categories, but generally not toward all. This essay is meant to be read by individuals from all of these sectors. Why is this important?

For many years my professional responsibilities involved working with persons who were in conflict regarding the special challenges surrounding the lives of persons who have disabilities. My role often placed me in the middle of passionate disputes between parents and providers, and between policymakers and service providers. It was evident that the varying perspectives of persons from these separate groups often led to significant disagreements due to lack of information, emotional struggles, and unfamiliarity with the impact of disabilities on people’s lives. Too often each other’s points of view were unappreciated, misunderstood, or simply not recognized.

In an attempt to create bridges of understanding across these various groups, this essay was intentionally written for any person whose life has been affected by the special persons in our world who have disabilities.

Part One: Disability: What did it mean? What does it mean in the 21st century?

It’s the 21st century and we still don’t know how to refer to people who have unique attributes about their bodies, minds, or sensory organs because they have disabilities. Too often we use outdated terminology and inadvertently offend persons. “Handicapped,” “Crippled,” “Retarded,” “Lunatic,” “Dumb,” remain words still used by too many uninformed people in our society. Some may say we’ve become too concerned about these kinds of sensibilities; those offended disagree. The point remains, however, that we don’t have an agreed upon comfortable lexicon for discussing what are now mostly commonly referred to as disabilities. That term has its own negative connotations due to cultural conditioning. While a disability may be considered negative for some, it isn’t perceived that way by everyone. The truism bears repeating that *disability is a natural part of being human*, as much a part of our shared biological legacy as many other traits. In the absence of no as yet ideal English or universal Esperanto term to describe persons who have disabilities, I often find myself using the less precise phrase *persons who have differences*. Is there a human who can’t find herself or himself somewhere in that language?

Too often it’s a common tendency to equate differences with something negative. Each of us remains the creator of our own world view. We place ourselves at the epicenter of the particular world we inhabit and rule; variations from that world view are, almost by definition, less than what we create for ourselves. Therefore, variants are frequently perceived as inferior.

Although that may be a logical, highly egocentric way to perceive others, it appears to be normal in western culture. In

other words, if we create our own understanding of normalcy and someone varies from our understanding of it, to us that person is abnormal.

What if we're wrong? What if our perception of normalcy is an outdated set of prejudices shaped by family traditions, history, literature, religion, cultural practices, education, and government policy?

What difference would it make if our self-created normalcy is flawed?

That's what this writing is all about. If you're reading this now, be forewarned that it comes with an explicit challenge. You will be asked to reconsider the infallibility of your world view as it relates to other humans. If you're certain that your world view is enduringly correct, there's no need for you to read further. However, if you're open to the possibility that your world view could be enhanced and you're comfortable with that, read on.

Children's narrower set of experiences relative to those who have lived longer often preclude their familiarity with persons who have significant differences. In the religious training that I had as a child there were frequent references to "the blind," the deaf," and "the lame," or "the crippled." There were also references to "lepers." At that time I had only limited familiarity with people with limited vision or hearing. I didn't understand intellectual disability. I doubt that there was a person with leprosy in my state. The context in which these persons were discussed was invariably negative. Each of these "conditions" was something that God, Jesus, or a saint was asked to cure. Our prayers beseeched God "that the deaf may hear and the blind shall see," and the underlying message was loud and clear that these were negative traits for anyone unfortunate to have one. You definitely didn't want to be blind, deaf, or crippled. The miracles attributed to the intercessions of saints invariably involved "cures" of these unfortunate conditions.

At the most formative stages in the

culture in which I grew up, there was something to be dreaded or considered wrong attached to humans who had these differences. It was never considered something positive or, at the very least, benign. There was an element of pity associated with all of this. Religious shrines where miracles had allegedly occurred invariably included collections of crutches, braces, canes, and dried-out leather orthopedic devices. When I first saw such a collection at the magnificent Quebec cathedral of St. Anne de Beaupré it made an indelible impression in my mind. Hundreds of devices were massed in almost macabre displays that had a certain uniformity of dark coloring that seemed to reflect a mysterious era from long ago.¹

A closer look at some language in the Bible clearly communicates this historical "something is wrong" thinking about what we now refer to as disabilities. A passage from the Old Testament, Leviticus 21: 16-23, can reasonably be interpreted as portraying disabilities as something very wrong:

And the Lord said to Moses, "Tell Aaron that any of his descendants from generation to generation who have any bodily defect may not offer the sacrifices to God. For instance, if a man is blind or lame, or has a broken nose or any extra fingers or toes, or has a broken foot or hand, or has a humped back, or is a dwarf, or has a defect in his eye, or has pimples or scabby skin, or has imperfect testicles—although he is a descendant of Aaron—he is not permitted to offer the fire sacrifices to the Lord because of his physical defect."

"However, he shall be fed with the food of the priests from the offerings sacrificed to God, both from the holy and most holy offerings. But he shall not go in behind the veil, nor come near the altar, because of the physical

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<https://www.fisheaters.com/votiveofferings.html>

*defect; this would defile my sanctuary,
for it is Jehovah who sanctifies it.”²*

It’s clear that in this passage from the Old Testament the concept of bodily perfection didn’t include the nonstandard physical variations commonly found from one person to another. From this hugely influential early shaper of western civilization, an attitude about human differences was portrayed, and it wasn’t positive. Perfection was narrowly defined and it didn’t include dwarfism, blindness, or acne. This concept of bodily perfection vs. imperfection reached a pinnacle during the well documented persecution of people with disabilities by the Nazis’ Euthanasia Program in which murder of “the unfit” was condoned. According to the United States Holocaust Memorial Museum, an estimated 275,000 adults and children were killed because of their disabilities.³

In Christian denominations it’s traditionally extolled that Jesus of Nazareth was reported to have conducted a number of miraculous healings. In the New Testament Gospel of Mark, a man from Bethsaida who was blind was “healed” after Jesus spat in his eyes and put his hands on them. Mark 8: 22 – 26. Another New Testament miracle was documented in the Gospel of Mark, 7: 31- 37. In this passage Jesus touched the ears and tongue of a man who was described as deaf and mute and commanded them to “Be opened.” Miraculous healings of people described as lepers or lame also became part of the story of Jesus’ life on earth.

Ever since the phenomena of miraculous cures were described the issue of why some people were “cured” while others were not presented a new challenge that lingers to this day: guilt associated with differences. It’s understandable why the idea emerged that some people’s disabilities weren’t cured due to their lack of faith, or their past misdeeds; this inevitably created an

unfortunate emotional morass for many persons. Too often this has proven to be especially difficult for parents struggling to navigate the wide range of emotions that frequently accompany the identification of a disability in their child.

There’s a passage in the Bible that illustrates that even though people who have “defects” aren’t welcome to offer sacrifices to God, they have worth. In the Gospel of Luke the benefits of being hospitable to those with differences is described:

“When you put on a dinner,” he said, “don’t invite friends, brothers, relatives, and rich neighbors! For they will return the invitation. Instead invite the poor, the crippled, the lame, and the blind. Then at the resurrection of the godly, God will reward you for inviting those who can’t repay you.”⁴

Emerging from this brief analysis of biblical language about disabilities, many would agree that a mixed message has been handed down across the ages. Whereas God will reward you for inviting “the crippled, the lame, and the blind” to your table, they may or may not be miraculously healed for unclear reasons. Unfortunately parents may feel that their child who has a disability is a consequence of something they have done that others may consider “sinful.”

Religion is only one shaper of attitudes and behavior. Other cultural expressions are derived from government, law, the arts, science, and commerce. William Shakespeare is revered in western civilization as having one of the greatest minds that ever lived. His plays continue to be performed, studied, and loved four hundred years after his death. Despite his brilliance, like all of us, Shakespeare was also a creation of his own time. In Elizabethan England traditional attitudes toward those citizens who had differences was often

² *The Living Bible*. Tyndale House Publishers, Wheaton, Illinois, Copyright c 1971.

³ [Http://www.usmmm.org/research/research-in-collections/search-the-collections/bibliography/people-with-disabilities](http://www.usmmm.org/research/research-in-collections/search-the-collections/bibliography/people-with-disabilities)

⁴ Luke 14: 12 – 14

negative. These attitudes are evident in Shakespeare's works. "These traditional notions include persons with physical disabilities being evil, the entertainment value of persons with disabilities, and those who were mentally ill being wild and animal like."⁵ Centuries after these masterworks of western civilization were conceived and written, it's not hard to understand how easily their enduring influence could shape beliefs and behavior toward people. Considering that we've only comparatively recently been conducting scientific research to understand the incredible range of human differences, it's easy to imagine how long ago, when so much less was known about cognitive, processing, or emotional disorders or the abilities of persons with sensory differences, how inaccurate and negative cultural perceptions could have embedded themselves in our culture.

Because I am a product of white, middle class, 20th and 21st century American culture, I have focused the initial portion of this writing on perceptions about disability in the culture I know best. In our 21st century global society it's important to acknowledge that not all cultures view disabilities as they've been described so far. In all of the cultures on our planet there is surely a continuum that could be created regarding positive or negative regard for and behavior toward persons who have nonstandard bodies because of their disabilities. How positive or negative regard and behavior toward other persons is measured is an exercise in cultural values. What's positive or negative in one culture may be considered much differently in another. The Third Reich's justification for its regime's murder of "the unfit" was rationalized by the Nazi leaders as a positive action in the development of a master race. To more modern sensibilities, that seems remarkably arrogant and unethical.

The circumstances surrounding a culture's environmental conditions could have been the overarching variables in shaping their practices toward persons with

differences. In nomadic cultures it may not have been considered practical to plan for the ongoing transportation and care of individuals with significant physical differences. When the culture's survival depended on rapid relocation due to conflicts, climactic conditions or to ongoing access to food and water, decisions were possibly made for the welfare of the larger community instead of for an individual. On the other hand, it's also possible to understand how a culture that was less mobile, had ready access to food, and felt a sense of security, could develop more inclusive values and behavior regarding those within their society who had disabilities.

This discussion of cultural perceptions doesn't just apply to cultures from long ago. In a 2004 paper regarding *Human Rights and Persons with Disabilities in Developing Nations of Africa*, Dr. David W. Anderson included a passage by R. Kwei that appeared in Ghana's *Daily Graphic*. Kwei described then current attitudes in some African cultures:

People with disabilities are often isolated, discriminated against and considered inferior. While sections of society consider them an accursed group, others subject them to various abuses that cumulatively make them bitter against society.

I wonder how accurately that same description applies to most modern cultures worldwide today. Bringing to worldwide awareness the Nazi leaders' inhumane attitudes about people who are Jewish didn't eliminate anti-Semitism. Our international news reminds us all too frequently about unconscionable cruelties still being imposed on children, women, and minority populations. Our painful current events routinely illustrate that engrained hatred is still an appalling distraction from rational behavior. Just as virulently cruel anti-Semitism persists, it's possible to see how

⁵ The International Journal of Aging and Human Development, Vol. 50, No. 3, 2000.

residual Nazi-inspired thoughts about eugenics regrettably live on. As history has shown us again and again, dehumanizing another human being makes it possible for a person to justify any behavior toward that individual.

A 2007 column by the Associated Press detailed a particularly horrifying abuse of people with intellectual disabilities during the recent Iraq war:

Two mentally retarded women (sic) strapped with remote-control explosives – and possibly used as unwitting suicide bombers - brought carnage Friday to two pet bazaars, killing 73 people in the deadliest day since Washington flooded the capital with extra troops last spring.

The first bomb was detonated about 10:20 a.m. in the central al-Ghazi market, the home of a weekly pet bazaar with various small animals but mostly birds. At least 46 people were killed and more than 100 wounded, said police and hospital officials.

Police said the woman wearing the bomb sold cream in the mornings at the market and was known to locals as “the crazy lady”.⁶

Somehow the cultural conditioning of someone allowed the consideration of this atrocity to germinate and to actually occur. That it was justifiable to strap bombs to the bodies of persons with limited intellectual ability and send them into a crowded marketplace to kill not only themselves but dozens of others is astonishingly wrong.

Observing cruelty but doing nothing about it has a morally anaesthetizing effect. If we become numb to heartlessness, we risk losing our hearts. In recent years, instances of bullying of students with disabilities in our schools rose to such a significant level that it became the focus of federal law and education policy. In America a massive

campaign to end the use of the word “retardation” resonated deeply with families whose loved ones had been cruelly teased by insensitive or ignorant persons. Although we may be evolving toward a broader sensibility about human rights and persons with disabilities, it’s my sense that this is an unending concern that will always require the vigilance of advocates for human rights.

The distinctions between various disability categories must be properly appreciated. It’s my concern that all too often the lines between discrete disabilities are blurred in our broader society’s haste to compartmentalize information. There are immense differences between deafness and intellectual disability, between emotional disturbance and a learning disability, between traumatic brain injury and blindness. I often see stories in the news that inaccurately describe or misrepresent the lives of persons who have very unique differences. In reality disabilities have clear distinctions even though the larger culture may see no need to appreciate those differences. Generalizations about “people with disabilities” can and do lead to assumptions about abilities that may be inaccurate and have a harmful effect. For individuals with one of these differences, and certainly for their families, the distinctions are real. But these distinctions may not be properly appreciated by persons whose lives haven’t-yet- been affected by a disability. Although each may present similar challenges for families and service providers, each must be properly understood and respected. Those whose lives are most significantly affected by these differences must be individually considered and appreciated as the unique human beings who they are. Any single person with one of these differences can probably say to their parents and service providers with full accuracy, “You don’t fully understand who I am.”

A story well known and often repeated about parents having a child with special needs is titled *Welcome to Holland* by Emily Perl Kingsley. The story is a metaphor

⁶ Copyright Steven R. Hurst, AP, 2007.

for parents expecting to have a child who is “normal,” then realizing that their child with a disability is quite unlike the one they had imagined. The parental expectations are likened to an airplane flight; parents visualize planning for and traveling to Italy but are shocked when their plane lands unexpectedly in Holland.

This story helpfully illustrates the “landing in a new world” experience shared by many parents who suddenly find themselves learning about the world of disabilities. One feature of that new world is a language and system of supports about which they may be entirely unfamiliar.

In America much of the current language of disabilities is contained in the federal law, the *Individuals with Disabilities Education Act* (IDEA) which defines a “child with a disability” as one who has been evaluated and determined to have an “intellectual disability, a hearing impairment (including deafness), a speech or language impairment, a visual impairment (including blindness), an emotional disturbance, an orthopedic impairment, autism, traumatic brain injury, another health impairment, a specific learning disability, deaf-blindness, or multiple disabilities, and who, by reason thereof, needs special education and related services.”⁷

Although you may feel no need to understand each of these disabilities, each one is of intense interest to some parents, some service providers, and some policymakers. In order to promote better understanding of these categories of disabilities that are used in special education, their definitions in the I.D.E.A. are included here:

1. **Autism.** A developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child’s educational performance. Other characteristics often associated with autism are engagement in repetitive

activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.

2. **Deaf-blindness.** Concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness.

3. **Deafness.** A hearing impairment that is so severe that the child impaired in processing linguistic information through hearing, with or without amplification that adversely affects a child’s educational performance.

4. **Emotional Disturbance.** A condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree that adversely affects a child’s educational performance: (A) An inability to learn that cannot be explained by intellectual, sensory, or health factors. (B) An inability to build or maintain satisfactory interpersonal relationships with peers and teachers. (C) Inappropriate types of behavior or feelings under normal circumstances. (D) A general pervasive mood of unhappiness or depression. (E) A tendency to develop physical symptoms or fears associated with personal or school problems.

5. **Hearing Impairment.** An impairment in hearing, whether permanent or fluctuating, that adversely affects a child’s educational performance but that is not included under the definition of deafness in this section.

6. **Intellectual Disability.** Significantly sub-average general intellectual

⁷ I.D.E.A., §300.8 *Child with a disability*.

functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child's educational performance.

7. Multiple Disabilities. Concomitant impairments (such as intellectual disability-blindness or intellectual disability-orthopedic impairment), the combination of which causes such severe educational needs that they cannot be accommodated in special education programs solely for one of the impairments. Multiple disabilities does not include deaf-blindness.

8. Orthopedic Impairment. A severe orthopedic impairment that adversely affects a child's educational performance. The term includes impairments caused by a congenital anomaly, impairments caused by disease (e.g., poliomyelitis, bone tuberculosis), and impairments from other causes (e.g., cerebral palsy, amputations, and fractures or burns that cause contractures).

9. Other Health Impairment. Having limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that is due to chronic or acute health problems such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, sickle cell anemia, and Tourette syndrome. It must also adversely affect a child's educational performance.

10. Specific Learning Disabilities. A disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, that may manifest itself in the imperfect ability to listen,

think, speak, read, write, spell, or to do mathematical calculations, including conditions such as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia and developmental aphasia.

11. Speech or Language Impairment. A communication disorder, such as stuttering, impaired articulation, a language impairment, or a voice impairment, that adversely affects a child's educational performance.

12. Traumatic Brain Injury. An acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance.

13. Visual Impairment Including Blindness. An impairment in vision that, even with correction, adversely affects a child's educational performance. The term includes partial sight and blindness.

A cursory review of these disability categories clearly shows immense differences; however, there are some similarities as well. Some can be loosely grouped as sensory impairments, e.g., deafness, hearing impairment, visual impairment including blindness; some have elements of a communication disorder, e.g., speech or language impairment, autism; emotional disturbance has a mental health basis; some are primarily physical, e.g., orthopedic impairments and some health impairments. Some of the disabilities are more difficult to categorize. Specific learning disability is a processing disorder; intellectual disability is an impairment of cognitive functioning and adaptive behavior.

How much does anyone truly understand another person? Is that possible to do? And yet, that's the goal true empathy seeks to achieve. Persons with severe emotional disorders may experience depths of despair or heights of elation unfathomed by those without this mental condition. The

hopelessness, the frustrations, the craving for understanding, the fears, the unique anxieties, and the inner worlds created by persons who have emotional disorders may be recognized but not fully understood by those who love and serve them; nevertheless, we must still strive to achieve full and compassionate empathy.

The mind of an individual who has an intellectual disability is first and foremost just that: the mind of an individual, someone who is unique and must be respected and understood based on her or his individual identity. There is a slogan often used by advocates of services for persons who have autism spectrum disorders: If you know one person with autism, you know one person with autism. I think this concept is powerful and I believe that it should be broadened to: If you know one person with a disability, you know one person with a disability. The implications of that truth are far reaching and can be equally applied to each person who has a non-standard body because of a disability. Personalization of care, education, transitions, and supports must always be our goal and must be singularly planned and provided.

During my training to be a teacher of children who were deaf and hard of hearing I remember people telling me they would rather be deaf than blind. Somehow it was easier for nondisabled persons to imagine themselves unable to hear in comparison to themselves being unable to see. To me it seemed like a gross misunderstanding of the comparative mental isolation of deafness in young children with whom no one was effectively communicating. Communication—to understand and to be understood—is a primal human need. The experience taught me that a person's perception of one disability in comparison to another disability is a highly relative and personal experience. In discussing human emotional response to disabilities, I've come to the conclusion that any disability can evoke any emotional response in parents or family members. Over time educators and service providers develop an understanding of the range of various disabilities, their

severity, and challenges. Often these professionals know about the high levels of achievement and positive outcomes that are possible. Yet, they're continually engaging persons, especially parents and family members, who may be encountering the world of disabilities for the very first time. This is the precise moment to pause and remember their own formative understanding of disabilities, and to remember how much they know now compared to when they were younger. What's especially important at this moment is that respectful appreciation of a parent's emotional needs may be far more essential than their need for technical information. As always, tune in to where the person is and much less to where you are. Parents will guide you as you seek to guide them, but only if you listen, watch, and respect.

Part Two: Societal reactions to disability.

Sociologists frequently refer to various world cultures. All of us come from one or more cultures. The Merriam-Webster dictionary includes a useful definition of this term:

Culture - 5 a: The integrated pattern of human knowledge, belief, and behavior that depends upon the capacity for learning and transmitting knowledge to succeeding generations; **b:** the customary beliefs, social forms, and material traits of a racial, religious, or social group; *also:* the characteristic features of everyday existence (as diversions or a way of life) shared by people in a place or time; **c:** the set of shared attitudes, values, goals, and practices that characterizes an institution or organization.

"The set of shared attitudes, values, goals, and practices" of our culture regarding disabilities is a powerful force within our nation. In our larger American culture we've been powerfully deplorable, as evidenced by our appalling history of slavery and our shameful treatment of citizens who have mental health conditions. We've been

powerfully arrogant, as evidenced by our easy presumption of limitations of people who have any type of disability. We've been powerfully ignorant, as evidenced by the institutionalization or incarceration of persons who have disabilities simply because we too often fail to understand them. And we've also been powerfully progressive (relative to many other cultures) with our laws such as the Individuals with Disabilities Education Act (I.D.E.A.) - even though it's never been adequately funded - and the Americans with Disabilities Act (A.D.A.).

With this working definition of culture, I hope to provoke some thinking about the kind of culture we want to have. It's ours to create. It's not something immutable; as our American culture continuously wrestles with highly sensitive and controversial issues, we are, in fact, shaping our culture. It's the set of attitudes, values, goals, and practices shared by people in our place and time regarding persons in our society who have non-standard bodies because of disabilities about which I want to encourage broader thinking.

Have you ever paused to wonder what the purpose of our society is? It's probably something for which we all have a tacit understanding. I think most people would generally agree that the purposes of our society are to maintain the safety, health, well-being, and continuity of a culture. Likely variations on those themes would be expected. During the entirety of my freshman year of college I took courses regarding *Western Civilization*. The professors faced the daunting task of compressing thousands of years of history into understandable epochs. Looking back on the content of those courses, much of what I remember is a blur of countless civilizations, each with a notable "rise and fall" - the Phoenicians, Sumerians, Hittites, Thracians, Etruscans, Greeks, Romans - all with their glories, unique attributes, leaders, and contributions to western civilization. Historians apply modern sensibilities in their evaluation of these civilizations' contributions to humankind. Some are lauded for their military inventiveness, others for their architecture,

commerce, the arts, or their governance. These are tangible, understandable measures of a civilization's significance. The measurement tool used reflects the perspective and values of the historian's own era of civilization.

An underutilized measurement of a civilization is also seriously worth considering. Although it's unclear whether Prime Minister Winston Churchill, President Harry Truman, Fyodor Dostoevsky, or Pope John Paul II, was the first to make this observation, an alternative measurement of a civilization's greatness was expressed in 1998 by Cardinal Roger Mahony: "Any society, any nation, is judged on the basis of how it treats its weakest members; the last, the least, and the littlest." This concept has always resonated in me while troubling me greatly because it's so often at odds with the observable reality in our society. Can we truthfully say that our American history reflects a society that has treated Native Americans, immigrants, slaves, women, etc., as equals with those in the prevailing dominant cultural power structure? The answer is clearly no. We haven't. Even though the term "weakest" implies something inferior, it's a reflection of our current cultural norms. I believe that those once considered weak can become strong; sometimes this occurs not because of what the so called "weak" did, but because those in the prevailing power structure came to realize their own perceptions had been incorrect. Ponder the palpable strengthening role of women in all facets of our society relative to a generation ago. On the current list of our American society's "weakest members" would be our fellow citizens who have disabilities. Are they held hostages on that list because of our outdated attitudes and underestimation of their abilities and worth? Even though I believe it may be unintentional, I think they are. This is a waste of human potential that no society can afford to overlook. In fact, I believe failing to consider persons with disabilities as full and equal members of our society presents an insidious long-term risk that will ultimately prove harmful to our country. The United

States of America is still considered the only nation in the world that was founded on the basis of a philosophy. Distilled to its essence, that enduring philosophy is that each person has an inalienable right to life, liberty and the pursuit of happiness. If we conveniently overlook the phrase “each person,” our society will never attain the true vision of civilization contemplated and fought for by our ancestors. In our time we have the ability- and more pointedly- the responsibility- to advance the interpretation of “each person” to be *truly* inclusive of each person, including those who have non-standard bodies because of a disability.

Within our American nation’s grounding language is the immortal phrase “To Form a More Perfect Union.” The underlying presumption of this phrase in our Constitution is improvement of ourselves as a country. We weren’t yet perfect at the time of The Constitutional Convention of 1787, *but we were improvable*. The great American abolitionist intellectual, Frederick Douglass, used this concept to advance freedom for the human slaves who were the “property” of a dominant society. Douglass advanced the concept of “absolute equality.” His goal is my goal. I think we are capable of improving our American society; how can any educator think otherwise? Continuous improvement of our great experiment in creating a truly democratic culture is an enduring quest.

Is it moralistic fear mongering to warn of a long-term societal harm for failing to have insufficiently high expectations for persons with disabilities? I suppose I could legitimately be accused of that. My response is shaped by history. When we humans have expectations for achievement that are too low for any group, that group has invariably surpassed our underestimation of their potential. Remember the delusional Nazi mindset about the physical inferiority of athletes of African descent that led to Jesse Owens’s embarrassment of the Nazi elite at their own 1936 Berlin Olympic Games?⁸ Even though modern sensibilities would

make any reasonable person scoff at the thought that women were incapable of leading roles in business, government, the military, or any sector of our society, it’s important to remember that very thought was once a prevailing opinion that was routinely used to justify discriminatory practices. As we read the vital signs of our own society at this point in history, what’s the temperature of our prevailing opinion about those who have disabilities? Do our culturally crafted opinions of our fellow citizens who have disabilities limit our ability to envision something more equitable in our policies and behavior? That’s my fear.

I’m inspired by the immortal Italian Renaissance artist, Michelangelo, who wisely noted “The greater danger for most of us lies not in setting our aim too high and falling short; but in setting our aim too low, and achieving our mark.” I think we, as a society, are aiming too low with our expectations for those who have differences because of disabilities. Evidence of this is our continuing impulse to consider too restrictive options before providing a truly comprehensive system of supports in more normalized settings. This isn’t an unrealistic fantasy; like all policies, it’s a question of priorities, will, and action.

Part Three: Reform: an ongoing work in progress.

The genesis of change is often discomfort. If everything is proceeding comfortably there’s no compelling motivation to change anything. In any culture it’s dangerously easy for those in positions of power to be insulated from discomfort, especially from the discomforts of minority groups who may be comparatively powerless. Persons who have nonstandard bodies because of a disability may exist in isolation and have a comparatively quiet-or no-voice. How are those in positions of power to hear them? Those who could speak for themselves, plus their families and advocacy organizations have struggled for decades to make their

⁸ <http://www.olympic.org/videos/jesse-owens-inspiring-history>

voices audible. Credit is deserved by those in power who listened, understood, and acted. My deepest hope is that our culture will continue its evolution to the point where the bright headlamp of human empathy will guide policy and societal behavior.

Is it realistic to think that continuous improvement can occur for persons with differences without pointing out their “discomforts”? At this point in our culture’s history it seems to me that we should have an intrinsic living universal moral compass by which humans coexist. This would lead to a proactive approach to planning and providing for each person, including those who may not be able to articulate their needs as a result of a disability.

The principles of universal design for learning offer an opportunity for human growth that can lead to better ways of life in our multifaceted society. Universal design for learning is an outgrowth of architecture’s move to design barrier-free buildings, homes, and public places. The liberating benefits of this inclusiveness have meant new freedom for millions of people who have special needs. The elimination of needless barriers and the addition of motion activated doorways have literally and figuratively opened our communities while providing new-found opportunities for fuller independence and equal participation in our society.

Universal design for learning is the extension to education of the same barrier-breaking principles of architectural design. In some ways it’s less tangible; it’s not just about bricks and mortar, ramps, or physical access. In its ideal realization this could more rightfully be called a universal design for *living* more inclusively on our planet. It’s a way of thinking and doing.

Because those in dominant cultures, and more pointedly, those who may not have awareness of the unique needs of those who have nonstandard bodies because of a disability, there’s the possibility of overlooking those needs. As a result when planning occurs it may not be naturally inclusive. It’s this consideration of *all* learners’ needs, not just the needs of a

numerically larger and dominant group, that’s the transformative greatness of universal design for learning. Just as much as motion sensitive doors eliminate architectural barriers for persons with special needs, practitioners of universal design for learning help eliminate unnecessary attitudinal barriers to understanding educational concepts. How can students with disabilities achieve their full potential if they’re unintentionally excluded through non-inclusive planning from learning what their non-disabled peers are taught? Benjamin Franklin wisely wrote “On education all our lives depend.” If education isn’t fully accessible to all citizens, how can we expect those with unique learning needs to achieve societal equality?

The principles of universal design for learning need to be extended far beyond education to all facets of our society. As I wrote earlier, in its ideal realization, it’s a way of thinking and doing, and it applies to *everything* we think about and do. In some ways the broader universal design for living is about creating new habits and teaching others to think inclusively. This may be initially difficult and time consuming, but it’s achievable. We can do this if we, as individuals (and as a society) decide this is appropriate.

My family’s pet dog has been blind for a number of years. I watched my wife develop her own personal understanding of the principles of universal design for living through her loving care of this dog in our home. My wife’s well-developed empathy allowed her to quickly anticipate barriers, dangers, and needs that could be planned for and dealt with in advance. This made it possible for our dog to live a remarkably unfettered, very full existence, despite blindness. My wife’s attitude made this happen. Our dog could have led a very restrictive, narrow, and boring life. But the inclusive attitude of my wife wasn’t going to let that happen. Remembering Michelangelo’s wisdom that most of us “set our aim too low and achieve our mark,” she aimed higher for her pet that routinely went on long walks, chased squirrels, moved freely

about the house, and jumped fearlessly down from sofas and beds. Would this pet have had this kind of life if an attitude of inclusion hadn't been developed? It's unlikely.

But it shouldn't be necessary for everyone to live with another person (or a pet) that has special needs in order to develop an inclusive way of thinking and acting. It shouldn't be by chance that persons who have unique needs get the opportunity to live fully realized lives. All persons who have non-standard bodies because of a disability should have the right to live in a society that thinks and acts inclusively.

For many years there's been a powerful mantra for special educators regarding the inclusion of students who have special needs: "All means all." These three words have immense implications. They don't allow for the marginalization of a single student. The needs of each child must be fully considered, including an analysis of the barriers that need to be eliminated in order for each child to be appropriately included in the life of her/his natural environment. Instead of wasting time thinking about why a child can't be included, "all means all" thinking requires time devoted to planning how to make appropriate inclusion possible. Like nearly all aspects of change, this is more of an attitude, a mindset, than anything else. To paraphrase the inspirational challenge voiced by President John F. Kennedy, our more proper goal is "Ask not how to separate this child from her natural environment. Ask how to create a personalized system of supports that will make her life as fully realized and meaningful as possible."

"All means all" is a direct derivative from the preamble to the American Declaration of Independence, a document always worth revisiting for any citizen. The Declaration of Independence familiarly holds this boldly beautiful passage:

We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain inalienable rights, that among

these are life, liberty and the pursuit of happiness.

Not to put too fine a point on this, but the preamble doesn't say "only some" are created equal. It says *all*. To my way of thinking "all" includes citizens who have nonstandard bodies because of a disability. If we are to live up to the vision of our country's founders, we can never rest until "equality" truthfully means "all means all."

Despite its imperfections, the United Nations still represents humans' most ambitious effort to plan for life into the future on our small blue planet. Peaceful coexistence is its operating premise. It's interesting to consider the much older American Declaration of Independence in the context of the United Nations' more modern *Universal Declaration of Human Rights*. The first sentence of Article 1 is "All human beings are born free and equal in dignity and rights." This is expanded in Articles 2 and 3:

2. Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty.

3. Everyone has the right to life, liberty and security of person.⁹

In these words we hear the yearning of people worldwide to create a global society that improves upon our tragic history of inequality, discrimination, misunderstanding, persecution, genocide, and war. I interpret this to mean that we the

⁹ <http://www.un.org/en/globalissues/disabilities>

people of this planet can do better than we've done so far. That inspires hope, the essential catalyst for change.

Part Four: Emotional landscapes of parents and families.

If you're not personally involved with a person who has a disability, you may find yourself at this point wondering why a portion of this essay is devoted to the emotional landscapes of parents and families. That's a perfectly natural response. Yet if you're a person who has a disability, or the parent, sibling, grandparent, or other relative of a person who has a disability, you probably aren't surprised by the inclusion of this topic about emotions evoked by disability. In working with conflicted parties related to disability, I had the opportunity to hear a professional mediator make an astonishing observation. She had previously worked as a mediator in typically mediated conflicts, such as divorce, property, or family disputes. However, when she began mediating with parties related to disabilities, she said the difference was amazing. She described disability mediation as "white hot" in comparison to her previous mediation experiences. That helped me greatly because I began to appreciate more fully how comparatively intense the conflicts were between parties with disagreements related to disabilities.

The term "raw emotions" has become a common descriptor of how many persons feel after experiencing a protracted and highly stressful ordeal. It's generally not associated with one of the emotions associated with well-being; on the contrary, it's typically used in describing someone who is numb or overwrought due to unbearable worry, anxiety, stress, or suffering. You've probably heard television and radio journalists use the phrase "raw emotions" in describing persons who are displaced as a result of natural disasters such as catastrophic floods, earthquakes, or tornadoes. With loved ones killed or missing, homes destroyed, and life as it used to be now turned upside down, it's easy for most people to understand how someone's emotions could indeed be raw.

Each person's emotional makeup is unique. We emotionally react to situations in similar yet very personal ways. The set of experiences that shaped you are not identical to those that shaped your parents, siblings, friends, or anyone else. That special set of experiences that created your emotional landscape helps explain why someone can react so differently than you to the same situation. Recognizing this natural emotional variation among ourselves is helpful in overcoming a tendency many of us have to be judgmental about how people behave. I recognize that being judgmental is not perceived by everyone as something negative. It's my premise that being judgmental about another person's emotions can prevent the opportunity for empathetic understanding.

Have you ever heard someone in a movie or television drama ask another character "How can you be so cold-hearted...?", or, "Why are you so angry about...?" The characters speaking to each other are clearly not on the same page emotionally; because of that difference many of us may tend to quickly judge the other person's emotional response as wrong or inadequate. Have you ever considered that another person's emotional response isn't wrong but simply different from yours due to his or her own personal emotional landscape? Your emotional landscapes may be similar, but the two of you haven't had identical experiences and your emotional landscapes have personal variations.

If we can recognize that it's natural for us to respond differently to an event, it's possible to recognize how it's natural for us to respond differently to a disability. In one individual's emotional landscape there might be ample experience to respond with comparative ease; for another, the emotional landscape may be so different that the person's overarching emotional response is shock. Neither response is wrong, just different from one another. Meeting people where they are emotionally is fundamental to eliminating judgmental thinking. More importantly it can nurture the process of emotional healing and personal growth.

At this point in our cultural evolution the identification of a disability is often a trigger of powerful emotions. We experience so many things that typically only evoke comparatively mild emotional responses, such as our jobs or daily chores. This helps explain why it's important to be open about the relationship between human disability and human emotion. To deny one is to deny the other. Too often it's still difficult for people to openly discuss their feelings, and this is especially true regarding feelings related to a child who has special needs. Yet it's hard, if not impossible, to grow forward as a person without placing emotions front and center at some point. They deserve our attention and ultimately our understanding.

A woman in a hospital delivery room who learns that her newborn has a disability may understandably experience wide-ranging emotions, none of them "wrong." A father in that same room goes through the same process of reacting to this information about his newborn child, but the emotional response might be very different compared to the infant's mother. Their individual responses depend on how similar their formative emotional landscapes are. If it's probable that their responses aren't identical, it's possible to see how the wedge of conflict can arise in their relationship. If one parent is feeling shock while the other is feeling joy or sorrow, their shared journey forward in dealing with their child can have separate paths that are very dissimilar. In my professional work with families I've often observed this parental emotional difference about a child with a disability. There's nothing that says parents must have the same emotions about their child with special needs; the greater challenge for them is to understand what it is that the *other* parent is feeling. This is the definition of empathy. Depending on the cultural norms for a family, the ease with which these feelings about a child are honestly discussed varies widely.

Dr. Elizabeth Kübler-Ross was a famous American psychiatrist who wrote the book, *On Death and Dying*. In that landmark work Dr. Kübler-Ross articulated the *Five Stages of Grief* describing the common

responses that accompany a person's awareness of his or her own approaching death. The five stages are:

- Denial
- Anger
- Bargaining
- Depression
- Acceptance

This sequence of phases isn't a universal path that must be strictly followed. It only describes a widely observable emotional passageway that many of us humans travel in processing our own or loved ones' imminent arrival at death's doorstep.

Because so many parents of children who have differences because of a disability do not have those differences themselves, the realization that their own child has one or more of these unique characteristics may result in emotional upheaval. The five stages of grief that Dr. Kübler-Ross identified related to death and dying are often used by mental health professionals to describe the emotional stages experienced by parents of newly identified children who have disabilities. Although this is neither good nor bad, it somehow strikes me as sad that the identification of a disability in a child is likened to a death in the family. This phenomenon doesn't describe the physical death of a child; however, it deals with the death of the idealized "perfect" child that a parent may have imagined throughout the pregnancy, and possibly fantasized about for many years prior to that while growing up. At age nine, how many children playing with dolls imagine that their play children have an emotional disorder? Are deaf? Have a learning disability? Have cerebral palsy or muscular dystrophy?

It's understandable why a new parent who suddenly finds herself in this situation might think "my baby is not who I thought she would be." If we're honest about it, I think it's perfectly natural that any parent might simultaneously realize that "my own life is not going to be how I thought it would be." No wonder this moment of understanding is so significant in a person's

life. Children's and parents' lives are inextricably entwined. Even when one or both parents are out of the parenting picture, for whatever reason, it's probable that their emotions are still in the picture. In my personal experience nothing in life has ever been as profound an experience as having a child. Children are opportunities to look into our personal ancestral history and observe the traits of generations who preceded us. Children are incredibly powerful focusers (demanders!) of our attention, givers of a vital purpose, and genetic travelers into the future. No wonder they inspire such powerful emotions! No wonder parental emotions about children inspire powerful lifelong thoughts.

So if you have very powerful emotions about a child with a disability, I think you're entirely normal. The question that seems more logical to me is why wouldn't you have powerful emotions about the identification of a disability in a child? This is a significant occurrence in your life. In all likelihood, in some ways your life will be different. I think that by creating a more normalized understanding of disabilities in our culture we can become a society that is far more supportive of parents in adjusting to their new roles as parents of a child with special needs, and more supportive of persons who acquire a disability at some point in their lives.

Let's explore various feelings that might be experienced in dealing with the identification of a child with special needs.

Using the stages of grieving map that Dr. Kübler-Ross outlined, the first phase is often characterized by denial and isolation. This is an unwillingness to believe that there's anything developmentally out of the ordinary about the child. Sometimes this is verbally expressed by well-meaning relatives who proclaim "He'll grow out of it," or by some generalization such as "all boys are like that." This is a natural protectiveness. People don't want to see their loved ones grieving, and that's exactly what many parents are doing at this stage: grieving the death of the child they imagined they would have. That's such an understandably profound experience

that it makes perfect sense to me why a parent might instinctively deny what some professional has told her about her child. Perhaps it's true that we see what we want to see and overlook those things that we don't want to see. This might be a simple emotional survival skill to get through the first painful stage of grieving.

If this period of denial is recognized by those in a parent's system of support for what it is—a *normal* phase in a *natural* process of grieving—it allows them to allow the parent to grieve freely, and healthfully. Human emotional growth happens. That's the truth everyone needs to keep in mind, even if they feel that someone for whom they care deeply is hopelessly mired in one of the stages of grieving. A larger perspective on this person's current suffering, true empathetic understanding, patience, and support are powerful forces. It's worth repeating: human emotional growth happens when someone's system of support isn't judgmental but is, instead, accepting and nurturing.

How long an individual remains in an emotional stage of grieving is entirely personal. There isn't a timeframe for denial, just as there isn't a set period of time for anger, bargaining, or depression. It's far too personal of an experience. Picture a parent walking on a path who is unaware of anyone in front of or behind her. It can be the loneliest path possible creating an emotional environment of isolation. Here's where those persons in the system of support for a parent who is grieving need to give her or him time to experience what's being felt. It's also a time for all to have confidence in the power of personal emotional growth and to remember that time has its own healing powers. With hope and a trust that "things will get better," they typically do. It's alright that you may deny there's anything to be concerned about regarding your child now, but denial isn't necessarily permanent. If it's viewed merely as a normal part of the pathway in a larger stage of emotional response, it becomes less monumental. It fits into a larger personal landscape; it's also likely to be in greater proportion to the other formative emotions of someone's life.

The culture in which I grew up resulted in my personal emotional landscape in which anger was viewed negatively. As a child, witnessing true anger must have evoked strong feelings of discomfort or negativity for me, especially in contrast to more tranquil emotions. I remember how seemingly out of character it was for me to hear the biblical story of Jesus chasing the money changers from the temple. The famous El Greco painting of this subject portrayed Jesus wielding a whip over his shoulder in anger at the people who were using a temple for commerce.¹⁰ Somehow that imagery didn't match with the understanding that I had of Jesus, the "Prince of Peace," which had been created in my mind. Yet there's no denying that Jesus was angry and that his anger moved him to take action. He wanted something to change and his angry reaction to what he saw in the temple resulted in change. If this pre-eminent figure in western civilization could experience visceral anger, why shouldn't a parent of a newly identified child with special needs be any different? Why can't a mother rage against the world? Is it wrong if a father is angry at anyone and everyone? Remember that the current perceptions of our culture still largely view disabilities as negative and unnatural. It would only be normal for a new parent, especially one unfamiliar with disabilities, to have a negative, and possibly angry, response to learning that his/her child is "different." That this child is not who he or she imagined it would be. That she probably won't be doing some things that the parent had imagined doing together with her. That she won't be ... It's probably best to leave it to the parent to fill in the blank of the countless activities and accomplishments that she imagined her child doing and having that she now gradually and painfully realizes may be unlikely to occur.

But life goes on; it doesn't stop, even if the identification of a difference in your child may make you feel that your life has

stopped. If you're a member of a person's system of support, now's the time to be patient, empathetic, and a tether to larger life. If you're the person experiencing anger and hopelessness, that's okay, but it's healthy to keep in mind that you're feelings are a common experience shared by many, many other parents and that you're not truly as alone as you may feel at this moment.

The stage in the grieving process known as bargaining is what I think is happening in the prayers expressed by sorrowful parents and family members for the "healing" of a child who has a difference due to a disability. Many years ago when I first learned about the stages of grieving I remember the essence of a parent's prayer to God that included the phrase "If you'll cure my child of his____, I promise that I'll always (or never) do _____for the rest of my life." This really is a bargaining with God that is made for the benefit of a child. It's quite selfless, yet in the larger, longer process of grieving, it's considered by most professionals and providers as a stage, something that someone grows through. Like anger, a parent isn't destined to remain in the stage of bargaining for the remainder of her life.

If a "miraculous cure" doesn't materialize, it's not unusual for a person who is grieving to search for a specialist, a method of treatment, a device, a supplement, a product seen on the internet, something that will either eliminate a child's disability or mitigate its effects. If you've done this or are doing it now, I think that's a normal reaction. Why wouldn't a troubled parent search for something that will change the way things are for a beloved (or resented) child? This is especially true in societies for which disabilities are considered abnormalities and/or something wrong. Remember that not all cultures view disability in the same way. A superintendent who is Native American and works in a reservation public school district told me that there were no problems

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<http://www.nationalgallery.org.uk/paintings/el-greco-christ-driving-the-traders-from-the-temple>

with teasing or bullying of students with disabilities in his school. When I asked him how he explained this he said it was because of their tribe's culture.

You may have been surprised by my use of a particular word in that last paragraph. In essence I opened the door on a seldom talked about aspect of having a child with special needs. The word I used was "resented." It does none of us any benefit to pretend that resentment regarding a child with a disability doesn't occur. Of course it occurs. Why? Because the person who may be experiencing this emotion about a child is a human being. It's natural to consider how someone's life is affected by the child. Again, I ask the question, who wouldn't have some fears, confusion, anger or resentment while processing these special circumstances in which one finds himself? Parenting a child with unique sensory, emotional, intellectual, processing, or physical differences isn't something most persons picture themselves doing with their lives. To suddenly find yourself facing this lifelong new reality can be overwhelming. That's why it so understandable to me why parents might bargain with God, or put much faith and money into someone's method or product that *might* possibly help their child. For loved ones and providers, this isn't the time for judgmental thinking. Remember the overall stages of the grieving process. Patience and understanding paired with accurate information will generally serve a parent well while she expectantly explores options and processes her own feelings.

The National Institute of Mental Health has identified that "...trauma, loss of a loved one, a difficult relationship, or any stressful situation may trigger a depressive episode. Women are 70% more likely than men to experience depression during their lifetime." Learning that their child has a disability is, for many parents, "a stressful situation." The previously discussed loss of an idealized child is, essentially, "the loss of a loved one," even though the real child continues to live.

A close friend of mine who is of Scandinavian ancestry regrets the demise of the word melancholia, a term often associated with the literature, dramas and films of Scandinavian cultures. There's often a tacit association between melancholy and the grey, cold, damp climate of northern Europe. Melancholia is defined as "a gloomy state of mind, especially when habitual or prolonged; sober thoughtfulness; pensiveness." (The American College Dictionary). My friend believes that over time we've turned melancholia into a more clinical condition. It's much more common now to identify someone with what was once referred to as melancholia as having depression. Depression is defined by one source as "a morbid condition of emotional dejection and withdrawal; sadness greater and more prolonged than that warranted by any objective reason."¹¹

What's the difference? If I understand my friend's position accurately, he suggests that melancholia was a gentler way of describing a normal human emotional condition; however, for many people the term "depression" often makes sadness more difficult to discuss openly. It may be perceived as a medical shortcoming that many persons are unwilling to talk about it.

Yet if depression is considered a natural step in the human grieving process, it shouldn't be a taboo subject for anyone to discuss; however, that's clearly not the case at this point in the 21st century. Many people adamantly refuse to let anyone know the extent of their emotional health. How many times have you heard someone generalize that "men are so closed-lipped about their feelings?" This cultural belief implies that a discussion of deep feelings comes more easily for women than men. That may be true. I suspect that experienced counselors and psychiatrists could answer that question more definitively. If it is true, consider that males make up fifty percent of our human population. That suggests many, many humans struggle to express a natural response to grief. If depression is hard for anyone to

¹¹ The American College Dictionary.

acknowledge- or is denied out right- it can be more difficult to grow through this natural period.

The National Institute of Mental Health (NIMH) describes the following signs and symptoms of depression and points out that “the severity, frequency, and duration of symptoms vary depending on the individual”.

Signs and symptoms of depression include:

1. Persistent sad, anxious, or “empty feelings,
2. Feelings of hopelessness or pessimism,
3. Feelings of guilt, worthlessness, or helplessness,
4. Irritability, restlessness,
5. Loss of interest in activities or hobbies once pleasurable, including sex,
6. Fatigue and decreasing energy,
7. Difficulty concentrating, remembering details, and making decisions,
8. Insomnia, early-morning wakefulness, or excessive sleeping,
9. Overeating or appetite loss,
10. Thoughts of suicide, suicide attempts, or
11. Aches or pains, headaches, cramps, or digestive problems that do not ease even with treatment.¹²

A helpful differentiation between normal sadness and depression is also offered by the National Institute of Mental Health:

“Everyone occasionally feels blue or sad. But these feelings are usually short-lived and pass within a couple of days. When you have depression, it interferes with your daily life and causes pain for both you and those who care about you. Depression is a common but serious illness.”

In consideration of our current cultural norms regarding how many of us perceive disabilities, why wouldn’t a father, mother, grandparent, sibling, aunt or uncle experience depression (or melancholia) about the identification of a disabling condition in a much loved child? In keeping with my theme of emotional normalcy, wouldn’t it be natural for a nondisabled person to be exceptionally sad about the child? Sad about his or her own life? I strongly assert that if you, or someone you love, are experiencing depression regarding a child who has a disability, you are responding in a natural manner. It’s okay. It’s what you do with your depression that concerns me.

Depression can express itself in an array of thoughts and actions. Silence. Tears. Questioning. Feelings of hopelessness. Immobilization. Isolating one’s self. Lack of concern for one’s appearance or health. And as the National Institute of Mental Health openly recognizes, suicidal thoughts.

These are the dark valleys of human existence. These are the loneliest places on earth. These are the most painful-or numbing-points on a person’s path through depression.

What’s especially important to recognize here is that depression doesn’t need to be a final destination; in reality, it’s a location through which people can pass on a longer journey. It needn’t, and doesn’t typically, last forever. With the proper care, support, and time most people can and do successfully grow through this stage of grieving. Remember, it’s a natural human response.

I don’t know if there’s any predictable timeframe for someone to experience depression regarding a child who has a disabling condition. Because we

¹² National Institute of Mental Health.

humans are so diverse, it's likely that this stage can be brief, lengthy, recurring, or possibly never experienced at all. I believe I've observed all of the above in my involvement with parents of children who have special needs. If you're not finding your personal experience in the description of depression in the traditional grieving process, you should understand by now that I suggest that's only natural. We're all individuals with our own emotional landscapes.

By suggesting that parental depression in response to the identification of a disability in a child is a natural stage in a larger process, it implies that it will be a period that usually passes with time. That may be true; however, in my experience it's often helpful if feelings of depression are discussed with a trusted person. Who that person may be is entirely personal. It could be a spouse, sibling, best friend, or an approachable person in whom you have a measure of trust. If you're experiencing depression and are motivated to do something about it, I highly encourage you talk with someone you trust, or to make an appointment with a professional who is trained in understanding emotional development and mental health concerns and who can listen to you confidentially and non-judgmentally. They can objectively help you find the initial steps on the path out of your depression, and can guide you along the way. Although this may sound like a personal impossibility if you're experiencing depression at this point, it is nonetheless a positive option for you to fully consider. If someone who cares about you has suggested professional assistance to you, I wholeheartedly encourage you to be open to this possibility. Regrettably, too often depression is never treated. As our National Institute of Mental Health explains "many people with a depressive illness never seek treatment. But the majority, even those with the most severe depression, can get better with treatment. Medications, psychotherapies, and other methods can

effectively treat persons with depression."

Earlier in this document when you read about Dr. Kübler-Ross' five stages of the grieving process, it's possible that you dismissed the fifth stage, acceptance, as a hopeless impossibility for yourself. At this moment it may seem truly impossible that you will ever accept what other people have indicated are significant differences in your child. Parents have said as much to me when I became involved with their child. This could be a combination of denial and acceptance, both natural responses in the grieving process. Heidi E. Sormuz, Ph.D., wrote "Acceptance doesn't mean we like it or are OK with it never changing; accepting is just being in the reality of how it is right now."¹³

The outward manifestation of this could blend with another stage that we previously discussed: anger. I've never experienced such forceful anger as that expressed by parents of children who have special needs as a result of an intellectual, physical, emotional, processing, or sensory difference. What I've generally observed is that the anger is often directed outwardly. Sometimes the target of this anger is the person who provided the results of an evaluation of the child. It can also be directed at school personnel, other family members, or even God. Because we're all human with different levels of sensitivity to anger directed at ourselves, it's best if everyone involved with a parent who is angry does one's best to react to this anger as non-defensively as possible. If possible, recognize it for what it is: justifiable rage about something that this person's emotional landscape generated in response to a profound life experience. No service provider should ever become so callous that emotional indifference desensitizes your responses to a parent experiencing such a strong-and-understandable-emotion. Now is not the time for people to be defensive or to throw up their hands in frustration (or their own anger) at a parent. Now is the time to be professional, to

¹³ The Great Courses, Copyright © The Teaching Company, 2014.

listen, to hear, to look as fully as possible into the parent's heart, to understand. Now is the time to be non-judgmental. Now is the time to be "an ear, not an answer."

I noted that parental anger can be outwardly directed towards persons in the family, medical or educational systems, or possibly toward God. I feel it's important to raise the possibility that a parent's anger could be directed at the child who has a disability. Although it may not seem socially acceptable in our culture to be viscerally angry at a child who has Down syndrome, let's be honest with each other. Anger is what it is, and the source of the anger could be the child who presented a life altering change of direction to the life path you thought you were following. This is truly a highly sensitive subject. But as an advocate for children who have disabilities, no guard can be dropped in preventing physical or emotional abuse and neglect of children with special needs. At the time of this writing there has been a frightening story in the national news about a distraught parent who hurled his young child with a serious medical condition off a bridge to her death. Although the behavior is inexcusable, the emotional landscape that led to that tragic moment must be understood. A child may be entirely "innocent" but may be perceived as clearly the single tangible reason why "my life isn't playing out the way I imagined it would be." If anger is there, you'll know by now that I see it as a natural part of a process on a longer journey.

So what do you do with this anger? If you're the parent, don't deny your own feelings. Don't pretend they're not there. Recognize them for what they are and remind yourself, "no matter how angry I am at this point in my life I will never physically or emotionally harm my child." If anger this deep is something you are experiencing, please strongly consider professional assistance. Remember that anger isn't wrong in and of itself. Anger can be a catalyst for change. Recognize the hope that anger may

eventually be followed in the process of grieving by acceptance. I like to remind parents that it's not just acceptance of their child and his difference, it can also be acceptance of themselves and all their personal shortcomings and human frailty. The concept of personal perfection is really an illusion. Was any holy one, saint, or Nobel Peace Prize laureate truly without flaws? Be kind and forgiving of yourself. You are truly worth it.

When I first became aware of the concept of unconditional positive regard it turned out to be personally transformational. It instantly resonated with me and became a personal quest for myself; I wanted to work and live with unconditional positive regard for every human I encountered for the rest of my life. Dr. David Luterma nicely explains this concept:

Unconditional positive regard is an essential concomitant of the counselor-client relationship, because it allows the client to feel free to explore all issues without fear of losing the counselor's regard by revealing so-called bad things. To have unconditional positive regard for an individual means that one respects the person regardless of the different values that might be placed on her behavior. The counselor accepts the client for what she is regardless of her behavior. Unconditional positive regard is similar to the feeling that a parent has for her child—that is, she values the child although she may not necessarily be in accord with all his behavior. By projecting unconditional positive regard, the counselor sends a clear message that he cares for and about the client.¹⁴

Unconditional positive regard was really a fresh way of explaining something my parents had tried to teach me as a child: It's okay to dislike what a person does, but you

¹⁴ David Luterma, Little Brown and Company, Inc. 1979

don't need to dislike the person. This powerfully liberating idea was a formative guide to my understanding of how to listen to and work with the parents of the students I tried to serve. I emphasize this because I still realize how the power of unconditional positive regard is neither fully understood nor widely practiced by many of us in our society. In an era of frequently expressed cruel private and public commentary of anyone and anything, I worry about the desensitization of our culture and the dangers that accompany that possibility. I worry that persons with differences are marginalized casualties in a society that doesn't wait to walk a mile in someone else's shoes before judging them. My concern is that failure to have unconditional positive regard for persons who have disabilities, or their parents, is an immense barrier to achieving the respect and "absolute equality" they deserve as fellow citizens.

Part Five: Full opportunity to experience the joys and sorrows, the opportunities and misfortunes, the ups and downs of life, in order to realize the fullness of human potential.

I've been privileged to share my thoughts about disability in public presentations with a variety of audiences. I've often used a specific word to refer to persons who have disabilities: *citizens*. The more commonly used "persons who have disabilities" is powerful in and of itself. It sends the powerful message that we are talking about human beings, real persons. My frequent use of the term "citizens" is intended to pointedly remind all of us in America that persons who have disabilities are also citizens in a democracy. As such, they are entitled to the same vision expressed in the preamble to the United States Constitution. Look carefully at these words:

We the people of the United States, in Order to form a more perfect Union, establish Justice, insure domestic tranquility, provide for the common defence, promote the general Welfare,

and secure the Blessings of Liberty to ourselves and our Posterity, do ordain and establish this Constitution for the United States of America.

In those powerfully articulated beliefs I don't see any exclusion for persons who have disabilities. Did the American nation's founders really mean what they wrote in our Declaration of Independence? Are all people created equal? I realize that America's history is sorrowfully full of behavior that contradicts that statement. Slavery and barriers for women and minority groups to vote are glaring evidence that all really didn't mean all. But times change. A society evolves over time, and so do its cultural norms. Just as citizen became a legitimate description of freed slaves and women who were suddenly able to fully participate in democracy and vote, we need to remember that all really does mean all. That's been a rallying cry for parents and special educators for a long time. As more and more persons recognize the fallacy of excluding children who have disabilities from any facet of our culture, it's time for our larger society to live up to the words of our nation's founders. Are we a society that truly believes in a restrictive *equality for some*, or the actual inclusive words of our nation's creators, *equality for all*?

There are those who can't abide the American Civil Liberties Union's (ACLU) defense of the rights of individuals who have been oppressed *and* the rights of their oppressors with equal impartiality. The ACLU's adherence to core beliefs about civil liberties, such as freedom of speech, is fundamentally correct. This tension periodically surfaces in the news when an organization or individual is trying to legally challenge a perceived injustice and is supported by the legal counsel of the ACLU. But the ACLU also occasionally represents organizations or individuals who are perceived by others as unjust. If we accept the premise that rights and laws, such as freedom of speech, apply equally to everyone, we come face to face with an uncomfortable reality of a democracy based on fundamental

constitutional human rights. By adhering to the premise of equality under the nation's laws, the ACLU seems to be saying that if you want to have a nation governed by inalienable rights and laws as opposed to the whims of a dictatorship "you can't have it both ways." If we're a nation of laws, and if all citizens are created equal, to my simplistic way of reasoning, those laws and that equality extend to everyone, including persons who have disabilities, just as much as they do to any other citizens.

Throughout human history around the world there have been identifiable basic goals that parents have for their progeny. Most of these are so fundamental that we hardly think about what they are. We just work toward them as we raise our children. I think parents from the Inuit culture of northern Canada and the parents of Kenya, Kansas, or South Korea all want their children to live. They want them to be healthy. They want them to be safe. They want them to grow and mature. They want them to find themselves as adults belonging to the larger culture and contributing to its well-being into the future. They want them to be self-fulfilled. They want them to be happy. They want them to know love, however it is expressed.

These universal aspirations of parents don't stop when a child is identified as having a disability. But I sometimes think that too many of the rest of us in our culture presume that parents of children who have special needs don't have the same dreams for their children. What parent of a child who has Down syndrome shouldn't be free to dream of her child having friends, going to the prom, graduating from high school, working, achieving independence, finding human fulfillment and happiness in the years of her life? In my opinion, these natural dreams of parents should serve as the guide for our larger culture's policy goals for serving citizens who have disabilities as well. Paired with the self-expressed dreams of those citizens themselves, we begin to think less about barriers and more about possibilities. Striving to make a universally mindful way of thinking and functioning creates limitless

opportunities for realizing a society that lives up to the constitutionally expressed *equality for all*.

There is stunning logic in the expression "nothing about us without us." This rallying cry of many citizens who have disabilities boldly declares that "we are the ones affected by our society's laws and policies and we should be involved in their creation and implementation every step of the way." At the foundation of "nothing about us without us" is an inherent self-respect about ability, and a clear message that no laws or policies can truly succeed unless they include the involvement of those most affected by them. I think there is likely to continue to be an inseparable relationship between parents, their children who have special needs, and the persons who serve them in schools, clinics, hospitals, and all other settings. In the past there may have been willful or unconscious neglect of persons who have disabilities. Individuals with those needs and their parents, as well as reformers in education, social services, and medicine, coalesced to advance more humane ways of serving our fellow citizens. Without their light enhanced by collaboration, the path forward would have remained much dimmer. Partnership in policymaking is more than just an idle expression. It is really the only way to effectively ensure lasting and meaningful creation of a universally designed society.

Part Six: Imagining what's possible: What kind of species are we capable of becoming?

There are daily reminders in the news of man's inhumanity to man. Cumulatively it becomes overwhelming. Wars continue to erupt. Mass slaughters are reported with sickening frequency. Genocide and torture are still occurring in the 21st century. The haunting lyrics of the old American folk song, *Where Have all the Flowers Gone?* come too sadly to mind: "When will we ever learn? When will we ever learn?"

But rather than being anaesthetized by the relentless onslaught of human atrocities, I think it's better to remember where we were on our shared journey, and to

consider what we're capable of becoming further down the path we're walking together.

Near the beginning of this essay I described some particularly horrifying examples of how we humans have treated our fellow humans who have unique needs as a result of disabilities. Perhaps paramount of these horrors is the systematic killing of a quarter of a million persons with disabilities during the Holocaust of World War II. But alongside this ugly peak in the tragic mountain range of man's inhumanity to man are equally horrifying crags of cruelty in the so-called asylums, institutions, and isolation that are part of our shared history. As a species inhabiting this small planet, we haven't treated our fellow humans who have disabilities with the dignity and compassion they deserve.

I learned something profound in my earliest days of teaching children who have special needs. As I struggled to be the best possible teacher I could be, *I realized my students were teaching me far more than I was teaching them.* In visiting with other special educators I learned that this is a common experience. My students were more patient with me than I was with them. They were quicker to spot humor than I was. They overlooked or didn't consider the shortcomings of their classmates and their teacher. They seemed more adaptable than me and weren't inhibited about expressing their emotions. Yes, these personal observations are somewhat generalized; but the overall impression that I developed of my students with special needs was that they became my personal mentors for living. As I was trying to help them develop their communication and literacy skills, they were showing me how to become a better person than I was. Many of these students came from unfortunate backgrounds and had justifiable reasons for being in pain, angry, bewildered, or sad. Yet time and again they inspired me and offered daily lessons about being less self-centered and more understanding of others. They put much of life in perspective

for me.

One of my students had severe juvenile arthritis and was profoundly deaf. Later in my life I often think of her smiling face in the midst of her daily pain. She put so much in perspective for me. Now when a physician or nurse asks during a medical visit, "how would you rate your pain today?" I always have to think how relative pain really is. I know my pain is nothing comparable to the suffering that little girl experienced. Yet she put forward such a positive face that she became an inspiration for many others besides me. She knew pain as a child that many of us may never know in our entire lives.

In my community we have a highly regarded organization called *Designer Genes*, a group of people dedicated to improving the lives of persons who have Down syndrome. Through their inspired leadership and hard work they have helped our community achieve new levels of understanding about the possibilities for citizens who have Down syndrome. They are steadily building a more inclusive city. The opportunity for so many of our community's citizens to experience the positive traits of our fellow citizens who have Down syndrome is remarkable. The open faces, affection, accomplishments, and example of how to treat each other demonstrated by these fellow humans are powerful forces. Time and again I've seen unlikely individuals respond in a highly positive manner when they get the opportunity to know persons who have Down syndrome and to experience their gifts.¹⁵

More than anything I think it's this opportunity to learn from those who have unique differences because of disabilities that makes me recoil at the thought of the callous policies that allowed the Nazis to kill a quarter of a million people who had such differences. For this type of inhumane policy to even be considered there had to be a presumption of superiority and inferiority; during the Third Reich's reign of institutionalized cruelty their presumption was that the world would be better off

¹⁵ <http://desinergenesnd.com/>

without these humans. There was no consideration given to the possibility that we might have something more fundamental to learn from them if only we were receptive to the lessons in living that they offered. The Nazi's policy never considered that the very persons they were systematically executing were in reality wise teachers for them who could help them become more humane. Instead they chose to kill them rather than to see them as opportunities for learning compassion, patience, and humility, all traits that could eventually lead us to a more tolerant and accepting world society.

Who's the teacher and who's the student? In a society truly based on equality we are all teaching each other and learning from one another. The world has yet to know universal peaceful coexistence. We can scarcely afford to dismiss the opportunities that our fellow citizens who have disabilities offer us for advancement on our shared journey.

During my work I've witnessed stubborn resistance to changes in our care and education of persons who have disabilities. Moving from segregated, institutionalized settings of service toward less restrictive, more inclusive practices has been a long struggle. Many times I've thought about the rich opportunities my own sons experienced growing up and going to school with classmates who had special needs. There were daily lessons for the learning from their fellow students who were experiencing life with sensory, intellectual, communication, health, physical, processing, or emotional differences. Unlike some previous generations, they had the opportunity to grow-up side by side in school with people who had special needs. The presence of these classmates demystified disabilities and made it possible to see them for who they really were: fellow kids sharing life and growing up together.

Whenever I've heard people make disparaging remarks about the costs associated with educating and caring for persons with special needs I always find myself saying, "We're all one banana peel away from having a permanent disability."

It's probably more realistic to say "We're all one car accident, one traumatic brain injury, one aneurysm, one combat injury, one illness, one act of violence away from having a permanent disability." All of us are potentially one child, one grandchild, one niece or nephew away from suddenly being immersed in the world of disability. Disability isn't restricted to a certain race, class, or type of person. Rich and poor, brown and black, white and yellow, rural and urban, Europeans or Africans, male and female, young and old, all demonstrate the undeniable truth that disability is indeed part of the universal human experience. Because of this universality disability offers common ground for all persons on our planet to experience lessons for human growth. We can be better people.

In the ongoing effort to erase negative impressions about persons who have disabilities, it's logical to look to those same persons. They are the ones who have led through the example of their own lives. They are the ones who have shown us that a difference doesn't have to be a deficit but another human attribute with its own possibilities. They are the ones who demonstrate capability while others perceive disability. There are countless persons, unknown and famous, who have done this throughout our shared history. They are the ones who have walked beside us even while we were the ones too blind, deaf, or insensitive to realize their presence and to learn their lessons. It's fair to ask, who has the disability?

I live in Bismarck, North Dakota, a small city located on the Missouri River. In 2004 our nation celebrated the bicentennial of the famous Lewis & Clark *Voyage of Discovery* of the land acquired through the Louisiana Purchase. In 1804 the expedition spent the first winter of their journey camped along the Missouri River north of present-day Bismarck. The events surrounding the bicentennial of this significant chapter of American history included opportunities to remember the early people visited by Lewis & Clark as they slowly paddled their way up the fast flowing Missouri River. While in this

region they had numerous encounters with the Mandan, Arikara, and Hidatsa people who had long lived here on the northern plains of North America. While here they met Sakakawea, the legendary woman who helped them on the remainder of their westward journey.

Subsequent to the *Voyage of Discovery* there was considerable interest in understanding these people and the land of the upper Missouri. In 1833-34 the Prussian explorer, Maximilian, prince zu Wied-Neustadt, traveled up the river to experience this area about which so little was known to the outside world. He was accompanied by a Swiss artist, Karl Bodmer, who documented the land and people they encountered. One great enduring contribution to history of these explorers is the beautiful body of art that Bodmer created. His superb watercolor paintings and ink and pencil drawings of the native people documented their unique civilizations' daily lives, ceremonies, clothing, food, and customs.¹⁶

In 1984 the Joslyn Art Museum and the University of Nebraska press published *Karl Bodmer's America*, a magnificent collection of Bodmer's art. For years I've kept one of the illustrations from this book on my desk. It's titled *Mandan Man*. The dramatic, statuesque illustration of this man adorned by a magnificent arced feather has this description:

There were several deaf-mute Mandans, among them two brothers named Máchsi-Níhka ("Young War Eagle") and Mahnu-Ningka ("Turkey Cock's Egg"). The brothers were strong, good-natured men who conversed readily in sign language. Industrious hunters, they were one of Maximilian's few sources of meat during the cold, hungry winter at Fort Clark.

This description of happy, competent, purposeful, full citizens of their society

inspired me as a young teacher. It made me wonder: if cultures so many years ago understood the natural, rightful role of all members of their society, why do we continue to mentally marginalize persons who have differences because of disabilities?

I think the perpetuation of our dominant culture's persistent generally negative perception about disabilities is a huge and harmful barrier. It keeps us from appreciating that:

1. Disabilities are truly a natural part of human existence; and
2. It's those without disabilities who must lose unnecessary and inaccurate attitudes that keep those with differences from being full and equal partners in our ongoing national experiment in government that will, one day, create a just society for all.

Where do you fit in this experiment in democracy? At the center. If you are a person who has a disability, or are the parent, relative, or friend of someone with one or more of these differences, or are a service provider, your voice, however it is expressed, deserves to be heard. We are a family united by our experience with a unique topic that, as you know all too well, is not always understood by others in our world. We need to shine light where there is darkness, provide hope where there is hopelessness, and demonstrate through our abilities what we are capable of doing. The kind of society that we want to have with absolute equality for all is what we make of it.

Robert Rutten is from Bismarck, North Dakota. He considers himself privileged to have worked professionally for more than four decades with a large number of persons who have disabilities. Mr. Rutten was a teacher, counselor, administrator, and mediator who also served as the state

¹⁶ <http://specialcollections.nal.usda.gov/bodmer-exhibit#illustrations>

director of special education in North Dakota for many years.

A native North Dakotan, he is a husband, father of two sons, and the first recipient of the national *Dr. JoLeta Reynolds Service to Special Education Award*. In 2012 the author was honored by the North Dakota Council for Exceptional Children and given its *Humanitarian of the Year Award*.

This document was created to honor and serve:

- **Persons I have known who have differences as a result of a disability;**
- **Their parents and families;**
- **The educators, advocates, and providers who have chosen lives of service;**

and

- **My ancestors:**

Edward Murphy Sr., my great grandfather, an immigrant and pioneer who successfully homesteaded in Dakota Territory while living with a significant physical disability; Genevieve Murphy Rutten and Margaret Murphy Wood LeDuc, my mother and aunt who were both teachers of the deaf; and Genevieve K. Rutten, an aunt who lived her life with low vision. All understood disability so well.¹⁷

¹⁷ What a privilege I have had to meet and know so many amazing persons in my life! Those persons are the single most important reason that I was motivated to write this small work. Many, many individuals who have non-standard bodies-people who think, move, process, and react to the world differently because of a disability-have inspired me with their lives. Time and again I was lifted by positive attitudes, achievements, kindness, humor, perseverance, acceptance, herculean struggles, and tolerance of me. Although I was both an administrator and special education teacher, it was always abundantly clear to me who was teaching whom. These individuals taught me more about the most important lessons of living a life than I ever taught them. The irony of this is perhaps the most profound truth I ever realized.

I will forever be grateful to the innately wise and loving parents of the children with whom I worked. If you are one of those parents and happen to read this, please know that I really

do mean *you*. You shared your deepest feelings with me, your worries, frustrations, hopes and dreams-an honor that humbles me to this day. Trust at that level is precious. Thank you for allowing me to share so personally in your life.

One of the greatest collateral benefits of working in special education is the opportunity to work alongside people who made conscious choices to live lives of service. This separates them, perhaps unintentionally, from those whose daily motivation is something quite unlike their own. I've always found special educators and service providers to have a bond that unites them in a larger sense of purpose. To all of the superb teachers, paraprofessionals, therapists, clinicians, administrators, advocates and program coordinators who chance upon this writing, I commend you for giving your lives in the service of others. Service is truly its own reward.