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Re-Imagining Deafness

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(Opening Plenary Presentation)

Denial

This is only my second ALDAcon. Perhaps reflecting on that fact would be a good place to start this morning. My hearing loss was identified when I was 20. In my 20's and 30's I worked to build a meaningful and workable life for myself as a deaf person. Each new level of hearing loss increased the amount of adaptation required for me to manage day-to-day. 12 years ago, I told my fiancée that I would likely be completely deaf within two years after our wedding. In fact, my rate of hearing loss slowed down—like the Bugs Bunny cartoon where the airplane is in a crash dive, but stops just short of the ground when it runs out of gas. Four years ago I finally gave up on using the telephone, after a long and losing battle. Blessedly, I had retained enough hearing using an FM loop to have a long phone call with my father the night before he had a heart procedure during which he died. Three years ago, I began using interpreters for every meeting involving more than one non-signing person. My deaf identity—or deaf “skin” as Dr. [Jane] Schlau¹ would call it, has grown, and I have developed an enormous affection and affinity for the Deaf community. I now count my deaf friends as among the most important people I know.

Yet all that time, over a decade from when I knew I had a hearing problem to my first ALDAcon last year, why did I avoid ALDA? Partly, I think there was residual **denial**. Denial has visited my brain frequently, and pitched camp for months or years on end. Denial made me feel I was lying when I applied to medical school and explained the sudden mid-college improvement of my grades as the result of being fitted with hearing aids for a previously unknown hearing loss. Inside, I “knew” that in fact I’d been lazy or crazy for those first two years.

¹ Former president of ALDA (2005).

Up until recently, I looked back on this denial in a negative light, but I wonder if it doesn't have a small positive side too. Denial means *not fully taking something in, not dealing with current reality*. Maybe there are times when that's not such a bad idea. For example, when you're trying to get something done, as I was with my medical training, or when you're imagining something so completely new and scary that you almost dare not look at it.

Television producer Richard Cohen, Meredith Vieira's husband, admits in his book Blindsided to being an expert at denial. He is not late-deafened; he was struck with Multiple Sclerosis in his twenties. His journalistic career was just beginning and his star was burning brightly. He intended to succeed, and he could not let a preoccupation with MS, or any of the disease's symptoms stop him. He relied on a form of denial to make it possible to continue his work, to accept difficult assignments in foreign places, to free energy for his rise to the top of television news.²

Cohen finally gave up his denial when he could no longer ignore his need for a cane. "For a while after taking up a cane," he writes, "I felt like an exhibitionist, parading my problems for all to see. My new wooden stick was in my mind a neon statement of vulnerability..." (p. 137). At the same time, he adds that his "relief was complete, even compelling. The unspoken lie had evaporated. I was who I was, and it did not matter anymore... Denial had taken me far. Reality would carry me the rest of the way." (p. 137) Among the realities that he discovered soon after making his disability visible was that the people in his neighborhood, who had seen him swaying and falling for years, had thought he was an alcoholic!

Lisa Fittipaldi was a nurse and then a hospital accountant, when she started becoming blind, an experience she recounts in her book Brushed with Darkness. She is—of all things—a successful painter now, something she'd never done before she lost her sight. Denial has a social side; we can deny to ourselves and we can deny to others. At work, fearful of losing her job she, "used every imaginable trick to give the appearance that I knew what I was doing. At the sound of footsteps, I would snap straight in my chair and type gibberish into my computer." (p.15)

Cohen and Fittipaldi's books started me on an odyssey of learning about other disabilities [than acquired deafness], seeking wisdom on dealing with acquired bodily loss.³ Fittipaldi notes that "there is no map that gets you from anger and depression to inner peace and contentment." Since I cannot make a map, perhaps I can simply offer

² References for each book I quote from are included at the end.

³ Before going further, I want to acknowledge the crucial fact that acquired deafness has a loophole, called Deaf Culture, a loophole I have personally used repeatedly to escape the experience of feeling disabled. It's a unique disability in having a strong culture associated with it wherein hearing "loss" is perceived not as a loss, but as a proud identifying label of membership in a minority language-using community. To be Deaf with a capital D is to experience no sense of disability, but a sense of wholeness and belonging.

signposts for issues that often turn up along the way. There are likely many people in this audience who have trod similar ground, such as Dr. Schlau, who earned her doctorate in this area. There are many here too who live with disabilities other than deafness. I invite you interrupt me as we proceed, and I will also leave time at the end for discussion.

Loss

Denial protects or hides us from the painful sensation of loss. What can I say about loss? We look squarely at the truth, and it hurts—and everyone here knows just how much. Sometimes we see the truth for ourselves, and sometimes others help us see it. Deafness—or any disability—upends us, and places us in existential crisis, trying to incorporate an uncomfortable new truth into our lives.

Like Richard Cohen and Lisa Fittipaldi, I too made use of denial to maintain my energy and focus, concentrating on my medical degree, then on general psychiatry and child psychiatry training without looking ahead to the potential effects of my increasing hearing loss on my planned career. I too gave up my denial when the time came, and began openly admitting that I had a problem and asking for help. A key moment for me was when I cleared an asthmatic girl to go home from the Emergency Room, because I heard no wheezes. The wheezes were still there, my supervisor found, and I was faced with the fact that I would not be using a stethoscope any more. The actual stethoscope I had to put down that day was my father's, and one of the dreams that died that day was his.

Obviously, denial has its risks, and there are reasons that it's usually thought of more as an obstacle than as a coping tool. I. King Jordan⁴ says it perfectly when he urges us to look in the mirror and acknowledge that we are, in fact, deaf.

Loss can make us feel less-than, unworthy. Lisa Fittipaldi (the painter) writes how she felt as she first explored her new blind reality:

“I felt my life had been reduced to the level of mold. Mold thrives in darkness, in damp cellars, tenacious and nonproductive. I wondered obsessively about the purpose of my existence. Here I was, a throbbing blob of consciousness breathing in and out, a body disconnected from its native habitat.” (p.55)

This makes a nice contrast to the frequent deaf experience of feeling trapped—as I experienced it, separated from the world of the living by a thick glass pane.

⁴ The outgoing president of Gallaudet University, and an ALDA member; the man who became president as the result of the “Deaf President Now” protest at Gallaudet in 1988.

Courage and Surrender

Last week, I interviewed a quadriplegic friend. Valerie's neck broke in a fluke accident, when her feet tangled in her sheets as she stepped out of bed in the morning. Her previous career as a dance teacher and her identities as a skilled athlete and a therapist who used ASL ended in an instant. Her boyfriend soon left her, commenting that she was worth less as a partner now that she could no longer engage in outdoor activities with him.

Valerie, like many people with spinal cord injuries, emphasized the need for **courage**, for constructive, persistent **effort** to push oneself through rehabilitation and to find solutions to the day to day problems of living happily with a disability. This pushing or fighting lives in tension with the opposite need which people with disabilities also experience: the need to **surrender**, to accept what has happened as real, and to let go the abilities or body parts that no longer are there.

Dependency

We fear dependency on others, particularly in this culture, where independence and autonomy are celebrated. Valerie experienced a partial recovery of function and can now walk short distances, laboriously. Yet the slightest crack or unevenness in the pavement threatens her stability, and she lives in constant fear of a fall that might re-injure her spinal cord, perhaps taking away the movement and independence that she has regained. If she falls, she cannot get up on her own. This is a humiliating and frightening experience for her, to have to ask a stranger to help her rise.

Dependency is a strong theme also in many accounts of blindness. I know blind people who sit at home agonizing over whether they can impose on friends or relatives yet again to help them get somewhere they want to go. Perhaps the best account of this experience is Jonathan Hull's amazing book, Touching the Rock. And dependency is an issue for us late-deafened people too.

Seeking Attitude

A constant in accounts of adapting to disability is the central importance of attitude.

Laurent Grenier was a young man who prided himself on his athletic prowess and great size and strength. At the age of seventeen, he dove into the shallow end of the pool, struck his head on the bottom, and was immediately rendered quadriplegic. "I was almost drowning when my friend notice my inert body in the water and rushed to my rescue. He grabbed me under the arms and lifted me partly above water into the warm light of the sunny day, 2 June 1974, date of my second birth." (p.15)

Grenier experienced years of anger, introversion, and frustration before locating the positive attitude that enables him to look back now and consider the date of his accident to be the date of a second birth. “Eight years of darkness passed before it dawned on me that happiness does not require any specific circumstances or the satisfaction of any specific desires. It remains attainable as long as one can survive and experience pleasure, dignity, and usefulness in some way or other.”(p.57)

If someone with no experience of disability tells us it’s all about keeping a positive attitude, we might be likely to brush him or her off. But when Laurent Grenier says it, we are compelled to believe him. While still in his early, bitter phase, he says, “It never occurred to me that I was less a victim of my circumstances than a victim of my attitude towards them.” (p.37)

At first, he “regarded an able body” as “indispensable to happiness” (p. 44). Later, found the “secret... to regard my plans for the future as desirable not as indispensable.” (p.132)

Ron Heagy was another athletic young high school student, who had a football scholarship in hand when he took a week’s vacation in Los Angeles. Diving into a wave on the beach, he hit a sandbar instead, and broke his neck. His scrawny thirteen year old brother, who had only accompanied him on his trip at their parents’ insistence, somehow saved him. His book, Never Give Up, is a very readable account of remaking one’s life around an unexpected event.

As he seeks to acquire new skills as a student, Heagy espouses a wonderful philosophy: “Anything worth doing is worth doing poorly—until you can do it well.” (p.248) Similarly, Grenier writes: “My motto is straightforward: I try my hardest to achieve my purpose, come what may.” (p.104)

Re-imagining

Internally, there is a process of **re-imagining** ourselves. This is in part about noticing what actually works, in part about loosening our moorings and wondering what other directions that we’d never before considered, we might move in. It’s about calling on all parts of ourselves, listening to the ideas of others, reading and seeing how others do it, allowing ourselves to be inspired by their accomplishments.

The process of accepting a disability is often likened to Elisabeth Kübler-Ross’s stages of accepting impending death. I believe there is a very important connection between accepting disability and accepting mortality, but they are not quite the same thing.

Notice, for example, that Kübler-Ross did not include fighting courageously to live as one of her stages.⁵

Speaking personally, I did experience losing my hearing as the premature death of a part of my body, and becoming deaf as the death of my previous life.

So the internal process involves denial, grief, anger, acceptance—and courageous fighting—and who knows how many other ingredients. Disabled people have to figure out how to keep living with the death of their old selves, and how to create new selves. As Dr. Schlaug put it in her dissertation, “Our identity as hearing people, an identity we never knew we had, is gone forever.” (p. 21)

Where do we “put” the hearing loss in our new vision of ourselves? Lisa Fittipaldi, the blind artist, writes: “I do not, as the medical community frequently advises, ‘battle’ my disease. It’s a battle I cannot win. You can neither battle nor embrace a chronic condition. I think the best stance is one of détente. I accept it. I adjust to its every-changing demands. I try to relax and let it be. Every action I undertake is based on a decision to maximize the moment while retaining balance.” (p.194)

Richard Cohen, the man with MS, does feel he battles his illness, yet says something similar: “I now see the illness [MS] as cohabiting intimately with me in my body.” (p. 148)

Laurent Grenier and Ron Heagy both bring a wonderful perspective to the question of re-imagining ourselves. Each of them considers us to have vast untapped talents. Grenier defines a “secondary nature,” made up of all that is second nature to us—our usual habits and activities, our plans and our goals. Behind that, though, is our primary nature, consisting of all the potential things we might be—but have either never tried, or never been forced to seek. Heagy and Grenier both discovered intellectual abilities that they, having seen themselves purely as athletes, never knew they had. Grenier writes, “Like a landowner who turns his trees into a profitable lumbering business, while he never taps the gold vein beneath, deep in his soil, I had never exploited my intellectual resources, which lay beyond my wealth of muscles...” (p. 33).

Forgetting

In her research, Dr. Schlaug found that this remaking of the self was accomplished via reflection, followed by purposeful change: reviewing what happened, seeing what works, and adjusting our behaviors and strategies to try to make things work better next time.⁶ One-third of her subjects accomplished this transition. She describes them as

⁵ Dylan Thomas urged his father to “Rage, rage against the dying of the light.” Thomas was raging against his formerly vigorous father’s blindness, weakness, and impending death. Does he want his father to rage for his own sake, or for the poet’s?

⁶ She draws on the work of organizational theorist Chris Argyris as a model for understanding the type of personal change successfully adjusting to deafness requires.

follows: “Those who were ‘Accepted’ all had deaf friends. They all had some family support; all signed to some degree; all found positives in deafness; all were willing to disclose their deafness and all reflected and learned to be deaf.” (p.161) Grenier notes, “...adaptation is not only a matter of wisdom, it also depends on the opposite of awareness: oblivion...” He feels that our ability to **forget** our old selves is an important tool in our ability to create our new ones.

Loving Ourselves

Another ingredient is **self-love**. I recall a time when I was agonizing over my newly diagnosed hearing loss, angry at my ears for failing me. My girlfriend at the time said, “You have to love your ears.” Steven Brown, a disabled man and activist, made a conscious decision: “A funny thing happened when I chose to like my body. I began to like myself. I embraced life.” (p. 62)

Spirituality

Behind his secondary and primary natures, Laurent Grenier perceived a deeper connection to all of life. His philosophy is essentially atheistic, and yet it was striking to me, when reading his book in parallel with the book of the openly and devoutly Christian Ron Heagy, that they had arrived at a very similar feeling, just called by different names. “My existence was divine, first and foremost. It included and exceeded my personal life, which was an infinitesimal aspect of it.” (p.134)

Obviously, religion is a source of meaning and comfort for many people when they suffer loss. On the other hand, I can’t help but recall when a well-meaning fellow mathematics student invited me to his Bible-study group, where they attempted a faith healing. Apparently, given that my ears rang just as loudly and I heard just as little after their efforts as before, God wanted me to be Deaf.⁷

Wholeness

Valerie does not currently feel **whole**. Wholeness, “OK-ness,” and normalcy are central issues in disability writing and theorizing. Among the most interesting ideas that I have encountered in reading disability history is that the concept of **normal** is a relatively recent invention, barely a century and a half old. Normal relates to “norm,” of course, a statistically likely finding. In the age of industrialization, regimenting and normalizing were important approaches, crucial to mechanization, to factories, to schedules and

⁷ After this talk, an audience member said he had puzzled over this for years: “On the one hand, the Bible seems to consider deafness an affliction. On the other hand, I have felt that God picked me [to be deaf].”

productivity.⁸ A person outside the norm, a person who might do things differently, who was no interchangeable cog in the machine, was an abnormal one, a defective product, and had no place.

Prior to industrialization, there was perhaps a better model of ability and disability: the notion of an **ideal**, which all of us aspire to, but which none of us reaches. In this picture, normal becomes meaningless, and the emphasis shifts to our common, shared, imperfection. That is the world in which deaf people could be trained in dozens of new schools for the deaf in the early 1800s, and could work, raise families, and feel “OK,” long before ASL was recognized as a language equal to English, and long before a civil rights movement among deaf and disabled people sought laws mandating greater equality with normal people.

If none of us is perfect, even those who are “normal,” it is easier for us to feel whole. The concept of whole is so complex. Partly, it’s **internal**—feeling that, despite no longer having some ability, you’re happy with yourself. Partly it’s **relational**, feeling that you’re loveable, acceptable to others, and that your relationships work. Partly it’s **societal**, feeling that you can walk—or roll—or like Valerie, wobble—down the street and not create panic and fear in others.

So far, I’ve been talking mainly about the internal experience, and now I’d like to move on to the relational and societal levels.

IN OUR RELATIONS WITH OTHERS

I believe it is important for us as disabled people to understand the *other’s* perspective. By *other*, I mean so-called normal people, who experience a range of reactions to physical difference, and who have been taught a very limited set of stories about who disabled people can be: the evil hunchback or the overcoming hero, for example, but not the “same as me” fellow human. In one of the books I read, there was a poignant story of a child whose mother’s deformed hand had no meaning beyond being the hand he held, the hand that caressed him. On the street, however, this same hand was transformed into a disability by others’ gaze. Where is disability located, then? In modern disability thinking, others’ reactions themselves constitute a large part of what transforms a physical difference into a disability.

The desire to help

My friend Valerie, whom I mentioned above, notes that she used to feel frustrated with parents who sought cochlear implantation for their deaf children. They explained that they were trying to do “everything they could.” She understood these parents’

⁸ These ideas are due to Lennard Davis (see bibliography).

perspective and feelings better after her accident, when her family rallied to her side and, just like those parents, wanted everything possible done for her.

So, a facet of others' reaction is a desire to help, which is often expressed via medical means—a medicalizing of the disability, a curiosity about the treatments and its curability, sometimes an offer of an unusual cure or a dark suspicion that the medical establishment is withholding a treatment. Valerie herself benefited enormously from an experimental treatment, and then lost those gains when the clinical trial ended. Now she must wait for the trials to be completed, and subsequent, much hoped-for, FDA approval.

The felt need to “cure” our condition can feel frustrating to us when we’re well on the road to making it part of ourselves, and have left our fantasies of cure far behind.

The need to stare

Strangers stare at those who are different. During my child psychiatry training, I worked at the Shriners Burns Hospital in Boston. There I met a man whose face had been horrifically burned. One was torn between staring at him and looking away. In the end it was impossible not to stare. “Everywhere I go,” he said, “people stare.” Parents tell their children, “Don’t, it’s not polite.” “But I tell them, ‘No, it’s ok, go ahead and stare. I know that I am extremely disfigured and ugly.’”

This man had somehow gained the confidence to hold his head high and make his disabled face visible to all. After others are done staring at him, he then explains, in matter-of-fact terms, how he acquired his injury, and about the skin grafts and surgeries that he has had. By engaging people in this manner, where they are, he overcomes their fear—and he is married and has an active social life.

There’s an amazing art exhibit now, showing close-up photographs of severely disfigured faces and bodies, exhibiting them as real rather than grotesque—beautiful, and human.

Sometimes we resent the effort to teach others, and we resent their confusion and awkwardness. Last year, on a visit to Gallaudet, I stopped at the airport’s office for disabled travelers to ask a question about the best subway stop to use. They gave me a large-print map. I still have that map, as a reminder of how the presence of disability, even to those who are designated helpers, paralyzes their thinking. A deaf person, they treated me as if I was blind.

We have a right to our resentment, of course, but I think humor is the better approach, and recognition that perhaps we are no better in our own responses to disabilities different than our own.

The fear of offending

Laurent Grenier, the man with quadriplegia, notes how reluctant his early visitors were to name his condition or face it squarely: “None of my visitors ventured to burst my bubble with a pointy realism.” (p. 20) There is no way for strangers to assess how fully we accept our disability—so we need to be fair in recognizing their trepidation. The able-bodied person is having a very busy emotional experience when encountering physical “difference”: busy processing the question, “How would I deal if this happened to me?” Busy trying to suppress shock, fear, and pity. Busy try to get it right, between the opposing desires to run away and to offer help paternalistically.

Guilt

When I went to see Valerie, I bicycled 20 miles to her worksite. I felt strangely guilty about this, a sort of survivor guilt. It felt wrong to be riding through the gorgeous New England landscape, my legs aching happily as I spun up and down the hills—to see a woman who once rode just as joyously (and probably faster!) through her native mountains out West, but could do so no more... and yet, if a friend says he’s taking his children to the symphony, or to a lecture that won’t be interpreted or captioned, I feel no pang of envy. Feelings we have about disability are deeply rooted, and the closer one looks at them, the stranger they seem.

Social Freedom

One of the benefits of the increased social awareness that comes with having a disability is that we sometimes experience a loosening of our social role. For me, deafness has brought a freedom. I’ve become quite un-self-conscious about not being able to hear something, or about using an interpreter. In general, I’ve become quite a bit less concerned about what others think of me, and more attuned to what I think of myself, and what I want for myself.

Our need for open-minded, caring people

When we are different, and there’s a certain standard reaction to difference from “normal” people, we need special people in our lives. People whose imagination is big enough, whose hearts are big enough, and who have enough self-confidence to manage the awkwardness and see the person rather than the disability. A perfect example from Ron Heagy’s book is his meeting with a new caregiver. Ron pulls up in his van and sees the man waiting on his porch—a large tattooed, unkempt fellow. He

thinks to himself, “I wish I’d locked my door today, he’s probably already robbed me blind.” The man overcomes this in his first interaction with Ron:

“Hello,” he said, a merry twinkle in his eye... Starting to reach out for a handshake, he quickly shoved both hands in his pockets instead, eyes still twinkling.” (p. 170). It’s that “eyes still twinkling” that captures the attitude. Daniel, the aide, was able to maintain his equanimity even after embarrassing himself by putting his hand out. That fear of embarrassment, and of managing the awkward encounter, is one of the main reasons people avoid those who are different in any way. We seek the easy, the comfortable.

I’ve often wondered if my hearing loss isn’t a kind of litmus test for people’s character. I get a lot of interaction with strangers around my sports activities especially—I do marathon ocean kayak racing, and therefore often have unusual boats on my car. I skateboard to work in Cambridge sometimes, and get questions about that too. When people approach me, and I answer “Sorry, I didn’t hear you, I’m deaf,” they either flee or they compose themselves, handle the awkwardness and find a way to communicate. Some show an immediate intuitive skill. One man saw me practicing a series of kayak rolls. Desperate to ask me about them, he gestured and drew pictures in the sand, ignoring the stares of others. He has become a good friend. Of course, I’m rationalizing a little in this rosy “litmus-test” view. I’m sure that I have lost the opportunity for many sparkling conversations and good friendships. This loss is part of the familiar pain of hearing loss.

DISABILITY IN SOCIETY

A third level at which our adaptation occurs is in our relations with the structures of society, its laws and norms.

Belonging

Socially, I have come to believe disability is about **belonging**, about who is “in” and who is “out.” Where this line is drawn is clearly arbitrary—societies choose the extent to which they include or exclude people with varying degrees of disability. In that mode of thinking, Deaf Culture is its own circle, with its own inclusionary line. And this ALDA convention is another circle, a place where we are all included—through great effort and attention on the part of the planners, through the hard work of our wonderful interpreters and CART stenographers, and through our own sensitivity to one another.

Valerie noted that those small things that scarcely attract the attention of able-bodied people—curb cuts, smooth paths, ramps, handicapped parking—create enormous differences in the feeling of **belonging** experienced by disabled people. As the baby boom generation ages, perhaps we’ll be see the boundaries of normal conversation

enlarged such that the “normal flow of conversation” widens to include the needs of lip-readers, permitting more people to feel they belong.

Managing Shame and Embarrassment

In the pilot study for her dissertation, Dr. Schlau found that 8 of her 12 interviewees would “do anything” to avoid revealing that they were deaf.

When we try to “pass” for normal, we paradoxically—and self-defeatingly—support the very system that oppresses us. Yet, as anyone hard of hearing knows, it is impossible to fight that system at every opportunity—our energy is limited.

I believe that acquired disability is an occasion to examine our self-consciousness, our need to look normal, our fears of standing out, and, especially, our fears of asserting ourselves to get what we need. This brings us to the final level of adaptation to hearing loss—one’s place in society.

Advocacy

The complexities of advocacy will be the theme of Dr. Schlau’s panel on Friday. I see advocacy as having several dimensions. In one dimension, there is a range from smallest circle of advocating for oneself with friends and family to the wider circles of the work world, involvement with advocacy organizations, and finally political advocacy, from the most local to the national level. In another dimension, advocacy ranges from subversive, angry and militant—as when the members of ADAPT crawled out of their wheelchairs and up the capitol steps to dramatize their support of the ADA—to the most nuanced working “within the system” to make change possible. I believe advocacy takes a chunk of energy out of us, though it also empowers us. Because of the energy and time required, I think there is a further dimension of our varying involvement with advocacy from one time and place to another. Many of us move in and out, feeling more radical and angry at times, feeling quieter at others. There is a risk of over-involvement, of losing oneself in the frustration of trying to improve an imperfect world. But if we don’t advocate for ourselves and others like us, then what are we? The most minimal act of advocacy is simply standing up and being seen for who we are.⁹

⁹ Lennard Davis, a disability theorist, suggests that disability has a far larger role in the general consciousness than we usually give it credit for. He notes that academics have learned to incorporate race and gender when considering human activities from history to literature to politics. We have learned to listen to the voices of women in history—to “*her-story*” as well as *his*. We have re-written our understanding of the settlement of this country given our new appreciation of events from the Native American perspective. In both cases, of race and of gender, recognizing the “other’s” experience has vastly enriched us. Yet we have not yet seen

Conclusion

Susan Sontag, in her justly acclaimed essay “Illness as Metaphor,” begins with the famous lines “Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and the kingdom of the sick. Although we refer to use only the good passport, sooner or later, each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.” She goes on to explore the history of tuberculosis and cancer as metaphors of different types. She concludes, “My point is that illness is not a metaphor, and the most truthful way of regarding illness—and the healthiest way of being ill—is one most purified of, most resistant to, metaphorical thinking.” Sontag wants us “liberated” from metaphor, and by extension, liberated from the fixed story lines available to people with disabilities.

A significant thrust in disability theory has been about how society creates disability. If all doorframes were 5 feet high, anyone over that height would become disabled. One of the most maddening aspects of the concept of “normal” is its covering-up of the vast differences that exist between one normal person and the next. Blind mountain-climber Eric Weisenheimer points out the absurdities in this position: How is it that a couch potato who can scarcely jog around the block is considered “normal” while a blind man who climbs Mount Everest is considered “disabled”? “Normal,” the rejection of physical differences, serves to protect the “OK-ness” of those who can call themselves normal. It saves “normal” people from comparing themselves too hard with others, or asking how well they are truly exploring the potentials that they carry within them. Valerie noted, as nearly every disabled person does, that she “would never have guessed” what she was capable of until she was forced to find out.

Thriving

Disability opens doors. It opens a door to self-awareness, and a heightened sense of one’s powers. It opens doors to a heightened awareness of the social constrictions we live under. It joins us to others in a quest to change things for the better. I want to invite you, during this few days of ALDAcon 2006, to re-imagine deafness—your own, or that of a family member. To re-imagine it with all the doors that attach to it—the door to Deaf culture, the door to a new job or career, the door to a new self-acceptance, the door to a new assertiveness that leads to action and advocacy, the door to a new connection and empathy for others with “different” bodies. Own your abnormality! Or redefine yourself as “normal,” whichever works better for you.

In Dr. Schlaug’s research, she found that her subjects, late-deafened people with various degrees of success, fell into three categories: struggling, resigned, and accepting. I

that disability perhaps plays as deep and central a role in shaping our perceptions. History, politics, literature are seen currently from an able-bodied perspective, while stereotypical ways of seeing disabled people prevail.

wonder if there's a subcategory among those who have generally accepted their hearing loss, a category called "thriving." I personally consider myself lucky to have been pulled off the career ladder that I was climbing by my hearing loss. Instead of becoming a fairly one-dimensional physicist, deepening my abilities in a single area—mathematical inquiry—I have become a far more well-rounded person, and have been forced to examine and experiment with so many parts of my life. I have discovered that I can be so much more than I ever thought I could be. [I was more disabled as a struggling college physics student with a mild hearing loss than I am now, as a practicing physician with a profound one.] Laurent Grenier considers himself lucky to have had his accident, for all that it taught him, as does Ron Heagy. Lisa Fittipaldi is equally explicit about the gift of her loss: "I'm a kinder, happier, person with a meaningful life." (p. 206) And so is Richard Cohen: "I've even come to believe that I might be a better, even gentler person for the baggage I must carry through life." (p.148) Lisa Fittipaldi writes, "I wouldn't trade my life today to have my sight back." (p. xi)

When we thrive, we feel energized to participate fully in life. Instead of being focused on all we can't do—talk easily to children, function smoothly at a large group gathering—we focus on all that we can, and we squeeze every bit of pleasure from it possible. Obviously this is not possible for all of us, all the time, and part of the interest in reading accounts of people with, say, quadriplegia, was for me to see that no matter how good or successful a day they had, it might still end with an embarrassing accident, a caregiver not showing up, or a new bedsore or urinary infection. Thriving doesn't really mean rising above illness. It's a state of mind we can strive for, but we shouldn't beat ourselves up if we don't live there full time. As Oscar Wilde put it, "We are all living in the gutter, but some of us are looking at the stars." Or, as my overly quoted Laurent Grenier puts it:

"I [am] determined to love life unreservedly, peel and pulp, until I [have] extracted all the good, all the juice, from this bittersweet and godly fruit." (p.135) "My body is still a place of suffering; but mostly it is a place of meditation and worship, where I deepen my sense of mission and joyfully apply it to the act of living." (p.104)

I invite you, while here at ALDA, to re-imagine your deafness... *as normal*.

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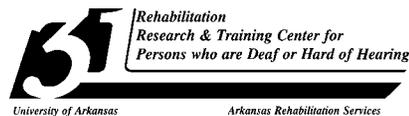
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Biographical

Sanjay Gulati, MD is a late deafened child psychiatrist. He lost hearing gradually due to osteosclerosis from ages 1 – 30, squeaking through medical school and residency with the last bit of his hearing. He began learning sign language at age 30, and has specialized in working with the deaf and hard of hearing of all ages. He teaches medical students, residents and psychiatry fellows. His research interest includes behavior disorders in childhood and the progress of disabled medical students since the enactment of the Americans with Disabilities Act.

In addition to academic work at Cambridge and Children's hospitals in Boston he consults with the American school for the Deaf and other school programs and agencies. The experience of losing hearing and adapting to it remains vivid to him and is a source of continued introspection and sharing with others.



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