

some of his observations about stigma. For example, he identifies the dilemma of an age — and perhaps all of human history — when he discusses how we scapegoat people to rid ourselves of fears and social problems, but after we have victimized the scapegoat and the social situation has not improved, official frustration mounts and persecution and terrorism increase. In that passage alone Gallagher may tell us more about the insidious robustness of racism, sexism, ageism, and all other forms of

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discrimination than has ever been told before.

In the last analysis, *By Trust Betrayed* is more than an important piece of scholarship; it provides the crucial anti-metaphor for the age we are entering, in which scarcity, demography, and technology clash — when health care is rationed and nearly every death will necessitate a decision based on some form of social deliberation. And from the standpoint of persons with disabilities in this calculus of interaction, Hugh Gallagher should have the last word:

If the story of this book means anything, it is that arching over all such assessments must be the principle that society may not — at its peril — abandon a person because he has become flawed in mind or body; because surely every man over the course of his life will reach such a state.

Thank You, Helen Keller

by Carter Martin

Ivy Green, where Helen Keller discovered language, is a national shrine in Tusculumbia, Alabama, only fifty or so miles from where I live. Anyone can go there and see the water pump in the front yard where Anne Sullivan's work set in motion the events to one of the world's great achievements of communication. When at long last I visited the place, my idealism surfaced with enough strength to form a resolve that all my students should read about Helen Keller and visit Ivy Green. I thought it would teach them something about language that I couldn't.

Most likely I was right, but except for sharing my good intentions with a few classes, I never followed through. A few of my students knew about *The Miracle Worker* and thought Patty Duke and Anne Bancroft were good. But they did not seem to understand my attempt to speak about the mysterious connection between water and the word for it. Maybe we were studying Archibald MacLeish's conundrum that "A poem should not mean/But be."

English teachers wish everyone occasionally experienced the startling illumination that flashes when objects and words interact. Many of us believe that the insight gleaned in such moments is a key to human identity and a resource for meaningful dialogue about philosophy, art, science, technology, and just living from day to day with ourselves and others.

How do people learn this linguistic equation? We know, at least superficially, how Helen Keller learned, and we devote many hours writing about it in professional journals for teachers of literature, philosophy, language, and psychology. But for all our earnestness in the academy, much of this highly beneficial learning is serendipity — an objectless word, by the way, coined by Horace Walpole in the 18th century.

Stephen Hawking, the Cambridge University physicist and author of the best-selling book *A Brief History of Time*, was recently the subject of a television program on the Public Broadcasting Service. Hawking, one of the 20th century's most creative scientists, suffers from amyotrophic lateral sclerosis (Lou Gehrig's disease), a progressively degenerative

disease. At first his words sounded slurred and the rhythms of his sentences seemed rhetorically off-beat, but if you listened closely (as you would to a non-native speaking broken English) you could follow him. At times his speech resembled the eerie sounds made by dolphins, which we believe may be a form of spoken communication. After working with him for only a short time, Hawking's colleagues and students had no trouble understanding him and even came to forget that his speech was out of the ordinary.

When I was growing up in York, South Carolina, we had more than one counterpart for Hawking, and although none of them was a genius, each provided us with knowledge about the profundity of the gift of speech. The most memorable of these people was Tom Wiley.

Like Helen Keller, Tom was struck early in life by a catastrophic illness, or perhaps he was born that way. Whatever the cause (we were not even curious about it, so accustomed were we to him), Tom's body, though complete, was twisted and bent the wrong way so thoroughly that his small oak wheelchair had to be made especially for him. His right arm was a tight "Z" close to his body, with the hand pointing down; his left was twisted like a vine and stuck out, immobile, behind his body. His legs, like his arms, did not match in their deformity, but since they were always covered with trousers, we could see only that one sharply pointed knee was much higher than the other.

His misshapen torso was quite small, his flattened head permanently turned to the far left so that he looked at you out of the right corners of his eyes unless you stood beside him. All of this chaotic bone and protoplasm moved only in jerks and pulls, which we came to understand as Tom's body language.

Tom's speech was difficult to understand. When he talked, his mouth gaped crookedly, showing strings of saliva and unoccluded teeth. His words were like barks and interjections, some drawn out, others clipped off by an uncontrollable signal from his brain or spine. I remember these things now as I try to describe them, but in 1946 when I was thirteen, I hardly noticed. Tom was my friend, not an invalid but a person whose identity appealed to me.

There was a shady vacant lot across
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the street from the small brick house where Tom lived. I don't recall now whether he lived with his mother or with his aunt, but in any event he was such a dominant person that we noticed them only because they conveyed Tom across the street into our world. On nice days from April to November, and often in winter too, Tom was there under the oak trees in his wheelchair, holding court or enjoying a quiet conversation with one of the regulars. When a group was there he talked loud, laughed a lot, and got excited to the point that we sometimes had to wait a good while for a word to come out, especially during the punch line of a joke. "C'mon, Tom, tell it," somebody would plead. "You just want to hear the dirty part," he would squawk and laugh. He led the local free speech movement a decade before it arrived in California.

If I were riding my bike after school and found Tom with an older person, both of them looking serious and Tom talking softly and without much body movement, I usually waved, called his name, and kept going, for I knew he was talking news or politics and preferred not to be disturbed. I didn't mind.

It's not that Tom was just a voice. He was somebody, and we came to understand the relationship between words and persons — between meaning and being — in a subtle way that may not have been possible without his lesson. Our culturally approved vanities and virtues were given the lie by our friend of the riotous body. He made us forget physical attractiveness, athletic prowess, fashionable clothing, vaulting ambition. Since we accepted Tom and admired him without qualification, we implicitly affirmed values related to being, not having. His language reflected the poetry of human existence and taught us that the song of life can be sung in ways other than those mandated by our acquisitive culture.

It is heartening to know that after I left York, Tom became more and more involved in civic life. He was invited to meetings, consulted on topics other than those relevant to the handicapped, given active roles on municipal and county committees, and awarded medals and honors, especially for his work with young people. He died ten or fifteen years ago, of some illness and at some age, both irrelevant because he achieved his identity as few people do. It is not what we die of or when that matters, but what we do with the days that are ours to live.

If only I could find a way for my students to see why I care about Tom, Helen, and Stephen. However, words won't quite do it justice. That's the trouble with trying to teach the ineffable.

In Search of Common Ground

by Paul H. Levy

People with disabilities have fought to secure access to common arenas of daily living: jobs, transportation, education, and community services. The opportunity to claim equal rights emerged only after disabled and non-disabled persons began to recognize and accept each other as peers and neighbors.

In health care, the challenge for disabled persons has been to effectively represent themselves so that providers offer reliable, affordable care. Unfor-

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tunately, the gap between what's actually available to a disabled person and what the medical profession is willing to provide remains wide. We must always keep in mind both sides of the conversation: the person with disabilities seeking competent, accessible medical services, and professionals trained to care for ill, dependent people attempting to live an independent lifestyle.

Before measurable changes can be expected in guaranteeing satisfactory health care for the disabled, the medical community must educate itself about disability and the people who live with it. The first step has to be honest conversa-

Paul H. Levy founded The Whole Person in 1978, Kansas City's first center for independent living. In 1988, he established the Coalition for Independence, an organization that addresses unmet needs of disabled people.

tion about several key areas of concern: awareness, communication, attitude, consideration, access, and choice.

Awareness

Physicians and nurses are too often uninformed or misinformed about the basic identifying factors of various disabilities. Moreover, health professionals often do not know the common dysfunctions associated with a disabling disease or injury. The disabled person needs to educate as well as be educated. Lack of awareness and knowledge often appears as insensitivity. One way partially to remedy this is for disabled people to work with medical, dental, and nursing schools.

Once someone with a disability is understood and appreciated for his differences, he or she can easily be seen as a person who has feelings, desires, and goals similar to those of a non-disabled person. We may look and move differently, but we are alive and able to work with others as equals.

As a disabled person, I look forward to the day when I am not met with surprise when I appear for medical services. My first visit to my primary physician at an HMO was revealing. I waited in an examining room, sitting in my power wheelchair. The doctor entered and did a double-take when he saw me. I asked what was wrong and he said, "I never know who I'm going to get next." Would he have been as startled if he had seen me first, instead of the wheelchair?

Another time a situation occurred at my eye doctor's office. I wheeled up to a young woman in white to tell her I was there. She looked past me, then asked somewhat bewildered, "Isn't someone with you?" I smiled and replied, "It's almost like I'm grown up, isn't it?" I was 40 at the time.

Communication

The health care provider should speak directly to the person with disabilities and respect him as a competent individual, not as someone needing to be