

Janet Shapiro 2003-2004

Acknowledgements

I am thankful for my luck in life. Many wonderful colleagues, friends and family have supported my work in so many ways. I thank my husband, Harvey, with whom I have shared a life of love and the best of friendship; my mother, Irene, who taught me everything about individual responsibility; my sister, Katherine, from whom I learned the importance of being true to myself; my two dads, Ernest and Leonard, who both taught me how to laugh and how to let go; my nephews, who constantly remind me to keep an open mind; my family and friends in England who keep me in touch with my roots; my husband's family who welcomed me to this country with generosity and continue to demonstrate the best of America; my friends in Australia, Canada, Denmark, France, Germany, Jamaica, Kenya, New Zealand, Switzerland, and Uganda, who give me perspective on the universe; my friends scattered all over America who have given me the gift of hospitality and the opportunity to learn about almost every state in the nation; my California friends who have shared much fun and laughter and provide warm support for life's turns; my colleagues at SBCC who have taught me about professional excellence and commitment; my colleagues around the globe who strive for a better world on behalf of persons with disabilities; and my brilliant DSPS family of professional colleagues, Susan, Steve, Mary, Laurie, Joe, Henry, Gerry, Eric, and Angela, with whom it has been a joy to share my professional journey at SBCC and teamwork at the highest level. I thank the DSPS students who remind me every day of the joy of discovering the complex truth of each individual.

I thank my colleagues who provided technical, academic, and administrative support for today's presentation:

Tom Zeiher is my smiling, reassuring media expert.

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David Wong matched sound to visuals for the pre and post lecture shows.
Tom Garey moved forward discussions and plans regarding future accessible theater design - and he advised me on my lecture outfit!
Jason Flynn amplified my quiet voice, and coordinated staging and lighting with experienced aplomb.
Jeff Barnes is my trusty videographer.
Ron Adler and Mary Wiemann gave me the best of their Communication expertise.

Karen Sophia and Grant Lepper lent their creative energy to the invitation and program.
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Kay Bruce provided publicity and photos from the past.
John Barron drew my friendly, funny, flying pig cartoon.

Linda Morse provided professional real-time captioning.
Deborah Lewis joined us from L.A. to provide expert audio description.
Pam Lasker provided theater access solutions in a challenging setting with a smile and can do attitude.
Jo Black not only interpreted today but also has provided a quarter century of sign language interpreting at Santa Barbara City College!

Dr. Peter MacDougall, President Emeritus of SBCC, gave twenty-one years of supportive leadership for DSPPS.
President John Romo, Vice President Jack Friedlander, and Dean Marilyn Spaventa are my current administrative team. They are unparalleled in our system for the level of importance they place on educational support programs for underrepresented populations.

Last, but not least, I thank my wonderful colleagues who trod this path as faculty lecturer over the last 24 years. I particularly treasure the memory of David Lawyer, our eighteenth faculty

lecturer, who died earlier this academic year. David and the other faculty lecturers gave me such wise advice.

Lecture Dedication



I dedicate my lecture to Dr. Elaine Cohen. Elaine was my colleague, friend, and mentor during my formative years as Coordinator of Programs and Services for Students with Disabilities at this

wonderful college. Many of you knew Elaine and worked closely with her, but for those of you who didn't know her, Elaine was the kind of person that would meet you with the warmth and humanity she showed to each and every individual. Elaine modeled an intelligent, open-minded response to the needs of a diverse population. She also had the leadership skills and courage to be a change agent for our college. Elaine faced her own disabilities and medical challenges with grace, dignity and a zest for life.

Lecture

**Whether Pigs Have Wings:
Disability and the Search for
Reasonable Public Policy**



**Janet Shapiro, Ed.D.
Professor, Disabled Student Programs
and Services**

Introduction:

Beethoven was deaf when he composed the beautiful Ninth Symphony that I played as you entered the theatre. In this final movement Beethoven expresses his vision of freedom, equality, and democracy by creating a memorable melody for Schiller's poem "Ode to Joy." When Beethoven conducted this piece he could not hear the music or the sound of clapping. At the end of his concert he had to turn around to face the audience so he could see hand movement. At the end of my lecture I invite you to vary your clapping with visual applause used by and for people who are deaf. Raise your hands in the air and turn them side-to-side. It's rather like a royal wave. This is your chance for a rehearsal!



The most wonderful aspect of being faculty lecturer is the opportunity to publicly acknowledge my support system of colleagues, friends, and family. I will say a few words of heartfelt thanks at the end of the lecture at which time I will be acknowledging my twenty-four esteemed colleagues who preceded me as faculty lecturer on this stage. Here is your second lesson in American Sign Language. To say, "Thank you," move your hand from your mouth towards your audience as though you are blowing a kiss. Thank you. Thanks to all of you for honoring me today.

And now - President Romo, Board of Trustees, honored guests, colleagues, friends, family, and students - I give you the twenty-fifth Faculty Lecture.

Embracing Organic Ambiguities:

"The time has come," the Walrus said,
"To talk of many things:
Of shoes-and ships-and
sealing wax-
Of cabbages-and kings-
And why the sea is boiling
hot-
And whether pigs have
wings."



The poem is from my favorite childhood book, "Alice in Wonderland and Through the Looking Glass." The author, Lewis Carroll, was a shy, gentle man with a significant disability in communication. He had a stammer that severely distorted his speech. Carroll demonstrated his ability in his eloquent writing, which explored the human effort to find reasonable sense and order in our unpredictable world. Alice cannot even rely on her own physical constancy. She keeps changing size.

"Who are you?" said the caterpillar.
This was not an encouraging opening for a conversation.
Alice replied, rather shyly, "I - I hardly know sir, just at present. At least I know who I was when I got up this morning, but I think I must have been changed several times since then."



In this brief exchange Lewis Carroll captures the essence of our fragile humanity: our inconstancy. We were born to be different. We are imperfect. Imperfection is the essence of being organic and alive.

Joan Tollifston is a writer who is missing her right hand and half of her right arm. They were amputated in the uterus before she was born, by

a floating fiber. She writes of the beauty of our imperfect world,



"Organic life is vulnerable; it inevitably ends in disintegration. This is part of its beauty. When we delve into this mystery of life and

death we discover how porous and momentary everything is. Life is the way it is, not the way we wish it was, and disability is a constant embodiment of this basic truth. People react to my missing right arm. People try desperately to pretend that they don't even notice. Nobody says a word. People swallow their curiosity and conceal their discomfort, hoping that the great dream of normalcy is still intact."

Tollifston prompts us to think back to our childhood and the first lessons we learned about disability. I remember my natural childhood curiosity, "What happened to your leg? Why don't your arms work?" stifled with adult reprimands, "Shh!" Don't stare!" What did you learn from your first lessons about disability?



We are all in such pain, trying to do the right thing, trying not to ask the wrong questions, trying to pretend everything is O.K. I agree with Tollifsten who believes,

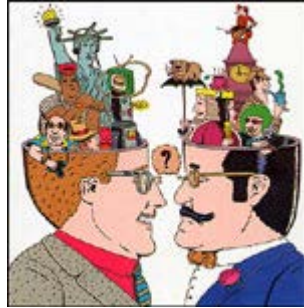
"If we need anything in this world, it's honest seeing and speaking, and the ability to be with the actual truth -including flawed bodies - and flawed responses."

Some writers suggest that our inability to accept the truth of our fragile organic state is a cultural issue. Philip Alcabes tells us, "Americans today

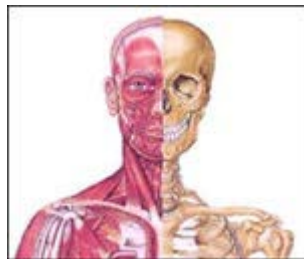
are great consumers of the hoax of a risk-free life."

When I became an American citizen I was presented with Jane Walmsley's book, "Brit-think Ameri-think." In her opening chapter Walmsley writes,

"The single most important thing to know about Americans - the attitude which truly distinguishes them from the British - is that Americans think that death is optional. If you jog regularly, eat more bran, and have a nose job your body will last. Brits, on the other hand, know the sword of Damocles is suspended above their head - events must be allowed to run their natural course - never run for a bus - and never skip tea."



Yes, today in my lecture I want you to reflect on your attitudes regarding our fragile organic selves, and our disabilities. In our community there is much debate regarding the negative connotations of the word "dis-ability." The variations in the meaning of the word are reflected in the variety of definitions in public policy. I believe there is respectful value to the label "dis-ability" as the definition of a social construct. I define "dis-ability" as society's barriers to the opportunity to demonstrate ability. We all look for opportunities to demonstrate our strengths and we all have organic limitations.





Some of you may argue that we were not all born with organic impairments. However, any one of us can acquire an impairment in a quick instant: a slip in the bathtub, a virus born disease, or some condition of the central nervous system. In many

communities we acquire impairments as the result of war, pollution, or misuse of drugs. As we live longer we acquire limitations as a result of wear and tear on our older bodies and brains. Statistics tell us that half a billion people around the world and one in five Americans fall into this quirky, lumpy, bumpy, or gnarly category.

In a recent lecture in this theater, Dr. Mel Levine challenged that statistic. He asked us to consider our brains, with 100 billion nerve cells and 100 trillion synapses. Dr. Levine believes it would not be an exaggeration to say that the rate

of neurodevelopmental impairment in our population stands at 100%. We are each unique, complex, and fragile. Is it reasonable that public policy be



designed to embrace our organic ambiguities? Is it reasonable to create public policy that focuses on the management of our abilities, whatever they may be? After all, whatever our physical impairments or neurological quirks, we all still have the same basic desires to find the means to be successful in our work, in our social life, in our home life, and in our love life. The challenge is to identify our organic abilities and have the opportunity to match our strengths to our life activities.

Purpose of Lecture:

Now, students, here is my statement of purpose for today's lecture: Embrace your organic ambiguities, search past policy, and decide future policy. While you are reflecting on your fragile, organic state, we will search through seven

models of public disability policy from the past. The goal of the lecture is for you to decide what you believe is the most reasonable public disability policy for the future and what role you play in influencing future policy. Having achieved this objective you will have the questions you need to analyze whether or not the flying pig is reasonable!

The Flying Pig:

On a flight from Philadelphia to Seattle In October 2000, US Airways agreed to allow a passenger to bring a service animal on board. The flight



attendants expected a guide dog. They were amazed to discover the animal was a large pot bellied pig weighing almost 300 pounds who barely squeezed under the feet of the passenger. The passenger claimed the pig was trained as a comfort animal for persons with psychiatric disabilities. However, during the flight the pig became very agitated, started to squeal frantically, fled from under the seat, and defecated in first class!

When we're deciding whether or not the pig should fly - or deciding whether or not to renovate the Arlington Theater so performers like Itzak Perlman could enter back stage without being carried up and down stairs - when we're deciding, we are faced with a variety of choices in how we respond. We ask, "Is this reasonable?"

Past Policy:

In order to decide what is reasonable policy for our future, it is important to review the past. We will consider policy options from seven American models that I have derived from the writings of disabilities studies specialists, most notably, Simi Linton, Paul Longmore, Tom Shakespeare and Joseph Shapiro. I will discuss policy based on (1) Eugenics, (2) Exclusion, (3) Medical Cure, (4)

Rehabilitation, (5) Civil Rights, (6) Cultural Identity, and (7) Universal Design.

Policy based on Eugenics:

The first model of public policy is based on eugenics.

"Lebensunwertes Leben" (life unworthy of life) was the concept Nazi doctors used to justify their

practice of medical euthanasia in order to annihilate over 200,000 persons who were disabled in the 1930s. It is sobering to read in Robert Lifton's book "The Nazi Doctors" that American public policy in the 1920s gave support to the German practice of euthanasia of people with disabilities.



The United States Supreme Court had endorsed eugenics as national policy, America had laws requiring sterilization of persons with disabilities, and large corporations such as the Rockefeller Foundation provided massive funding for eugenics laboratories.



The idea that it is somehow reasonable to end the lives of disabled people never went away in American public policy.

In 1942, Dr Foster Kennedy, president of the American Euthanasia Society, outlined a proposed policy for killing disabled children, referring to them as "defective products" and "nature's mistakes."

In 1991, David Larson, the director of the Center for Christian Ethics was asked about the ethics of the Baby Fae case, the first human to receive a heart transplant from a baboon. Larson replied,

"If a primate's capability was higher than that of a human - say a severely mentally handicapped child - I think it would be appropriate to support the opposite approach of Baby Fae - a transplant

from a child to save the life of a healthy baboon or chimpanzee."

The debates rage today. What is a reasonable policy approach to the debate over the right to die or selective abortion on the basis of disability?

Medical ethicist Adrienne Asch, who is blind, argues for the importance of a women's right to choose but believes that selective abortion solely on the basis of disability is wrong and is often based on the lack of knowledge as to what could be done to establish reasonable policies to support families and children.



Dr. Jack Kevorkian, the "suicide doctor" is seen either as a compassionate man or as a frightening figure echoing Nazi Germany rhetoric that people with severe disabilities should end their lives.

The debate over the "right to die" reminds me of two contrasting stories in Joseph Shapiro's book, "No Pity."

At thirty-four years old Larry McAfee was unlucky to be disabled in Georgia, in a motorbike accident in the 1990s. There was no support for independent living, home care, transportation or a portable respirator. Larry was dumped in a state hospital. His insurance was eaten up. He plunged into a deep depression. He wasn't dying and he wasn't sick. Larry asked an attorney to help him with his "right to die." It was chilling that it took the attorney, the judge, and the public barely



three weeks to support Larry's request and agree that this was "life unworthy of life."



Contrast Larry's story with Ed Roberts who was lucky enough to be disabled in California. He worked successfully to establish state support through Independent Living Centers addressing the need for attendant care, transportation, and a portable respirator. Roberts graduated from Berkeley, became the director of the State Department of Rehabilitation, married, and had a son, Lee, now twenty-six years old.

Is it reasonable to base public policy on eugenics?

Cheryl Marie Wade, a poet who has progressive arthritis, expresses her opinion in this excerpt from her poem "Cripple Lullaby."



I'm homeless in the
driveway of your
manicured street.
I'm Evening Magazine's
SuperCrip of the Week.
I'm a whisper, a heartbeat,
I'm that accident, and goodbye.
One thing I am not is a reason to die.

I'm the girl in the doorway with no illusions to
spare.
I'm a kid dosed on chemo, so who said life is
fair?
I'm a whisper, a heartbeat; let's call it suicide,
and a sigh.
One thing I am not is a reason to die.

I'm that Valley girl, you know, dying of thin.
I'm all that's left of the Cheshire Cat's grin.
I'm a whisper, a heartbeat, a genocide survivor,

and why?

One thing I am not is a reason to die.



As a summary of the first model let's apply policy based on eugenics to our flying pig scenario. Eugenics policy means the pig would never board

the plane because the person with the disability is "life unworthy of life." The pig would be returned to the farm!

Policy based on Exclusion:

We move our discussion to the second model, not as extreme as extermination, but equally challenging in terms of reasonability: public policy based on exclusion.



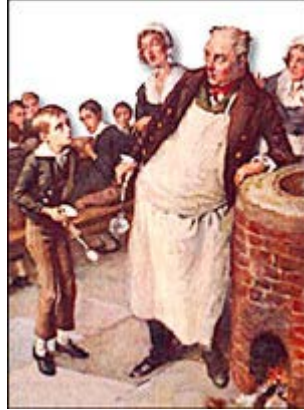
In 1882 the first major American immigration law prohibited entry to any "lunatic, idiot, or any person unable to take care of himself or herself without becoming a public charge."



People with disabilities born in the United States before industrialization lived in the context of kinship networks. With the industrial revolution, provision for persons with disabilities shifted to local

government authorities.

At the beginning of the twentieth century, asylums and workhouses became the main means of social control. This was the era of institutions supported by private charities or religious groups. Is it reasonable for our current government to establish public policy that will return us to faith-based initiatives?



In 1965 Robert Kennedy reported on the hellish conditions of state institutions where people with disabilities were excluded in abject conditions, sitting emaciated and naked in their own feces. Such expose prompted policies to move residents to community group homes.

It appears that we have replaced the exclusionary institutions of the past with modern day equivalents: state hospitals, nursing homes, and prisons. Without government benefit programs, educational support, job training, or employment, many persons with disabilities cannot live independently, become homeless, and often turn to crime.

Theda Skocpol comments that our American government benefit programs have not solved the policy challenge because their basic design is exclusionary. The first disability pensions excluded all persons other than disabled military veterans. These government pensions were justified in terms of a moral obligation to those who had sacrificed in their service to the nation. Military veterans had "earned" the right.



In the language of the first drafts of Social Security Disability Insurance, exclusions were based on worthiness and moral obligation only to those who had contributed to payroll taxes. The

policy makers expressed concern about abuse and malingering. They excluded those who did not "earn" their eligibility.



Is it reasonable that policy regarding long-term health care excludes those who cannot afford insurance or the costs of assisted living, residential care, and in-home care? Rappaport points out there is increasing evidence of the inability of entitlement programs such as Medicare or Medicaid to cover the costs of long-term care for those who cannot afford

insurance. Is it reasonable that the current political climate of managed health care in the United States creates such a deep fear among people with disabilities who worry that life, access, and opportunity are constantly being weighed on an economic scale?

In Michael Berube's book he writes about his family's experience of having a child born with Down Syndrome.



"Among the many things I fear coming to pass in my children's lifetime, I fear this above all: that children like James will eventually be seen as "luxuries" employers and insurance companies cannot afford, or as "luxuries" the nation or planet cannot afford. I do not want to see a world in which human life is judged by the kind of cost-benefit analysis that weeds out those least likely to attain self-sufficiency and to provide adequate "returns" on social investments."

Sociologist Paul Higgins believes educational public policy for targeted populations reinforces exclusion. Special education, Special Olympics, and special buses, for example, separate people with a diagnosis of impairment from those who do not yet have a diagnosis. The challenge is to

provide reasonable accommodation and an opportunity to demonstrate skills, without excluding the population.

Public policy based on exclusion has been reflected in specific laws throughout our history such as a 1911 City of Chicago Ordinance known as "The Ugly Law," not repealed until the 1950s.



"It is hereby prohibited for any person who is diseased, maimed, mutilated, or deformed in any way so as to be an unsightly or disgusting object . . . to expose himself to public view."



The policy of exclusion is supported in the media. As recently as 1987 Ann Landers wrote in her column, "In my opinion, restaurants should have a special section for handicapped people - partially hidden by palms or other greenery - so they are not seen by other guests."

As a summary, what would happen to our flying pig under the exclusion model? The pig would never get as far as the plane because the person with the disability must return to the institution, nursing home, or prison, in their country of origin or, at the very least, hide behind palms and greenery. The pig would be returned to the farm!



Policy based on Medical Cure:



The third model of public policy is based on the search for a medical cure. According to the medical model, disability is seen as a malfunction in need of cure. The person is defined by the impairment. The implication is that there is nothing else in life more important than the cure.

Cryogenics is at the extreme of this model, "Freeze me until they find a cure!" In the face of technologies such as genetic manipulation or cloning, that may cure, but will alter our identity as human beings, who will we become? Is it worth waiting for such a medical cure? If you do not believe there is anything that needs to be cured or genetically prevented, then doesn't disability become little more than a social construction?

It seems more than reasonable for Christopher Reeve to search for a medical cure to extend his life or relieve pain and discomfort. However, persons with disabilities worry that the focus on impairment devalues life with a disability. Reeve plays into the horror and fear of severe disability in his efforts to be a symbol of potential cure. This emotional appeal simply trumps the idea of disability rights.



Many persons with disabilities believe Christopher Reeve is building cruel false hopes. Most people cannot afford basic medical treatments let alone expensive treatments with ten nurses round the clock and the best medical specialists in the world.



Is it reasonable for Christopher Reeve to use his image to shift public policy and resources away from disability civil rights in his search for a cure?

If medical technology and genetic manipulation will not free me of my disability in my lifetime, then am I considered a failure? Will I be an object of pity? What is life worth without the cure?

Historian Paul Longmore points out that the medical model provides for great economic benefit to vendors of over-priced medical products and treatments. In the search for a cure for dyslexia and language learning disabilities, American families spend thousands of dollars on traveling around the country experimenting with treatments such as inner ear medications, cranial massage, bio-feedback or colored lenses. If indeed our brains are organic and unique, if indeed dyslexic brains have clusters of nerve cells slightly displaced in the cortex, is it reasonable to embrace hopes of a cure in our lifetime?



The most famous person who embraced the medical model is probably President Franklin Delano Roosevelt, FDR, who carefully built his image as the "survivor cripple." Although there are over thirty-five thousand still

photos of FDR at the Presidential Library there are only two of him seated in his wheelchair. Was it reasonable for FDR to make a deal with the press corps to keep the true nature of his paraplegia hidden in order to appear to "overcome his disability?" Paul Longmore believes such a deal could only be struck in a

society that views disability as a kind of transgression.

In public, FDR presented the image of the medical cure by using the aide of heavy metal braces and the support of walls, podiums, crutches, or he pretended to walk for short distances by leaning on the arms of two strong bodyguards and letting his legs swing. Most of the major government buildings had massive ramps built over the steps for FDR's motorcade to pull up level with the main entrance so that FDR could appear to "walk" into the building. The day after FDR died all the ramps were destroyed.



As a summary of policy based on the medical



cure let's apply the model to our flying pig. The doctor would prompt extra medication for the patient with the psychiatric disability in the hopes of

curing her need for a comfort animal so she could travel alone on the plane. Maybe the doctor would prescribe a sedative to cure the pig's anxiety. The pig would be returned to the farm!

Policy based on Rehabilitation:

If the medical cure doesn't work then maybe our fourth model of public policy, based on rehabilitation, will approximate normalization. The goal of rehabilitation policy is independence and employment. This policy approach was written into law in the 1973



Rehabilitation Act, and a new industry was born. Along with it came Disabled Student Programs

and Services in higher education to support the training necessary to transition to employment.



Past employment for persons with disabilities in the last century had a sad history of freak shows, circuses, and fairground exhibits. During World War II people with disabilities were suddenly employed in record

numbers, and in positions never before open to them, because non-disabled persons were at war. After the war, unemployment rates rose again.

In "The Body Silent" Murphy comments on the public's involvement in helping rehabilitation policy. We do it from a safe distance by contributing to the March of Dimes, the Muscular Dystrophy Society, or by dropping coins in the beggar's cup. Murphy believes we can lull our consciences without getting too close. The contradictory reaction of kindness and rejection help make the rehabilitation of people with disabilities an arena of enormous conflict of values.

The goal of policy based on rehabilitation has been to

secure employment for persons with disabilities.

However, social scientist

Wolfensberger has argued that

America has generated a huge rehabilitation industry in order to secure employment for professionals in the industry!



Traditionally the industry has been paternalistic, with an emphasis on professionals taking responsibility for developing service plans to present to their clients. However, in 1992 the Rehabilitation Act was reauthorized to reflect a changing philosophy in rehabilitation policy

towards partnerships with counselors in order to build self-advocacy, empowerment, and responsibility for clients who are now labeled "consumers" or "customers."

In this new century, one of the biggest challenges for rehabilitation policy is the impact of the growing number of older Americans. Kadlec's research on those of us who are between 55 and 64, and are still working, shows that 95% of us plan to work after retirement. In this older age group, one out of every two seniors is dealing with impairments that limit functioning. Rehabilitation policy will have to address this growing population of older consumers.

Another policy challenge is the eligibility process for rehabilitation services. Recent court decisions involving Boston University and the University of Mississippi have emphasized how critical it is for institutions to establish publicized policy that assures a process for persons to present documentation of limitations to disability specialists in order to determine eligibility for services and accommodations



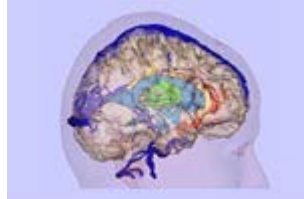
Tanya Titchkosky's essays on social mapping of disability challenge this traditional rehabilitation focus on documentation of limitations, inability, negative progression and the need for extensive therapy. Is it reasonable to prepare for employment and life by focusing on inability and negation?

For example, defining blindness as "not seeing" misses the truth that people who are legally blind do see. The question is what do they see, how do they see, and how is that sight changing? Is it reasonable for disability specialists to focus on

limitations or should they give primary focus to the identification and management of abilities?

In her poem "Attention Deficit Disorder" Emma Morgan has a postmodern approach to describing for her therapist what she can do verses what she cannot do.

When you speak to me of
Russian borders
rearranging,
Your hair do,
The glimmer of your nail
polish,
The dream I had last night,
And the pattern on the wallpaper
At your back,
Vie for my attention
Like a class of eager children
Sliding off their seats
With the sheer potency of the right answers.
Your world of global puzzles
Loses me in a grand collage of universes,
Each the size of the pen cap
Held between your teeth.
But just give me your shoe,
Or one braided lace,
To you a detail -
To me a world of six strands,
Each a set of threads
The tension of the weave precise,
And I can see what isn't visible to you.
You couldn't stand to pay attention
In that small world
Snaking through the eyelet of your shoe.



In our flying pig
summary, policy
based on
rehabilitation would
require the
passenger to
present verification
of the psychiatric
disability and maybe refer the person with the
disability to a "fear of flying" therapy group. If in
the actual case US Airways had applied a
rigorous rehabilitation model, the airline would
have discovered that the passenger did not have
a diagnosed disability and was only transporting



the pig to work as a comfort animal for a client with a psychiatric disability at the final destination. In this case the pig could fly - but would have to travel as cargo!

Policy based on Civil Rights:

In the fifth model of public policy based on Civil Rights, people with disabilities are viewed as having a legitimate grievance as members of a minority group. The definition of disability shifts to the sociopolitical realm. The quest is for equal access, equal



opportunity, and collective identity. Is it reasonable that disability was left out of the 1964 Civil Rights Act and it wasn't until twenty-six years later that the Americans with Disabilities Act was passed?

The disability rights movement had no Martin Luther King, no attention from the press, and no easy way to build coalitions from the hundreds of different disability groups. However, one in five people have a diagnosed disability. They began to speak out. Rehabilitation policy had moved people with disabilities out into society. The resulting Independent Living Movement led the fight for disability civil rights across the states.

The most surprising supporter of the 1990 Americans with Disabilities Act was President George Bush, senior. Bush had a past record of attempting to deregulate the guarantee of education for children with disabilities and access for college students with disabilities.

A key player in influencing Bush in the fight for civil rights was Evan Kemp, a Republican attorney. Kemp, a paraplegic who used a wheelchair, convinced Bush by articulating a conservative argument, "People with disabilities want to get out of the welfare system and into

jobs and do not need a paternalistic government to help them."

Bush finally put his pen to the passage of the Americans with Disabilities Act with his declaration, "Let the shameful wall of exclusion finally come tumbling down." Bush then moved to the attorney, Evan Kemp, who was sitting in his wheelchair on the podium, and Bush gave him a kiss on top of his head.



Visualize yourself as Evan Kemp, a successful attorney, a leader in the party, sitting in your wheelchair on the podium, proud that you've influenced major civil rights legislation. The President walks over to you and doesn't give you a handshake or a touch on the lower arm as he does with others, but does what a father might do with a three-year-old child.

Joseph Shapiro writes, "It was an odd victory: as radical as the ADA's passage would be for people with disabilities, Americans still had little understanding that this group now demanded rights, not pity."

Bill Bolt in the magazine "New Mobility" argues that the law was so weak it has done nothing to improve the status of persons with disabilities. Today, two out of three persons with diagnosed disabilities are unemployed and the Supreme Court is in the process of gutting the ADA. Linda Krieger, a Berkeley law professor, believes the ADA is based on a socio-cultural model of disability the judges simply don't understand. The judges understand disability law as eligibility for benefits or rehabilitation. The judges still look at cases to see if the plaintiffs are sufficiently impaired to earn protection under the ADA. The judges are still considering who is "deserving." The judges are not considering the socio-cultural issues of discrimination and equality of

opportunity.

In his book, "Success Without Victory: Lost Legal Battles and the Long Road to Justice in America," Jules Lobel reminds us that no civil rights movement succeeds overnight.



The pentimento of political protest and policy change, as in art, is often imperceptible in the present but builds through history towards a desired outcome. The ADA was not the end point of the disability rights movement but a beginning.

Mary Johnson in her book "Make Them Go Away" points out that one of the reasons the Bush administration was so willing to support the ADA is that they truly believed few disabled people would file lawsuits. They were proved wrong when the promise of the Americans with Disabilities Act was brought to reality in an array of Justice Department decisions. The one in five Americans with disabilities began to assert their civil rights.



The owners of the Empire State Building made its observation deck accessible because they realized a mobility problem is caused by the presence of steps verses an impairment of the hip, knee, or leg.

A drugstore chain changed its no pets policy to allow people who use guide dogs in the store.

When John Hockenberry, journalist of "Dateline" fame, showed up at a Broadway theater with his \$60 ticket in hand, having called in advance to ask if the theater was accessible, the theater manager refused to allow him to transfer from his wheelchair to his seat, complaining, "You are a fire hazard, sir." Hockenberry filed his first bias suit and then proceeded to request an accessible

rest-room in the National Public Radio's offices where he had worked for years.

The Americans with Disabilities Act gave Casey Martin the right to use a golf cart when he plays in Professional Golf Association tournaments. The degenerative disorder of his right leg prevents him walking long distances. Martin is a competitive golf player and the Supreme Court argued that walking long distances is not a fundamental part of the game.



Marilyn Bartlett's ADA case demonstrated that civil rights access is not limited to physical modifications. Bartlett, an accomplished professor at the New York Institute of Technology, has dyslexia. She won her case for extended time and the use of a computer on her New York bar exam.

Disability civil rights became a theme in the media. In the film "Philadelphia," Tom Hanks plays the employee who is fired because he has AIDS. Denzel Washington plays his attorney who uses the Americans with Disabilities Act to win the case against Hanks' employer.

The Americans with Disabilities Act has shifted our thinking: from "dependence" to "empowerment", and from "a focus on the individual" to "a focus on society."

The success of policy based on civil rights has been to shift our perceptions and challenge our stereotypes.

Lynn Manning, a poet and actor who uses a cane because he is blind, challenges our stereotypes in his poem "The Magic Wand."

Quick-change artist
extraordinaire,
I whip out my folded cane
and change from black man
to blind man with a flick of
my wrist.

It is a profound
metamorphosis -
From God-gifted wizard of
roundball
dominating backboards
across America

To God-gifted idiot savant
pounding out chart-busters on a cock-eyed
whim;

From sociopathic gangbanger with death for eyes
to all seeing soul with saintly spirit;

From rape driven misogynist
to poor motherless child;

From welfare-rich pimp
to disability-rich gimp;

And from 'white man's burden'
to every man's burden.



It is always a profound metamorphosis.
Whether from cursed by man to cursed by God;
or from scripture-condemned to God-ordained,
My final form is never of my choosing;
I only wield the wand;
You are the magician.

A summary of the
Civil Rights Model
looks to the flying pig
once again. The
passengers know
they are guaranteed
equality before the law. The pig might assert his
civil rights. "If the guide dog can fly, I can fly!"



Policy based on Cultural Identity:



Folks with disabilities are beset by challenge in the effort to consciously build a positive cultural identity. This is the focus of the sixth model of public policy. Other groups may proclaim "black is beautiful" or "glad to be gay," but equivalent claims are challenging for persons with disabilities.

We search for a balance between our effort to take pride in our organic differences and our refusal to glorify or disrespect incapacity. Is it reasonable to assert the value of our fragile organic lives through notions such as "disability pride" or "celebration of difference?"

John Hockenberry, a journalist who uses a wheelchair, discusses how his cultural



identity differs from the dominant American culture: "Americans expect things to work. It is one of the consequences of being a superpower. Disabled people expect things not to work whether they are

American or not. In Israel and the occupied territories I shared no language or religion with the people I met. To my surprise, I discovered that we shared a world view that had always isolated me in the United States."

Disquiet among the disabled community over negative cultural stereotyping has prompted policy change in the media in an effort to develop positive cultural identity: advertising





that embraces organic differences in body images, theater companies such as the National Theater of the Deaf, magazines such as "The Disability Rag," and performance groups like "Wry Crips."

Much can be done to foster positive cultural identity through educational policy.

Simi Linton argues for the need to include the cultural analysis of disability in our humanities and social science curriculum in order to gain a broader understanding of the significance of human variation. Cultural analysis of disability deepens the historical comprehension of American values, beliefs regarding human nature, gender, sexuality,

American notions of individualism, equality, and the social or legal definition of what constitutes a minority group. Science and medicine might turn their attention to the adaptive aspects of disability. In



literature or linguistics, disability as perspective should be employed to flush out the hidden themes, images, or metaphors of the field's guiding principles. In education the analysis of learning styles, multiple intelligences, and perceptual processing abilities places the issue of organic ambiguity in a respectful light and fosters positive cultural identity for those of us with learning disabilities.



A discussion of cultural identity must include the debate over charity advertising. Is it reasonable to present a stark, negative cultural image of disability to secure public donations for the Muscular Dystrophy Association? Is it reasonable for Jerry Lewis to

infantilize adults with disabilities referring to

them as "Jerry's Kids?" Many will argue that charity is itself oppressive, no matter what image is employed.

Paul Longmore points out how stereotypes of cultural identity are reinforced in the media, literature, film, or photography. Longmore argues, "What we fear, we often stigmatize and shun."

Quasimodo ringing the bells but losing the girl reminds us that hunchbacks do not have a sex life. Tiny Tim reminds us that little boys who use crutches are a source of abject pity. The Beast attempting to bewitch his Beauty reminds us that youth and purity guarantees recognition as the fairest in all the land. The twisted face of Scar plotting to destroy the Lion King reminds us of the inherent evil in the deformed creatures of the world.

In an attempt to produce a new cultural identity, Kim Bretton Hetrick challenges historic cultural stereotypes in this excerpt from her poem "Brother Beast."

Let Quasimodo drop the bell
rope,
And say to Esmerelda,
"I think you have the
kindest eyes,
I'd like to buy you lunch,
And talk with you
About our hopes and
dreams."



Perhaps they'd find some common ground,
And have a charming tryst.



Let the little Cratchit boy
Lean his crutch against the
wall,
And tell his uncle
Ebenezer,
"I would like to go to
M.I.T.,
be the top ranked of my
class,
and learn to be an
engineer,

and learn to be a man of means,
and keep my kindly father Bob,
and my dearest mum,
in finest style when they decide
to take their pensions and retire."

Let Beauty's beast decide

He likes himself
Just the way he is,
Canine teeth and claws, and all,
And if she wants to cherish him,
And share his comfy bed,



She'd better get accustomed
To his shedding every spring,
And buy him kibble for a shiny coat,
And beef bones for his teeth.

Let Scar forsake the cackling gang

Of humor-impaired hyenas,
Get a membership at Bally's,
Tone up his wasted limbs,
And meet some lioness,



Who thinks his scar is cute,
Grants him an air of mystery,
And takes long walks with her,
Across the sunny veldt of Africa.



A summary of the Cultural Identity Model takes us back to our flying pig. Under this model, educational policy would have required the airline staff to receive

training on the positive cultural identity of persons with psychiatric disabilities and their use

of comfort animals. They would recognize the pig is not a farm animal and maybe treat him with the respect due a trained comfort animal so that the pig would not squeal with anxiety. If the passenger really had a psychiatric disability, and the pig was appropriately trained, then the pig would be allowed to do his job. The pig would fly!

Policy based on Universal Design:

The seventh model of public policy focuses on the concept of universal design for the twenty-first century. The world is very different than a hundred years ago. The number of people who are functionally limited by impairment is increasing at a dramatic rate. In every age group medical advances keep more people alive, with impairments

One in five Americans has a diagnosed impairment. We're talking about you, your family, and your friends.



We are in a new era because, today, technology can be the great liberator in disabled people's quest for independence. People born with organic limitations have access to fascinating technologies and tools. Our politicians are realizing that these populations are no longer an insignificant or silent minority. The business community is realizing that people with disabilities are a huge pool of consumers and we do not all use products in the same way. The educational community is recognizing that each and every brain has its own unique convolutions. We do not all learn the same way and we do not demonstrate our knowledge and skills in the same way.

We have begun to recognize the universal value of many accommodations that we thought were originally designed for people with impairments. In the bar we put the TV on mute when it gets

too noisy and follow the action with the captions. At the airport we use the accessible bathroom stall because it's big enough for our rolling bag and computer bag. In our cars we listen to books on tape.



Picture the universal design of a curb cut. Your cousin in her wheelchair crosses the street with her husband walking by her side pushing their baby in the stroller. Your

grandfather with his cane avoids the step and follows behind the young couple. Do we stop to think that for every one wheelchair, ten to a hundred bicycles have rolled across that curb cut?

Another example from the world of sports is from Gallaudet, a university for students who are deaf. Their football team invented the huddle in order to hide their sign language. The huddle is now accepted as part of football everywhere.



At Santa Barbara City College for many years we have provided voice recognition systems for your brother who has dysgraphia or your neighbor who has orthopedic limitations, in order to dictate their assignments instead of using a keyboard. Our Computer Applications Department now teaches voice recognition as a universally designed tool that benefits writers, doctors, deans, and presidents!

Last year this College submitted a proposal to the state for a universal redesign of this Garvin Theater. The building was designed in the early 1970s before any

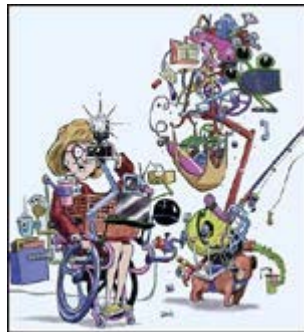


legislation to provide integrated access and before architects embraced the key universal design question, "Who am I excluding in this design?"

We have made improvements over the years such as side handrails, assistive listening, automatic door openers, and a live captioning system. However, we look forward to our new design which will consider the theater lovers who need hand rails down the center aisles or who use wheelchairs and who have a right to a choice of seat price, a choice of sight lines, and the opportunity to sit with family and friends. Some of you are hoping the redesign will consider the need for more room between seats for that tall, tall student whose legs go on forever!

Our College not only wishes to provide a universally designed environment but also needs to take a reasonable approach under the current fiscal constraints in California. Policy change is always to do with economics. We cannot forget that our community's fiscal policies and priorities do reflect our attitudes as citizens. We can celebrate the attitude you demonstrated this month by voting for proposition 55 and moving forward our plan for the Garvin Theatre redesign!

Designers and politicians are beginning to realize that conscious policy decisions based on universal design would reduce enormous costs to society by allowing persons to function independently in a universally designed world.



Educators are realizing that the universal design of assessment measures and teaching methodologies increases the opportunity for more students to have successful outcomes. Universal design policies might move a population of a few million people with disabilities into employment and self-sufficiency or allow more seniors to stay in their own home living independently.

Universal design combined with reasonable accommodation might free us to focus on managing ability instead of focusing on limitation.



We have to dream. It is our nature. Imagine a world where we have glamorous commercials for virtual reality headsets to take you places that you may not be able to visit physically; workplaces where employees operate computers with eye

movement; sleekly styled wheelchairs that climb stairs; classrooms equipped with a variety of adjustable ergonomic furniture; instructors who provide choice and variety of opportunity in learning and demonstrating ability; web sites that all have text and audio alternatives for graphics and video; built in screen readers for persons to listen to text; audio global positioning systems; radio frequency identification technology that responds to our presence, desires, and needs; and government sponsored technical aid centers where everyone would go to see the latest hot items in universally designed technology.



The most challenging aspect of universal design is getting the new devices to the people who need them the most. Few people can afford the universally designed technology that Stephen Hawking can afford or systems that are donated to him because he is famous. Is it reasonable to design public policy to fund access to universally designed products to assure the opportunity to function independently?

Nancy Scott, a poet who is blind, captures a sense of opportunity and independence in her writing about universal design and the tools that allow us to live our lives in our unique ways. This

poem, "Hearing the Sunrise" is dedicated to the light sensor on Nancy's kitchen windowsill.

The sun rises in B
major
To sing one verse of
"My Way."
Pitch to remind,
tempo to awaken.
Twenty-three
seconds of song,
bordered by silence,
serenade through any window I choose,
on any morning.
No long gazes.
No missed opportunities,
Twenty-three seconds
is more than enough time
when you hear the light.



As a summary of the Universal Design Model we look again to our flying pig. Universal design policy applied to the plane would mean more

legroom and therefore more space for the pig!



- Eugenics
- Exclusion
- Medical Cure
- Rehabilitation
- Civil Rights
- Cultural Identity
- Universal Design

Whatever aspects of the seven policy models you choose as reasonable, can we change personal attitudes? With the most reasonable policy in place Mel Brooks might still have exclaimed, "If

God had meant pigs to fly he would have given them - tickets!"

As you review the seven policy models, keep in mind their limitations. You must consider the opinion of researchers such as Tom Shakespeare who reminds us that the global experience of people with disabilities is far too complex to be rendered within one unitary model. Consider the range of impairments under the disability umbrella and the different ways they impact on individuals over a lifetime. People do not fit into two sharply distinct groups, with and without disabilities, but reside at all points along a spectrum of capabilities. We all have organic ambiguities.

Future lectures topics must look at the intersection of disability with other axes of inequality such as gender, ethnicity, sexual orientation, or nationality. Today, you begin your search for reasonable public policy for our future.

Your Role in Setting Future Policy:

The challenge that remains is for you to choose your role in setting future public policy. What can you do to influence policy change? I have the beginnings of your to do list.

Listen to your political representatives. What are their opinions on disability policy? Call or email your legislators with your opinion. Influence by your vote. Tell the League of Women Voters not to put the polling place up a flight of steps!

Engage with organizations of people with disabilities and disabled people who are not members of organizations. Take a lesson from your elders who have made the American Association of Retired Persons a powerful force and encourage your friends and relatives with disabilities to join the AAPD, American Association of People with Disabilities.

Spend your money at businesses and restaurants that are accessible to people with disabilities. When the local supermarket installs an automatic door, compliment the manager and assure her

that you - and your aunt who uses crutches - will be shopping there on a regular basis.

At your work, remind your colleagues that not only text alternatives and captioning for your web site are essential but also the multiple choice options cannot be color coded - because you know your colleague in the next office is colorblind.

Teach in your social life. When you're eating in a restaurant with your nephew who is blind and wears dark glasses and the waiter says to you, "What does he want to eat?" say, "I don't know. Why don't you ask him?"

Email or write to producers with your critique of films that portray people with disabilities such as, " Stuck on You," "Forrest Gump," or "As Good as it Gets."

Deal with the pressure for body beautiful: include photos of your friend who has facial dysplasia next to the photo of your even-featured, clear-skinned friend, in a prominent place on your desk.

Central to a process that transforms social policy must be ongoing empirical research. Engage in social research on the topic of disability.

Throughout your education, in all academic discourse, seek out and request perspectives from people with disabilities.

Future Direction:

As you look to the future, I turn your attention to the perspective of one of the most interesting role models of the age, David Blunkett, the British Home Secretary. Blunkett is blind and has a lot to say about reasonable public disability policy for our future. Many believe that Blunkett wants to



replace Tony Blair and become the first blind Prime Minister.

A recent article by Oliver Letwin in Prospect quotes Blunkett,

"I count not being able to see as an inconvenience rather than a disability . . . The whole point, of course, is that we should all be judged by what we do and how effective we are, irrespective of any disability. There is only one world we all inhabit and, whether blind or not, we all have to come to terms with that."

As Blunkett says in his book, *Politics and Progress*,

"A modern commitment to equality . . . must consider personal responsibility - whether people have made free and informed choices about what to do with their lives."

Blunkett believes it is reasonable to establish policy to distribute society's resources to compensate people when inequality arises through no fault of their own. He also believes that once society has provided a basic level of social security then the individual is in a position to take responsibility for making choices and that the distribution of resources in our society should reward these efforts.

Blunkett believes his personal experience was transformed into political commitment by the recognition that his opportunities in life were not the result of chance, but the product of political strategies by those who battled against inequalities in the past and influenced changes in public policy for the future. Blunkett says that he did not succeed because public policy did something for him but because it gave him the opportunity to do things for himself.

However, Blunkett leaves us with a challenging question. What about the needs of people who are so organically fragile that they cannot take advantage of the current opportunities in our age of challenging technological advance? How do we develop policy for persons who cannot meet the fundamental requirements of our complex, technological environment, even with the most reasonable accommodations and the best of universal design?



What policies will provide opportunity for all persons to demonstrate ability, whatever that ability may be?

Today you reviewed seven models of public policy, many of which you no doubt found unreasonable. John Kennedy said, "Our task is not to fix the blame for the past, but to fix the course for the future."

As you leave this lecture decide on the most reasonable course for future public policy regarding the disabilities you face yourself or in your family. In what direction should our society move? In what direction will you move?

Lewis Carroll addresses the question of future direction in his description of Alice meeting the Cheshire cat.

"Would you tell me please, which way I ought to go from here?"

"That depends a great deal on where you want to get to," said the Cat. "I don't much care where," said Alice.

"Then it doesn't matter which way you go," said the Cat.

"-so long as I get somewhere," added Alice as an explanation.

"Oh you're sure to do that," said the Cat, "if you only walk long enough. In that direction, lives a



Hatter: and in that direction lives a March Hare.
Visit either if you like: they're both mad."
"But I don't want to go among mad people," Alice
remarked.
"Oh you can't help that," said the Cat: "we're all
mad here. I'm mad. You're mad."
"How do you know I'm mad?" said Alice.
"You must be," said the Cat, "or you wouldn't
have come here."

Conclusion:

As I bring the twenty-fifth annual lecture to a
close, please indulge me by promising to spend a
few minutes reading your program, where I have
written my heartfelt thanks to all of you who
have supported my life's work and today's event.

Last but not least, in honor of the twenty-fifth
anniversary of the faculty lecture I thank my
wonderful colleagues who trod this path as
faculty lecturer over the last 24 years. I
particularly treasure the memory of David
Lawyer, our eighteenth faculty lecturer, who died
earlier this academic year. David and all the
lecturers here gave me such wise advice.

In honor of twenty-five years of this tradition I
invite the previous lecturers on stage for a group
photograph. While we are gathering on stage I
end my lecture with photos of all twenty-five
faculty lecturers accompanied by Beethoven's
Ninth Symphony, as a reminder of Beethoven's
theme of freedom, equality, and democracy - and
as a reminder that - when the time has come -
when we can no longer hear - we still have the
ability to listen - and maybe we will discover that
pigs really do have wings!



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