

**Diversity and Human Rights:
Protections for Neurodiversity and Physical Disabilities
Under International Human Rights Law"**

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*Prepared for: The Center for the Study of Human Rights, Columbia University
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Special thanks to Prof Peter Juviler, Barnard College Columbia University. Ilise L. Feitshans JD and ScM is an advocate on health issues whose work led to the creation of the Special Education Review Commission in New Jersey, which is presently gathering testimony and recommending solutions to policy issues that impact the rights of students with disabilities. She holds a Masters of Science in Public Health from Johns Hopkins University, a law degree from Georgetown University Law Center, and is particularly proud of her BA from Barnard College, where her Senior Scholars Honors Thesis about international health laws "launched" her work. She is the author of DESIGNING AN EFFECTIVE OSHA COMPLIANCE PROGRAM (Westlaw.com since 1990) and BRINGING HEALTH TO WORK. She is the Former Acting Director, Legislative Drafting Research Fund, Columbia University School of Law. Feitshans has presented major papers in Sweden, Mexico, Canada and provided two workshops at the United Nations Fourth World Conference on Women (China 1995) Her current paper is part of the Work, Health and Survival Project.

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I. The role of international human rights norms in preventing discrimination against people with disabilities

“Rights are not mere gifts or favors motivated by love or pity for which gratitude is the sole fitting response. A right is something that can be demanded or insisted upon without embarrassment or shame”¹

Disability poses profound challenges to the workings and conceptual underpinnings of the apparatus for protecting individuals under international human rights laws. Every individual in society may be ill, recuperate and regain health or lose health again many times in their lifetime. So the population to be considered “disabled” will change across time, even for people with long-term conditions that are disabling; no person lives an entire lifetime devoid of illness, infirmity or physical disability or impediments to their quality of life from genetic conditions or the accidents of nature, daily modern life or war². Disability is therefore a universal, ubiquitous and pervasive facet of the human condition: Universality is a fundamental cornerstone of all human rights norms, so disability protections, including the freedom from prejudice that harms the implementation of civil rights for persons with disabilities would seem natural, if not positively codified, under human rights norms. But this is not the case.

Paradoxically, disability presents the inherent challenge of understanding, accepting and allowing society to benefit from the most individualized of all individual

¹ Henry Shue, BASIC RIGHTS: Subsistence, Affluence and US Foreign Policy p 58-59 citing Feinberg, who was citing Wesley Hohfeld, FUNDAMENTAL LEGAL CONCEPTIONS New Haven, Yale University Press 1923. It is useful to recall too that when this text was first published, women in the USA had obtained suffrage only four years before. It is easy to imagine some very dignified strident women demanding their right to vote in Hohfeld’s then-recent experiences.

² Ilise Feitshans, "Law and Health: A Global Perspective on Workplace Protection" Society of Medical Jurisprudence, New York City, April 10 1995.; Columbia University Seminar on Death and Dying: "Preventing Death in the Workplace", Columbia University Faculty House April 12, 1995. Those presentations form the underpinnings of Chapter 23, “Occupational Health as a Human Right” Chapter IN: ILO Encyclopaedia of Occupational Health and Safety_ (Jeanne Stellman, Ed.) Fourth Edition, International Labour Office, Geneva Switzerland (1997, hard copy & CD-ROM)

rights.³ Disability, although universal in its likely incidence in the lifespan of any given human being, also challenges the operationalization of a fundamental tenet of equality: that every person is the same and consequently, equal rights for all people—men⁴, women⁵ and children⁶ (as protected in separate international conventions) have equal rights and should be treated the same. The problems of disability among humans therefore compel the international system to squarely and candidly confront the unique nature of individual differences which cannot be replicated, which make each individual a human with their own set of memories, gifts, limits and experiences. Everyone is different yet everyone must have the opportunities to be treated the same.

The international human rights law has yet to address several issues such as the respect for differences in sexual orientation or opportunities for people with disabilities. Is this a function of prejudice, stigma and lack of understanding of the gifts⁷ among people with disabilities, or is it merely a “hole” in the fabric of the law that can be easily plugged up and filled with text from long-standing human rights norms or the new draft

³ On November 1, 2006 this paper was presented at the Columbia University Human Rights Seminar invited paper speaker series. "Protections for Neurodiversity and Physical Disabilities Under International Human Rights Law"

⁴ Declaration of the Rights of Man and Citizen, France, 1789, US Constitution, 1793. Consistent with this heritage, the notion of rights of men has been expanded to embrace the rest of the world. Therefore, the United Nations's founding documents, the United Nations Charter, and the United Nations Declaration on Human Rights, call for "respect for human rights and for fundamental freedoms for all without distinction as to race, sex, language or religion"

⁵ Ilise Feitshans, "Is There a Human Right to Reproductive Health?", *Texas J of Women & the Law*, Fall 1998.; International Commission on Occupational Health (ICOH), Brazil Feb 2003 FP 40.6 WORKING FOR REPRODUCTIVE HEALTH AT WORK: TOWARDS MATERNALISTIC VIEWS OF HEALTH AND SURVIVAL, Free Paper Session REPRODUCTIVE HAZARDS IN THE WORKPLACE (FPS 40); *American Society of Law Medicine and Ethics*, Oct 1 2001 *Working for Reproductive Health at Work: Health and Survival of the Next Generation. (also presented at Yale Medical School Spring 2002)*; Invited article for the State of the Art Reviews (STAR) on Ethics and Occupational Health Practice, "Occupational Physicians Ethical Obligations to Pregnant Workers" (Sept 2002)

⁶ The rights of children with disabilities are protected in Article 23 of the Convention on the Rights of the Child, G.A. Res. 44/25, Annex, U.N. GAOR, 44th Sess., Supp. No. 49, at 167, U.N. Doc. A/44/49 (1989), available at <http://www.unhchr.ch/html/menu3/b/k2crc.htm> (last visited July 5, 2005) hereinafter CRC . Disability is a prohibited ground of discrimination in Article 2(1). Id. art. 2(1)

⁷ "Everyone has a disability. Everyone has a gift. .Your job is to find the gift and remove the obstacles of disability" Sylvia Feelus Levy, 1974 cited in Ilise L. Feitshans Gifts and Disabilities: Two Sides of the Same Coin presentation at Barnard College Department of Education November 2004

protocol from the United Nations? To the extent that there is arguably adequate discussion of the protections for people with disabilities⁸ under international human rights laws, does the law lead society, as an instrument of positive social change towards the elimination of discrimination,⁹ or is it an oppressive apparatus that the general public ignores for good reason?

This paper discusses the social constructs of disability¹⁰ insofar as inabilities in individuals might be treated as a distinct segment of international human rights norms. This paper then describes existing international human rights laws that can be applied to implement protections of the equality of people with disabilities, including a critique of the Draft Protocol prepared under the auspices of the United Nations August 2006¹¹ and

⁸ See United Nations, Standard Rules on the Equalization of Opportunities for Persons with Disabilities, Gen. Assembly Res. A/RES/48/96 (Dec. 20, 1993) (available at <<http://www.un.org/esa/socdev/enable/dissre00.htm>>; United Nations, Ad Hoc Committee on a Comprehensive and Integral International Convention on the Rights and Dignity of Persons With Disabilities, Gen. Assembly Res. 56/168 [P 1] (Dec. 2002) (available at <<http://www.ohchr.org/english/issues/disability/convention.htm>> (accessed Apr. 1, 2005)), UN GAOR, 56th Sess. Agenda Item 119(b), UN Doc A/RES/56/168 (2002). Revised August 2006, Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities Eighth session, New York, 1425 August 2006 DRAFT CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES and the Draft Optional Protocol to the International Convention on the Rights of Persons with Disabilities to be adopted simultaneously with the Convention

⁹ “The belief that justice triumphs over oppression, exemplified by the popular phrase, ‘the law is on our side’ implies that a strong relationship exists between legal authority and the desire to rectify past injustices within society. The phrase echoes a traditional view of the law as protector of rights, as an arbitrator, or interpreter of facts, serving to define and uphold the individual’s rights, be that individual a feudal lord, President, King or former slave” Ilise Levy Feitshans, *Law As an Instrument of Social Change*, unpublished paper for Peter Juviler Barnard College 1977.

¹⁰ “Historically people with disabilities have been perceived out of a medical model of deficiency and dysfunction... To continue to position the person with the disability as the problem and to try to change him or her is to chase the wrong butterfly. What is needed is a shifting of culture” Al Condeluci, *Cultural Shifting: Community Leadership and Change Training Resource Network St Augustine Fla 2002* at 35-36.

¹¹ Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities Eighth session, New York, 1425 August 2006 DRAFT CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES and the Draft Optional Protocol to the International Convention on the Rights of Persons with Disabilities to be adopted simultaneously with the Convention

its heritage rooted in the US statute, 42 USC 1983 (passed a century and a half ago). This paper argues that there is no shortage of international law protecting people with disabilities for two reasons. First, the protections transcend the artificial dichotomy between “civil rights”¹² and “economic and social rights”¹³ under international law, for reasons discussed below. Second, the draft protocol supplements the terms of many treaties and conventions and offers an exhaustive exposition of best practices for implementing human rights protections under law. This paper argues for an expansive definition of “disability” that goes beyond the broadened frame of reference implicit in the term “diversity”, in order to embrace the universality of disability as a legitimate fundamental source of human rights law because disability impacts every individual differently, at some moment in their lifetime¹⁴. This paper concludes that the positivist codification of rights is an excellent use of the law as an instrument of social change, and

¹² United Nations, International Covenant on Civil and Political Rights art. 27 (Mar. 23, 1976) (available at <http://www.unhcr.ch/html/menu3/b/a_ccpr.htm> opened for signature Dec. 16, 1966, Gen. Assembly Res. 2200A (XXI), 21st Sess., U.N. GAOR Supp. (No. 16) at 52, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 171, entered into force Mar. 23, 1976 [ICCPR]

¹³ United Nations, International Covenant on Economic, Social and Cultural Rights [ICESCR] Consistent with the principles articulated in many other international human rights documents, Article 12 employs deliberate language that recalls constitutional notions of health. Article 12 reads: "The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. 2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for: ... (b) The improvement of all aspects of environmental and industrial hygiene; The prevention, treatment and control of epidemic, endemic, occupational and other diseases....;"

¹⁴ This view is consistent the approach taken by the drafters of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities Eighth session, New York, 1425 August 2006 DRAFT CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES who specifically refrained from defining disability, or offering a laundry-list approach to conditions that qualify as a disability. Instead, the Purposes wisely stated that “Persons with disabilities includes those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” . For the purposes of the draft convention, “Discrimination on the basis of disability” means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation; (which the convention later defined).

that the remaining battleground is within the hearts and minds of individuals who encounter, and must challenge, myths to be dispelled about disability in daily life.

II. Different understandings of the concept of diversity in daily life

A. For some, diversity is a social fact; for others, it is an objective.

“If we are to achieve a richer culture, rich in contrasting values, we must recognize the whole gamut of human potentialities, and so weave a less arbitrary social fabric, one in which each diverse human gift will find a fitting place” Margaret Mead¹⁵

As an ideal vision of society, diversity is either viewed as a means of apportionment to bring forth a fresh perspective, that can be applied to policies in a whole set of issue areas, or as a dangerous notion that may contribute to the alteration of the character of a particular entity. Yet the quest for diversity has been part and parcel of the human rights lexicon; in issue areas like self-determination, immigration, participation, and freedom of expression, for example, claims and counter claims have been advanced by reference to key human rights principles including universal moral respect, non-discrimination, and equal treatment under laws.

From the standpoint of diversity, disability has been addressed by international human rights laws, but this presumes something less than a universal facet of disability. If viewed appropriately as a universal component of the human experience, this may remove it from the diversity discourse. If so, one may question whether it is appropriate for disability to be considered a separate and arguably equal component of diversity at all. A different perspective on the world, brought to the table by any individual who, for example, has a neurological impairment, enriches discourse and provides a unique opportunity for rethinking basic assumptions about the world. Protection of the human rights of integrity or security of the person¹⁶ with disability therefore garners the last corner of human rights riddles to be solved in order to achieve equality for all humanity.

The notion of diversity is in itself unevenly accessible among people with disabilities. Some people believe there is a “disability community” which has some type of qualifying criterion¹⁷. Both: legal systems and people who do not consider themselves

¹⁵ Quoted in: Al Condeluci, Cultural Shifting: Community Leadership and Change Training Resource Network St Augustine Fla 2002 at ix.

¹⁶ United Nations, Charter of the United Nations art. 1 pt. 3 (June 26, 1945), (available at <http://www.un.org/aboutun/charter/chapter1.htm> (accessed Mar. 1, 2005)) 59 Stat. 1031, T.S. 993, 3 Bevans 1153, entered into force Oct. 24, 1945; United Nations, Universal Declaration of Human Rights art. 2, 3 (Dec. 10, 1948) <<http://www.un.org/Overview/rights.html>> adopted and proclaimed by Gen. Assembly Res. 217 A (III), U.N. Doc A/810 p.71 (1948).

¹⁷ The strong variation between definitions of disability under law, even within the social services systems of a given nation, is beyond the scope of this paper. The validity of this approach is underscored by the absence of any definition of disability in the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities Eighth session,

to be disabled often segment the disabled population by the type of disability itself: the law is different, for example, when discussing genetic conditions¹⁸, cancer, chronic long-term illness¹⁹, communicable diseases, pandemic disease with many co-morbid conditions such as such as HIV/AIDS²⁰, physical disability, misunderstood conditions such as alcoholism²¹ or mental health²². Inevitably, the different types of disability discussed under a given component of the law, or the severity of permanent versus short-term conditions, or incapacity due to acute episodes of illness or disease, each challenge notions of culture, health, economic status, security of person or ways of thinking and also the statutory rights²³ relative to the rest of society under national laws²⁴. For

New York, 1425 August 2006 DRAFT CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES and the **Draft Optional Protocol to the International Convention on the Rights of Persons with Disabilities** to be adopted simultaneously with the Convention

¹⁸ Ilise Feitshans, "From Chance to Choice: Genetics and Justice, Invited Review" New England Journal of Medicine Sept 14 2000

¹⁹ Krishna Rampal and Ilise Feitshans "Legal Requirements for Medical Surveillance of Asbestos Workers in Malaysia and the USA" as published in the Proceedings of the VIIeme International Conference on Pneumoconioses, Pittsburgh, PA. 1988 (NIOSH)

²⁰ Ilise Feitshans, Foreshadowing Future Changes: Implications of the AIDS Pandemic for International Law and Policy of Public Health: A Review of AIDS In The Industrialized Democracies: Passions, Politics and Policies, by Ronald Bayer and David Kirp and The Social Impact of AIDS in the United States by the National Research Council, National Academy of Science", 15 MICH. J. INT'L L. 807 (1994), Spring 1994; "Confronting AIDS in the Workplace: Balancing Equal Employment Opportunity and Occupational Health" Detroit College of Law Review Vol 1990 #3 (1990)

²¹ Ilise Feitshans, "Alcoholism in the Workplace: Legal Issues Facing Rehabilitational Medicine Alcohol Rehabilitation: State of the Art Reviews, Vol 3, March-June 1989, Curtis Wright, Ed. Hanley and Belfus Publishers; also Legal and Ethical Issues In Rehabilitation and Involuntary Commitment of Alcoholics Physical Medicine and Rehabilitation: State of the Art Reviews Vol 2. No. 2 Hanley and Belfus Publ. May 1988.

²² As discussed by Rosenthal and Sundram, "many people are subject to discrimination based upon the improper perception that they have a current or past mental disorder." Eric Rosenthal & Clarence J. Sundram, International Human Rights In Mental Health Legislation, 21 N.Y.L. Sch. J. Int'l & Comp. L. 469, 469 n.2 (2002) Cited by Aaron A. Dhi, HUMAN RIGHTS TREATY DRAFTING THROUGH THE LENS OF MENTAL DISABILITY: THE PROPOSED INTERNATIONAL CONVENTION ON PROTECTION AND PROMOTION OF THE RIGHTS AND DIGNITY OF PERSONS WITH DISABILITIES Stanford Journal of International Law Summer, 2005 *181

²³ Ilise Feitshans, Counsel of Record, Brief Amicus Curiae February 2002, In the Supreme Court of the United States CHEVRON U.S.A. INC., v.ECHAZABAL, BRIEF FOR PHYSICIANS WHO TEACH OCCUPATIONAL MEDICINE, Dr. Mark Cullen, Yale University Medical School Department of Occupational and Environmental

example, deaf “culture”²⁵ has a politically-expressed view of its inherent rights as a community under international human rights law ²⁶. But, as a political constituency, it is actually not cohesive, but sorely divided, as witnessed by the recent arrest of protesting students at Gallaudet University²⁷ in Washington DC. Many of those students reportedly view deafness as a source of community and identity with implications for self-worth, thus demanding respect for the person consistent with existing principles of international human rights. One student on campus captured the essence of the analytical plight that seeks to synthesize respect for difference, the ability to learn from difference (that is

Medicine and Dr. Tee L Guidotti, The George Washington University Department of Occupational and Environmental Health, concurring with ACOEM

²⁴ This concept, that different types of disability and the severity or duration of disability are treated inconsistently under national laws is beyond the scope of this paper, and is mentioned only to underscore the magnitude of the analytical problem of attempting to represent the “diversity” of people with disabilities..

²⁵ “Contemporary trends within the human rights discourse tend to embrace the argument that the Deaf community, with a capital “D,” is an ethnic or linguistic minority group that is entitled to rights of recognition and preservation. Based on linguistic orientation, usage of sign language as a primary language, and the Deaf culture, members of the Deaf community further argue for an inherent right to take an active role in the education and the medical decision-making that concern a deaf child. This last contention is founded on the concern expressed by members of the Deaf community that hearing parents have an inherent conflict of interest between their hearing culture and their *1026 child's deafness. Thus, it is argued, their decisions may result in an “inappropriate” oralist education and in cochlear implants for their pre-lingual deaf child. Furthermore, these decisions significantly impact “community membership,” and encourage the child's assimilation into the mainstream hearing culture. Maya Sabatello DISABILITY, CULTURAL MINORITIES, AND INTERNATIONAL LAW: RECONSIDERING THE CASE OF THE DEAF COMMUNITY Whittier Law Review Summer 2005 *1025

²⁶ See: Discussion of: Article 27 of the International Covenant on Civil and Political Rights (ICCPR),”In those States in which ethnic, religious or linguistic minorities exist, persons belonging to such minorities shall not be denied the right, in community with the other members of their group, to enjoy their own culture, to profess and practice their own religion, or to use their own language.” ...members of the Deaf community define their community as a “tightly knit linguistic minority” Maya Sabatello *1025 DISABILITY, CULTURAL MINORITIES, AND INTERNATIONAL LAW: RECONSIDERING THE CASE OF THE DEAF COMMUNITY Whittier Law Review Summer 2005

²⁷ ABOUT 50 STUDENT PROTESTERS at Gallaudet University occupied and locked down an administrative building before dawn on Wednesday, and later that morning, a handful of protesters were injured when they attempted to prevent campus security officers from opening a gate that students had blockaded for about two weeks. The Chronicle of Higher Education October 2006 --> SEE <http://chronicle.com/daily/2006/10/2006102602n.htm>

theoretically expected from diversity) and the realities of living with difference on a daily basis as a thinking human being: "I don't need to be fixed, my brain works fine"²⁸

Although its rhetoric is similar in its desire for respect of human dignity, integrity of the person, autonomy and adequate health care when necessary, these concepts are governed by a different regime under law when referring for example to mental health²⁹, genetic conditions that impact health and well-being³⁰ and mental retardation.³¹ Empirically, "the true, unrecognized source of social bigotry, (is) that literally every woman, child and man walking the earth has a capacity for madness within them, without exception. One variable is the trigger, of which there are perhaps as many variations as there are human beings on the planet. ... such variables are as numerous as is humankind itself. But the basic capacity for a sudden, dramatic shift in perception, belief structure, personal goals, feelings--in fact, the very foundations of a typical life structure--is an attribute shared by all of us, without exception."³² Or, as President George Bush Jr. warned in his nomination speech in 2000, the dangerous "soft bigotry of low expectations" regarding the education and potential achievement of people with disabilities.³³

²⁸ Diana Jean Schemo, "Turmoil at College for Deaf Reflects Broader Debate" NYTimes, October 21 2006 p A9.

²⁹ Aaron A. Dhi, HUMAN RIGHTS TREATY DRAFTING THROUGH THE LENS OF MENTAL DISABILITY: THE PROPOSED INTERNATIONAL CONVENTION ON PROTECTION AND PROMOTION OF THE RIGHTS AND DIGNITY OF PERSONS WITH DISABILITIES Stanford Journal of International Law Summer, 2005 at 182

³⁰, Ilise Levy Feitshans "Genetic Testing During Pregnancy: Implications for Womens' Autonomous Medical Decisions Under the Genome Project" Johns Hopkins University School of Hygiene and Public Health, Thesis for the Degree of Sc.M Department of Health Policy and Management 1996

³¹ Robert M Veatch, The Foundations of Justice,: Wehy the Retarded and the Rest of US Have Claims to Equality Oxford University Press New York 1986.

³² Aaron A. Dhi, HUMAN RIGHTS TREATY DRAFTING THROUGH THE LENS OF MENTAL DISABILITY: THE PROPOSED INTERNATIONAL CONVENTION ON PROTECTION AND PROMOTION OF THE RIGHTS AND DIGNITY OF PERSONS WITH DISABILITIES Stanford Journal of International Law Summer, 2005 *181 citing - Graeme Bacque, Psychiatric Survivor,. Ctr. for Addiction and Mental Health Empowerment Council, Submission to the Canadian Standing Senate Committee on Social Affairs, Science and Technology "Roundtable on Mental Health" 2 (2003), at 182.

³³Consistent with this promise to raise expectations for the disabled, the President of the USA stated "My focus will be on making sure every child is educated, as the president of the United States as well. Both parties have been talking about education reform for quite a while. It's time to come together to get it done so that we can truthfully say in America, , "No child will be left behind, not one single child." (*President Bush's Statement Announcing the Start of His Education Initiative: THE NEW YORK TIMES*

B. Diversity as a social construct that defines disability

Disability, if viewed appropriately as a universal facet of the human condition, has the potential to become a powerful weapon for the solidification of human rights constituencies, because it is a cross cutting issue that unites all people: Everyone has a disability, everyone has a gift.³⁴

Society needs the benefits from each of these features of individual variability to promote human progress and benefit from interdependence³⁵, but this facet of disability is rarely mined in the trenches of daily battles to protect the civil rights and human rights of people whose society gives them the label of “disabled”³⁶. Unfortunately, despite its universal character, disability has too often played out in society as the great divide that separate the vulnerable from the strong: healthy or well versus disabled or infirm, unable to produce. Sabatello has characterized this problem eloquently, “Grounded in assumptions of societal influences and powers, this approach draws attention to the societal environment accounts in order to understand the construction of disability. It stresses that disability is a social construct, an ancillary of the domination of the able-bodied and the subordination of persons with disabilities.”³⁷.

The seminal importance of this medical reality is understated by the term “diversity”. The term diversity implies something static that can be represented proportionally when assembling a meeting or convening a governmental body, in order to ensure a different voice or unusual perspective has been included in the process at hand. While acceptance of difference is essential to understanding, accepting, tolerating and ultimately benefiting from the gifts of individuals despite their disability, there can be no magic formula that proportionately represents people with disability; there is no recipe for disability that predicts or guarantees which people will endure whatever cocktail of

Jan 24, 2001 <http://www.nytimes.com/2001/01/24/politics/24BTEX.html> Federal News Service Inc)

³⁴ Ilise Levy Feitshans and Jay Feitshans, citing Sylvia Levy, WALKING BACKWARDS TO UNDO PREJUDICE: REPORT OF THE US CAPITOL CONFERENCE INCLUDING DISABLED STUDENTS: WHAT WORKS, WHAT DOESN'T (Emalyn Press 2003);

³⁵ Feitshans Jay, Gifted Disabled Deserve Study Retrospect Newspaper p5 May 13 2005 Jay Feitshans, Invited Presentation to New Jersey Office of Special Education Programs (OSEP) Statewide Special Education Advisory Commission (SSEAC) “Not Understood” June 10,2004, Trenton, NJ-

³⁶ Jay Feitshans, Testimony in Support of S. 2142 An Act to Establish the Gifted Disabled Community Needs Study Commission, New Jersey Senate Committee on Education January 24 2005 (archived on the New Jersey Legislature webpage).

³⁷ Maya Sabatello *1025 DISABILITY, CULTURAL MINORITIES, AND INTERNATIONAL LAW: RECONSIDERING THE CASE OF THE DEAF COMMUNITY Whittier Law Review Summer 2005

illness and disabling conditions they must endure in their lifetime. Even when illnesses share a classic co-morbidity, such as the obsessive-compulsive nature of young children with ADD or ADHD to cling to the information they do understand as a compensation mechanism once they realize that their process information differently—pairing of co-morbid conditions is not automatic. Disabling conditions may be acute, long-term or chronic, but there is no predictable formula for their duration or their severity, just as the dilemma posed by co-morbidity. Such linkages as co-morbidity or prognostications of cause and effect can only be estimated and they are never static. Therefore, protecting people with disabilities against societal discrimination and providing appropriate necessary services or accommodations is part of the nature of human variability itself: the population that is to be protected is fluid, changing as new technologies offer treatments and cures, despite the happenstance of daily life.

Even in among the people who are born with a disability deaf, there are some who may be able to leave that community through controversial surgeries or compensatory training. Thus, the community is not static, no matter how its parameters are defined. Instead, awareness and acceptance of individuals who have recognized disability must be ubiquitous in every facet of daily activity, just as it is fluctuating in severity and proportion of the population in daily life. New research and new technologies also may reveal dangers from the empirically under-studied applications of new technologies³⁸. These realities confound any static social construct of disability in society and under law, including the notion of representation implicit in the term “diversity”.

III. The challenges presented to society by problems of Neurodiversity

A. People with disabilities don't fit the “one size fits all” view of society

Life is full of surprises, but none so surprising as the achievement of human potential. The building of the great cathedrals and the vision of the minds that led to them; the writings, backwards, by Leonardo Da Vinci, the beauty of the music from the human voice; all challenge our predisposed sense of reality, our myths about ordinary life as it is supposed to be. Gifts and talents, once demonstrated to society as whole are taken for granted, but what are they really like in their social context? What is it like to live with them? To live among people so unusual that things mundane to them are the stuff of other people's great dreams? And what of the people around them, to whom they express those dreams?

“Neurodiversity” refers to a world of disabilities that was rarely described before the twentieth century—neurological pathways that are unlike those most people assume are the underpinnings of existing cultural norms. These neurological differences manifest themselves in unusual behaviors compared to the traditional modes of expression that are culturally defined, although the individual's contribution to society is no less important.

³⁸ Ethical and Legal Issues Raised By Lymphocyte Proliferation Testing (LPT) Among Previously-Exposed Beryllium Workers at the Request of the Secretary of Energy for the Beryllium Rulemaking Advisory Committee (BRAC) Washington, D.C. Sept. 30, 1997.

According to Selznick,³⁹ invisible disabilities result in the creation of unusual neurological pathways for the language system, spatial order system, motor system, higher thinking system, social thinking system, attention control system or memory system of an individual. Neuropsychologists may debate whether there is a change in the ambient environment or an artifact of better diagnostic tools and reporting as the root cause, but there is a consensus that there exists a higher incidence of autism in the post-World War II generations. Asperger's syndrome and a variety of neurological impairments among high-functioning individuals along the "autistic spectrum" are only a small fraction of the myriad invisible disabilities that impede the typical process of conventional learning. "If 100 LD students were lined up, they may have 100 different variations on the theme of LD"⁴⁰.

People with learning disabilities, who have impairments that affect their visual processing or auditory processing, therefore possess a different way of seeing the world that is innate to them, but unlike the world view theoretically shared by the surrounding collective society. Invisible neurological impairments interfere with processing information, as if the student had two brains: one very fast, taking in information, and one sending out information very slowly. Invisible disabilities make a difference in the ability to perform daily major life activities in the hyper literate society of the 21st century, which might not have mattered a century or two before. For example, slow processing can make it unsafe to drive a car, if the driver needs extra time to understand and process the information on road signs while driving at fifty miles an hour or cannot recall the difference between a left and a right turn. Such conditions held little or no consequence in a society that drove a horse and buggy and did not move with the contemporary technology's lightning speed, but can have lethal consequences in a society where information for highway traffic is displayed on rapidly changing electronic signs.

Thus, neurological impairment impacts an individual's performance of major life activities: seeing hearing, walking, learning even social interactions are governed by a host of auditory and visual cues that must be received by an individual, processed in a manner consistent with the social conventions of their cultural context, and then interpreted into information that can be used by the individual when formulating a response that will be understood as communication within the cultural context of the society at large. Disabilities make the work more difficult, the struggle longer, the triumph of the human spirit that much greater. When listening to the magic sounds from Perlman's violin or Randy Chang's concert piano, the audience does not focus on the crutches of the master violinist or the face of a pianist with Down syndrome; they appreciate the beauty of their talent. When admiring a painting made by a person who

³⁹ Richard Selznick, "Myths and Realities of Dyslexia and Other Invisible Disabilities" IN: Ilise Feitshans and Jay Feitshans, WALKING BACKWARDS TO UNDO PREJUDICE: REPORT OF THE US CAPITOL CONFERENCE INCLUDING DISABLED STUDENTS: WHAT WORKS, WHAT DOESN'T (Emalyn Press 2003); at 22

⁴⁰ Richard Selznick, Myths and Realities of Dyslexia and Other Invisible Disabilities presentation at the conference Great Kids, Great Schools: Identifying Gifts and Disability so that No Child Is Left Behind" Haddonfield New Jersey March 8 2003.

must hold the brush between his toes, many viewers cannot imagine how such beauty was created by the artist's use of his feet.

Once presented with the full package, the gifted person amid the glory of performance, of creative arts, of honored schoolwork, many people will overlook or even deny the presence of flaws or disabilities. Some viewers may never see the disability behind the gift. Not even Frieda Kahlo's tortured images of human pain can mask her inner beauty or betray her disability beneath, to the uninformed observer. And only the trained art critic can find the subtle differences between Monet canvases done in the prime of adult vigor compared to later works created despite failing eyesight. With a gift so obvious and the disability invisible to a viewer miles away from where the canvas was worked, no one knows from the face of the work itself about the disability that just happens to be in the background. Disability, although present, that can easily be denied.

Gifts may not be so obvious, however, when the work is incomplete. A student's goal may seem to be unrealistic or overly ambitious, when viewed from the embryonic or infant moments of time before a great human project is done. Examining the person before the time of results, in the early years of childhood when potential is everywhere and no one has yet uncovered the individual's gift, may be a very hard time. In those first three to five years of life, only the extraordinary gifts are obvious, often in the form of a prodigy who is unlike anyone else and therefore, by definition, has few peers and learns differently from everyone else. In those early years, disability masks the gift.

There are many myths about the role of disabled students in a mainstream classroom, which can only be dispelled by greater information to the general population⁴¹. One myth is the belief that extended time is an advantage given to some disabled students. Yet no student would sit inside a classroom, taking an hour or two longer than peers to complete an exam when that student can be playing outside instead. Extra time will not give a student knowledge the student lacks, or provide talent that is not already present. Many people will never be able, for example, to dance the lead role in Swan Lake or play violin or undertake translation of literature from Ancient Chinese to Modern Greek, even if they are given fifty years to do the tasks involved. Extended time is therefore a low-cost mechanism of ensuring that students who have difficulty in writing, reading or organizing their written expression can perform at their strongest level.⁴² Like a still, deep pool of water with many facets and reflections, the wonder of finding someone's gifts despite or because of their disabilities unleashes all the questions of existence, and unfurls all the beauty of divine mysteries. Surely, in finding the gift in even the least obvious of populations, there is only faith in a master plan of nature or pure unvarnished human spirit to be the guide.

⁴¹ KristenGraham, "Sharing Views and Dispelling Myths About Disabilities: At Conference on Inclusion, Students Address Disabilities" Philadelphia Inquirer April 11 2001

⁴² Lambros, Katina M. and Leslie, Laurel K, "Management of the Child With a Learning Disorder, Pediatric Annals Vol 34 Number 4 April 2005 p. 275-287 at 277

⁴² Desmond P Kelly, "Learning Disorders" Pediatric Annals Vol 34 Number 4 April 2005 p. 260

There is human potential in everyone, and the educator's job is to bring that potential forward into the rest of the world. If people refuse to ask the deeper hard questions about potential and performance, gifts remain hidden except when they are most obvious. And if no one aggressively seeks to unlock the gift that has been covered by disability, the label that child bears for life is one of stigma and disability. Too often, in generations past, acknowledging a child's disability was akin to a death sentence. The life ahead was one of disappointment for parents, who realized in their child only in terms of lost potentials. The child was likely to be spirited away for a closet life in an institution. Retardation, nervous conditions, contagious diseases, mental illness and low functioning associated with the unstable economic status of orphan children all share a torrid history of segregation away from the so-called norm – even though there really is no norm. Even though no child is really in the middle of the mythological continuum in every place; even though the norm is a composite of aggregate human experience; a science fiction for learning and teaching.

Two roads to promoting the human potential long ago emerged in the parted theories of disability education. For children who have disabilities, the road taken has made all the difference. In one – a charity model – views people with disabilities as having limited potential. Their disability, whether physical or cognitive, limits where they can go in society, what they are capable of achieving and ultimately, their ability to contribute to human progress. In such a view, the educator's job is to make life better for those “poor suffering disabled people.” Somehow, the human potential of the individual gets lost in this model and people are easily relegated to segregated settings that accentuate their difference from the mainstream population and limit their ability as socially defined.⁴³

Then there is the human potential model. This model presumes that everyone has a gift; that each person, no matter how obvious their physical or mental disability may be, has something to contribute to the greater society. This model eschews conventional notions of “survival of the fittest” and redefines “fittest” to entertain the possibilities that in one context may appear normal, but in another context is just strange. Like the rocket scientist, whose concerns and ideas about the composition of cosmic gasses are welcomed by NASA but are so odd at a family dinner table. One can only wonder what the world would know had Da Vinci not been so constrained by the conventional views of his world that he felt compelled to fill his notebooks backwards. Unless of course, he was undiagnosed although dyslexic or dysgraphic as well as unconventional.. There is an alternative approach, a road not taken all that often because it is so uncharted. A path that relies on instinct that drives human potential, with almost a divine mysticism about the belief that people, given a wide variety of exposures and opportunities at a very young age, can express their gifts despite any flaws or disabilities. Under this belief system, flaws can actually be converted to assets in the right context. Like the obsessive-compulsive who makes for an excellent research scientist, meticulously trying the same

⁴³ Ilise L Feitshans, *Gifts and Disabilities: Two Sides of the Same Coin*, Lecture for the Barnard College Department of Education November 2004, excerpt from **WALKING BACKWARDS TO UNDO PREJUDICE: REPORT OF THE US CAPITOL CONFERENCE INCLUDING DISABLED STUDENTS: WHAT WORKS, WHAT DOESN'T** (Emalyn Press 2003).

experiments again and again, making minor alterations in methods until getting it to come out right. Gifts and disabilities are not polar extremes. In fact, these features are inextricable facets of every person, each deserving a fair and equitable opportunity to explore creative avenues. Use technology—videos, PowerPoint, music, performance and assistive devices—to replace written expression. Offer unusual opportunities for those with disabilities to excel and to try new programs; measure personal progress against their own level, not communitarian benchmarks.

The contributions from preserving neurodiversity are thus a social good. In this sense, difference is a benefit, a source of creativity that is derived from the perspective of their unique way of seeing, hearing, learning and processing information in the world.⁴⁴ Thus, it behooves international human rights systems to ensure that neurodiversity is preserved and equal treatment of people with invisible disabilities is not denied.

B .People with disabilities fit the principles or human rights norms but are not represented adequately under law.

The World Health Organization (WHO) Constitution states:

"The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being.... The achievement of any State in the promotion and protection of health is of value to all".

The dilemma for human rights systems devoted to promoting diversity insofar as that notion applies to people with disabilities⁴⁵ is a question of balance. A social and legal dilemma posited by the demands for respect; a community; and the right to maintain their identity despite their disability so vociferously expressed by deaf people, (discussed above), people with other invisible disabilities believe that they have much to contribute to society. There is a balance to be struck between learning compensatory strategies that enable people with identified disabilities to blend into the larger society, in contrast to a lack of respect from society that requires one to be “fixed”⁴⁶ or changed. Diversity might present the larger population within a community with a novel approach or vulnerable population’s view, and compensation strategies may help some individuals swim in the mainstream of society, but this can only be successfully accomplished without sacrificing basic human rights such as identity or respect for the individual, as codified in existing international human rights laws.

Several international human rights instruments, such as the United Nations Charter and the Universal Declaration of Human Rights (1948) and more recently, the International Convention on Population and Development, Cairo 1994 contain discussion of human rights to health; the theoretical counterpoise to disability. The most widely accepted definition of “health” in the international corpus of human rights is articulated in the preamble of the World Health Organization (WHO). Its Constitution has a two-

⁴⁴ Jay Feitshans, Testimony Before the New Jersey Special Education Review Commission, Trenton New Jersey, October 17 2006

⁴⁵ Arguably, this is a flawed approach if one accepts the notion that the universality disability as a part of the human condition requires awareness leading to tolerance and acceptance, rather than tokenism reflected by “diversity”.

⁴⁶ NY Times October 21 2006

page definition of health, which has been widely copied in literally hundred of international conventions, treaties and multilateral agreements, beginning with the terms:

“Health is a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity”.

This remarkably broad definition of health as an ideal and as a succinct statement of the human condition bespeaks the basic human need for health. For this reason, it has been the undisputed benchmark of many practical standards as well as a host of national health laws. The referent power of this definition in international human rights law has been so vast that it has survived and been adapted to unforeseen problems in health, such as the HIV/AIDS pandemic, as effectively as it has been used to cure and prevent ancient problems, including the eradication of some diseases through international co-operative efforts without being modified or amended through international legislation.

This definition therefore provides an outstanding theoretical framework for practical standards and for the goals of public health policy in general and reproductive health programs in particular, as well as disaster planning and emergency evacuations. The drafters of the WHO Constitution also understood the notion of latent disease, which is of increasing significance in the areas of reproductive health and human reproductive toxicology, whereby long-term exposures that may appear to be harmless at the outset may, after many years, take their toll due to a cumulative effect.⁴⁷ This development is of fundamental importance for all health protection programming, and explains the rapid and widespread acceptance of this seminal language in all international health jurisprudence. These principles⁴⁸ are addressed, if not fully resolved, in the United Nations Charter; in the Universal Declaration of Human Rights (UDHR); Articles 7 and 12 of the International Covenant on Economic and Social Rights; and subsequent standards by the International Labor Organization (ILO) and World Health Organization.

The next problem is how to characterize or prioritize the various rights and attributes to be protected associated with disability. Although Shue eschews prioritization of human rights, even he concedes that in some contexts, one right will take center stage over another and therefore implementation of international human rights protections generates priorities⁴⁹. Under which rubric should the human rights community prioritize the protections against harmful discrimination and obligations to

⁴⁷ Frank P. Grad and Ilise Levy Feitshans "Article 12- Right to Health" IN: Hannum, Hurst and Fischer, Dana, [Eds.] U.S. Ratification of the International Covenant on Human Rights American Society of International Law, Washington, D.C.; Transnational Publishers, Inc. Irvington-on-Hudson, New York (1993).

⁴⁸ A mutual dependence holds both between enjoyment of rights to some liberties and enjoyment of security and subsistence and, in the other direction, between enjoyment of rights to security and subsistence and some liberties” Henry Shue, BASIC RIGHTS: Subsistence, Affluence and US Foreign Policy , at 70

⁴⁹ “. . . it is hopeless to construe the problem so broadly as a contest between the economic and the political”. Henry Shue, BASIC RIGHTS: Subsistence, Affluence and US Foreign Policy at 7

provide basic human needs that are brought to the fore in discourse about the rights of people with disabilities?

Social and economic rights as usually attributed to health? Or is it a civil right? The answer is probably an admixture of the two characteristics of each human rights domain reflected in the two separate covenants. Certainly health rights are necessary to support a vulnerable disabled individuals, regardless how disability is ultimately socially or legally defined. At the same time, it is clear that the equal treatment of individuals with disabilities is a matter of security of person against the state and as against the violative behaviors of other individuals. While Shue and his contemporary commenters viewed protection of security and integrity of person as everyone's "reasonable demands upon the rest of humanity", in the case of the rights of people with identified disabilities, societal attitudes create an artificial separation that confounds the implementation of the beautiful ideals at the bottom of this analysis.

Prejudice overtakes understanding of individual difference, tolerance gives way to fear of the uncertain and unknown. Disability rights therefore tantalize international human rights norms by appearing at first blush to be a matter of economic rights, involving: well-being; the right to learn and be educated regardless of a necessary change in format; and access to the delivery of appropriate medical care. Yet, in essence the various quirks genetic idiosyncrasies and health status short-comings of individuals are perhaps the greatest difference between individuals. Thus, protecting the international human rights of people with disabilities ultimately challenges the implementation of essential protections for the integrity of the person and calls into question each person's understanding of basic human rights.

IV. Opportunities for the promotion of human rights standards.

Differences that pertain to individual disability enable the human rights community to explore the essence of rights to health, education, security of person, privacy, freedom from governmental intrusion into the person and protection from discrimination by asking, "Human Rights? *Are they for Everybody?*"

At the end of World War One, "the War to end all wars" a world illuminated by optimism began exploration of an international legal system to protect human rights. According to Shue, quoting Hohfeld,

"Rights are not mere gifts or favors motivated by love or pity for which gratitude is the sole fitting response. A right is something that can be demanded or insisted upon without embarrassment or shame"⁵⁰

As often summarized, "Since the end of the Second World War, the international community has adopted seven binding treaties dealing with the human rights of persons with a wide variety of different statuses. Only one, however, even refers to the issue of disability despite the acknowledged fact that persons with disabilities make up one of the

⁵⁰ Henry Shue, BASIC RIGHTS: Subsistence, Affluence and US Foreign Policy p 58-59 citing Feinberg, who was citing Wesley Hohfeld, FUNDAMENTAL LEGAL CONCEPTIONS New Haven, Yale University Press 1923. It is useful to recall too that when this text was first published, women in the USA had obtained suffrage only four years before. It is easy to imagine some very dignified strident women demanding their right to vote in Hohfeld's then-recent experiences.

largest global minority groups, and that the rights of this class of persons have been systematically violated in virtually all societies. Indeed, while the development of contemporary international human rights law since the 1948 Universal Declaration of Human Rights has advanced the interests of a number of marginalized, equality-seeking groups, it has simultaneously neglected those who are arguably the most vulnerable to powerful, legalized coercion: persons diagnosed with mental disabilities. Degrading living conditions, coerced "treatment," scientific experimentation, seclusion, restraints--the list of violations to the dignity and autonomy of those diagnosed with mental disabilities is both long and egregious⁵¹."

It has taken the three decades since the founding of the Center for the Study of Human Rights at Columbia University to scratch the surface of this inevitable analytical problem: how to recognize individual variability that takes its expression in a diverse and rich panoply of differences, while ensuring that people are treated the same. In the late 1970's many human rights institutions were enmeshed in the Cold War ideologies, whether inadvertently or in response to funder's design. Several USA-based human rights institutions focused very sharply on international human rights in one half of the United Nations Charter: the International Covenant on Civil and Political Rights⁵². The sound of freedom that resonates from civil and political rights rings hollow to a newborn who has low birth weight, because the baby's mother had no access to a clean workplace, or died due to occupational accident or occupational disease. Freedom from these harms is every child's birthright., and, as Shue attempted to explain in 1979⁵³, the attempt to prioritize these rights is both important and silly at the same time due to their ongoing interdependence. This did not prevent the great divide of Civil and Political versus Economic and Social from becoming the Cold War's version of a political football. The home team won, with the dismantling of the Berlin Wall, appropriately carried by satellite thanks to a free press internationally on tv. Many artificial divisions between civil and social rights were also destroyed with the removal of the Berlin wall, and that opened the floodgates for an undivided international human rights community to embrace the interdependence of human rights concepts such as "Health for All" 2000.

⁵¹ Aaron A. Dhi, HUMAN RIGHTS TREATY DRAFTING THROUGH THE LENS OF MENTAL DISABILITY: THE PROPOSED INTERNATIONAL CONVENTION ON PROTECTION AND PROMOTION OF THE RIGHTS AND DIGNITY OF PERSONS WITH DISABILITIES Stanford Journal of International Law Summer, 2005 *181

⁵² United Nations, International Covenant on Civil and Political Rights art. 27 (Mar. 23, 1976) (available at <http://www.unhchr.ch/html/menu3/b/a_ccpr.htm> opened for signature Dec. 16, 1966, Gen. Assembly Res. 2200A (XXI), 21st Sess., U.N. GAOR Supp. (No. 16) at 52, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 171, entered into force Mar. 23, 1976 [hereinafter ICCPR]

⁵³ "I will not be defending the thesis that all economic rights take priority over all other rights, a thesis as crude and implausible, I think, as its sometime rival, the thesis that all political rights take priority over all other rights" Henry Shue, BASIC RIGHTS: Subsistence, Affluence and US Foreign Policy at 7

These basic rights, in turn, must be respected in a societal setting, whether the acting party who encounters an individual with disabilities is another person, a corporate entity or the government⁵⁴. The importance of civil rights against discrimination and favoring respect for the integrity of each person therefore are of co-equal importance when discussing the role of international human rights laws in the lives of people with disabilities, as demonstrated by the discussion of each of the International Covenants that amplify the Universal Declaration of Human Rights, in the next section.

A. Money Money Money: Disability as Subject Matter of Social Economic and Cultural Rights Under the ICESCR

When evaluating policies about the needs of people with disabilities, there can be little doubt that the overarching importance of protections assured by the International Covenant on Social Economic and Cultural Rights (ICESCR) leaps to mind. Few people can imagine a loss of physical or mental health status without a concomitant set of health services—medicine, treatment or long-term assistance in the major activities of daily living. And, one of the most destructive myths experienced by people with disabilities is embodied in the notion that due to certain aspects of their individual inability, they can't do anything without help.

So too, education, although problematic from the standpoint of international human rights assurances, takes on a different complexion when young students need help to read, write, develop fine motor skills, process data or endure the logistics of education that seem ordinary to peers who do not request help. Multi-sensory learning techniques and major breakthroughs of inexpensive, labor saving “assistive technology” have changed the educational prognosis and thus the lives of many individuals with neurological impairments or physical disabilities. These factors would therefore lead policy analysts to the conclusion that the whole matter of international human rights regarding disability, and the diverse needs and diverse perspective that such individuals brings to human rights discourse is solely a matter of health and education. Whether this notion is correct, however, depends on the context of the rights to be discussed. In some instances yes. For example, when assistive technology can provide the answer to the inability to speak in a manner that is understood by the general public in the society at large; when voice activated software can take notes for a student who cannot write due to the lack of fine motor skills or the inability to decode using visual processing. This is the rare situation, however; it is therefore unlikely that the criterion that determines these issues is money. Instead, prejudice is an overarching obstacle to realizing every child's right to learn. this situation can be remedied by changing attitudes and the use of assisted technology. for high-achieving, gifted disabled students. In both the public and private sector, garden variety prejudice against the disabled is an obstacle to education. Prejudice prevents assimilation into the mainstream; a barrier to realizing the right to learn⁵⁵.

⁵⁵ The litany of state and federal complaints in just a one family (Campbell, Sara, a Disabled Minor and Cynthia Cline Campbell, Her Mother v. Haddonfield School District US DOE OCR Case No. 02-991244; Sara Campbell, a Disabled Minor and Cynthia Cline Campbell, Her Mother v. Haddonfield School District, US DOEOCR Case No. 02-

One core value of in the USA, as in many other nations, involves preparing posterity for the future through education. Schools and academic institutions fulfill this function, which is considered to be part of the Economic, Social and Cultural rights matrix that operationalizes subsistence rights under international human rights laws. Public education in particular, has long been a pillar of promoting the collective understanding about culture, subsistence and individual rights in many nations. This is borne out by the demographic reality that millions of people in this nation have attended and benefited from public education for centuries.

Education is not a constitutional right in the USA, but, using the magic legal theory called "federalism" which defines the role of the federal government for funding public schools in relationship to the individual states, the US Congress mandates not only standards for education, but also the requirement that students who are classified as having "special needs". The "Individuals with Disability Education Act" (IDEA) purposes include but are not limited to: identify disability, remediate disability and enhance the areas of their abilities to become productive leaders, taxpayers, voters and parents for the benefit of all society⁵⁶. In the USA, the notion that students with special needs who fit certain categories of disabilities is protected by the statutory right to a "Free Appropriate Public Education" (FAPE). Consequently, there is a tacit, if not express, social contract between the individuals, the federal government and the states to provide for FAPE beyond any statutory requirements. When a situation rises to the point where parents must sue a school district in order to educate their child, there is an implicit question of accountability and a sense of betrayal by the school district in upholding its part in this long-standing reliable social contract.

As a result, there is an unmet need: to fix a broken system for students with identified disabilities, despite the prohibition of discrimination and the vehicles for advancement of equal opportunity under state and national statutes, consistent with the fundamental tenets of international laws and the 2006 UN Draft Convention, discussed below. Everyone needs more information about laws protecting people with disabilities, and about treatment or support for people with disabilities. Public school districts, although strapped by tight budgets, might well save money by simply providing necessary services that many schools fail to provide. By respecting human rights under existing laws society can do more with the existing resources without spending a dime. It costs nothing to give a child ungraded spelling or to intervene when a disabled child who

00-1220; Sara Campbell, a Disabled Minor and Cynthia Cline Campbell, Her Mother v. Haddonfield School District NJ DOE Complaint No. C2000-1019; Sara Campbell, a Disabled Minor and Cynthia Cline Campbell, Her Mother v. Haddonfield School District NJ DOE Complaint No.2002-1510 demonstrates the problems implementing these rights within nations.

⁵⁶ In order to promote these goals, under US Law, every student in the USA has a right to claim the need for services or special education. Under the IDEA, a State must have in effect "policies and procedures to ensure that .. [a] free appropriate public education is available to all children with disabilities residing in the State...." 20 U.S.C. § 1412(a). (FAPE) IDEA's statutory mandate requires the creation of Individualized Education Plans (IEPs) in order to achieve the potential in each disabled student

needs assistive technology is harassed by peers; yet few people have the time, money or knowledge of the system to expend in order to ensure the wise use of these resources. It is very likely therefore, that the root cause of the widening separate but extremely unequal system of education is garden variety prejudice: attitudes that have been ingrained for centuries suggesting the need to provide charity to the disabled while overlooking or denying their human potential. Consequently, all of society suffers by bearing the cost of low expectations that, in turn reduce the viability of each individual's economic and social rights as protected by international laws. Few people will deliberately violate laws when compliance is the social norm; few people will wake up in the morning with the mindset to state a racist comment, break laws or deliberately hurt a disabled student once they have been taught the rights and obligations regarding equal opportunity under law. But the prejudice that results from lack of awareness of individual rights can be, in itself, an obstacle to the implementation of the full panoply of protections and rights to be enjoyed by people with disabilities under law.

B. Whose Prejudice Is It? Civil and Political Rights That Amplify the UDHR

Everyone is different .. but... Everyone is the same
There is a fundamental tension in this paradox. No two people have precisely the same DNA or life path following personal decision; yet everyone has basic human needs whose protection is reflected in international human rights laws and fundamental accepted tenets of the US constitution and civil rights acts. The entire legal apparatus of our social protections for civil rights and civil liberties is predicated on this notion that individual difference and universal components of the human condition are Not mutually exclusive. We are different, yet we are all the same.
Balancing this paradox is not easy. It is easier to forget the balance needed in this paradox in daily life, even when discussing laws such as the Universal Declaration of Human Rights, UN Charter and human rights covenants. There is inequality, harm to individuals, whether inadvertent or deliberate, when the delicate balance of this paradox is forsaken. In daily life, it is easy to overlook human qualities such as intellect and ability to love in people with disabilities or people of a different race, religion or ethnicity. Yet, it is universally true that each person needs to be respected, to use housing, public health care, equal opportunities to education, and freedom to express our differences with impunity, in order to survive. Each house, each disease, each method of learning may be different, but regardless whether one discusses prevention of discrimination based on race, religion, ethnicity or disability there are basic human needs. *Everyone has a disability and everyone has a gift* that when addressed properly teaches us, informs and enriches our lives. Like a fine silk thread in the social tapestry, learning from difference without harming people based on difference is a difficult balance that the authors of the US Constitution profoundly understood. When there is balance, We embrace our diversity yet we are one

The concept of this fine balance runs like a thread throughout the law, but it is fragile. When people are overwhelmed by difference and cannot figure out how to restore the delicate balance and prevent further harm, there is indifference to human rights. Ending this imbalance requires a conscious effort to protect freedom from the effects of prejudice stigma, discrimination and the impact of physical harm rooted in prejudice

The role of diversity in this area soon becomes self-limiting, because it can ensure representation and a celebration of difference from which people learn, but the concept cannot be operationalized in a manner that makes the protections under the International Covenant on Civil and Political Rights (ICCPR) manageable in the daily lives of people with disabilities. For example, *Article 12 Everyone lawfully within the territory of a State shall, within that territory, have the right to liberty of movement and freedom to choose his (sic) residence*⁵⁷”

Applying this concept in the daily lives of people with disabilities is problematic and often the flashpoint for major controversies, within families, within health care institutions, and on a national policy level. This is evinced in the text of the draft protocol before the United Nations, wherein people with identified disabilities have especially noted the rights to autonomy and privacy that able-bodied people may never find questioned⁵⁸. For this reason, protocol’s text tries to fill this void. Concepts first articulated in ICCPR are found throughout the draft, including but not limited to: Articles 18, 19, Living independently and Being Included in the Community; 20 and 23 to be adopted simultaneously with the Convention

As the draft convention tracks the ICCPR, in so doing it also calls into question embedded prejudices that are part of many English-speaking nations, including the international human rights culture. The most startling of these examples is the notion that a legal process is a “hearing” and that the right to communicate and express oneself with impunity involves “Freedom of Speech”, a term of art that is used within the draft itself despite the its unspoken dilemma as a lexicon for people who are deaf or who cannot communicate due to autism, cerebral palsy, after-effects of chemotherapy or other medical treatments, or a variety of physical disabilities. The multisensory definition of “Communication” in the draft can only enhance “Free Speech”, it includes spoken and signed languages, display of text, and Braille, and tactile communication, large print, written, audio, accessible multimedia, plain language, human reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology;⁵⁹

⁵⁷ United Nations, International Covenant on Civil and Political Rights art. 27 (Mar. 23, 1976) (available at <http://www.unhcr.ch/html/menu3/b/a_ccpr.htm> opened for signature Dec. 16, 1966, Gen. Assembly Res. 2200A (XXI), 21st Sess., U.N. GAOR Supp. (No. 16) at 52, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 171, entered into force Mar. 23, 1976 [hereinafter ICCPR]

⁵⁸ Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities Eighth session, New York, 1425 August 2006 DRAFT CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES and the Draft Optional Protocol to the International Convention on the Rights of Persons with Disabilities

⁵⁹ “Communication” includes spoken and signed languages, display of text, and Braille, and tactile communication, large print, written, audio, accessible multimedia, plain language, human reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology; Ad Hoc Committee on a Comprehensive and Integral International Convention on the

Similarly, ICCPR Article 21 “the right of Peaceful assembly” and Article 22 “Everyone shall have the right to freedom of association with others” are problematic for people for whom daily life activities are fraught with questions of autonomy. The ICCPR does not discuss, but the draft convention does fully contemplate, a method for striking the balance between illusory rights to autonomy and interdependence with respect ad dignity for people whose lives are governed by the abilities and limits of their assistants due to the individual’s disability. For individuals with severe disabilities, regardless whether acute or long-term, issues of autonomy swiftly can consume any efforts towards successful political activity. Article 25 “Every citizen shall have the right and the opportunity without... unreasonable restrictions...(a) To take part in the conduct of public affairs... (c) to have access, on general terms of equality, to public service in his (sic) country”.

The far-reaching impact of implementing such protections for freedom, autonomy and respect for individual rights implicit in this notion goes deeper than merely providing a ramp to the voting booth, although such reasonable accommodations, in clear juxtaposition to “unreasonable restrictions” may be a place for the political rights analysis to start. Similarly, ICCPR Article 27 “minority rights” as discussed above in Section I of this paper, provides a limited appropriate analysis because of the universality of disability in the human experience, despite the possible existence of an identifiable deaf subculture or subcultures of associations that coalesce around long-term chronic disease or lifelong illness, (ie autism, cystic fibrosis, breast cancer, etc)

Lastly, no discussion of the ICCPR would be complete without mentioning its limits, which are far more ubiquitous than the absence of food, health care or sound and accessible institutions for education that can act as a self-check on ICESCR compliance. By contrast to compliance with its sister covenant which may be evaluated using standardizable outcome measures (reduced infant mortality, increased levels of education in a general population, etc), the value and in turn the actual realization of the protections ensured in ICCPR are subjective at best, illusory at worst.

The ICCPR has long been criticized for its promise of remedies articulated by *rticle 2 Part II Article 2 “Each State Party to the present Covenant undertakes to respect and to ensure all individuals... 3.(a) To ensure that any person whose rights or freedoms as herein recognized are violated shall have an effective remedy , notwithstanding that the violation has been committed by persons acting in an official capacity.*

As in the case of many United Nations documents, this language is strongly tied to the USA’s civil rights heritage. The Covenant tracks, almost verbatim, the US Congressional statute from the nineteenth century that granted individuals the right to sue their government for harms and injuries against the person, 42 USC Section 1983, (discussed below) Historically the first expression of individual rights against

Protection and Promotion of the Rights and Dignity of Persons with Disabilities Eighth session, New York, 1425 August 2006 DRAFT CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES and the Draft Optional Protocol to the International Convention on the Rights of Persons with Disabilities to be adopted simultaneously with the Convention

government activity that abridges rights of an person is therefore well rooted in precedent, articulated mid-twentieth century in the United Nations international human rights documents, and bears a close nexus to current UN draft (Aug 2006). In sum, the law and precedent exists; implementation is a matter of social morality and political will.

C. United Nations Draft Convention On The Rights Of Persons With Disabilities

After many years of writing and lobbying throughout the United Nations system progress has been made towards a more concrete view of human rights for people with disabilities under international laws in the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities Eighth session, New York, 1425 August 2006 DRAFT CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES and the Draft Optional Protocol to the International Convention on the Rights of Persons with Disabilities to be adopted simultaneously with the Convention. Inclusion is the key to successful interdependence; exclusion runs the risk of losing the precious human resources that will save all of society.

The Preamble in Section C- bis avoids a definition of disability, but does offer a suggestion of the target population for the protections articulated in the draft Covenant,

“Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others,...

Persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

According to the draft covenant, “Discrimination on the basis of disability” means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation; (which the convention later defines, using an approach that closely follows the USA model in the Americans With Disabilities Act). The notion of “help” or caregiving assistants such as nurses and health care staff is replaced with the non-labor –specific term, which can embrace assistive technology, or even social infrastructure implied by the term “intensive support”.

Significantly, there is no definition of disability in this document. This decision was not an oversight, but does avoid problematic thorny questions such as who is disabled? Does coverage in one jurisdiction imply reciprocal obligation for coverage in another? The flexible framework can be used to address new diseases as addressed by WHO so artfully, without the problem raised when offering a “laundry list” of acceptable diseases or disabling conditions—a list that can be too short too sweeping as technology advances medical care globally across time. Most importantly, this approach taken in the draft avoids recrimination for those nations that do not have a national health care system, because there would not be a way to include protections of disability analytically without embracing the national term for disability.

This draft convention is comprehensive but is it too long to be practical? The draft covers the gamut of available concepts for individual rights protections, drawing on precedents from many areas of international human rights legislation, including but not limited to Equality And Nondiscrimination ; Article 6 - Women With Disabilities; Article 7 - Children With Disabilities ; Article 8 Awareness-Raising; Article 9 – Accessibility; Article 10 - Right To Life; Article 11 - Situations Of Risk And Humanitarian Emergencies; Article 12 - Equal Recognition Before The Law; Article 13 - Access To Justice ;Article 14 - Liberty And Security Of The Person ; Article 15 - Freedom From Torture Or Cruel, Inhuman Or Degrading ;Treatment Or Punishment; Article 16 - Freedom From Exploitation, Violence And Abuse; Article 17 - Protecting The Integrity Of The Person; Article 18 - Liberty Of Movement And Nationality; Article 19 - Living Independently And Being Included In The Community; Article 20 - Personal Mobility; Article 21 - Freedom Of Expression And Opinion, And Access To Information; Article 22 - Respect For Privacy; Article 23 - Respect For Home And The Family; Article 24 – Education, and an innovative section on “Awareness” that reads like the outline for a sound textbook on public health policy.⁶⁰

Whether the draft will gain acceptance and become practicable is not, however, as important as it may seem. The immediate need is to end prejudice, already outlawed by international human rights systems, and to end the harm that prejudice brings. According to Ne’eman, “The long term societal effects of educational prejudice is an issue that have been discussed at length. Experts today look at many of the greats of the past and identify traits that today would be classified as disabilities. Da Vinci, Einstein, Michaelangelo, Mozart, Jefferson and Newton all have been identified by many as sharing the same neurology that originally resulted in my placement in an out of district placement. There is insufficient understanding - by the general public and by the medical and educational establishment- that the perceived deficits of different styles of thought and perception are inseparable and often identical to the significant and important gifts that the neurodiverse so often possess. Focusing on that will allow this project a unique opportunity to make an impact. A handful of students represent the systemic success stories - in college, studying towards interesting and successful careers and so on. But there are still so many who don't get to where we are. They suffer and they lose out on success and prosperity

⁶⁰ In this sense, much of the draft legislation in the “Definitions” section reads as if it were a textbook for “social change Language” includes spoken and signed languages and other forms of non-spoken languages; “Reasonable Accommodation” means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms; “Universal design” and “inclusive design” mean the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. “Universal design” and “inclusive design” shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.

needlessly. So much of what can be done to improve the system has to do with changing attitudes and fighting ignorance. No one can do that if we do not.”⁶¹

D. Individual protection against government at the heart of 42 USC 1983 and the human rights conceptual matrix

§ 1983. Civil action for deprivation of rights

Every person who, under color of any statute, ordinance, regulation, custom, or usage, of any State or Territory or the District of Columbia, subjects, or causes to be subjected, any citizen of the United States or other person within the jurisdiction thereof to the deprivation of any rights, privileges, or immunities secured by the Constitution and laws, shall be liable to the party injured in an action at law, suit in equity, or other proper proceeding for redress, except that in any action brought against a judicial officer for an act or omission taken in such officer's judicial capacity, injunctive relief shall not be granted unless a declaratory decree was violated or declaratory relief was unavailable. ...”

Although 42 USC Sec 1983 was written in 1871 and has been used successfully to protect the rights of individuals for nearly a century and a half, few non-lawyers even know of its existence. Its genius is in its simplicity, which extends rights and privileges to anyone in the USA who has had their rights infringed upon under the “color of authority” This series of rights includes statutory rights, and thus, by extension, all rights to protection against discrimination based on disability under ADA. Federal funding for schooling through IDEA and Rehab Act means that 42 USC 1983 also applies to special education in the USA. The US Congress intended that § 1983 be construed in light of common-law principles that were well settled at time of its enactment⁶² According to Dowling, “The due process clause brought down from Magna Carta was found in the early state constitutions and later the Fifth Amendment to the [USA] federal constitutions as a limitation upon the executive, legislative and judicial powers of the federal government ... The due process clause requires that every man shall have the protection of his day in court, and the benefit of the general law, a law which hears before it condemns, which proceeds not arbitrarily or capriciously but upon inquiry, and renders judgment only after trial, so that every citizen shall hold his life, liberty, properties and immunities under the protection of the general rules which govern society”⁶³

The social context in which this revolutionary notion that rights such as those articulated in 42 USC 1983 were written by the US Congress involves the need to protect the integrity of the person against violent harm and severe economic discrimination, in

⁶¹ Ari Ne’eman, college student and member, Special Education Review Commission, for the State of New Jersey, personal correspondence by email.

⁶² . Kalina v. Fletcher, U.S.Wash.1997, 118 S.Ct. 502, 522 U.S. 118, 139 L.Ed.2d 471.

⁶³ Noel S Dowling, Cases on Constitutional Law, Third Edition The Foundation Press Chicago, 1946, Citing Hurtado v California 110 US 516, 535, 4 S Ct 111, 120; 292 28 L.Ed 292

the wake of the US Civil War of the 1860's.⁶⁴ This notion is consistent with commenters regarding the US Supreme Court, which declared unconstitutional other portions of the same statute, but maintained this unique set of statutory rights against harm to the individual despite the acts of the federal government under the guise of using its “color of authority” under USA laws.⁶⁵ The imprint of this tiny statute remains clear in the cultural matrix of international human rights protections for individuals, including the UN Draft in 2006⁶⁶.

E. A View From the Trenches of Civil Rights Warfare On Behalf of Disability Rights to Education in the USA

Winning Civil Rights is not a spectator sport. Discrimination that results in the abridgement of social and economic rights to education and health care, or the abridgement of civil rights for disabled students impedes the achievement of every student's Right to Learn.

Although there is no such thing as spending too much money on education; at the same time when billions and billions of dollars have been spent, whether for public or private education, it is fair to question whether those dollars have been spent wisely or equitably. Millions of students enjoy some mainstream coursework in so-called “regular education” classrooms, with relatively small overhead for items such as notetaking, some assistive technology (AT) ungraded spelling, a private room for tests, sitting at the front of the room for purposes of attention or vision, and extended time on exams³. Some students use AT such as draftbuilder, inspiration or co write software for writing; or scanned documents from Kurzweil Reader or Winword program. Such students use AT equipment that represents a one-time fixed cost to the school system, and the increased usage of said equipment provides in effect a reduced cost because of economies of scale,

⁶⁴ Louis M Hacker and Benjamin T Kendrick, *The United States Since 1865*, Third Edition New York F.S. Crofts and Company 1947, Chapter II Fruits of Victory.

⁶⁵ Charles Warren *The Supreme Court in United States History In Two Volumes Vol II* Revised Edition Boston Little Brown and Company 1935, “The Civil Rights Cases” at 617-618

⁶⁶ Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities Eighth session, New York, 1425 August 2006 DRAFT CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES and the Draft Optional Protocol to the International Convention on the Rights of Persons with Disabilities to be adopted simultaneously with the Convention, See generally, ARTICLE 12 - EQUAL RECOGNITION BEFORE THE LAW; ARTICLE 13 - ACCESS TO JUSTICE ; ARTICLE 14 - LIBERTY AND SECURITY OF THE PERSON; ARTICLE 15 - FREEDOM FROM TORTURE OR CRUEL, INHUMAN OR DEGRADING TREATMENT OR PUNISHMENT ; ARTICLE 16 - FREEDOM FROM EXPLOITATION, VIOLENCE AND ABUSE; ARTICLE 17 - PROTECTING THE INTEGRITY OF THE PERSON; ARTICLE 18 - LIBERTY OF MOVEMENT AND NATIONALITY

³Lambros, Katina M. and Leslie, Laurel K, “Management of the Child With a Learning Disorder, *Pediatric Annals* Vol 34 Number 4 April 2005 p. 275-287 at 277

even though the funding is granted on a per capita basis. Additionally, some students are granted separate proctors who read aloud problems or assignments, and have assistance with organizing their assignments⁵¹ Often at low cost, specialized teaching methods include “Accommodations or bypass strategies allow for modification of the learning environment or expectations (such as using a word processor and provide a scaffolding to support more successful functioning. It is important to build on the child’s skills to support areas of weakness, such as the child with stronger visual than language skills using pictures and diagrams to help understanding of written material⁶⁷”..Such approaches are effective but unconventional. For teachers who have no training in special education or multi-sensory teaching techniques, these approaches may be intimidating or threatening because they are unfamiliar and thus have become a flashpoint for controversy⁶⁸.

The US Congress mandates not only standards for education, but also the requirement that students who are classified as having "special needs". The “ Individuals with Disability Education Act” (IDEA) purposes include but are not limited to: identify disability, remediate disability and enhance the areas of their abilities to become productive leaders, taxpayers, voters and parents for the benefit of all society.. In order to promote these goals, under US Law, every student in the USA has a right to claim the need for services or special education. Under the IDEA, a State must have in effect "policies and procedures to ensure that .. [a] free appropriate public education is available to all children with disabilities residing in the State...." 20 U.S.C. § 1412(a). (FAPE). IDEA's statutory mandate requires the creation of Individualized Education Plans (IEPs) in order to achieve the potential in each disabled student. The IEP is a contract under law. Signing the IEP creates a legal document that binds the student, parent and school to its terms. A complex web of teacher, administrative and systemic accountability permeates the methods for implementing an IEP.

The US Congress, when writing IDEA, understood the speculative nature of its requirements setting forth written strategies prospectively that would compensate for an individual student’s disabilities. Congress allowed for the IEP document to be flexible, due to the changing nature of development in young children; the prospective nature of the IEP as a planning document for further instruction, and the reality that new technologies will be developed or become commonly available. As more information is developed about the student's special needs, through evaluations and detailed discussion of progress in light of accommodations, the IEP can be modified to embrace successful methods of accommodation that might not have been tested at the time of its writing⁶⁹.

⁶⁷ Desmond P Kelly, “Learning Disorders” *Pediatric Annals* Vol 34 Number 4 April 2005 p. 260

⁶⁸ Hunsburger, Marianne A *Radical Idea: Teaching Kids With Learning Disabilities* PEOPLE WITH DISABILITIES Magazine, New Jersey Developmental Disabilities Council (NJDDC) September 2000 p41

⁶⁹ Jay Feitshans, “Not Understood” testimony before the New Jersey Statewide Special Education Advisory Council (NJS-SEAC) June 2004. While receiving an award for Student Self-advocacy and Leadership, Feitshans spoke candidly and forthrightly about the absences of support services for Honors classes and the lack of peer support or tolerance. Noting that he had been asked to speak about services, "What services?" he

Although goals may change across time, in order to operationalize these rights, the IEP is only meaningful if parents are able to hold local school districts accountable for implementing the contract upon which their child's education relies⁷⁰.

Thus, the IEP is a living contract, prospective in nature, with a built-in mechanism that enables a well-written IEP to reflect changing needs of developing students in the course of the academic year. For this reason, the law provides a period of up to fifteen (15) days which can be extended in special circumstances. In this time, parents and students can review the document and discuss its meaning. Parents can ask themselves, their children and other educators whether the goals for the academic career of the student are correct based on the available data and functional assessments, when evaluating whether the objectives for the academic year. Therefore, many parents have a lawyer or student advocate representative at IEP meetings, and many more people consult professional representatives before signing the document. Also, a series of procedures called "due process" enable parents to file a complaint on behalf of their child when the school district fails to provide FAPE by refusing to follow its own IEP or failing to provide reasonable accommodations or necessary services.

Many students have unrecognized disabilities, and the confusing labyrinth of IDEA law compounds the situation. Thus it is very difficult to enforce special education rights. School districts would rather litigate than provide services connected with special education. The budget to cut is their litigation funding, the right to hire and pay outside counsel. In one school district, one case spends over 100 thousand dollars for outside counsel. "The greatest cost in this system is the price of outside counsel for school district litigation against parents. This is a hemorrhage that is bleeding our taxpayers dry."⁷¹ Outside counsel average between \$350-800 per hour. That is the same price as many hours of OT, twenty or thirty hours of one-on-one tutoring, or software and license for a scanner. In one hour we have saved or spent all those services, depending on the choice we make to litigate or not. A cap on litigation would force staff to learn more about new labor-saving assistive technology and force them to improve services instead of hiding behind litigation. Presently, there is no cap on the amount of money a school district can spend on outside counsel. Limiting the ability of school districts to fight parents who want basic statutorily guaranteed services..

said. The services to help me in school are non-existent. Therefore there are not even services to prepare me for transition services. That is a silly sentence, but true. Personally I believe that most LD students end up dumped in lower performing colleges because of the lack of support in high school."

⁷⁰ See: Ilise L. Feitshans, Counsel of Record Brief Amicus Curiae That Was Not Granted Permission By Respondent On Behalf of Parents of Students With Special Needs in New Jersey filing Individually and on Behalf of Their Children, In the Matter of Schaffer v Weast US Supreme Court Docket Number 698 04 698.

⁷¹ Ilise L. Feitshans, Proposal for the Creation of an Office of Inclusion Specialist/ Parent Advocate following the JAG Corps Model Statewide and Within Districts for NJ Public Schools Testimony BEFORE THE SPECIAL EDUCATION REVIEW COMMISSION TRENTON NJ New Jersey Legislature October 17 2006. Questions: sercommission@doe.state.nj.us,

Consequently, a fundamental break in communication, has exposed a concomitant lack of trust between school staff , parents and students, resulting from that disconnect. Information does not adequately flow from school districts to the public and private schools in communities that surround them. Information doesn't flow from the federal government to states; nor to school districts from state legislatures. Taxpayers and students and parents who do not perceive themselves as having disabilities do not understand the fundamental precepts of inclusion; students who have a label of disability do not receive adequate support services with goals for high achievement. Thus, there is no check on the resulting pattern of practice of segregation between disabled and non-disabled student populations. This problem remains consistent across the spectrum from independent to public schools, and seems to vary only slightly by SES or geography. As one parent from Cherry Hill New Jersey has stated, "the courts don't understand what a dramatic thing that is. Parents who sue school districts never in their wildest dreams expected to sue-they bring their child to school and they expect a reasonably good education. For a parent to sue a school means that there is more than just frustration, there is a situation where the child is hurt, the child is not being educated and there is nowhere else to go".⁷²

This emotionally charged backdrop of most due process claims was not brought to the attention of the court. People: voters, taxpayers whose children attend public school-- care about their children's needs, regardless how defined. When their children are harmed or not educated, people will muster whatever available resources to fight for their child's right to a Free Appropriate Public Education (FAPE). In 2005, the US Supreme Court decided that the party bringing the action bears the burden of proof in special education due process cases under IDEA in *Schaeffer v Weast*,⁷³

The reality that since the *Schaeffer* decision, any parent-plaintiff bears the burden of proof for any questions regarding the adequacy of services or the provision of reasonable accommodations may provide a disincentive for the school district to make an appearance at hearings, wherein the school district is not the plaintiff⁷⁴. In 2006 in

⁷² Ilise Levy Feitshans, "You Don't Know What You Got Til It's Gone" presented at the conference "Right to Learn: The Future of Gifted Special Education, Nov 2 2005 and then at Asperger's Parent Education Network (ASPEN) Burlington County NJ Chapter Nov 9 2005.

⁷³ ***In the Matter of : Schaffer v Weast US Supreme Court Docket Number 698 04 698*** In *Schaffer*, a family was awarded reimbursement for half of a school year's tuition because the school district did not provide appropriate services to a disabled student.. On appeal, in litigation that already cost each side more than the amount of money in dispute, the Fourth Circuit Court of Appeals decided against the family. After a second trial, and after the student involved had graduated from high school, the case made its way to the attention of the US Supreme Court. The question presented to the high Court was: what burden of proof should be assigned to a plaintiff who seeks relief under the Individuals With Disabilities Education Act , know as IDEA, 20 U.S.C. § 1412(a). (FAPE) .

⁷⁴ Ilise Levy Feitshans, "You Don't Know What You Got Til IT's Gone" presented at the conference "Right to Learn: The Future of Gifted Special Education, Nov 2 2005 and then at Aperger's Parent Education Neetwork (ASPEN) Burlington County NJ Chapter Nov 9 2005.

Audubon, NJ, school districts have begun a new strategy regarding the ability to use litigation and the prejudiced myth that students with learning disabilities cannot learn or are very difficult to teach in order to avoid providing reasonable accommodations for special education for a child that has been identified with autism. The parent alleged that the school district has failed to provide services required by federal law, and then filed a complaint under the statutory mechanism in IDEA called “Due Process” The school district failed to appear at the hearing and did not disclose their evidence in a timely manner before the hearing⁷⁵.

Public school districts with complex fixed formulas for funding the services to be rendered to students with identified disabilities have a great deal to gain by litigating against parents-- they may not know how to provide services but they do know how to hire outside counsel. A subsequent case, *Arlington v Murphy* (2006) also excluded reimbursement for expert fees. So not only do frustrated parents who sent their child to school without ever expecting to sue the school district bear the burden of proof under this construct, but also the fees for the expert evidence that must be generated to win. This can be changed by the legislature—or perhaps individuals harmed under the statute will file a complaint for abridgement of their rights to be protected against discrimination at the Inter-American Commission of Human Rights, which accepts complaints from individuals as well as non-governmental organizations.

V. Conclusions: Embracing the Universality of Disability in Order to Accept Difference and Achieve Equal Treatment Under Law

Disability is the source of one of the greatest unifying facets of the human condition, although it is manifest in each individual differently. Civil rights norms, including the those within the rubric of international human rights, require, as a general matter, that everyone be treated the same. Or so it is commonly believed. Achieving Equality does not mean treating everybody the same. Dealing with disability as a source of individual variation in human rights informs the human rights discourse about the importance of recognizing differences and providing a fair and equal opportunity to achieve and contribute to society.

Disability laws within nations and as expressed in the United Nations (draft) Convention⁷⁶, prohibit discrimination and attempt to instill a sense of fairness through a level playing field of equal opportunity are consistent with overall civil rights goals, but confound and challenge society’s working assumptions that everyone is the same. By contrast to traditional paradigms of civil rights analysis, the individual variability

⁷⁵ Anecdotal email correspondence, from the list-serv for parents with students who are enrolled in special education programs.

⁷⁶ Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities Eighth session, New York, 1425 August 2006 DRAFT CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES and the Draft Optional Protocol to the International Convention on the Rights of Persons with Disabilities to be adopted simultaneously with the Convention

expressed in human disability requires that people be treated differently, according to different needs for services and reasonable accommodations, in order that their opportunity to achieve their potential and contribute to society will be the same. Equality may be an outcome, but a presumption of equal empowerment and equal ability to achieve the goals of civil rights norms cannot always be the starting point for civil rights analysis. This is actually a reverse paradigm of other areas of human rights treaties and conventions under international law. For example, races are not treated differently under international human rights laws. Theoretically, all races are treated the same. Although many projects argue for equal respect of the rights and freedoms accorded individuals, with an equal measure of human dignity for each person, laws prohibiting or remediating discrimination based on disability pose a stark contrast to this model.

Neurodiversity is an important precept of society, but it is difficult to implement appropriate accommodations without the proper tools. The toolbox should, but too often does not, include as deep as possible an understanding of individual rights. Depriving people with disabilities of the equal opportunity to express, explore and demonstrate their individual gifts explains in large part the under-representation of disabled students in higher education and the difficulties they face when confronted with college or graduate school and campus life.⁷⁷ Equal treatment is therefore part of a greater process that must recognize that every individual is different even when standards for government behavior attempt to grant everyone rights that are the same. Insofar as disability constructs are concerned, one can only strive for equal treatment from the standpoint of due process and equitable treatment regarding outcomes, for few disabilities are ever the same in their manifestation or their co-morbidity.

Sound public policy should first recognize the practical limitations and benefits imposed by natural differences, and then attempt to reconcile those differences in society in a manner that will result in equal outcomes to the extent feasible. Limitations imposed by individual disability militate in favor of different treatment in order to strive to produce outcomes that are the same. Rather, the universal need for tolerance and acceptance from the rest of humanity that everyone shares is the same

In conclusion, the international human rights movement paradoxically faces its greatest challenge when confronted by individual disability: to accept the greatest possible level of individual difference in order to strive towards equal treatment for all.

⁷⁷ According to “Inside Higher Education”, the article ‘Unique Learners’ states: “The ‘last bastion of prejudice in higher education,’ according to Cynthia Johnson, is the belief that developmentally disabled students don’t have a place in colleges. These students, many of whom would have been called mentally retarded in an earlier era, have a range of skills.” Scott Jaschik, Inside Higher Ed, “Unique Learners” June 24 2005.