## Initial Perceptions of Labels to Initial Perceptions of Common Humanity: A Paradigm Shift in the Disability Field

The Psychology of Humiliation Teachers College, Columbia University Allison Buehler 12/27/04 The disability field endlessly battles stigma and harmful assumptions in its attempts to provide services to those who need them the most. The challenges and questions presented in this paper stem from a paradox: the need for a system that identifies those who need the services without labels that are accompanied by stigma. This paper will examine the psychologically damaging effects of past and present label and classification systems. It will also recognize the necessity of labels under the current structures of society to securing necessary service. When the psychologically damaging effects of labels are weighed against their utility, it becomes apparent that a paradigm shift that offers new solutions is necessary. However, labels themselves may not be the fundamental problem. This paper will suggest that a paradigm shift in how we as human beings initially perceive one another may preclude the necessary changes in the classification systems.

These questions and complications faced by the disability field represent a broader problem faced today by the global community. The future provides the hope for a paradigm shift, changing the ways in which humans perceive one another as full human beings both in theory and in practice. Under a new paradigm, the initial perceptions humans have of one another will be based on commonalities, and will unite everyone on our most fundamental quality of being human. This differs from the old paradigm we are transitioning from, under which humans' initial perceptions are based on differences. This new paradigm is based on a human rights vision of approaching one another in a way that recognizes our common humanity before we begin to differentiate and appreciate diversity. The human rights paradigm is an approach to human relations that will become increasingly useful for functioning effectively and peacefully in what Evelin Linder calls our "global village".

The human rights paradigm will be particularly useful in the field of disability, where over generalized classifications have in the past defined who and what a person is in his or her entirety. Horrific assumptions are made into all-encompassing labels, and become the only source for identifying individuals.

Howard Adelman, a professional in the disability field, wrote the article, "Appreciating the Classification Dilemma" where he cited Aristotle, the father of classificationists, as saying that "to think is to order" (Adelman, 1996, pg. 97). Those who are wise will suggest that a more prudent approach would be to pause before this method of thinking places items into a less then rational order. According to Adelman, "It is commonplace to use political processes in establishing guidelines that define problems, differentiate one phenomenon from another, and shape the planning, implementation, and evaluation of intervention" (Adelman, 1996, pg. 96; from Adelman & Taylor, 1994). This is particularly relevant in the disability field, where services must be reserved for those who need them the most; however, political processes require proper terminology to determine who those people are. The terms chosen will frequently amount to gross generalizations, assumptions, and harmful stereotypes. Conflict resolution processes may be useful for identifying a solution that will get necessary services to those who need them the most without labels that carry harmful stigma. Past changes have remained ineffective, indicating that much broader change is needed.

It may be useful to understand the harmful effects of labels in a broader context than the field of disability. Understanding the psychology of humiliation helps us to understand how labeling is a differentiation process with psychologically damaging side effects that typically do much more harm than good. In one vision for a global village, as described by Evelin Lindner, there are layers of hierarchy under which "every human being would be assigned a higher or lesser amount of human value according to his or her status level in the pyramid of power" (Lindner, 2002), thus perpetuating a psychologically damaging and volatile notion of masters and underlings. Labels in the field of disability help to perpetuate this notion.

The human rights vision offers a new paradigm for a global village, under which our commonalities are initially perceived. One such commonality is the right to be treated as full persons entitled to equal dignity. The new human rights paradigm offers enabling environments for equal treatment and equal dignity. Egalisation, a new concept introduced by Evelin Lindner, represents the notion of treating fellow human beings with equal dignity as the globalization process takes place and we all function interdependently in our global village. Egalisation does not claim that there are no differences between people, or that everyone will be intellectually equal, physically equal, or of equal merit. Egalisation instead emphasizes that all human beings should be treated as full people, deserving of equal respect and dignity. Human rights ideals such as egalisation and equal dignity will be instrumental in the set up of future peaceful global institutions with foundations that allow us to embrace a new conception of one another under which we will recognize first and foremost our common humanity and equal dignity.

This approach will be particularly useful for those whose disability affects their intellectual, physical or merit abilities. Differentiation is a humiliating process in most contexts, but it can be particularly harmful in a disability context. The disability rights movement demands "new thinking by disabled people that there is no pity or tragedy in disability". The new paradigm rejects Joseph Shapiro's notion of the "supercrip" or the "pitiable poster child". Shapiro claims that these terms imply that a disabled person is "presumed deserving of pity" (Shapiro, 1994, pg. 16). The new paradigm has created an approach where persons with disabilities "insist simply on common respect and the opportunity to build bonds to their communities as fully accepted participants in everyday life" (Shapiro, 1994, pg. 16). Under the new paradigm offered we will recognize our common humanity, and all persons will remain entitled to equal dignity regardless of ability or disability.

The United Nation's Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, which is currently being drafted by a UN Ad-Hoc Committee, exemplifies the movement to recognize individuals with disabilities as full and equal persons, particularly before the law. Many advocates of the realization of this document believe in its necessity, as persons with disabilities have not been fully recognized under prior international human rights documents. This new document gives hope that the paradigm shift that will recognize a persons common humanity before disability is well underway.

The disability field represents an area in which the proposed paradigm shift may be most needed. The paradigm shift may be particularly complicated in a field such as disability where labels and classification systems seem so embedded and necessary. Labels and classifications seem to reduce our ability to recognize our common humanity. Because there are those who are unable to take a wise pause before making harmful assumptions, it may still be necessary to find ways to eliminate the process of labeling

and classification all together. In the disability field it has been assumed that labels are necessary for the service delivery system, particularly when it comes to providing educational services. A paradigm shift that allows us to recognize our common humanity first and foremost may be undermined and perverted by any system of classification, particularly in a field where stigma is seemingly inherent. The vulnerability of stigma in the field of disability makes it worth looking at not only changing paradigms, but also ways to do away with classification all together. Even professionals and advocates within the disability field report that it is time that the field find, "better conceived classification scheme and valid procedures for making differential diagnoses" (Adelman, 1996, pg. 108).

History shows that labels in the field of disability are a particularly sensitive issue, as there is a tendency for new labels that are initially free from stigma to evolve into pejorative terms that place a psychologically damaging weight on those who bear them. History shows that repeated terminology change is a perpetual process in the disability field. Politically correct terminology has evolved from "idiot," to "retard," to "mental disability," and to its current term, used only in the most progressive circles, "intellectual disability." Adelman notes the historically used terms, "idiot" and "feebleminded," while he and other professionals in the disability field express concern for these "frequent changes in diagnostic history" (Adelman, 1996, pg. 97). Staying politically correct in this field is a field within itself, indicating a more important underlying problem in the process.

The problem of finding appropriate labels is not only a problem of the past. "Consumer" is a term used in the field today. "Consumer" lies on the cusp of being considered outdated or identified as misused. Some consider it a dehumanizing label, while others see it as an empowering term. It was chosen by a group of individuals with disabilities and their advocates who interpreted it to be an empowering term, indicating that persons with disabilities are participants in the economic market, and purchase their services amongst other consumers. The term was once amongst other legal jargon, but is no longer interpreted within the context in which it was chosen. It is currently used in the context of interpersonal relationships. "Consumer" is a dehumanizing term, as it refers to any potential buyer. It may be appropriate within an economic context or amongst legal jargon, but in interpersonal relationships this sort of dehumanization applied to actual individuals is humiliating. Many circles in the field recognize this and have since tried to do away with the term, while others, either ignorant or blinded by their faith in the empowering abilities of the term, continue to use it

Being politically correct in identifying other human beings is an endeavor that carries a negative stigma in itself. In the disability field it is a particularly necessary endeavor, a minimum required of those who work within the field. As soon as you apply a name or label to an underling minority group, it almost inevitably becomes a pejorative term that carries psychologically harmful stigma. This inherent tendency makes label changes an endless process in the field. Some professionals in the field seem to have settled on this solution of continuously updating terminology and being politically correct. However, recently the disability field has recently begun to recognize that ongoing terminology change is ineffective. New, better and lasting solutions must be found. A closer look at the functions that labels serve will help to find better solutions that coincide with and support the new paradigm offered by human rights.

The function of a label in the disability field is to provide services for those who need them most. For example, when it comes to educational services the U.S. federal government requires that a child be diagnosed with one of thirteen specified disabilities as defined the Individuals with Disabilities Education Act (IDEA). This 1990 legislation enumerates the thirteen categories of disability. If you can define a child's disabilities within these categories, he or she is entitled to a number of additional education services. This process implicitly ties the label to the funding, requiring parents to seek out potentially harmful labels for the services their children need.

This identifies other problems in the labeling process. Some parents fight for the labels to get better services for their children, while others avoid them at all costs. Wealthy and savvy parents may in effect pay for diagnoses, taking a child to numerous doctors and psychologists in search of a label that will entitle the child to additional education services. In upper ruling class neighborhoods the label "learning disability" does not carry with it the same stigma that it does in lower class neighborhoods. One reason for this may be that the services might not exist in poorer districts, rendering the label functionless except to differentiate a child from the rest of his or her peers, and providing an inherently psychologically damaging stigma. Underling parents in poorer districts do what they can to keep from giving their child any sort of differentiating label, particularly when it is without function.

In practice, labels and classification processes can be shown to serve vital functions in special education. Professionals, teachers and parents report increasing difficulties placing children with special needs without them. Civil rights lawyers in New York City cite problems and confusion that stem when the education system turns away from old labels to define the classroom in terms of its student to teacher ratio instead of according to the types of services provided by that classroom.

The issue of classification brings about an even more heated debate in today's disability field. According to Adelman, "The roots of much of the backlash against special education probably can be traced to the inadequate state of the art with respect to assigning differential diagnostic labels" (Adelman, 1996, pg. 108). Disability advocates debate over whether a continuum of services for children with disabilities best fits the needs of children with disabilities, while others advocate for full inclusion. Under full inclusion children with disabilities are educated amongst their peers, and not differentiated by receiving a separate educational. Full Inclusionists seek to "end labeling and educating students with disabilities in segregated special classes" without ending "the necessary supports and services" (Rothstein, 2000, pg. 135).

Those who argue for full inclusion seek to strictly apply the U.S. Supreme Court's Brown versus Board of Education decision, which holds that segregated placements are inherently stigmatizing. This court decision set the legal precedent in the United States that separate services are inherently psychologically damaging, and anything less than full inclusion is in fact segregation. Full Inclusionists advocate that learning to be good citizens, globally, nationally, and locally, is the primary function of education. For this, children should experience school as a microcosm of society, which does not take place when children are educated separately.

Advocates for a continuum of specialized services claim that to associate services that provide for alternative placement with the term "segregation" is an "arrogant assumption of the moral high ground" (Rimland, 1993; from Webb, 1999, pg. 1).

Furthermore, it is problematic to use the term "segregation" because it is manipulative (Cohen, 1994, pg. 35), suggesting ideals against equality and democracy.

Proponents for a continuum of services and alternative placements contend that differentiated and separate services may be desirable for some people who have a disability, claiming that special education services outside of the mainstream classroom may best fit the needs of a child, as well as the needs of his or her peers. IDEA regulations provide for a "continuum of alternative placements," which provides for the general education classroom as the least restrictive placement and ideal goal, to a hospital placement as the most restrictive environment (Rothstein, 2000, pg. 135).

The burden of proof is upon those seeking differentiated placements. The current standards in the field of disability hold that mainstream services must be the norm, and differentiated services may only be provided when more inclusive settings cannot meet the needs of a child with a disability. Due to the inevitable stigma that comes with a diagnoses or label of disability, and differentiated placements from peers, extensive assessment processes are required before a child can be diagnosed as having a disability. These are useful safeguards under the current paradigm, but the need for such safeguards suggest an inherent perverse nature in the current paradigm's chosen process of applying labels and differentiated services. Full Inclusionists will argue that the services needed can be obtained without differentiation.

According to Adelman, "The criterion of a 'good' label is that the designation helps more than it hurts" (Adelman, 1996, pg. 97). Conflict resolution processes identify this type of conclusion as a compromise, which is typically insufficient to be a lasting solution. Professionals in the disability field cite that "one of the most frequently discussed issues is that of the impact of a label on the individual who bears it" (Drew and Hardman, 2004, pg. 35). The negative effects of a label that outweigh their necessity include emotional effects, self-fulfilling prophecies of disability and placing a child into grossly over generalized categories, and also the fundamental problem that the label "substantially influences expectations" (Drew and Hardman, 2004, pg. 36). The issues surrounding stigmas from labels will continue until solutions and practices support the broader paradigm shift to recognizing our common humanity. Differentiated classroom placements will be unnecessary when individuals can obtain proper education services in a mainstream classroom. The differentiation process should be done away with entirely, as it weakens the important notion behind the new paradigm in which initial perceptions are based on our common humanity.

The label and classification process continues in the United States—if for no other reason than that funds for services are tied to it. Current laws that mandate classification must be done away with. The system of international order is in the process of a transition that will hopefully result in a new approach to how humans perceive one another, to a fully comprehensive and inclusive notion of the human being, and then these international ideals will inevitably begin to influence national and local legislation.

The new human rights paradigm and the concept of egalisation give much hope to the field of disability. Equal dignity, equal chances and enabling environments will hopefully be the results of an international order under the new paradigm. It is precisely the prescription needed for persons with disabilities to have their equal dignity be realized.

The disability field is already showing signs that it is undergoing a paradigm shift that parallels the international community's shift. The new conception of disability embraces "person-first" language, so that the common humanity is recognized before the disability. "Disabled persons" is replaced by "persons with disabilities". Furthermore, in 1992 the American Association of Mental Retardation (AAMR) changed the definition of Mental Retardation, rejecting its old medical model approach to disability, in order to embrace a new environmental model. The new environmental approach is based on the conception that an individual is only "disabled" at the time he or she "experiences" the disability. An individual is not "disabled" but rather "experiences a disability;" therefore there is no longer an all encompassing label. For example, a person in a wheelchair is not always disabled, but only disabled when he or she is unable to go up three steps to get inside a door. If a ramp is put in place of the steps, the individual no longer experiences a disability. A blind person may experience his or her disability while walking along an unfamiliar street. If that person were in an entirely dark room he or she would probably be able to function better than those who do not have any visual impairment. The goal of this new approach is to identify an individual in terms of the services he or she needs to be able to function within his or her environment, eliminating much need for particular labels and classifications.

The new paradigm offers solutions that replace harmful and psychologically damaging stigma with a new approach to human relations that is based on initially perceiving our common humanity. The new paradigm does not inherently eliminate labels and classification processes, but simply makes them secondary to the initial perception of a common humanity, reducing the effects of harmful stigma. However, in the particularly sensitive field of disability, where stigma is particularly prevalent, it would be particularly effective to reject the labels and differentiated services in support of the new paradigm.

The new paradigm offered by the vision of international human rights, under the notion of egalisation and equal dignity, allows for differences in ability and other characteristics to be appreciated secondary to initial perceptions of one another that are based on our common humanity. Under this new paradigm, persons with disabilities no longer have to fight the battle of stigma. The recognition of our common humanity will result in equal treatment, equal dignity, greater peace and greater life. This is the hope for the future and the hope for the new human rights paradigm.

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