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Editorial Comment: Special Issue on Disabilities

Guest editor John C. Bricout, PhD, comments on this special issue on disabilities.

Editorial Comment

Social work practice and research are too often situated in an unexamined conceptual space whose fundamental assumptions go unquestioned. The values undergirding human rights and accessibility for persons with a disability may seem uncontroversial today—commonplace, if not universal. As is so often the case, however, easy virtue founders on the particulars—the ramp by the loading dock, the assistive learning technology in the wrong language, the reliably late paratransit bus. Accommodations are seemingly estranged from the principles upon which they are based. The three very disparate articles in this special issue share a common purpose—to reconcile the contradictions between our espoused and operant values toward the citizenship of persons with a disability in North American society. In broad terms, the articles collectively raise our sights and serve as a call to consciousness, supported by elegant reasoning, compelling arguments, and poignant examples. This special issue was a project of CSWE's Council on Disabilities and draws upon some of the latest thinking about values and ethics in social work practice and research.

Tasking our basic assumptions about parental genetic screening and the role of social workers as genetic counselors in health care settings is the focus of Ajandi's article. Drawing upon the research literature, social work placement field notes, and archival data from a community-based agency in Ontario, she triangulates on the lag between public debates on prenatal genetic screening and advanced diagnostic tools that raise a slew of unanswered ethical and rights issues in their wake.

Explanatory legitimacy theory is the basis for the analytical framework advanced by Depoy and Gilson, situating disability in the context of human variation, in a space of unqualified personhood, or better still, humanity, freed from the captivity of normality-other nomenclature and thought, as in "persons" qualified by "disability." The authors provide an historic perspective on the philosophical and intellectual foundations of explanatory legitimacy theory as a pluralist and pro-human rights alternative to essentialist and deficit-focused lens for understanding the full spectrum of human variation.

The ethical dilemma presented by having recourse to self-defeating labels to the self-determination of persons with a disability is the focus of Hill and Lightfoot's article, the predicament borne of eschewing disability labels while simultaneously denying the need for adaptation that is the reality for persons with a disability—indeed all people. They explore the costs to self-knowledge, consumer self-determination, and service efficacy resulting from the negative connotations, and limited practical utility of the available disability labels, using semi-structured interviews of program staff and participants at a transition program for youth in foster care.

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Ethical Considerations for Prenatal Screening and Genetic Testing

Ethical Considerations for Prenatal Screening and Genetic Testing

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Abstract

With the advancements made in medical technology, decisions that were once made with caution and information are now routinely handled in an automated fashion. When deconstructing the issues involved in prenatal genetic screening, we must ask, what are we screening *for*? This papers calls for social workers to play key roles as genetic counselors in health care settings.

Key Words: Prenatal screening, Genetic Testing, Genetic Counselors, Ethics, Disability Rights

1. Introduction

In this paper, I am exploring the practice of prenatal genetic screening. Specifically, I am analyzing the ethical implications to this particular kind of screening. I am using

feminist (e.g., St. Denis, 2007), anti-oppression (e.g., Mullaly, 2002), and disability rights theories (e.g., Garland-Thomson, 1997) to critically analyze the effects of prenatal genetic screening for the populations involved. The literature I have reviewed includes articles from academic peer-reviewed journals as well as field notes I recorded during a social work placement in a health care setting at a large urban hospital in Ontario. I also reviewed the community-based agency, DisAbled Women's Network of Ontario (DAWN), which focuses on social justice issues as well as specifically the rights of women and girls with disabilities. I was able to access resources through the DAWN (2008) Web site regarding the balancing of reproductive rights for women with the decision to terminate a pregnancy that has had a fetus diagnosed with a disability (Rothman, 1986). Currently, the rapid rate of technology advances has stifled potential debate concerning prenatal screening for women. "With increased detection of congenital anomalies, more women and their families are faced with difficult choice" (Fertel & Reiss, 1997, p. 48). Policies need to be developed and implemented that involve promoting true informed choice for women. Community members and populations affected by potential policies, such as people with disabilities, need to be represented and involved in these processes.

2. Practicum Setting

While I was completing my graduate degree in social work, I was offered a practicum at a well-known urban health care setting in Ontario, Canada. The social work team provided services to women who experienced high-risk pregnancies, had premature babies born in, or transferred to, the Neonatal Intensive Care Unit (NICU), or to families who experienced perinatal loss. According to information from the United States, the birth of a baby is considered premature when the woman delivers between the 20th and 37th week of pregnancy (Bachman & Lind, 1997, p. 7). According to Preyde (2007), the criteria for categorizing an infant as premature or "very preterm" is that the baby is born at less than 30 weeks gestation or weighs less than 1500 grams (p. 70). This classification adds in the weight of the baby as a factor for determining her/his prematurity level. However, I would caution drawing any conclusions regarding what steps are taken to preserve life in the hospital, based on the number of gestational weeks alone. It is common practice, in the hospital where I did my practicum, not to encourage parents to resuscitate their babies if they are born under 24 gestation weeks. Whereas it is not expected a baby will survive if she/he is born before 24 weeks gestation, I have worked with families whose babies did. Conversely, I have worked with families who had babies born at older gestational ages who did not survive. Generally, at this hospital, we would see babies between 23 weeks gestation and 32 weeks gestation. In situations in which the baby is not expected to survive, the issue of when to withdraw or withhold treatment is contentious, as many times the decisions are made on an individual basis between the doctors and the families.

A pertinent issue in my placement setting was the process involved for women and their families when they were faced with the decision to terminate a pregnancy or request a withdrawal of care for their baby after she/he was born. In order to illustrate these experiences, I have drawn upon examples of current practices (both formal and informal) pertaining to women who undergo prenatal screening. What follows is a look at the difficult decisions women are faced with if they are informed of potential genetic complications with their fetus or child. I use the term "fetus" for before the birth, and "child" for after the birth,

as genetic complications can be detected both in utero and after the birth. Most often, if a fetus or child is not expected to survive, this is referred to as being incompatible with life.

First, it is important to note the larger structural conditions that are occurring in Canada. Canada is known around the world as being a leader in providing accessible and affordable (or "free") health care for its citizens. It is true, that as a Canadian citizen, I am fortunate to not have to worry about whether I have enough money to pay for an appointment with a doctor if I get sick, because many traditional or Western health care services are insured under the provincial government. However, this does not mean the health care system is accessible to all. Many people in rural communities, especially Aboriginal peoples, are underserved or served poorly by our health care system (Bourassa, McKay-McNabb, & Hampton, 2006).

Health care in Canada, specifically in Ontario, has experienced drastic cuts to its funding. The restructuring of the health care system has led to the privatization of many services that were once insured under the Ontario Health Insurance Plan (OHIP) (Bezanson, 2006). A reduction in funding also contributes to reducing the number of staff. However, the amount of work does not decrease. Health care staff experience unrealistic workloads, and this can also be felt by social workers. With more work to do and fewer people to do it, health care settings can be stressful places to work. Social workers begin their days with an idea of what to expect according to their schedules. Their "schedules" change several times throughout the day because of the crisis nature of their work. For example, a social worker may have appointments with three different families who need information and various resources to assist them in feeling prepared for when they are discharged from the hospital. However, in the event of a baby's death or if the health of a baby declines, those babies' families become top priority, and all other appointments are rescheduled accordingly. The role of the perinatal social worker fluctuates depending on the current crisis at hand. Perinatal social workers at the hospital where I did my practicum also needed to work in several departments concurrently, because they were understaffed. There are several reasons why patients are referred to social workers. They can include: mental health issues, lack of housing/under housing, poverty, substance use, intimate partner violence, stillbirth, miscarriage, parenting concerns, child protection issues, and the diagnosis of a child or fetus with genetic anomalies or with being incompatible with life.

3. Critical Appraisal of the Literature

In this paper, the right to self-determination of women regarding their reproductive health and bodies is not put up for debate. As a single mother, I find many strengths and advantages to this status. However, I have also endured several challenges. I learn to cope with the stress associated with being poverty-class, balancing school with paid work, unpaid work, and the new role of motherhood. Being able to go through these experiences has only enhanced my passionate belief that women must have control over their reproduction. This not only includes the right to terminate pregnancy, but also the right to continue a pregnancy, as many women of colour, Aboriginal women, women with disabilities, and poor women have had to fight for. On a professional level, self-determination is mandated in our *Code of Ethics.* Social workers are guided to respect the dignity and self-determination of all of our clients/service users/patients (CASW, 2005).

To explore the tensions around prenatal screening, we must first look at how power and knowledge are created and then reproduced. I am deconstructing the production of knowledge using a critical lens informed by feminist, anti-oppressive, and neo-colonial theories. With respect to the development of the medical profession, I am also using perspectives informed by the social model of disability, which locates the roots of problems in a society that creates ableist structures, as opposed to locating the problem in the disability itself (Oliver, 1990). According to Smith (2005), Western, scientific thought has developed in support of modernism (p. 59). Modernism represents a particular stream of thought that views facts and truth in society as being objective, measurable, and controllable (Hugman, 2003; Mullaly, 2002). The medical profession has grown out of a primarily white, male, able-bodied construction of scientific knowledge and reason. This began with the era of Enlightenment, in which objective "expert" knowledge emerged as the dominant form of treatment (Boetzkes, 2001). The physical body itself is objectified, pathologized, and examined/diagnosed in terms of "normal" and "abnormal." By using these dichotomous phrasings such as healthy/unhealthy, male/female, and able/disabled, there is little room for variations of the body represented on a continuum. This modernist ideology is still present in many hospital settings as well as in streams of different helping professions, such as psychiatry, psychology, and social work. Social workers must be cognizant of ethical guidelines that we are to do no harm (CASW, 2005). What does this mean, and what does the current knowledge and practice say about issues in society? It is just as important that we in the helping professions critique our own practices. It was not too long ago that "women were frequently counseled to calm down and return to abusive situations, and they, rather than the perpetrator, were often defined as the problem" (Hill, Glaser, & Harden, 1998, p. 105).

Individuals are still labeled as the problem. For example, in a multi-disciplinary meeting in the health care setting, one of the families assigned to me had an infant girl who some of the nurses brought up may have additional male body characteristics. There was an obvious tension in the room as nurses and neonatologists discussed sending the baby to the local specialized hospital for genetic "abnormality" testing or to the "dysmorphology clinic." The staff was debating what direction to take, so as a point of clarification, I asked if the baby was intersex. I used the category/identity intersex out of respect for children born with various gender and sex identities and as a way to verbally normalize this body against the deficit model being espoused in the room I was in. The production of modernist knowledge needs to be challenged for attempting to maintain dichotomous categories of the body (Garland-Thomson, 1997). I received no response from the health care team—just an awkward silence. I found this lack of response problematic, considering I was a colleague. How would medical staff interact with families regarding sensitive issues such as these if they could not even address me? Although there has been much resistance to reducing the power differential between patient and professional, in theory, community-based care, interprofessional care and patient-centered care is the current trend being supported in health care settings in Canada (New Health Professionals Network, 2005).

Genetic ethics is emerging as an important discourse with the advancing of medical technology at increasingly rapid rates; however, public discussion and debates seem to lag far behind. Implicit in different types of knowledge are underlying sexist, racist, and ableist assumptions. We can see racism highlighted from the push to "immunize" against fertility in the "Third World," sexist assumptions that contributed to the pathologizing of menstruation, and performing hysterectomies to prevent menopause (Boetzkes, 2001). It is realistic and appropriate then that consumers and professionals alike question dominant discourses put forth within the medical profession.

4. Informed Consent for Prenatal Screening

According to Garcia, Timmermans, and van Leeuwen (2007, p. 754), "In many countries prenatal screening has become normal antenatal care." When prenatal screening becomes routine during antenatal care, does informed consent cease to exist? Informed consent is an important process that social workers and allied health professionals use both ideologically and legally when providing services. However, as professionals and in different disciplines, each person may enter into these processes with varying intentions. In terms of prenatal screening, Boetzkes (2001) argues that women need to be "maximally informed" (p. 304), but what does this mean? In Canada, social workers follow the Canadian Association of Social Workers' (CASW) *Code of Ethics.* However, it was not until Ontario implemented the Social Worker and Social Service Work Act 1998 that social work as a profession became regulated. Regardless of the degree obtained, social workers in Ontario cannot use the title "social worker" unless they are registered with the Ontario College of Social Workers and Social Service Workers (OCSWSSW, 2008a). There are many ethical considerations social workers are obligated to adhere to in the OCSWSSW's *Code of Ethics* pertaining to women and prenatal genetic screening. They include: confidentiality, a right to information, to be informed of foreseeable risks, and to have the social worker serve as an advocate for clients (OCSWSSW, 2008b). It is also important to note that the right a client has to confidentiality is balanced with a social worker's duty to report a situation to authorities if a client threatens to harm her/himself or someone else (Mishna, Regehr, & Antle, 2003), and especially in Canada, if the person is a child under the age of 16 (Lundy, 2004, p. 101).

Kohut, Dewey, and Love (2002) consider informed choice "as a process of decision-making, which evolves through the evaluation of information and personal values related to testing" (p. 266). This is different from informed consent. Informed consent is a legal category that is requested from the doctor in order to perform a medical intervention, whereas informed choice involves all of the background knowledge and information to specific medical interventions. Lundy (2004) emphasizes the importance for social workers to obtain informed consent in their practice, according to the *Code of Ethics* in both Canada and the United States (p. 96). Informed consent is meant to be a process in which all information pertaining to a procedure is discussed between the patient and the health care staff. Furthermore, according to the Canadian Tri-Council Policy Statement (2008), informed consent is mandatory and at the heart of ethics in research, designed to protect participants. In the United States the language of the policies governing informed consent appears to be more stringent, and may be in response to the threat of litigation. It is stressed that complete and accurate information must be given in order to obtain informed consent, or it is not valid (United States Department of Health and Human Services, 2008). Also, according to informed consent policies in the United States, it is strongly advised that consent be obtained in writing, whereas in Canada, the policies have given explicit accommodation to cultural groups that may communicate informed consent orally or by a handshake (Tri-Council Policy Statement, 2008). Whether health care staff uses the notion of informed consent or informed choice, there needs to be an organizational and cultural shift toward a less paternalistic approach of interacting with patients. Instead of doctors and other helping professionals being seen as the "experts," patients need to be given time to be involved in the actual process of information gathering and then be able to process this knowledge for the purpose of decision-making (Kohut et al, 2002).

5. "Choice"

Currently, there is a prevailing cultural story present within the institution of health care. It involves scientific merit and diagnostic ability (Truog, 1996). With the advances in medicine and technology, it can be argued that women's choices surrounding issues of reproductive health are also increasing. However, "choice" is a contentious issue. Does a woman have reproductive choice if she wants to keep her baby but fears the economic disadvantages she will experience if the baby is diagnosed with a disability? Choice is contextual as an example from my placement setting will make clear; women most often take the recommendations of the doctor or will pick up on the doctor's tone, which helps to sway the decision one way or the other, independent of other valid sources of information or concern. Truog (1996) maintains that an informed choice can only be made if women receive all the information relevant to the decision to undergo or forgo the test and feel free of coercion or persuasion.

Women are overwhelmingly represented in the highly stressful primary caregiver role. These stresses are compounded when women experience poverty. The decision to give birth to a child who will be diagnosed with having disabilities is especially difficult if the family does not have sufficient economic and emotional resources available. Unfortunately this issue is exacerbated when taking into account that the caregiver role is seen as an operation in the private sphere (predominantly by women) with little or no systemic supports (Mullaly, 2002). However, even women who are financially secure may have second thoughts when faced with the possibility of having a child with disabilities, as there is a fear of who will care for the children after the parents die (Boetzkes, 2001).

When women make the decision not to have prenatal testing, they may be looked at as selfish or uncaring. If her child is born with a disability, some members of society blame the mother, because it is expected that if she were a loving and caring mother, she would have "prevented this tragedy." There is a dominant hegemonic assumption of what a good quality of life looks like. In the United States, there are cases in which insurance companies refuse to insure the health care of a child with disabilities if it is known the disability could have been prevented (Harmon, 2005). In a study conducted in the Netherlands, pregnant women were asked their reasons for accepting or declining the offer for prenatal screening. In the Netherlands, prenatal screening is not a part of routine prenatal care. Most of the participants who decided on having the prenatal screening did not feel they could raise a child with disabilities. Some reported they desired a life of "normalcy" and feared how society would view them and their families. However, "All participants worried about the obsession with physical perfection in society. They feared that prenatal testing would be used as a eugenic means, leading to the commodification of children" (Garcia, Timmermans, & van Leeuwen, 2007).

In a study conducted in Ontario, focus groups were used to elicit information from women regarding their experiences of prenatal screening (Carroll, Brown, Reid, & Pugh, 2001). It is clear that the participants were assumed to know what the screening was without being fully informed. Participants also expressed concern for whether they would have the resources to be able to support a child with disabilities if the screening results were positive for "genetic anomalies." An important discussion in this study focuses on the need to have counselling before the tests are actually performed (Carroll et al., 2001).

6. Ethical Issues

As prenatal genetic testing is ever expanding, there are legal, ethical, medical, and social concerns that need to be considered. Genetics research has serious implications for communities. Because the outcomes of specific testing may serve to further marginalize or discriminate against an already vulnerable group of people, communities and the public need to be a part of the policy making process. People who have genetic conditions may feel isolated and not valued in society when there are specific tests made available to detect their conditions and these most often result in termination of the pregnancy. The head of self-advocacy for the National Down Syndrome Society describes feeling a "child" when thinking of genetic testing that is done to remove lives like her own (Harmon, 2005, p. 1). This is especially relevant when taking into account a disability rights perspective, which explores how disability should be seen on a continuum as various kinds of people with different abilities, just as there is a range in eye and skin colour in human variation. It is advocated that disability be seen as a human rights issue, not a medical one (Devaney, 2008).

Policies regarding prenatal testing—when to offer it and to whom, and the explanations that are given pertaining to that disability—are usually done by professionals, unrepresentative charities and governments, not by the people who have disabilities themselves, who are the best experts on their own lives (Gollust, Apse, Fuller, Miller, & Biesecker, 2005). An important concern around prenatal screening is that it reinforces the medical model standpoint – that disability is the problem – instead of focusing on strategies to dismantle societal discrimination toward people with disabilities (Parens & Asch, 1999). Research shows health care staff view the increasing occurrence of prenatal genetic screening and conditions to be screened for as inevitable (Williams, Alderson, & Farsides, 2002). Currently, there is little room for collaboration and debate regarding the ethics involved with prenatal genetic screening, and medical advances are increasing at a rapid rate. Williams et al. (2002) argues for:

> *inclusive, integrated and collaborative debate and research. This is to ensure that as far as possible the wider consequences and implications of prenatal screening technologies – both the promises and the potential side-effects – are debated ahead of their implementation, and also to help ensure that public policy represents and serves contemporary society.* (p. 752)

7. Surveying Women

There are ethical implications involved when going through the decision making process around whether to terminate a pregnancy if it is diagnosed the child will be born with disabilities. These include the current biomedical model that pathologizes disabilities, skewing the picture because of a lack of information surrounding a strengths perspective of disabilities or, at the very least, information from a community member point of view. For example, using surveys with people who are affected with inherited "dwarfism" highlights the experiences of this population from their own perspectives. These data have been used in policy development, as well as clinical practice contexts (Gollust et al., 2005).

Research has found that surveys are good tools because they can reach a large number of people in a short period of time. Surveys that are accessible online can also increase the likelihood of a more geographically diverse pool of women participating. Surveys that have large sample sizes, averaging 1000 people, enable the researcher to highlight certain trends that emerge from the data. This can then serve as the basis for further research into a specific area through such means as qualitative open-ended and semi-structured interviews with women, providing a more experiential and complex perspective on prenatal screening in health care settings. Results from a recent study showed that women preferred face-to-face genetics counselling with a mix of knowledgeable printed material. Also highlighted was the desire to connect with other women who decided to undergo prenatal testing, suggesting that a support group may be beneficial (Jacques, Bell, Watson, & Halliday, 2004).

When advocating for policy changes or implementation, having such a large representative sample carries some political weight. However, a limitation to using self-report surveys is that it is not possible to capture the complexities of individuals' lives, which is where qualitative research can play an important role. For example, in a study of 120 women who underwent amniocentesis and received a diagnosis of disability for the child, all women decided to terminate the pregnancy. Rothman (1986) describes with empathy the pressures these women experienced and constructs them as victims of technology, sacrificing themselves to spare their children from suffering.

Researchers need to take into account different models of health care service and delivery when analyzing their data. In one study, data was collected from women who received prenatal care from an obstetrician and a midwife. The results were highlighted that more than half of the women made decisions regarding prenatal screening without true informed consent. It seems a contradiction when the medical intervention of prenatal screening was designed for the purpose of enhancing informed consent regarding the health of the fetus (Van den berg, Timmermans, ten Kate, van Vugt, & van der wal, 2006). It would be beneficial to do a comparison study involving informed choice or consent between women who were involved with midwives compared with obstetricians. It is important in the research to distinguish between these health care providers, as both operate within a completely different ideological framework, and therefore these different theoretical frameworks of care will influence the experience of the patient.

8. Implications for Practice

There is a clear gap in the literature around social work's role with patients who consider genetic testing and more specifically prenatal genetic screening. In existing literature social work interventions are seen as of major importance. However, it is almost completely absent from professional writing (Gagin, Oded, Cohen, & Itskovitz, 2001). As this is a new and emerging focus within the health care setting, it would be beneficial for the field of social work to develop a genetics specialization within the health care stream. In the United States, the National Association of Social Workers' *Code of Ethics* emphasizes guidelines that support social workers in the field of genetics including: self-determination, informed consent, and social and political action (Taylor-Brown & Johnson, 1998).

The role of a genetics social worker, given the expansive knowledge base, is vast and complex. It involves emphasizing a focus on values and ethics, social policy in genetics, ongoing counseling for coping and adaptation, identifying clients with potential genetic disorders through case-finding and bio-psychosocial assessment, knowledge of the person in environment paradigm, and biological knowledge, specifically with the Human Genome Project (Taylor-Brown & Johnson, 1998). This in addition to the already varied roles of social workers in health care settings presents quite a challenge. An important aspect of a social work role in genetics would be identifying the alternative resources (and lack of alternative resources) available to patients. Public involvement into genetic policymaking is recommended in the literature, and similarly, from community members, although the norm is currently not to include a community voice (Mattison, 2000). A vital role for social workers in this field will be to provide that information and documentation. Are patients given information and research that supports not only negative quality of life outcomes but also positive outcomes for families who have children with disabilities as well? Is empirical data available that describes individuals' quality of life through participatory research? Callahan (2004) emphasizes the role of feminist thinking in policy making. There is relevance for learning from the everyday experiences of women and the particular challenges they face in order to construct a bottom-up approach to policy development and implementation. This is important as the process of marginalization works in a way to exclude whole groups of people from meaningful participation in society (Mullaly, 2002).

Based on the reviewed literature and systematic studies, I conclude that women are not provided with genetics and options counseling and, in effect, do not have sufficient information to properly undertake the process of decision-making for prenatal screening. However, the Ethics and Public Policy Committee of the Canadian College of Medical Geneticists supports women's right to autonomy and right to informed decision making regarding prenatal interventions (Kohut et al., 2002). Prenatal genetic testing is highlighted in this paper as a rapidly emerging field in medicine. The implications of scientific and technological advancements in medicine need to be publicly debated and/or a dialogue created so voices can have a platform where marginalized discourses are heard.

9. Proposed Evidence-Based Interventions and Policy

In our role as social workers, we must continuously use reflexive practice, so as to question our values and assumptions. We cannot take ourselves out of the equation when counseling and providing services. It is important to recognize that our actions are framed by our beliefs and how we view the organization of our society (Mattison, 2000). By constantly reflecting on and questioning our motivations in practice, it is more likely we will be able to start with the client/patient where s/he is, instead of where we are. Furthermore, I would suggest that it is important for the profession to deconstruct the dominant societal discourse and messages as these greatly influence our own perceptions and ideology, directly influencing how we practice and, most significantly, narrowing or distorting client choices.

Through the review and analysis of field notes during my graduate practicum, it has become clear that it is a moral imperative to reflect on these ethical issues. Moreover, this experience has instilled in me a desire to teach university courses in ethics and values. I shall address some ways to address these issues in a multi-pronged fashion. First, on a

macro and institutional level, participation of people who belong to marginalized groups such as persons with disabilities must be involved and represented at all policy levels. It is time that the policy making process shift its direction from a paternalistic top-down approach, to incorporate minority and advocate voices. The dominant paradigm in medical institutions is the medical model. This paradigm views the body based on a deficits model, examining the person in terms of disease and treatment, instead of validating strengths and human variations (Graybeal, 2001). Creating change and shifting organizational culture is a slow process. One of the ways to help facilitate this is to infiltrate the education system. Besides the family, educational institutions are one of the first organizations that contribute to the socialization of people and professions. There needs to be a challenge to dominant discourses such as the medical model. Incorporating the social model of disability would present a view that is not bio-deterministic. Thus, it would recognize a social-determinants-of-health perspective that deconstructs structural inequalities, locating the problem with systemic issues, not the individual person.

On a direct practice level, employing a social worker specializing in genetics would be an important step in being able to present information to the patient regarding her choices. When adequate information is not present, social workers could connect patients with key members in the community who would act as education liaisons. These education liaisons would offer perspectives not necessarily influenced by the medical model to balance the ideological context of the information given to the patient in the hospital. Another aspect of this kind of genetics/ethical counselling would be in the support work that may be required after the woman has made a decision regarding prenatal screening, either counselling after termination or connecting to appropriate resources if continuing with the pregnancy.

Social workers could use their skills with facilitating groups. An ad hoc session for women considering their options for prenatal screening and/or termination could be explored to reduce isolation and feelings of confusion or guilt. However, in group situations, it is difficult to ensure the emotional safety of group members especially considering the subject of discussion.

10. Strengths and Limitations for a Genetics Social Worker

Unfortunately, it is unrealistic to envision departments of social work expanding in hospitals, considering the increased cuts to health care. The strongest limitation for having a genetics social worker in perinatal departments may be purely based on a lack of resources and funding. Also, even though the concept of true (i.e., meaningful) informed consent could be challenged by a social worker, the medical staff might not be receptive to that kind of criticism, so the actual lack of staff support may be an additional barrier. Furthermore, if disability continues to be viewed as pathology and "dysmorphic," there may be an unwillingness to reconceptualize disability as a healthy variation of people, as some people with disabilities contend.

Working toward social justice for marginalized populations is at the core of the profession of social work and codified in our ethical guidelines (Lundy, 2004). Working in secondary settings often requires us to be mediators, educators, advocates, and allies. We skillfully challenge the dominant discourse when we see it to be oppressing patients with

whom we work. I argue we need to develop a strategy to implement a new role for social workers and suggest that we use our interests and skills in research to develop a proposal that would support prenatal genetic counselling. This is an exciting opportunity for social workers to highlight our wide scope of practice for the benefit of some of the most vulnerable clients served by our profession.

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Easing Service Access Through a Clear Diagnosis of Disability and Unease in Assigning Labels

The Dilemma Between Easing Service Access Through a Clear Diagnosis of Disability and Unease in Assigning Labels to People with Disabilities: A Case Study

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Abstract

This article examines how the dilemma regarding using disability labels to help people with disabilities access services versus promoting consumer self-determination that includes rejecting labels gets played out in a practice situation through looking at a case study of youth with disabilities receiving services from a foster care transition program.

Key Words

Youth with Disabilities, Strengths Perspective, Foster Care Transition, Self-Determination, Labeling

People with disabilities are often served by multiple service systems, including child welfare, education, health care, and social service and support systems specific to people with disabilities, such as vocational rehabilitation, developmental disabilities services or Centers for Independent Living. Each of the systems may take a different approach to how they work with clients or consumers, what their goals and outcomes are, and what methods they choose to employ to reach these goals. Often, a key difference among these systems is how they perceive and understand disability, and the importance they place on having the "label" of disability attached to the client. A lack of professional knowledge, training and comfort about disability services and disability rights may lead to lower quality and less appropriate services and supports for people with disabilities from service providers outside of the disability-specific realm. Whereas professionals in these other fields may be practicing to the highest standards of their discipline, their lack of disability knowledge and training may be detrimental to their clients with disabilities achieving the best possible outcomes.

1. The Dilemma

In general, in order to access services designated specifically for people with disabilities, a person with the disability needs to have an acknowledged diagnosis of disability. The public sector has created multiple definitions of disability and degrees of disability (Rothman, 2003), but a person must meet the appropriate pre-determined criteria in order to access publicly funded services. Depending on the particular service, the diagnosis can come from a number of sources: medical professionals, education professionals, social workers, or the person with a disability himself or herself. However, for many individuals with disabilities, as well as for many social work professionals, there is a reluctance to self-identify or "label" someone as having a disability. Many social work professionals, strongly committed to a strengths-based approach to practice, are reluctant to label their clients as having a disability, viewing it as a negative attribute that limits opportunities and options, rather than as a key to access many of the community supports and services that are available. This article explores this ethical dilemma faced by social work practitioners through an introduction to social work and disability perspectives on this dilemma, and through a qualitative case study of both program staff members and program participants of a foster care transition program that provides services to many youth with disabilities.

1 (a). Social Work Perspective on the Dilemma

A commitment to strengths-based practice lies at the heart of social work practice. It is incorporated in the NASW *Code of Ethics,* into social work education, and into practice at all levels and settings. The strengths perspective of social work practice is based on the idea that all people have a wide range of talents, abilities, capacities, skills, resources, and aspirations. These strengths drive human growth, when they are identified, recognized, and developed (Saleebey, 2006; Weick, Rapp, Sullivan, & Kisthardt, 1989). Conversely,

focusing on problems and deficits in people and communities inhibits growth. Therefore, social workers are encouraged to focus on strengths in order to enhance growth and bring about positive change with their clients (Saleebey, 2006; Weick et al, 1989). For many social workers, a disability diagnosis, rather than being neutral or a positive attribute, may be seen as negative or detrimental, and, therefore, something to avoid attaching to clients whenever possible.

Despite the good fit of the strengths model with social work values, some strengths theorists argue that it is a challenge for social workers to abandon a problem-solving model and focus on strengths because of the widespread acceptance of the problem solving approach (Hill, in press; Saleebey 2006; Weick et al, 1989). A central tension in social work practice is between this strengths-based approach and the need to assign diagnosis and classifications to clients to achieve appropriate diagnosis, referral, or services (Weick et al, 1989).

Compton and Galaway (1989) discuss the inherent tension between social work's responsibility to value the "…individual uniqueness and dignity…" (p.178) of clients while simultaneously performing necessary classification of individuals to diagnose, refer, and treat. Social workers, like all human beings, must use classification and labels to sort and make sense of the vast amount of information that is presented to them. However, at what point does a label become a negative, rather than a positive tool for organization? Compton and Galaway (1989) argue that "not only does labeling, or classification, lead to distortion of individual differences, but, as labeling theories and their supporting research have noted, when a person is labeled deviant, those doing the labeling and the surrounding audience frequently respond to the deviant based on the label rather than based on individual characteristics" (p.179). The classification, while providing an entrée to effective treatment, may also limit the self-determination opportunities available to the client, and remove opportunities for self-direction of services and supports for clients with disabilities (Compton & Galaway, 1989).

Despite its long-standing commitment to working with oppressed and disadvantaged populations, the social work profession has not been a leader in work with people with disabilities nor greatly involved in the disability rights movement (Mackelprang & Salsgiver, 1996; Saleebey, 2007). Most people entering the social work profession do not intend to work with people with disabilities, and there are few people with disabilities entering the social work field as practitioners (Mackelprang & Salsgiver, 1996).

Mackelprang & Salsgiver (1996, 1999) attribute the relatively small presence of social workers in organizations that work with people with disabilities to two primary obstacles. First, social work practice has historically drawn upon the medical model of intervention, which puts health care professionals, including social workers, in an expert role, directing patients' lives, treatments, and interventions (Mackelprang & Salsgiver, 1996). Although in some ways social work has moved away from this model in the recent past, incorporating a more strengths-based approach, many of the systems in which social workers practice still are structured according to the medical model. Further, social work's past adherence to the medical model has helped to foster a difficult relationship between people with disabilities and many social work service systems and has created a reservoir of distrust for many people with disabilities.

A second reason Mackelprang and Salsgiver (1996) propose that social work is not consistently perceived as supportive of people with disabilities is the profession's traditional focus on individual problems and pathologies, rather than on individuals' abilities and

community accessibility. The medical model typically views a disability in a pathological way, and professionals work to rehabilitate individuals so they will function within society. An alternative view of disabilities that is commonly employed by disability activists, the social model of disability, views disability more in terms of how society can be changed to accommodate people with disabilities (Oliver, 1983). However, the social model of disability is not routinely included in social work education, nor is this model used to structure social work interventions. The focus of the social work intervention with people with disabilities is often at the individual level, rather than systemic or community levels. Thus, a person's disability is often perceived as an individual problem or deficit, rather than a failure of a community to provide appropriate supports or accommodations. Social work interventions from the individual perspective tend to focus on alleviating an individual's "problem," which is often seen as paternalistic and intrusive by people with disabilities, rather than focusing on improving the interactions between the external environment and the individual (Gilson & Depoy, 2004; Mackelprang & Salsgiver, 1996; Saleeby, 2007).

Indeed, social work and people with disabilities have not always been an easy match, as "...the social work professional maintains the status quo by accepting, supporting, and enforcing diagnostically based legitimacy criteria and responses that maintain disabled individuals and groups in marginal positions" (Gilson & DePoy, 2004, p.135). Because of this, the disability community is often skeptical of social work and social workers. However, social workers often work with individuals with disabilities without adequate training and experience. They simply are unfamiliar with the social model of disability, unaware of the services and supports that are available, unclear on how to access services they are aware of, and/or uncertain how to best blend and braid disability services with the services and supports that are within their agency's specific purview. While there has been a growing emphasis on disability issues within the field of social work and a more strengths-based approach is taking root in providing services and supports to people with disabilities, there are still reverberations of the historical perceptions and approaches that color present work.

1 (b). Disability Perspective on the Dilemma

Generally, the disability rights movement has fought for people with disabilities not to be pigeonholed by their impairments. Disability is often seen as neutral—neither good nor bad—and is as much a function of society's accommodation of the impairment as it is the impairment itself. Recently there has been a growing movement toward viewing disability as a cultural category, which has both positive and negative characteristics (Peters, 2000). This has been seen most notably among Deaf people, who have an entire Deaf culture and view themselves as a distinct cultural group (Padden & Humphries, 2005), but also amongst people with all types of disabilities. Some people with disabilities prefer to reject labels altogether (Mason, 2005), and particularly dislike being labeled by professionals. However, without a clear diagnosis or "label," many services for people with disabilities are simply not available. An individual needs that diagnosis to access these services. This is clearly a systemic problem, not an individual one; however, it directly affects many individuals. One way that disability-rights proponents have addressed this disconnect is through an emphasis on self-determination and self-advocacy for people with disabilities.

In the United States, an independent living movement promoting self-determination for people with disabilities began in the 1970s and is still strong today (deJong, 1979). For

disability advocates and service providers, the concept of self-determination is rooted within the client's or consumer's self-identity as a person with a disability. Gilson & DePoy (2004) describe self-determination within disability studies as an approach that places the locus of decision-making and control with the person with the disability. This decision-making can extend beyond selecting which services to receive, to choosing to abstain from any services at all. In the independent living movement, individuals with the disability are viewed as the foremost expert in any supports, services, or accommodations that they might need (Gilson & DePoy, 2004; Wehman 1993). Some publicly funded services have begun to respect the notion of consumer-controlled services, and there are now options under Medicaid that allow people with disabilities to have more control of their services, including in some instances the ability to hire and fire their own support givers (Benjamin, 2001). Consumer self-direction requires an individual with disability to have an in-depth knowledge of their support needs related to their disability. The concept of self-determination in disability practice does not call for people with disabilities to self-define solely in terms of their condition; however, it does call for an ownership, as it were, of the diagnosis and its attendant constructs, when consumers are directing the services and supports that they need.

Closely linked with the concept of self-determination is a strong emphasis on avoiding "labeling." Unfortunately, there is a common societal misperception that having a disability is equivalent to being "sick," "deviant," or "deficient" (Mackelprang & Salsgiver, 1999). Understandably, people with disabilities choose to self-identify in ways that are more positive. At the most basic level has been the push in the United States for using "person-first" language when referring to people with disabilities. The notion behind people-first language is that a person or group of people should not be identified first or solely by their disability ("a disabled man" or "the blind"), but rather a disability label, if used at all, should come after the ("a man with a disability," "people who are blind") (Lynch, Thuli, & Groombridge, 1994). However, there also are many who do not want a label attached to them at all. This becomes complicated when there is a need for a label for service provision, and there is a need for social work services and assessment to move toward a more contextual approach to assessment, rather than focusing on the presence or absence of pathology (Mackelprang & Salsgiver, 1996).

The dilemma between easing access to services through a clear diagnosis of disability and unease in assigning labels to people with disabilities is highlighted in work that is done at the boundaries of social service systems. Services that are provided to individuals who are eligible for services in multiple systems, or who are about to transition from one service system to another, often put additional stress on the need for clear definitions, labels, and prescriptions for services. Professionals from multiple service systems must "talk" with one another, share information and referrals, and attempt to streamline the rough edges between systems. In many cases, this magnifies the system's desire for clear labels and diagnoses. At the same time, however, both the service recipients and providers may be resistant to labeling as they move into a new system of care. Social workers' commitment to self-determination and empowerment for their clients may also affect their desire to shun labels and, instead, focus on their clients' strengths. However, if they choose to do this, how does it affect access to services for clients? In addition, by choosing not to focus on disability, are "teachable moments" being lost in work with consumers who could benefit from practicing self-determination and self-advocacy?

2. How the dilemma affects practice: Findings from a case study

This study examines how the dilemma regarding accessing services versus labeling people with disabilities gets played out in a practice situation through looking at a case study involving youth with disabilities in a foster care transition program, from both the perspective of the youths with disabilities and from the social workers working within the foster care provider agency. Although evidence is sparse, research has shown that a high percentage of youth in the child welfare system are youth with disabilities. The most rigorous studies of maltreatment of children and youth with disabilities estimate that the rate of maltreatment for children with disabilities ranges from 1.7 times (Westat, 1993) to 3.4 times (Sullivan & Knutson, 2000) greater than that of children without disabilities. A 2004 GAO report found that 30% to 40% of youth in foster care have chronic medical problems (GAO, 2004). Nearly half of the former foster youth in the Chapin Hall's 2005 Midwest Evaluation of Adult Functioning of Former Foster Youth had received special education services (Courtney et al, 2005). Thus, of the 20,000 youth who transition from foster care each year (GAO, 2004); a large proportion will also have some sort of physical, mental, developmental, or intellectual disability. While all youth transitioning from care face barriers, youth with disabilities face additional barriers. In general, these youth interact with many systems simultaneously, including the child welfare system, the adult disability system, the education system, the juvenile justice system, and potentially many others.

A young person's transition from youth serving systems to adult serving systems serves as an excellent case study of individuals with disabilities who are involved with multiple service streams. This transition generally takes place around the young person's 18th birthday, when many federally and state mandated youth services end. When a young person is enrolled in secondary school, the school identifies the young person as having a disability and provides an Individual Education Program (IEP) team that develops a yearly service plan for the young person. This plan identifies the young person's needs, contains the plan to meet those needs, and manages the services identified to meet them (Hart, Zimbrich, and Whelly, 2002; NCSET, 2004). Similarly, youth transitioning out of the child welfare system are mandated to have a plan that focuses on preparing them for adult life. In these youth-serving systems, the onus for identification and planning sits with the experts, rather than with the young person. However, when the young person turns 18, the responsibility for identifying service needs, providing the documentation necessary to access those services (such as disability diagnosis), and making any requests for specific services, supports, and accommodations moves onto the young person's shoulders.

The purpose of examining how the dilemma regarding accessing services versus labeling people with disabilities is played out for youth with disabilities in a foster care transition program is to gain exploratory knowledge regarding how a strengths-based approach fits with the need for a diagnosis to access services. Further, this examination will help to develop strategies for social workers and service systems to provide effective services for people with disabilities. For this consumer group in particular, this study aims to give some guidance on whether or how social workers should help young people self-identify as having a disability, and how the social service system can better serve youth with disabilities in light of this dilemma.

2 (a). Methods

To explore how the dilemma regarding accessing services versus labeling people with disabilities gets played out in a practice situation, this article pulls from data gathered as part of a qualitative case study of a transition program for youth in treatment foster care. The program provides supports and services, independent skills training, and case management for youth ages 17 and older who are residing in foster homes managed by the treatment foster care agency. Semi-structured interviews were conducted with six program staff and three program participants. Program staff included both program managers and individuals who worked directly with the young people. Each interview lasted approximately 1-2 hours. Interviews were conducted over the course of several months.

The focus of the study was on the efficacy of the program and the perceptions of its success by both program participants and program staff. Program staff members were asked specifically about their knowledge of the disability diagnosis of youth in the transition program, what disability-specific supports they were accessing or might access, and how they felt having a disability affected the young person's transition. Program participants were asked if they had a disability diagnosis, about their knowledge and understanding of their disability, and if they accessed specific supports and services for their transition, including disability-specific programs and special education programs during high school.

Preliminary data analysis occurred during data collection, through an informal review of transcripts as they were completed. This preliminary analysis was used to hone interview questions with participants for better examining themes and addressing gaps in the information (Merriam, 1998). The interviews were tape recorded and then transcribed. Each of the two researchers independently reviewed the transcripts for themes and then compared and crosschecked their findings. The themes were refined, through comparison of the researchers' independent findings, to create finer categories and subcategories of data (Merriam, 1998). Refinement and discussion of the themes was continued until categories and subcategories of themes were developed that were exhaustive, mutually exclusive and conceptually congruent (Merriam, 1998).

This exploratory study does not intend to provide generalizable results for a wider population, and certainly, it is not possible to generalize from a case study of a single program. However, it is the researchers' hope that this case study will cast some light on the dilemma of services to people with disabilities and will lead to a wider discussion in the profession about the tension between labeling people with disabilities versus ensuring access to services.

3. Findings

From this case study, several themes emerged related to the central dilemma about labeling versus self-determination. These themes included a general discomfort and lack of knowledge about disability labels by both program staff and program participants, a strong commitment to self-determination of program staff, and limited or poor experiences with the disability service system by both staff and participants. These themes are explored below.

3 (a). Discomfort and lack of knowledge of disability labels

Both the youth in the program and the program staff expressed discomfort and/or lack of knowledge about disability labels. This theme was the most predominant theme that emerged from the case study, and it was repeated in various ways throughout the interviews of both staff and youth. Youth were resistant to being labeled as having a disability, viewing it as negative. Program staff were uncomfortable with the label, not wanting to "put it on" the program participants. For both program staff and program participants, having a disability was viewed negatively, rather than neutrally.

On a programmatic level, the program's staff members are not required to have specific training on disabilities. The staff members have training in social work, psychology, education, or other related disciplines, but they do not receive disability-specific training as part of their work with the transition program. The program itself does not gather or report disability diagnosis information about its participants, even though likely a majority of its participants has a disability. This information may be available through other sources—for an example, the school system or a medical provider—but is not part of the agency's intake screening. When asked, the administration of the transition program estimated that approximately 50% of the youth who have participated in the transition program are youth with disabilities. When one of the front-line staff was asked how many of the youth on her caseload had a disability, she replied, "Some of them are on IEPS, not all of them. I would say 60% or 70% are on IEP." Another staff respondent indicated that nearly all program participants had a disability, saying "I consider every one of our kids to have a disability. I mean, everyone is impaired or delayed in some way, shape, or form. And developmentally, definitely."

Based on the interviews with program participants and staff, it would appear that program participants are not comfortable in naming a disability diagnosis, nor have they been specifically encouraged to do so by program staff. This is not to say that youth are unaware of their disability diagnosis; rather it was clear that they had not chosen to use it to access additional services and supports. Instead, they chose to ignore it or refuse the services that it might bring to them, preferring to be independent of the label and its attached services. For example, when asked if he had a disability, one program participant replied:

No. I don't have a disability! I can do calculus in my head, I can do trig. I'm really good at math…. they had to get back at me. One of the teachers put EBD on me. So, I was kind of frustrated with that.

Another respondent was more comfortable with his disability diagnosis, but stated that he preferred to not access the disability-related services that he knew were available to him through his community college. He said:

I can [access services], but sometimes I don't want to. Because I think I'm at about that age now, I should start trying to do things on my own. Because when I'm an adult, I'm not going to have a teacher there to help me out when I don't understand things. I'm trying to kind of start learning how to start drifting away from that, I'm kind of ....I know I have it, and I know I have the ability to go get help, but I just try to learn how to do it on my own.

All of the program staff members who participated in interviews were asked if the youth participants were able to self-identify as having a disability. The responses to this question were mixed. Several of the respondents felt that the youth would not know, while others thought that some would know but be unwilling to self-identify. For example, one respondent described how it depended on the individual program participants, saying " ...It depends on the kids, yeah. Some kids have no problem, they'll tell you, others … you may have to prod them a little bit."

Another staff member, when asked if the youth would be able to self-identify as having a disability said:

No. You could say things like "what kind of things are you working on your treatment plan? Do you go to IEP meetings?"….But people with disabilities are in wheel chairs. People don't say, "you are disabled," they say, "you don't learn as well as other kids."

It is notable that not only did the program staff not report a high level of knowledge or expertise in disability or disability rights; they also clearly felt that having a disability is a negative label. The program participants also reported this belief in the inherent negativity of a disability diagnosis--they saw it as a punishment, or at best, as a sign of weakness that they should leave behind as they become adults. Despite acknowledging that the majority of the youth in the program had a disability diagnosis, the program staff indicated that they did not work with the youth on self-determination or self-advocacy skills related to disability, nor did they feel that it was necessary for the program to reframe disability in a neutral context.

3 (b). A commitment to self-determination

A second theme that was evident in this study was that the program staff had a strong commitment to a strengths-based approach to their work with youth. There was a universal desire to empower the youth in the program, and to work to provide them with opportunities for growth and self-actualization. For example, one staff respondent said, "Because we really believe in the self-determination. We don't want to impose anything on them." Another said,

That's one of the things I always tell them. I have no agenda. I have to do these things for funding, otherwise, as far as your future is concerned, I don't have an agenda regarding what has to happen. That's your job. If you tell me what you want to do, then we'll go do it.

However, the staff's commitment to self-determination seemed to encompass a belief that a disability diagnosis or label was somehow negative and disempowering for the youth. The service providers indicated a reluctance to label program participants as having a disability. For example, when asked about the link between self-identification of a disability and accessing accommodations and supports, one respondent was quite negative about youth self-identifying as having a disability. She said, "But at what cost? You have to self-label or self-degrade to get the help you need...." Similarly, another respondent said:

It was another little tricky, "oh it's ok, because they can write out the notes for you, it's not about a disability" but, unfortunately, in school, they call it a disability office. I mean really big letters. Like you're going to want to go with that? It's kind of like a stamp on their forehead. I think they felt very stigmatized by that name.

Finally, the emphasis on self-determination also meant that the youth were able to refuse to access disability-related services, even if the program staff had identified it as helpful and necessary. For example, when asked if she ever referred youth with disabilities to a disability-specific job-training program, one staff member responded:

We tried to connect them with some of that stuff... We definitely expose them to it, but not all of them took advantage of it. It was more trying to get them to know that these things were out there and they could do. And some took advantage of it, and some didn't.

Program staff clearly felt that the youth's ability to refuse services was not always in their best interests, and felt a tension in adhering to their strengths-based approach. For example, one respondent, describing a more extreme case, discussed some of the serious ramifications of self-determination. She shared the following story:

Some of those kids refuse the help, which is normal, but they tend to not do very well. I had a lot of kids who had bipolar, a lot of my kids through care. I have three different cases, they all have the same offense, they have bipolar. One went to adult care, and went to college and did great. One went home and was in jail in 20 days

and pulled a gun on his dad. It's just ridiculous. It just depends on what kind of support they are willing to take.

The program staff members are very committed to providing strengths-based services to the youth in the program. They clearly want to help the young people succeed based on their own goals and desires. They worked closely with the youth to set goals and to help them achieve those goals. However, acknowledging a young person's disability diagnosis was viewed as stigmatizing and negative, rather than neutral. Young people were made aware of disability-related services and supports, but were not specifically encouraged to access them, even in the extreme cases. It would appear that staff felt that the negativity of a disability diagnosis outweighed the positive of connections to specific services.

3 c. Youth are over-serviced, and disability-specific services are excessive or unnecessary.

A final overarching theme that emerged from this case study is that respondents reported that youth are over-serviced in general and that disability-specific services have been of limited or no utility to them. Youth were asked if they received any disability-specific services, with the researcher going through a list of possible services (for example, Centers for Independent Living, disability services in college, IEP/Special education services, vocational rehabilitation). With the exception of school-based services such as IEPs, none of the youth who participated in the study reported accessing any other disability-specific services. For those who had an IEP, their experiences with the IEP were mixed. One respondent very clearly felt that being on an IEP while in high school was insulting and unnecessary, saying:

It was a pain in the neck! Cause you have to go to these meetings and you get pulled out of your class when you have a big project you have to do! It's quite annoying. And then you fall back, and it's like, thanks. And it's like, it's not our fault, you have to work harder! Well, take me off the IEP then!

Another young person had a different experience, reporting that the extra help he received as part of his IEP was, in fact, helpful. However, this respondent was very clear that he did not want to access similar services as an adult, preferring to work on his own in the future. He said:

I'm just trying to make things on my own. I like to try to figure stuff out on my own. Because when I become a parent and have a family, I'm going to have to make it on

my own anyways, besides the support of my wife or girlfriend. I'm kind of like an independent person, I'd rather be there for everybody else than for myself. I've kind of learned that, just being alone, being an adult.

Program staff also reported mixed experiences with disability specific services. Several reported concerns with the appropriateness of disability services, wondering if the services were helpful for the youth they were working with. Another concern for program staff was that young people were simply over-serviced. They did not want to bring more services into a young person's life without certainty that it would bring something new and a tangible skill or outcome for that young person. One staff member said:

…some of these kids got so many services that they started getting really over-serviced. They'd be like "don't tell me one more thing. Because my therapist tells me that, and my foster parents…" So, I really had to struggle with that with a lot of kids, they'd be like "why are you guys always telling me this? Why does everyone keep harassing me about it?" And there were times where I'd have to be like, ok, let's think this through. …Because it's too much! It's too much. And they don't like being told what to do. They don't need it from 500 people….

One staff member felt that the services that one young person was referred to were not appropriate to his needs and, in the end, ended up hurting him.

….well, one time I had a young man who had been diagnosed with schizophrenia and needed to have a neuropsych done. So his county worker got all that organized, and then she wanted a certain person to do it. Well, his report came back and it was oppositional defiant disorder. And we were like, who is this kid? It was completely….all the things on there were not this kid at all. It was the worst report I've ever seen. It was like, did you even talk to this kid? Because it's not accurate in any way. So, he didn't qualify for adult services. And we were like, what are we going to do?

Staff also reported that, in some cases, youth did not qualify for adult disability services, despite being on an IEP. This caused some frustration for both the youth and for the staff. A program staff member shared the following observation about how difficult it was to get adult services for kids transitioning from foster care:

A lot of them unfortunately did not make the cut. A couple of them did, but unfortunately, because it's voluntary, it was a struggle. So, I would say a small

percentage, a very small percentage got some disability services. Some were offered and then refused, and the majority was not severe enough.

Finally, staff reported difficulties in getting disability services and foster care services to work collaboratively. The rules and regulations for one set of services were often contradictory to what was available through another funding stream.

The findings from this case study indicate that some of the reluctance to access disability specific services comes from a belief that the services are not unique in what they provide, are difficult to access or qualify for, and may not be appropriate for the needs of the youth in the program. Additionally, the negative perception of disabilities also colors the young people's willingness to access these services, even when they have been helpful in the past. The program staff members were less likely to acknowledge that disability specific services had been helpful to the youth, often feeling that they were repetitive or ineffective or worked in opposition to the services that youth were already receiving. Why risk the negative implications of a disability label if it will not lead to the highest quality, most useful services?

4. Discussion

The findings from this case study indicate that there is tension between the need for program participants who have a disability to carry a diagnosis or label of disability with them to access adult services, and participants' and program staff's discomfort with disability labels and diagnoses. However, without these labels, many publicly funded services may be unavailable to the youth program participants, not just as they transition out of this program, but as they move on into their adult lives. Indeed, in some instances, respondents indicated that forgoing services was preferable to having a disability label.

One of the most notable findings of this study is the universally negative perception of disability by all of the respondents in this case study. The program staff clearly felt that having a disability diagnosis or label was, at best, neutral, and more often, negative. These findings are not surprising, as many studies have shown that social workers who are not in the disability field are not comfortable working with people with disabilities (Manders, 1996), have little information about disabilities (Lightfoot & LaLiberte, 2006), and are in need of disability training (Lightfoot & LaLiberte, 2006; Orelove, Hollahan, & Myles, 2000). Whereas negative perceptions cannot be changed overnight, there is clearly a need for more efforts to promote a positive image of disability among social workers. Providing specific training to social workers and other service providers on alternate, non-medical model perceptions of disability could begin to bring about a positive change in the way disability is perceived and understood. In particular, there is a need for social workers to have training on how to integrate a positive perception of disability within a strengths perspective practice approach. This training should be integrated into both academic and post-academic training, such as professional in-services or licensure trainings, and should not be limited to those in the field of disability services.

The youth with disabilities in this study also had a generally negative perception of disability. While youth with disabilities in general lack positive role models (Burgstahler & Cronheim, 2001), youth in the child welfare system may have even less access to these role models. Many studies have shown that youth with disabilities need exposure to peer and mentor role models (Burgstahler & Cronheim, 2001; Lynch & Lynch, 1997; Rousso, 2001). Perhaps introducing foster youth to disability culture and providing opportunities for youth to relate with other youth with disabilities and young adults with disabilities could help them change their negative perception of disability. However, social workers should have no illusions that this negative perception will change quickly, as it may be deeply ingrained.

The findings from this case study also point to the need for more universal services for youth that do not require specific labels for entry. If programs were designed to help any youth that needed assistance, such as independent living skills development, job hunting, or post-secondary training, youth would be able to receive such services without obtaining a disability label. However, as desirable as universal programs may be, they do have funding implications that often make them untenable. Further, programs that are universally designed might have more difficulty in providing appropriate services to the youth who need them most, and youth with disabilities might not get the tailored services that would best fit their needs. An alternative to developing universal programs is for programs that serve youth with disabilities to downplay the disability label in the marketing of its services to youth, so a youth who is apprehensive of his or her disability might not feel so uncomfortable in initially obtaining its services. However, programs must be careful not to play into the negative perceptions of disability, and find ways to introduce a positive perception of disability within their programs.

The findings from this study point to the possibility that children with disabilities who have no parents or family members available to advocate for them may be less likely to have a disability label, or less likely to use the disability label to obtain services. The current system of special education services creates an important role for parents, in which the parents are involved in claiming the disability label for their child in order for their child to get services, and then the parent "carries" the disability label throughout the child's development, until the young person is able to claim it for him or herself. Youth without parents or other close family members may have no one who will work with them on building a healthy self-identity, practicing self-determination, and learning to self-advocate for the services and supports that they need. Service systems, especially for youth and young adults, must stop assuming that there are parents or family members available to do this work for them, and there is clearly a need for youth with disabilities to be aided in understanding their own disabilities. In addition, disability advocates and professionals need to target people with disabilities who are not currently being reached, such as youth with disabilities in foster care.

Finally, existing disability services need to be of the very highest quality. While this is true of all types of social services, a number of respondents in this study did mention the futility of labeling in the face of the poor services available. It will not help to assist youth in self-identifying and self-advocating so that they can access disability services only to have the services be inappropriate, low-quality, or unavailable as a result of budget, time, or service constraints.

While the findings from this study cannot be generalized to other professionals and participants involved in youth transition programs, it does provide some insights into how the tension between labels and self-determination play out in a social services setting. There is a need for further inquiry into how to best serve people with disabilities in non-

disability specific settings. In particular, young people with disabilities who are vulnerable in some other way, such as those in foster care or in the justice system, may be in particular need for services and supports from a system that does not view their disability status as inherently negative.

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Social Work Practice with Disability: Moving from the Perpetuation of a Client Category to Human Rights and Social Justice

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Abstract

In this article, we propose an alternative stance to the ways in which disability is theoretically and practically approached within the field of social work. We begin with a critical analysis of how contemporary views of disability and response praxis came to be. Building on history and current scholarship from humanities, social sciences, and natural sciences, we then advance a progressive theoretical framework, explanatory legitimacy theory (DePoy & Gilson, 2004, 2007). Explanatory legitimacy theory locates disability within the broad context of human diversity, uncouples diversity and thus disability from the bodies and backgrounds mentality of current diversity thinking, and illuminates an alternative value and philosophical frame to inform and guide social workers concerned with furthering the profession's mission of social and distributive justice for all people.

Key Words:

Explanatory Legitimacy Theory, Human Diversity, Disability, Response Praxis

Over the past several decades, disability and social work have become increasingly strange bed fellows. In this article, we discuss why and then propose a philosophical and theoretical direction for reconciliation. We begin by gazing backwards in time to set the chronological context for current debates about the term "disability." Building on history and current thinking, we then advance a progressive theoretical framework, explanatory legitimacy theory (DePoy & Gilson, 2004, 2007), which locates disability within the broad context of human diversity, uncouples diversity and thus disability from the bodies and backgrounds mentality of current diversity thinking, and thus illuminates an alternative value stance to inform and guide social workers concerned with advancing the profession's mission of social and distributive justice for all people.

1. What Came Before Us

There is record of concern with "the atypical human" as early as ancient civilizations (Longmore & Umansky, 2001). This history creates an opaque but important window on how civilizations responded to embodied difference. Unfortunately, in this short space, we cannot do justice to the richness of this history, but we can provide a brief chronology that summarizes the critical historical turnings necessary to inform current debates and understand contextual responses to atypical humans in contemporary times. Whereas diverse notions of and approaches to atypical bodies have occurred, the following commonalities can be seen across chronology:

 (1) in each era there have been many potential and accepted explanations for a single atypical human characteristic,

(2) these explanations form the basis for categorization and subsequent response to category members, and

(3) the responses proffered provide an analytic window on the beliefs, values, politics, economics, intellectual trends, and level of technological development of the times.

We enter our history through a linguistic portal, as this symbolic element of social and cultural groups is critical in revealing contextually embedded values and meaning (Belsey, 2002; Baudrillard, 1995). First, note that we use the terms typical and atypical to denote a full range of frequency from most to least respectively. We have selected this terminology, rather than normal/abnormal, to circumvent the value judgments that are embedded in the normal/abnormal binary.

The term "disability" has only recently become a signifier for the grand category of atypical bodies. Its predecessor, "handicap," was alleged to have emerged from the cap-in-hand proclamation, in which Henry VII in 1504, recognizing the plight of injured soldiers, formally allowed these worthy citizens to beg in the streets as a means to their own subsistence. More broadly, the recognized use of the term handicap is an equalizing scoring system in which disadvantaged persons are artificially boosted to increase the likelihood of their success when positioned against a superior opponent. In the early part of the 20th century, the term handicap was ascribed to individuals with bodily differences that ostensibly placed them at a disadvantage, and ultimately the word "handicap" in this sense, came to mean a specific embodied condition such as a "physical or mental handicap." Given the pejorative notion of bodily inferiority, it is no surprise that a euphemistic term to replace "handicap" was sought to describe bodies that did not conform to the "typical." It is curious that the term "disability" was selected, given that the prefix "dis" emerged from DIS, the name given by ancient civilizations to the ruler of Hades, or the underworld. DIS was portrayed as punishing mortals by extracting their health, wellbeing, and capacity to function in their environments. The use of DIS is consistent with the disdain for atypical bodies in Ancient Greece. While those who were mildly atypical were excluded from community life (with the exception of those who were saluted because they sustained bodily injury in war), extreme deviations from the typical were considered inhuman (Martin & Volkmar, 2007; Braddock & Parish, 2001) and left to die. Thus, myth, symbol, and tolerance in ancient Greece demonstrate the historical common denominator of multiple explanations and responses to atypical bodies on the basis of why the atypical had occurred, rather than on the atypical characteristic or need itself.

In the Middle Ages, the typical tapestry against which the atypical emerged was frayed and threadbare, characterized by poverty and deprivation. Human conditions such as blindness, deafness, and lameness that are so often associated with impoverished living conditions were woven into daily life and image (Braddock & Parish, 2001; DePoy & Gilson, 2004; DePoy & MacDuffie, 2004). So rather than embodied phenomena such as blindness or lameness being considered atypical, only extreme deviations were located as marginalia, and in concert with the religious and intellectual trends of the middle ages, were attributed to supernatural causes, followed with responses that were consistent with the degree of worth ascribed to each explanation (Braddock & Parish, 2001; Winzer, 1993). Of particular note in this time period are the historical roots of charity and faith healing responses to disability (DePoy & Gilson, 2004). Whereas people with atypical bodies were devalued themselves, their place on earth was fabled to be a test as well as an opportunity from God, for those who were fortunate, to demonstrate their charity and tolerance. Faith-based care only for those who approximated the low end of worth was born, and serves as the archetype of contemporary secular charities and institutions.

Moving forward in chronology, as the complexity and differences around the globe became known to civilizations, history moved beyond a single story of one's own people. Because of this vast history, we narrow our discussion to colonial America where our focus will reside

on the North American continent for the remainder of our brief but purposive historical expedition. In the fledgling U.S., an amalgam of both enlightenment and religious thinking, peppered with economic prosperity, increasing economic concern, and the juxtaposition of indigenous and immigrant people created a complex backdrop for understanding responses to atypical bodies. The rationale for inclusion and in-home responses to the atypical that were apparent in early colonial America were breaking down and quickly became supplanted by "medical" explanations (Axinn & Levin, 2000), setting the stage for medical and ultimately broader professional colonization and ownership of the "atypical body and mind" (Mink, Solinger & Piven, 2003; DePoy, & MacDuffie, 2004).

Of particular historical importance to understanding contemporary disability theory and practice responses were the abstract creations of Quetelet, who invented the mathematical constructs of the normal or bell shaped curve and measures of central tendency. These two ideas form the foundation of contemporary empirical knowledge and fabricated the dissection of humanity into the two categories of "normal" and "abnormal" (DePoy & Gilson, 2007a). Applying the bell shaped curve to human variation, Quetelet extrapolated the concept of "the normal man," who was considered to be both physically and morally normal. Synthesizing probability theory with the "normal man" construct, normal was not only interpreted as the most frequently occurring phenomenon, but morphed in translation to what "should be." Observation, therefore, turned to prescription, and anyone with observed phenomena on the tail ends of the curve was categorized as "abnormal." Fields of study and professions (with medicine in the lead) that espoused and reified these positivist approaches to inquiry as truth (such as normal and abnormal psychology, medicine, special education, social work, and so forth) all distinguished between normal and abnormal and claimed the "abnormal" as their epistemic and ontological property as well as their axiological obligation (DePoy & Gilson, 2007a; 2004).

It is curious to note that the term disability in the early 20th century did not include medical diagnostic conditions, as revealed in the1906 edition of the Standard Dictionary of the English Language that proffered the following:

- lack of ability of some sort,
- impotence,
- the state of being disabled,
- a crippled condition,
- lack of competent means,
- inability as, the disabilities of poverty.
- Legal incapacity or the inability to act; as the disability of lunatics and infants

Note that these definitions are both expansive and progressive in that they do not delimit disability to specific diagnostic explanatory conditions or exclusively embodied phenomena, but rather approach disability from a broad descriptive stance not entwined with explanation.

In an effort to create a politically correct moniker for its current pathologized synonyms (handicapped, incapacitated, crippled, physically challenged, impaired, injured, maimed, hamstrung, wounded, mangled, lame, mutilated, silenced, run-down, worn-out, useless, wrecked, stalled, bedridden, weakened, helpless; confined to one's bed, confined to one's home, confined to a hospital, confined to a nursing home; impotent, castrated, halting, limping, hobbling, palsied, superannuated, paralyzed, paraplegic, quadriplegic, brain damaged, senile, decrepit, on one's back*, laid up*, done for*, done in*, cracked up*, banged up*, broken down*, out of action*, counted out*; see also hurt, useless 1,

weakened) the term disability was adopted by professions and now labels one of the largest industries in the United States (Gill, 1992).

Although medical explanations remain primary in defining disability even now, the history of disability took an important turn in the latter half of the 20th century that has significantly influenced responses to it. Disability rights scholars and activists eschewed the medical explanation for disability, since such explanations of permanent deficit were impotent in advancing social justice, equality of opportunity, and rights as citizens for those who were members of the disability club (Nussbaum, 2006; Stein, 2006; DePoy & Gilson, 2004). Rather than accepting themselves as the "work" for the disability industry, disabled scholars looked external to the body to explain disability. Early scholars such as Oliver (1997) and Linton (1998, 2006) proposed the intolerance and rigidity of social and built institutions rather than medical conditions, as the explanation for disability. Words such as inclusion, participation, and non-discrimination were introduced into the disability literature and parlance reflecting the notions that people who did not fit within the central tendencies of Quetelet's "normal curve" were disabled by stigma, prejudice, marginalization, segregation, and exclusion. Demands for equality of opportunity were anchored on theory and research that documented the locus of disability within systems of oppression and discrimination rather than internal to the organic body. With the view of disability explained by external factors such as social, economic, political, marginalization, exclusion, and abrogation of human rights (Nussbaum, 2006; Stein, 2006) rather than an internal medical condition, the locus for disability and thus for necessary responses has become a moving and complex target. Still, professions, policies, and theory, despite their assertions to look beyond the body, situate disability within the organic human domain, as evidenced by embodied eligibility criteria even for human rights and anti-discrimination legislation, and further exposed by terms such as physical, cognitive, learning and mental disabilities. Because deficient bodies are the object of disability rights discourses and responses, this conceptual quagmire reveals the inherent hegemony of medical abnormality in explaining the atypical and locating disability within the body regardless of the narrative indicting systems of oppression rather than bodies as disabling factors.

Before we move on to disability in social work, we highlight what we have named "the tyranny of the opposite." We began this paper with a discussion of language because of its powerful and reciprocal role in reflecting, as well as shaping values. And as reminded by the post-structuralists and post-modernists, identical narratives may produce different meanings. Moreover, language is not simply restricted to what is apparent, explicit, and articulated, but is powerful in its negative spaces or what we refer to as the tyranny of the opposite, or what is NOT said. Words and phrases such as "person first language," while cobbled by committee so to speak for the purpose of political correctness, are often opaque in what is NOT spoken. That is to say, modifiers that are part of human experience, such as disabled, crippled, retarded, and so forth, rather than being reconceptualized as human diversity, remain NOT desirable, and rather are lexically relocated after "personhood" to obfuscate what is NOT desirable. Inherent and perhaps not effectively shrouded in these linguistic finaglings is the unworthiness of these modifiers and a hierarchy of "worth and NOT worth" on the basis of category membership. Moreover, given the penchant of most schools of social work to equate HBSE with theories of human development, the foundation of social work's view of humans as structuralists and cleaved into normal or the tyranny of the opposite (NOT normal) is set into motion before students even engage in practice.

1 (a). Disability in the House of Social Work

The history and current residence of disability within social work is a curious one. Given the social justice mission of social work and its mandate "to {attend to}the environmental forces that create, contribute to, and address problems in living" (NASW Code of Ethics, 1999), one would expect that social work would have taken a progressive lead in disability rights. Yet, according to the scholarship of Mackelprang and Salsgiver (1999) and endorsed by Yuen, Cohen, and Tower (2007), Murphy and Pardeck (2005), May and Raske (2004) and Rothman (2002), social work had not attended to disability as a category of oppression, but rather had ministered to "people with disabilities" through the provision of clinical services. And while several social work scholars have asserted their espousal of the social construction of disability (Yuen, Cohen, & Tower, 2007; Murphy & Pardeck, 2005; Mackelprang & Salsgiver, 1999), these same authors encounter the conceptual quagmire from which disability rights theorists cannot extricate themselves, how to think about, talk about, and thus respond to disability as something other than an embodied phenomenon. The use of person first language, which locates disability within a person no matter where the "heinous" condition is lexically placed, as well as the sub-categorization of disability into types such as learning, mental, physical, neurological disability and so forth (Rothman, 2002, May & Raske, 2004) divulge social work values and beliefs even when well-intended claims of disability as constructed are made. And for the majority of the field, disability is a pathological condition that immediately catches the social work clinical eye. By analyzing what is NOT articulated but what is actualized in professional behavior, the tyranny of the opposite once again exposes the social work view that disability is NOT desirable, is NOT strictly a function of environment, and is in need of repair, perhaps through improving the world for citizens with disabled bodies and minds and most likely through providing services that "clientize" (Cowger, 1998) the atypical body. Whatever practice approach is followed to address the category of people with atypical bodies and minds, social work joins full tilt in the disability industry (May & Raske, 2004). Moreover, through succumbing to the politicalization of education, subscribing to developmental theory, and decreasing many of the required disciplinary areas of scholarship beyond social work itself, social work education has perhaps inadvertently reified disability as a category with embodied deficit as the binding and defining element of membership and identity, and as one in which members needs "help."

Before we suggest how social work and disability can reconcile, we acknowledge our own conceptual strugglings and ask that, as we did and continue to do, the reader "flips his/her brain." What we mean by "flipping your brain" is before dismissing unfamiliar ideas that on the surface may create axiological and ontological tension, engage the work, be reflexive, consider alternatives that have not been articulated, and examine thinking that challenges well honed beliefs, values, and ethics. As you might have noticed, we also fall prey to the conceptual paradox, in that we argue against the usefulness of the category of disability itself, but we teach and write about it, and this article is appearing in a special issue devoted to the construct that we wish to eliminate.

2. Moving Forward-Rethinking Disability as Diversity through Explanatory Legitimacy Theory

We now introduce a framework, explanatory legitimacy theory, that invokes and synthesizes diversity and legitimacy theory for thinking about human difference, variation, and categorization in which we parse and then locate diverse bodies and minds. As we will discuss in more detail, the name of the framework depicts the basic tenet that legitimate category assignment and response to category members, in this case assignment to the disability category, is a value judgment that is made on explanations for human phenomena, ergo the appearance of "explanatory" in the theory name.

Legitimacy theory had been advanced as early as ancient civilizations. It examines and predicts what is essential for the assignment of legitimate roles and power positions (Jost & Major, 2002). As it applies to diversity and disability, legitimacy theory informs a complex analysis of what is both gained and relinquished in exchange for membership in legitimate categories. As we discuss later in the paper, we propose an explanation for disability that transcends the debate about whether disability is explained by embodied conditions or environmental discrimination.

Because we view disability as an important element of human variation, diversity theory is a second critical grounding that comprises our theoretical framework. Moreover, as we have noted, whereas we apply explanatory legitimacy to the category of disability in this article, the framework is applicable to a broad swath of human categorizations.

The term "diversity" has changed significantly over time. In the 1906 edition of the Standard Dictionary of the English Language, "diversity" is defined as: dissimilitude; multiplicity of differences; variety. Some prevailing and representative examples of contemporary definitions of diversity are; biological difference (Wilson, 1996), racial difference (Shiao, 2004), noticeable heterogeneity (http://www.hyperdictionary.com, 2005), and minority group membership (Basson, 2004; Healy, 2004). These definitions, which we refer to as diversity patina (DePoy & Gilson, 2004, 2007), are typical of current superficial perspectives in which diversity is viewed as a primary characteristic ascribed to groups possessing specified bodies or backgrounds, which not only describe the essential membership criteria but explain appearance, behavior, and experience of group members because of their possession of the criterion that admitted them to the diversity club. Moreover, in much of contemporary literature, policy, and practice discourse, the term diversity has been further delimited to a characteristic that belongs to groups perceived as non-dominant and non-privileged such as ethnic and racial minorities, women, non-heterosexual groups (Anderson & Middleton, 2005; Healy, 2004) and more recently, disabled groups (DePoy & Gilson, 2004; Mackelprang & Salsgiver, 1999). Note that the tyranny of the opposite implies that people who are NOT members of these predefined groups are NOT diverse.

Numerous historical and political factors have been advanced for this lexical and conceptual recalibration (Parillo, 2005; Healy, 2004; Tomlinson, 1999). In agreement with Shaio (2004) we suggest however, that a major emphasis in this shift was the failure of multicultural efforts to advance axiological symmetry among groups. That is to say, multicultural efforts fail to rise above proscribing the label of diverse to all people and therefore situate diversity within historically devalued groups with certain bodies and backgrounds pedigrees.

The bodies and backgrounds perimeter fails to achieve what Goldberg (1994) has referred to as incorporationist multiculturalism. Different from less progressive but prevalent contemporary approaches to multicultural equality in which marginalized groups are granted membership to predominant cultures only through assimilation or specialized, group specific

strategies that can be eroded or even eliminated, incorporationist thinking locates diversity within all groups, and thus values the contributions and power of each to beneficially transform the other through interaction.

Whereas there are essential and warranted benefits to restricting diversity theory and related responses to selected diversity patina subgroups who have experienced discrimination, there are many limitations, as well. First, viewing diversity as a characteristic of "otherness" sets the theoretical foundation for separation and scrutiny of marginalized groups by those who are in the position to marginalize (Shaio, 2004; Schneider, 2004; Bonilla-Silva, 2003; Rodriguez, 2002; Moller-Okin et al., 1999) and by positing homogeneity within the very groups that are defined as diverse. Assuming group homogeneity on the basis of a single bodies and backgrounds diversity patina characteristic has the potential to promote essentialist thinking and identity politics, and to restrict theory application and community responses to assumed nomothetic need. Second, categories in themselves are constructions. That is to say, the way in which we carve up our theoretical universe can be as diverse as the phenomena that we seek to describe and explain. Third, categories and the theories that fit within them are axiological, dynamic, and change in response to contexts. Fourth, special responses to groups who exhibit diversity patina can be diminished and even revoked as we currently are observing with specialized legislation such as the ADA. Finally, bodies and background views of diversity do not account for the expansion of global, technological communication, and virtual environments in which bodies and backgrounds are irrelevant.

 Expanding the theoretical paradigm of diversity to include and extend beyond bodies and backgrounds to include the uniqueness of all people provides many opportunities not only to maintain the important theoretical and applied gains that have occurred from civil rights concepts and movements, affirmative action, and other diversity patina-specific responses, but to advance the social justice mission of social work. We refer to this approach as diversity depth.

2 (a). Explanatory Legitimacy Theory

Explanatory legitimacy theory was initially developed in theoretical opposition to vague and debated definitions of disability. Different from approaches that describe disability as abnormal, or from the binary that explains it as embodied or environmentally imposed, we suggest that it is simply a set of axiological judgments about the explanatory legitimacy criteria that elucidate and apply membership. There are three elements to the theory: description, explanation, and legitimacy. Description encompasses the full and diverse range of human appearance, behavior, and experience from atypical through typical and expected, in which atypical and unexpected description (or what is infrequent in a context) serves as the domain of interest and engenders multiple explanations for its occurrence. Explanation is the "why" of description. Specific to disability, explanation is the set of reasons that the atypical occurs and forms the foundation for judgment and legitimate category assignment. As we have noted, the binary of disability explained as constructed (which includes the social, minority, political, and cultural models that appear in the literature) or embodied (explained by a medical-diagnostic event) is the current forum for debate. Through this theoretical lens, legitimate category membership is determined on the explanation, not because of the atypical description. And in our current climate, medical explanations,

whether explicit or shrouded with social justice language, are the primary passwords to enter. Just imagine requesting ADA protection because you are disabled by employers' negative attitudes toward your appearance. As we noted above, the judgments are anchored on the explanations for the atypical, not the atypical description itself.

The third element is legitimacy, which consists of legitimate category assignment on the basis of an acceptable and valued explanation, and a legitimate response, in concert with the explanation, to category members. Of critical importance here is the recognition that the explanatory criterion not only creates the permeability and perimeter of the category but ultimately shapes legitimate responses to its members. Applied to disability, boundaries that only admit those with legitimate medical diagnostic explanations guide responses such as remediation, rehabilitation, and special accommodation of individuals, whereas explanations that accept constructed reasons as legitimate would guide the response of barrier removal to economic and community participation, universal design, and creative and significant systems change.

Because of the false binary and the conceptual quagmire that we discussed above, in which constructed explanations are only applied to those with bona-fide diagnoses, thereby obfuscating the primacy of medical/diagnostic explanations as the only acceptable and valued legitimate disability club membership criteria, we have posited a third, integrative explanation, disjuncture theory. We assert that this explanation has the potential to heal the explanatory cleavage, to expand responses to a full range of human diversity, to refashion physical, abstract, and virtual environments that promote equality of opportunity and human rights, and to provide an important direction for social work.

2 (b). Disjuncture theory

 By disjuncture, we mean the ill fit of the body (broadly defined) with the environment. Current built, virtual and abstract (social, cultural, economic, policy, professional, and so forth) environments are explicitly or implicitly based on standards that hearken back to the enlightenment and in large part continue to be a function of nomothetic thinking. That is to say, what is theoretically typical and average forms the basis for architectural, social, virtual, professional, policy, and functional design of environments, products, practices, and other resources. As an example, our recent inquiry into the rationale for and derivation of architectural standards for door sizes, counter heights and so forth, revealed the continued hegemony of DaVinci's Vitruvian man as both the foundational ideal and basis for estimating average adult body sizes. This male-centric, adult image is the design bedrock for mass produced and standardized building and product design practices (Gilson & DePoy, 2007). Similarly, assumptions about typical bodies, such as the ability to use both hands for manipulation, to think typically, to behave in an expected manner, to walk with a typical gait, to hear, to see, and so forth provide the prevailing data on which environmental design and professional practice are anchored. Bodies that do not conform to prescriptive averages, therefore, are challenged to participate in environments in which they do not fit, setting up an environmental binary of juncture and disjuncture (See Figure 1).

Figure 1
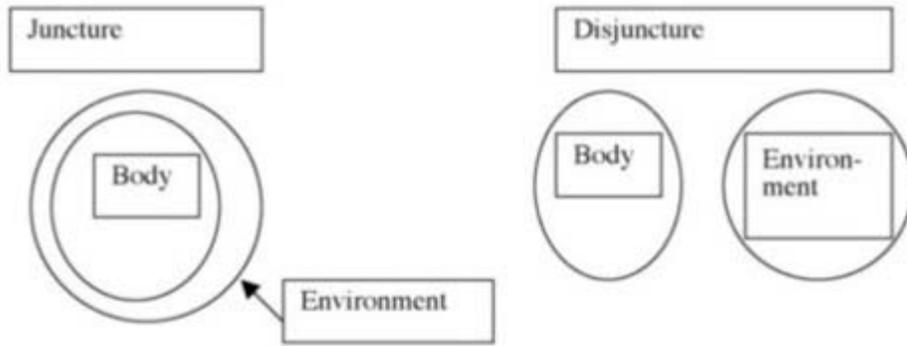
However, the disjunctures between atypical bodies and their contexts, in and of themselves, are not the explanatory locus of disability. Rather, the intersection of bodies and diverse environments (including but not limited to built, natural, virtual, social, expressive, service, policy contexts) explains ability and the tyranny of the opposite, what ability is and is not respectively.

We assert that disability is a complex element of human diversity that should be viewed by social workers through pluralistic rather than essentialist lenses. Disjuncture explanations serve this professional master. By accepting the explanation for disability as an ill-fit between embodied phenomena and the environments in which one acts, the opportunities for social workers to expand the range of legitimate responses becomes boundless. This framework creates a conceptual forum for creative and progressive social work thinking and action that uncouples diversity from bodies and backgrounds, unlinks disability from its pejorative diagnostic deficit model, and aims at improving the world for diversity depth. Given that disjuncture theory guides legitimate responses that transcend the false explanatory binary of bodies versus environments as the locus for intervention, the interaction of the two becomes the analytic unit as well as the broadened opportunity for responsive change that accomplishes the social work missions of advancement of human rights for the full range of human diversity.

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Book Review: Critical Multicultural Social Work

Sisneros, J., Stakeman, C., Joyner, M. C., and Schmitz, C. (2008). Critical Multicultural Social Work. Chicago: Lyceum Books, Inc. http://www.lyceumbooks.com

Reviewed by Peggy Pittman-Munke, PhD, MSW

Book Review Staff, Journal of Social Work Values and Ethics

The authors bring varied and impressive credentials from both academe and professional practice to the task of writing. Jose Sisneros, PhD, has 32 years of professional social work practice experience and now is an associate professor at New Mexico Highlands University. Catherine Stakemore, PhD, is the executive director of the NASW Maine Chapter. Mildred Joyner, MSW, is professor of social work and director/chairperson of the Undergraduate Social Work Program at West Chester University. Cathryne Schmitz, PhD, is professor and director/chairperson of Social Work at the University of North Carolina at Greensboro. Sisernos, Stakeman, and Schmitz have also focused on global and international issues and bring this perspective as well to their book. Joyner brings an additional perspective as a consultant for higher, secondary and elementary education, and for business and human service agencies in the area of race relations .

The authors explore multicultural social work practice from a critical perspective. This is the first book to do so explicitly. The authors provide not only a history and a basic framework for examining and evaluating issues of diversity, but also guided self reflection to enable practitioners to become more aware and sensitive as they work with clients. All of the authors have impressive practice backgrounds and are able to move beyond the mere examination of categories of oppression and diversity to an understanding that identity is fluid and shifting across categories of diversity, including race, ethnicity, sex, gender, sexual orientation, and ability/disability. They work from an empowerment perspective and a recognition of the strengths that the various elements of diversity bring to the table. Techniques and tools that enable the reader, whether practitioner or student, to recognize her/his own perspective and find meaning and importance in what s/he is learning are major strengths of this book.

The authors point out that one issue in social work education is that, although there has been an emphasis on diversity and on oppression, there has yet to be an explicit educational framework that includes oppression and diversity. This book was written to remedy this deficiency. Another issue with the way both diversity and oppression content are currently taught is that there has been no easily accessible work to prepare social workers for exploration of multicultural practice from a critical perspective, although there have been many books on cross-cultural practice and cultural competency. This book links multiculturalism, anti-oppression work, and social justice practice, making it particularly important to readers of this journal. The first chapter focuses on oppression and on the basic theoretical frameworks for evaluating multiple issues of diversity and unequal access to power. The remainder of the book shifts the focus to self reflection through an examination, analysis, and deconstruction of specific oppressed groups within a multicultural context. This context emphasizes the structural and power dynamics of oppression of each group. Another important contribution of this book is the interweaving

of class and economics in an understandable clear fashion into the discussion of structural and power dynamics.

The authors use the metaphor of a web to present the complexity of intersection between race and ethnicity, gender, sex, sexual orientation, ability/disability, and readers are forced to think critically about these dynamics in relation to class and economic situation as they create their own web. This forces the reader to understand that multiple oppressions are not simply additive in their effects, although this is horrific enough. The final chapter moves the reader into the areas of practice in which these issues are more likely to surface and demonstrates how the tenets of critical multiculturalism can be best applied.

I found especially helpful that the authors lead the reader to understand the differing world views and hidden assumptions that produce many of the views of both people in the dominant culture and of those who are members of an oppressed group. I especially liked the fact that the authors recognized the unique culture, family, community, and history of each of the readers. The case examples taken from many different settings pay tribute to the richness of experiences of the book's authors. The application of a critical framework aids the reader to take a critical analysis of oppression and institutional injustices as well as the impact of privilege, and the processes for achieving real change. This is where this book performs signal service. Helping the reader to shift the focus from his/her own world view to that of the other is as important as helping the reader understand that change not only is possible but must and can happen. This book provides the reader with the tools to begin this change. These tools are what makes this book so important to readers both in the academic world and in the practice world. These tools give us the ability to begin to create a world that is in keeping with the tenets of the NASW *Code of Ethics,* one in which oppression is addressed and social justice becomes a focus.

This book should be read by every practitioner and is useful for both graduate and undergraduate classes related to diversity, oppression, and multiculturalism. The reference list pulls together an impressive group of references spanning social justice, cultural competency, oppression, and diversity should readers wish for further information to deepen and enrich their knowledge in these areas.

Book Review: Shock Therapy: A History of ECT in Mental Health

Shorter, Edward and Healy, David. (2007). Shock Therapy: A History of Electroconvulsive Treatment in Mental Health. New Brunswick, NJ: Rutgers University Press.

Reviewed by Stephen M. Marson, Ph.D. ACSW

Editor, Journal of Social Work Values and Ethics

As a result of preparing a book review of Ottosson and Fink's Ethics in Electroconvulsive Therapy (published in the Journal of Social Work Values and Ethics, Volume 5, Number 3), I felt compelled to also complete an analysis of Shock Therapy: A History of Electroconvulsive Treatment in Mental Health. My compulsion to read this scholarly work emerged from ethical principles. For decades, I was one of the people who condemned the employment of Electroconvulsive Therapy (ECT). I believed that I had an in-depth knowledge, but in fact, did not. Now, I feel that my action regarding ECT is a violation of NASW Standard 1.04 Competence (a):

Social workers should provide services and represent themselves as competent only within the boundaries of their education, training, license, certification, consultation received, supervised experience, or other relevant professional experience.

I can only gain comfort from the fact that I am part of a long list of professionals who condemned the employment of ECT without completing the prerequisite study and analysis. The sad fact is, because of the systematic rejection of ECT by psychiatrists, psychologists and clinical social workers, thousands of needy clients were denied an opportunity to have their emotional distress resolved. This review serves as my apology to leaders of the ECT movement and my effort to spread the word within the clinical social work community.

Shock Therapy: A History of Electroconvulsive Treatment in Mental Health is an important document, because it lays out the groundwork for understanding how misinformation can successfully emerge in the scientific and applied communities. Thus, it is not just a story of ECT, but provides insight into the historical dynamics of a wide variety of controversial but critically important scientific findings.

How does the history of ECT begin? "Strange" is the best adjective to summarize the constant theme of ECT history. As ECT was slowly unfolding into a meaningful therapeutic strategy, I found the interactions among the scientists reminiscent of the interactions I can recall as an average day in high school. We see personal attacks, petty jealousies, and efforts to sabotage one's work to make another person look better. As we look back into history, we can easily identify these interactions as immaturity. However, I fear that I have seen the same pattern in contemporary university life. The groundwork for contempt for ECT lies in its early history.

Besides the dimension of personal immaturity, ECT found opposition among the followers of psychoanalytic theory (if Freud was right, ECT must be wrong), the pharmaceutical

treatment (a drug conspiracy?), and the general public who saw films like The Snake Pit and One Flew Over the Cuckoo's Nest. Sadly, even professionals who should know better succumbed to the inaccurate influence of Hollywood's portrayal of ECT. This pattern of objection led news reporters (including some scientific reporters) to fail to include the positive aspects of ECT within their writings. The momentum against ECT was like a snowball rolling down a mountain.

Some of the commentary began quite rudely. On page 251, the authors describe a presentation on ECT by Max Fink, MD, in Munich. One of the attendees is quoted as saying, "As a Jew, how could you support such a NAZI treatment?" I wish the authors would have included Dr. Fink's reply. In my mind's eye, if "only Nixon could go to China," then only Fink could alter the perception of ECT. Apparently, the comment was articulated with such contempt, the host had to step in and demand courtesy. As a consequence, Fink may not have had the opportunity to reply – too bad.

Evidence-based or empirically-based medicine carries some of the burden in at least two ways. First, everyone who has completed a basic course in statistics will immediately recognize that if data is analyzed enough times, statistical significance will emerge. Scientists protect the public against type I errors by employing a predetermined or newly constructed theory to explain the statistical inference. Constructing a theory or employing an established theory in an ex post facto manner raises scientific creditability issues. Here lies the major scientific problem with ECT. Theories for the success of ECT were constructed only after patterns of success were determined. The sad fact is, even with all the success demonstrated with ECT, there is no adequate scientific theory to explain how and why clients can be successfully treated.

Second, this ex post facto process between empiricism and theory is the hallmark of discovering the linkage between cancer and smoking. The huge difference between smoking/cancer manuscripts and ECT manuscripts is graphic illustrations. In the work of Shorter & Healy and Ottosson & Fink, most of the data is presented in the form of percentages, but there is not a single graphic to illustrate a comparison between ECT and an alternative. Within smoking/cancer reports, graphic illustrations were the mainstay of the documentation. A graphic can clarify in a manner that merely listing percentages cannot. Research clearly demonstrates that graphic illustrations clarify a position. Proponents of ECT need to employ more graphics.

The best illustration of a problem of ex post facto theory construction in ECT is memory loss. Complaints regarding memory loss are statistically ambiguous. The disorders that are treated by ECT (i.e., depression) could just as easily cause memory loss with or without ECT. Then, of course, there is the interaction effect – the combination of the disorder and the treatment could cause the memory loss. The impact of ECT cannot be viewed within a simple bivariate model. If a robust theory existed, assessment of interactional effects could be controlled, meaningful research questions would emerge, and practitioners would have guidance in addressing the possible side effects.

The most unsavory aspect of ECT history is the Machiavellian tactics employed to suppress it. Empirical findings have been usurped by hidden agendas, political prestige, and a wide range of tactics that have weak scientific support. The title of the last chapter sums it up— "Irrational Science." Problematically, ECT is founded on affirmative and consistent empirical support that is theoretically barren. Thus, public and professional confidence in ECT can only emerge with a sound theoretical framework. The future of ECT lies in the hands of

neuropsychologists and biological psychiatrists who are able to produce a theory that explains nearly 100 years of data

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Book Review: Ethics in Electroconvulsive Therapy

[Ottosson, J-O & Fink, F. (2004). *Ethics in Electroconvulsive Therapy*. NY: Brunner-Routledge.](#)

Reviewed by Stephen M. Marson, Ph.D. ACSW

Editor, *Journal of Social Work Values and Ethics*

Although I received my clinical training at Ohio State University in the mid 1970s, I decided not to pursue a clinical path. In those days, Electroconvulsive Therapy (ECT) was held in low esteem. In fact, I can think of at least one book that nearly condemns ECT as an intervention strategy. Years later, as a gerontologist, I adopted McInnis-Dittrich's [Social Work with Elders](#) for my Gerontological Social Work course. I had one major misgiving regarding this text. Contrary to my clinical training, the author creates a positive image of ECT. I needed a resource for my students that offered an opposing point of view. Thus, I picked up Ethics in Electroconvulsive Therapy to reassure myself that ECT should not be used for the elderly.

My immediate reaction can best be described as cognitive dissonance. The first chapter of Ethics in Electroconvulsive Therapy unexpectedly supported McInnis-Dittrich's text. My first reaction was to assume that Ottosson and Fink were quacks. The more I read, the more I surrendered my out-of-date perspective. Two particular aspects of this work are compelling. First, are the citations. Although a short book with 127 pages, it includes 420 reputable citations. The number and quality of citations were adequate evidence that the authors are not quacks. Second, the authors include a large number of clinical scenarios -- many of which incorporated gerontology patients (one in his 90s). The authors offer an impressive balance of scholarly research (often including experimental designs) and case illustrations. The combination of impressive scholarship and case illustrations is profoundly compelling to the use of ECT. The authors changed my mind.

Some years ago, I read Salzman's [Psychiatric Medications for Older Adults](#). Salzman guides social workers to assist medical staff in identifying the devastating impact that psychotropic medications can have on some nursing home residents. In comparing ECT with what we know about psychotropic medications, ECT appears to be the safer alternative. Throughout Ethics in Electroconvulsive Therapy, the authors contend that many clinicians are misserving their clients.   Currently, the standard protocol is to employ ECT as the last alternative. That is, ECT is employed only after drug intervention has failed with damaging effects. The authors advocate the inverse. They suggest that ECT is safer and demonstrates greater successful treatment outcomes. Thus, they contend that failure to use ECT first is an ethical issue. In my mind's eye, the clinical and research evidence strongly supports ECT.

I strongly recommend that every clinical social worker read Ethics in Electroconvulsive Therapy. In addition, readers should also consider Salzman's Psychiatric Medications for Older Adults. Both of these books create a profoundly important picture of psychiatric intervention that has strong ethical implications.

Book Review: Understanding Human Rights

Reichert, E. (2006). Understanding human rights: An exercise book. Thousand Oaks, CA: Sage Publications. http://www.sagepublications.com

Reviewed by Laura Gibson, PhD, MSW, LCSW

Dr. Reichert is a professor of social work at the University of Illinois at Carbondale. Reichert first received her social work degree, the equivalent of an MSW, from the Fachhochschule fuer Sozialwesen in Mannheim, Germany. She received an MSSW and a PhD in Health Education from the University of Tennessee at Knoxville. She has authored two previous books: Challenges in human rights: A social work perspective, Social work and human rights: A foundation for policy and practice, and numerous journal articles on the topic of human rights.

The stated purpose of this book is to help social workers identify human rights, recognize the value of human rights, analyze human rights, and take action to protect human rights, so that they might apply these principles to the social work profession. It is intended as a supplemental text for advanced undergraduate and graduate social work students.

Reichert begins by acknowledging that human rights can be difficult to define. She offers different ways of viewing human rights, and then explains the strengths and weaknesses of each view. She also offers the definition of human rights given by the United Nations. She further conceptualizes human rights in terms of three sets: 1) political rights, 2) rights necessary for the well being of individuals and families, and 3) national rights. She acknowledges that it may seem logical to favor one set of rights over another, but strongly asserts that "every individual is entitled to the same human rights" (p. 2).

Reichert quickly connects the concepts of human rights to the social work profession and states that social workers have an obligation to advocate for human rights. She comments that the social work profession is concerned with helping people and that human rights relate to a range of political, economic, and cultural needs. Although the field of human rights is clearly a good fit for social work, not all may agree that needs equal rights.

Each chapter concludes with exercises to help readers better understand the ideas discussed, analyze them, discuss their application and to think critically about them. A total of 52 exercises are presented throughout the book. Chapters include a discussion of a) concepts, b) historical influences, c) the Universal Declaration of Human Rights, d) the link between political and civil rights to economic, social, and cultural human rights, e) vulnerable groups, f) cultural relativism, g) ethics, and h) the relationship to social work practice.

Reichert traces the concept of inalienable rights to the writings of Plato and Socrates more than 2000 years ago. She identifies some of the historical events surrounding WW II as the catalyst for the development of a human rights framework. The contributions of significant

individuals and documents are discussed as they relate to our present understanding of a human rights framework.

The strength of this book is its ability to help students analyze complex concepts in theory and in practice. Although Reichert's own beliefs about human rights are clearly present in the book, it is her passion about this subject that makes it engaging, thought provoking, and cutting-edge for social work practice. Although I did not agree with some of her ideas, I found myself questioning whether this disagreement was truly the result of a different opinion or of my own cultural relativism. Perhaps by having spent time in Germany, she is able to view American culture in a more objective fashion than I.

I must say, however, that I was somewhat distracted by Reichert's repeated criticisms of the United States' position on the human rights of its own citizens. She states that the protection of social, economic, and cultural rights is sorely lacking, and she gives some valid examples. However, she does not offer positive examples when they might be appropriate. For instance, she states that the United Nations does not recognize people who are gay and lesbian as a vulnerable group, but there is no specific comment about the US in relation to this topic. She fails to mention that some states have individually made strides in protecting the rights of people who are gay or lesbian. For instance, Massachusetts has protected against sexual orientation discrimination in the areas of employment, housing, public accommodations, and credit since 1989 (MGL 151B), and other states have implemented similar protections.

Overall, the book is full of interesting, thought-provoking exercises to help social workers understand human rights, analyze the complexities of them, and apply these concepts to social work practice. The book advances social work values and ethics and guides readers to view them in a human rights context.

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