Table of Contents

RDS v5 i3

Book Reviews

Guest Editorial: Human Security, Social Cohesion, and Disability

Kirk C. Allison, Ph.D., M.S.
University of Minnesota

Forum on Economic Security

Abstract: Elements comprising this *Review of Disability Studies* issue title - Human Security, Social Cohesion, Disability – invite reflection on inter-relationships and tensions: Security with or against impairment; insider/outsider status; impairment as impropriety; health definitions; measures (DALYs); elimination; professional discourse; bridging social capital; possibilities and constraints on flourishing; and concrete global examples.

Key Words: human security, social cohesion, disability

The elements comprising the title of this forum of *RDS* include a goal (human security), a mediating dimension (social cohesion), and a specific lens (disability). Disability here indicates the negative impacts of an environment – physical or social - in interaction with impairment or human variation (Walker, 1993).

Thus framed, disability and human security are inversely related.[1] Human security is multi-dimensional (physical, economic, health-related, educational-functional, axiological, spiritual). Its aim is "to protect the vital core of all human lives in ways that enhance human freedoms and human fulfillment" (Commission on Security, 2003). It transpires or fails in community to a significant extent through social cohesion - a process dynamically informing social inclusion and exclusion through distributions of values, resources and actions (see Jensen, 2002).

In the horizon of this RDS issue lies more than the security of persons with impairments or atypical variations: Implications inform human security generally, both deductively (who is included) and inductively (the particular case). Examples include the intersection of food sovereignty, poverty and disability (V. Hiranandini); literacy and disability in South Africa (C. Dube); and the context of community-based rehabilitation engendering social capital and social cohesion between persons with and without impairments in a community in Thailand (T. Cheausuwantavee).

Whether framed via human rights (United Nations, 2006), hierarchies of needs (Maslow, 1943), or conditions for flourishing given (or deviating from) natural goods, capacities and capabilities (Foote (2003), Sen (1993), Nussbaum (2006)), the security and social well-being of persons with impairments in a society provides a criterion for social health with positive external effects across the society - presupposing an inclusive orientation reflected in personal, private- and public-institutional commitments. This may be applied contextually, such as in considering a democratization of place in socially equitable community planning (K.M. Christensen).

Security vs. Impairment?

It is not trivial to ask which humans count in a society in matters of human security. Historically race and ethnicity provided dominant frames for exclusion and awareness of the same, with impairment subdominant. The dyad of security and impairment is double-edged to the present moment: even the presence of impairment can be viewed and represented as an opportunity cost to economic efficiency or as impediment to personal happiness for first and third parties. In measures from comparative cohorts, persons without an impairment or condition routinely project a greater negative impact on a person's life than those actually having a condition (Gabriel, Kneeland, Melton, Moncur, Ettinger, & Tosteson, 1999).

Should an impairment be congenital (whether or not genetic), its presence may be framed as a threat to hereditary or intergenerational security. This thought has driven both ancient and more contemporary eugenics (Pernick, 1996). Such variations are also framed as a threat to familial security (the disabled family under lack of social support). These "threats" may be managed societally through increasingly predictive technology, avoiding downstream costs through prenatal elimination as when modeled under assumption of a "normal replacement child" (Miller, Ransom, Ayoub, Krivchenia, & Evans, 2000). Additionally replaced is a contrasting network of relationships and values (Koch, 2004).

In the recent routinized drama of American presidential politics, an unroutine, if conventional, public introduction of a candidate's family included an infant with trisomy 21 (Down Syndrome). This, linked with the candidate's restrictive views on abortion, raised concerns among some medical professionals in the U.S. (Parikh, 2008) and Canada (Weeks, 2008) regarding the implications (if not propriety) of the presence of this infant-other in the public square. One such response is illuminating from the standpoint of insider/outsider positions, social cohesion, implications of professional discourse, and the possibilities and constraints of social well-being.

Responding to the rupture, physician Parikh (2008) instructs that, "[C]hildren with Down Syndrome have a variety of problems, starting with a distinct look …" A distinct look however is a problem to a social other before it is one for the person with DS whose affective development may be amplified through appropriate interaction with others (Carvejal & Iglesias, 2002).

Parikh casts limits of financial and emotional resources as an individual parental crisis not as a societal deficit that is impaired social cohesion with general implications for human security.

The conclusion tendered is that a privileged individual (such as the candidate) may afford such a child "financially and emotionally" while this "may not be the case for other families who have to struggle to balance work with home and family" - implying families welcoming a member with DS must not similarly struggle to the same degree to balance work with home and family.

Alluding to a circa 90% prenatal elimination rate, "[R]abid anti-choice activists have called that trend eugenics via medicine. But try telling that to a mother who is told early on in her pregnancy that she will be raising a child who will have a host of medical and developmental problems, requiring intense medical and social attention for the rest of his or her life. It can be tragic and nearly impossible news to bear" (Parikh, 2008).

Paradoxically for that analysis, a study of postpartum-only DS diagnoses sheds a different light on the experiential structuring of receiving such an unexpected presence, focusing on predictors of more or less positive experiences. Factors significantly predicting decreased positive experience for such an arrival, higher levels of fright and higher levels of anxiety were fewer prior pregnancies, higher levels of education, higher income, and physician negativity (Skotko, 2005).

Perceptions of adequacy (implicitly embedded within networks of social support) being inversely related to income and education flies in the face of common assumptions regarding education moderating attitudes towards human variation and income as expanding capacity. Skotko surmises:

"Perhaps these mothers were more likely to live in social circles in which a disability would be viewed as unfortunate or unpopular. In addition to or as an alternative, these women might have had more demanding jobs, which caused them to worry about how they would find time to raise a child with a disability" (p. 73).

Skotko found "almost no" reports of suicidal ideation associated with the unexpected news. Those few who did have such ideation notably reported two physician communicative behaviours: "their physicians had pitied them […] or emphasized the negative aspects of DS" (p. 72). The pitying physician was also most systematically significantly associated with not having a positive birth experience; not being told about positive aspects of DS; being told about the negative; not emphasizing positive aspects, but rather the negative; not providing sufficient telephone numbers of parents who also had such a child (disabling social support); not providing enough up-to-date printed materials on DS; receiving printed materials not emphasizing positive aspects, but rather negative, or not receiving materials presenting an equal mix of both; receiving unhelpful/difficult to understand materials; being frightened; being anxious; feeling negative; and having no prior knowledge about this genetic condition (as illustrated in Table 6, Skotko, p. 71).

The American College of Obstetricians and Gynecologists (AGOC) now recommends both universal screening for trisomy 21 (Down Syndrome) at any age of pregnancy and routinely offering odds ratios (ACOG, 2007). From the standpoint of Disability Adjusted Life Years (DALYs) under the analysis of the World Bank, eliminating Down syndrome falls conceptually under disease control (World Bank 2002a; 2002b).

Counting Disability

A DALY is a composite loss indicator combining a measure of premature mortality given condition x with duration lived with that condition, providing some measure also of durative nonfatal condition impacts that can be summed across a population (A comparison of measures reflecting models of health and disability is provided by Wolbring [2005, pp. 74-85]). For any suspected impairment or variation correlated to shorter lifespan or functional limitation, pre-

natal elimination adds 0 to DALY population (societal) totals despite a 100% loss of benchmark standard years that were selected against precisely due to a condition or a probability of a condition intersecting values and social structures.[2]

Murray and Acharya (1997) state, "[I]ndividuals [sic] perception of their own health may not coincide with their actual health status" (p. 708). DALYs exclude nonbiological dimensions and determinants of well-being. Including only age and sex personal characteristics as differentiating elements within the calculation is egalitarian in terms of not assigning differential value to, say, productivity correlates not related to age. "The DALY approach does not take into account the likelihood of the fact that effects of illness can be worsened by lack of income, friends and public services etc. because the use of DALYs is to guide public policy that affects directly or indirectly the onset and the treatment of diseases" (p. 723). One must look elsewhere for social cohesion and alternative sector investments. "In fact, the concept of DALYs avoids any notion of one being satisfied with one's health. Rather it seeks to measure health by the degree of deprivation experienced by a person in being able to use one's own body" (p.724).

Social Cohesion and Whose Health?

At the intersection of human security and disability the mediating dimension, social cohesion, is often double-edged. Social cohesion can be framed normatively or descriptively. Normatively it may imply inclusion or access to social goods with secondary impacts toward conformity or diversity. Descriptively social cohesion (invoking norms) is also possible on the basis of exclusion. Regarding the human rights of persons with disabilities this is perhaps most extreme in North Korea at the ideological intersection of racial mysticism and radical autarchy (juche). In October, 2006, a North Korean physician who defected, Ri Kwang-chol, reported "there are no people with physical defects in North Korea"

(Sheridan, 2006). Medicins sans Frontiers left North Korea in 1998 when denied access to so-called 9-27 camps where disabled children were reportedly exiled. From the present issue, M. S. Glennon's title *Making Social Cohesion or Marking the Human Security Threat* applies.

Glennon analyzes U.S. contexts where rival sources of social capital sought by developmentally disabled persons collide with ostensibly benevolent institutions intent on their social integration and normalization. He raises to the fore (via M. Foucault, G. Deleuzes and F. Guattari) collisions between authorized and rival non-authorized social capital.

Where typical capacities are taken to be the normative root of minimal human value (or tokens of membership in personhood eliciting protective claims upon society) the absence of one or more capacity weighs against positive social solidarity – on a particular utilitarian scale such may be considered a misinvestment of resources and sentiments where both subject and solidarity can be pathologized (Joseph, 2005).[3]

Koch (2004) points to rival paradigms informing moral language and societal attitudes towards humans who are atypical or vulnerable through iconic representatives Peter Singer and Harriet McBryde-Johnson. For McBryde-Johnson (per Koch a "critic from difference") human being is relational, irreducible, and beyond exchange. Whatever the impairments, diminished capacities, or nontypical structures, *quality of lives* (pl.) in relationships of care (personhood in community) is of defining import, with failures to support being social failures and harms, contrasted to Singer's ("a critic of difference") isolating quality of life (sg.) of enumerated capacities upon which inclusion in, or exclusion from, personhood, societal protection, or expenditure of resources is based: the greater the impairment the more diminished any "substantive" as opposed to "sentimental" justification for social protection and investment. The distinction of views is of import for evaluating the health of

society, likewise relational, not merely biological, at the intersection of human security, social cohesion and disability - differently situating the potentials of community (*Gemeinschaft*), diversity, and autonomy in society (*Gesellschaft*).

M.A. Burke advances "operationalizing human security and human rights through a dynamic model of health" addressing health development models and WHO's asymptotic definition of health ("a complete state of physical, mental and social well-being and not merely the absence of disease and infirmity," WHO, 1946) in the context of a project with Kyrgyzstan. Ought a person effectively empowered to work around an impairment be considered unhealthy? Are species of atypical, idiosyncratic adaptations to be viewed as essentially different in nature from nearly ubiquitous adaptations likewise indicating inadequacy of a human structure to flourish in an unmediated environment (for example, generic dependence on shoes raises no eyebrows in the health derby, only need of "adaptive" shoes, in the context of DALYs)?

The WHO constitution preamble casts its nets wide to articulate principles "basic to the happiness, harmonious relations and security of all peoples" (WHO, 1946), citing "the health of all peoples" as fundamental for achieving peace and security, dependent on cooperation of both states and individuals. It continues toward social cohesion: the promotion and protection of health is of value to all; unequal development is a common danger; the healthy development of the child; distributing benefits of health related knowledge; informed opinion and active public co-operation (participation?), and state responsibility for adequate health and social measures. It also famously declares enjoyment of the highest attainable standard of health a fundamental right "of every human being without distinction of race, religion, political belief, economic or social condition." In essence Burke's socially situated dynamic model of health and functional well-being additionally appends under WHO's "without distinction" impairment and variation

- an omission of note in 1946 given the then recent history of targeting persons precisely due to variation and impairment. Human security and social cohesion necessary for human flourishing, with or without impairments, invites a broader purview, as does this issue, for ongoing engagement.

Kirk C. Allison, Ph.D., M.S., is the Program Director of the Program in Human Rights and Health of the University of Minnesota School of Public Health and lecturer in the Division of Health Policy and Management.

References

American College of Obstetricians and Gynecologists (2007, January 2). New recommendations for Down Syndrome: screening should be offered to all pregnant women. *ACOG News Release*. Retrieved September 14, 2008, from http://www.acog.org/from_home/publications/press_releases/nr01-02-07-1.cfm.

Carvejal, F. & Iglesias, J. (2002). Face-to-face emotion interaction studies in Down syndrome infants. *International Journal of Behavioral Development, 26*(2), 104–112.

Commission on Human Security. (2003). *Human Security Now*. Commission on Human Security. Retrieved September 28, 2008, from http://www.humansecurity-chs.org/finalreport/English/FinalReport.pdf.

Foot, P. (2003). The grammar of goodness: an interview with Philippa Foot. *Harvard Review of Philosophy, 11*, 32-44.

Gabriel S. E., Kneeland, T. S., Melton, L. J. 3rd, Moncur, M. M., Ettinger, B., & Tosteson, A. N. (1999). Health-related quality of life in economic evaluations for osteoporosis: Whose values should we use? *Medical Decision Making, 19*, 141-148.

Jensen, J. (2002). Identifying the links: Social cohesion and culture. *Canadian Journal of Communication, 27*, 2. Retrieved September 28, 2008, from http://www.cjc-online.ca/index.php/journal/article/view/1289/1309

Joseph, J. (2005). The 1942 'euthanasia' debate in the American Journal of Psychiatry. *History of Psychiatry, 16*(62 Pt 2), 171-179.

Koch, T. (2004). The difference that difference makes: Bioethics and the challenge of 'disability.' *Journal of Medicine and Philosophy, 29*, 697-716.

Maslow, A.T. (1943). A theory of human motivation. *Psychological Review*, 50, 370-396.

Miller, V. L., Ransom, S. B., Ayoub, M. A., Krivchenia, E. L., & Evans M. I. (2000). Fiscal impact of a potential legislative ban on second trimester elective terminations for prenatally diagnosed abnormalities. *American Journal of Medical Genetics, 91*, 359-62

Murray, C. J. L. (1994) Quantifying the burden of disease: The technical basis for disability-Adjusted life years. *Bulletin of the World Health Organization, 72*, 429-445.

Murray, C. J. L. & Acharya, A. K. (1997). Understanding DALYs. *Journal of Health Economics, 16*, 703-730.

Nussbaum, M.C. (2006). *Frontiers of justice: Disability, nationality, species membership*. Cambridge: Harvard University Press.

Pernick, M. S. (1996). *The black stork: Eugenics and the death of 'defective' babies in American medicine and motion pictures since 1915*. New York & Oxford: Oxford University Press.

Parikh, M. K. (2008). Sara Palin's choice. *Salon*. Retrieved September 14, 2008, from http://www.salon.com/env/feature/2008/09/05/sarah_palin_down_syndrome/

Sen, A. (1993). Capability and well-being. In A. Nussbaum & A. Sen (Eds.), *The Quality of Life*. Oxford University Press.

Sheridan, M. (2006). Nation under a nuclear cloud. Racially impure children killed. (2006, October 15). *The Times Online [The Sunday Times]*. Retrieved April 22, 2008, from http://www.timesonline.co.uk/tol/news/world/article600929.ece

Skotko, B. (2005). Mothers of children with Down Syndrome reflect on their postnatal support. *Pediatrics, 115*, 64-77.

United Nations (2006). Convention on the Rights of Persons with Disabilities and Optional Protocol. United Nations. Retrieved September 29, 2008, from http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf.

Walker, J. M. (1993). The difference between disability and impairment: A distinction worth making. *Journal of Occupational Rehabilitation, 3*, 162-172.

Weeks, C. (2008). A message of hope – Or pressure to keep the baby? *Globe and Mail.* (2008, September 9). Retrieved September 14, 2008, from http://www.theglobeandmail.com/servlet/story/RTGAM.20080909.wxldown09/BNStory/International/

Wolbring, G. (2005). *The triangle of enhancement medicine, disabled people, and the concept of health: a new challenge for HTA, health research, and health policy*. HTA Initiative #23. Edmonton: Alberta Heritage Foundation for Medical Research, Health Technology Unit. Retrieved September 23, 2008, from http://www.ihe.ca/documents/HTA-FR23.pdf

World Bank Group. (2002a) *DALYs lost to Down Syndrome, by World Bank region description.* Disease Control Priorities Project. World Bank Group. Retrieved September 15, 2008, from http://www.dcp2.org/slides/462/preview

World Bank Group. (2002b) *DALYs lost to Down Syndrome, by World Bank region (slide).* Disease Control Priorities Project. World Bank Group. Retrieved September 15, 2008, from http://www.dcp2.org/slides/462/1.ppt

World Health Organization (1946). *Constitution of the World Health Organization* [as adopted by the International Health Conference, New York, 19-22 June, 1946]. Retrieved September 13, 2008, from http://www.searo.who.int/LinkFiles/About_SEARO_const.pdf

World Health Organization (2001a). *International classification of functioning, disability and health. Final draft. Full version. WHO/EIP/GPE/CAS/ICIDH-2 FI/ 01.1 Geneva: WHO*. Retrieved September 13, 2008, from http://www.sustainable-design.ie/arch/ICIDH-2Final.pdf

World Health Organization (2001b). *International classification of functioning, disability and health*. Geneva: WHO.

Yaruss J. S. (1998). Describing the consequences of disorders: stuttering and the international classification of impairments, disabilities, and handicaps. *Journal of Speech, Language & Hearing Research, 41*, 249-257.

Endnotes

[1] The 1980 WHO International Classification of Impairments, Disabilities and Handicaps (ICIDH) distinguished between impairment ("any loss or abnormality of psychological, physiological or anatomical structure or function"), disability ("any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" – 'in the manner' pathologizes efficacious nontypical functional modes) - and handicap ("a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual") (WHO, 1980 in Yaruss, 1998). Disability highlights the additional role of contingent cultural and environmental constraints in disabling an individual. The ICIDH-2 shifts terminology from disability and handicap recasting such in terms of activity restriction and participation restriction, integrating medical and social models into a "biopsychosocial" model. The ICIDH-2 was then renamed International Classification of Functioning, Disability and Health (WHO, 2001a). Under the new model, health conditions, personal factors and environment impact body structure and function, activities and participation (WHO, 2001b).

[2] If prenatally considered, the time-with-disability-component limits to 0 while premature mortality maximizes. The DALY benchmark lifespan for its mortality measure is the highest national life expectancy (Japan) (Murray, 1994). More specifically the comparison is to a model life-table adjusted slightly for estimated biological survival differences and weighting different ages unequally according to a functional estimation of value such that birth = 0, age 10=1.0, 25 ca. 1.5, and 100 ca. 0.3 (Murray, 1994, Figure 4). Murray and Acharya (1997) justify age weightings instrumentally: the "well-being of some age groups…is instrumental in making society flourish." The morbidity measure originally assigned weights 0..1 to 6 classes (baskets) of functional limitation characteristics. A revision (1996) assigned weight partitions to conditions in 7 categories. Murray and Acharya (1997) report revised elicited weights (in place of US expert panel estimates 1994) using international regional health care provider informants in a recursive deliberative process "to evaluate the average individual with the condition described taking into account the average social response or milieu for the world" generating a rank order of condition severity for treated and untreated forms of a condition. The 1994 functional weighting categorization appears much closer to a capabilities or functionings approach than the 1996 condition categorization, despite claims of the 1997 article.

[3] An instructive example of this is found in the context of the euthanasia debate in the American Journal of Psychiatry in 1942. The accompanying editorial in favor of euthanizing children with significant impairments pathologizes the attachments of parents: "A third variety of reaction results from an accusing sense of obligation on the part of the parents towards the defective creature they have caused to be born. The extreme devotion and care bestowed upon the defective child, even with sacrifice of advantages for its normal brothers and sisters is a matter of common observation. This position is understandable, but to the impersonal observer may appear to partake of the morbid" (Anonymous, as cited in Joseph, 2005). "Impersonal" here denotes without relationship.

Guest Editorial: Human Security, Social Cohesion, and Disability

Anita Ghai, Ph.D.
Jesus and Mary College, India

Abstract: The editorial underscores the issues of security in disabled people in context of poverty. The submission is that disabled people are not considered equal, as globalizing forces dominate the paradigm of profit.

Key Words: developing countries, poverty, cohesion

Introduction

Evolving Disability Studies in terms of the themes of social cohesion, human security and social capital is significant. For too long disabled people have been marginalized and disqualified, debarred from "mainstream society". There is no country in the world that can assertively claim that its disabled citizens have realized equal rights and equal opportunities. In developing countries, and I presume other developed countries, disabled people cannot attend school or college, gain employment, use public transport, and live independently – the basic rights that most non-disabled people take for granted. Disabled people do not require "rehabilitation needs". It is critical that we understand the nuances of the identities of disabled people in terms of not only medical biographies. Disability, in the context of poverty, raises important questions about security, cohesion and productivity. The question is not whether we want to achieve these objectives, but what we are doing to accomplish concrete efforts. Though we want to cut world poverty by half in the Millennium Development Goals, disability as an issue is not included. Even if we somehow include disability into the developmental discourse we need to understand the dynamics of poverty. To begin with, we need to reflect on what is global poverty? Is it the same as reducing poverty in each country? What kind of poverty are we talking about? How can figures and targets capture all that is needed to provide for a person's well-being? And when we move into the individual goals there are more questions. Similarly issues of security related to education, reproductive health rights, HIV/AIDS and most importantly health systems. What is there significant is understand the nuances of security and cohesion.

Human Security

As the Commission on Human Security (2003) indicates, "The protection of the vital core of all human lives in ways that enhance human freedoms and fulfillment." In other words, human security is understood as security of survival (mortality/injury, health), security of livelihood (food, water, energy, environmental needs, shelter, and economic security), and dignity (basic human rights, capacity, participation). In accepting these definitions, the question arises, Are people with disabilities secure? The answer does not seem to be positive, as disabled people are not fully integrated into our society. For many of us, a fundamental part of our daily life involves support that can maintain our bodily integrity. People with disabilities feel that the right of being secure and autonomous is not evident. Issues about disabled people's security correlates with the abject poverty in the developing countries and perhaps to a lesser degree, the developed countries. While disabled activists in industrialized countries debate about issues such as independent living, assistance with care needs, and facilitated sex, disabled people in the majority of the world are still struggling for survival. My desire is not to create a dichotomy, but to point out the enormity of pressures that characterize the lives of those for whom disability is closely linked with poverty.

As Misra and Tripathi (2001) point out, "Though manifest in concrete ways, the nature, causes, and consequences of poverty are difficult to articulate in precise terms. Being multifaceted and relative, a unidimensional characterization omits the range of factors bearing on the phenomena of poverty" (pp. 122-123). The 2006 Human Development Report (United Nations Development Programme, 2006) states that:

"People with disabilities are among the most vulnerable members of society—and among the poorest. A vicious cycle links disability and chronic poverty: if you are poor you are more likely to be disabled, and if you are disabled you are more likely to be poor. In Ecuador 50% of people with disabilities belong to the lowest 40% of the income distribution. Similarly, surveys of the living conditions of disabled in Malawi, Namibia and Zimbabwe show that their average households' incomes are a pittance. In Namibia 56% of households with a disabled member have no one employed in the formal sector, compared with 41% for households with no disabled members" (p. 114).

Specifically, financial insecurity implies social vulnerability, as it results in subordination of disabled people who are discriminated against via inaccessibility to education, gender (women), and/or ableism. Further, this vulnerability destroys the individual's feelings of efficiency, utility, and social competence, leading to a pessimistic view of society, marked by conflict, disorder, and injustice. The establishment of selfhood and identity do not come easily to those who accrue no social security and other benefits or receive such minimal amounts that leave them below subsistence levels, hardly - and not always - able to survive. Research indicates that 20% of the world's poorest people are disabled (United Nations, 2009).

Poverty

Poverty has been analyzed in innumerable ways. For example, the poverty line in India measures only the most basic calorie intake, recording not nutrition, but only the satiation of hunger. "At present, the poverty line stands at 368 rupees ($9.20 USD) and 559 rupees ($14 USD) per person per month for rural and urban areas respectively, just about enough to buy 650 grams of food grains every day. A nutritious diet itself would cost around 573 rupees ($ 15 USD) per capita per month, let alone the cost of securing other basic needs" (Infochange, 2009). However, such measures do not incorporate the costs of shelter, clothing, transport, fuel, health care, and education. According to Guruswamy and Abraham (2009), the Indian Council of Medical Research (ICMR), prescribes 3,800 calories for an adult male doing heavy activity and 2,925 calories for an adult female carrying out heavy activity. Consequently, millions of poor, unskilled wage laborers in India who do heavy manual labor every day, a stipulation of 2,100 - 2,400 calories in urban and rural areas is grossly insufficient. Mabub ul Huq (as cited in Shariff, 1999, p. 45) states, "Nearly one-third of the total number of absolute poor in the world live in India. What is more distressing is that while 46% of India's people survive in absolute poverty…about two thirds are 'capability poor' i.e. they do not receive the minimum level of education and health care necessary for functioning human capabilities Notwithstanding the fact that official figures show a decrease in poverty, but the fact that only the basic calorie intake is considered as critical is alarming.

The continued intolerance of disabilities in Indian society is reflected in the case of Hakimuddin Khan, a daily wage laborer of Kamalpur village in Bhadrak, Orissa. No longer able to sustain his three disabled children - Raffimuddin (35), Hapimuddin (33), and Mustaf (28) - Khan, has written to the President of India, the Prime Minister, and the chief minister in Orissa for permission to die. His plea states, "I have urged all of them to take the responsibility of my three disabled sons or else give us the permission to die. There is no point in living like a vegetable. None of them can stand or

move an inch without the parents' help". (Times of India, 2007). Such a scenario does not make disabled people safe. Insecurity stems from the fact that disabled people are unable largely to make themselves self-sufficient and are (dis)empowered financially through unemployment. It is the reason that people such as Hakimuddin Khan opt for their children dying rather than living. Consequently, people with disabilities lead a lonely and vulnerable life, almost devoid of any physical or emotional security. Within this context, there are instances when disabled people are not safe from their own families from abuse, bullying or at a high risk of neglect from a lack of responsiveness (ChildinIndia.org, 2009).

A discussion of the definition of poverty in India is also relevant to an international audience because the one-dollar-a-day poverty line adopted by the United Nations borrows substantially from the Indian poverty line. This fact raises questions of how policymakers conceptualize poverty and whether there are opportunities for making poverty reduction strategies more effective through a re-identification of the nature and causes of poverty. Is there any recognition of the fact that poverty de-individualizes and alienates those affected from the mainstream of society? Marked by feelings of helplessness and hopelessness, poverty places limitations on the person, in terms of the personal and environmental resources to improve the quality of his or her life. "Researchers and advocacy groups have come to view poverty not simply as a lack of financial resources, but as both the cause and consequence of social exclusion." (Government of Newfoundland and Labrador-Canada, 2005). Also, a lack of money and resources prevents individuals from fully participating in the social and economic activities of their communities. In this context, a community with a strong sense of identity and shared goals is considered to be more cohesive than one without these qualities. Can disabled people be cohesive and part of the community? (Mehta, 2008). Are the disabled people tightly joined, stout and unified in a community?

As an optimist, Tavee Cheausuwantavee uses participation action research in context of appropriateness and consciousness in community suggests implications which indicate that (1) a philanthropic model, a medical model and a social model can be integrated into the CBR approach. Thus CBR is not only a social model, but may also be a medico-social model, a philanthropic-social model, as well as a philanthropic-medical model corresponding to the particular community context. (2) Further studies of consciousness, meaning, and discourse on CBR within particular contexts need to be done in order to gain more understanding and expanding the body of knowledge of CBR and disabilities.

Another strand of understanding disability discourse appears in Kabbara's article. Kabbara indicates that resistance and agency of working against the oppression of disabled people is definitely getting "mainstreamed." According to Kabbara, in war-torn Lebanon the difference between disabled and nondisabled people is getting mixed up, without clear-cut distinction, and in many instances, disability is temporary (such as long-lasting injuries). In some cases, this difference is less than permanent or is recurrent (e.g., people with psychosocial disability, survivors). Indeed, the war and violence-causing trauma have a significant impact on the mental health of the entire population and particularly of youth and children. Indeed, psychological trauma itself is the most widespread disability resulting from the repeated civil wars and armed conflicts. As one of Kabbara's respondents, Amina, (a female NGO staff with mild physical disability) says, "Yes, disability is becoming a political agenda now. People see it as a human rights issue, as recently our civil conflicts have increased the scope of disability in this country. But people are not yet interested in us, disabled women or those with congenital disability. Particularly women with intellectual disability are so marginalized."

While there is hope for alleviating suffering and feeling secure, international realities should

make us realize the dangers within which disabled people live. What is upsetting is that insurgency in Afghanistan gathers exigency, the Taliban and other forces are recruiting marginalized and vulnerable groups to carry out suicide attacks while men from their own ranks keep up the ground offensive. "Almost 90 per cent of [suicide bombers] are people with some form of disability," indicated forensic expert Yusuf Yadgari (as cited in Fatah, 2007). He also stated that disabilities such as "muscular dystrophy, amputated toes, blindness, skin diseases and signs of mental illness were detected in the bodies of suicide bombers." As Firoz Ali Alizada who lost his legs to a land mine realizes that disability seems to be associated with shame and the belief is that "there is complete loss of hope in being able to live a normal life" (as cited in Fatah, 2007). Usually people who are "incapable" of supporting and feeding their families are encouraged to be suicide bombers, as there are financial incentives. In a place like Afghanistan where there is a very weak economy, disabled people's security becomes problematic (Fatah, 2007).

Power

In this forum, Mary Anne Burke analyzes the power issues in an ablest society. I identify with these issues because, "Whether we, who are designated as 'different' do not see ourselves as 'dalit,' poor, crippled, or disabled, these terms nevertheless describe an essential reality in a society tuned to the tyranny of normality and perfection" (Ghai, 2003, p.17). As Burke explains, "Power structures within a society serve to reinforce and maintain the ableist hierarchy and the distribution of resources according to an individual's position within the hierarchy. The machinery of oppression– in this case institutionalized ableism is maintained by cultural, economic, political, trade, monetary, health and other systems." In an era of globalization, the emphasis on power and profit has systematically dislodged vulnerable groups from access to even basic resources such as food and livelihood (Sadgopal, 2006). I argue that the increasing priva-

tization and a recasting of citizens as consumers results in the state losing power because the locus of control shifts from the public domain of politics to an individualized and privatized world of economic cost and benefit analysis. This privileges the paradigm of profit over humanity, which then pervades all aspects of life. Access to capital and markets is controlled by relatively small elites, primarily male-centric and mostly based in rich countries. For the developing countries this leads to an ever-increasing estrangement with the marginalized groups. The most devastating impact of the neo-liberal policies is that they restrict the revenue of the state for use for welfare purposes. Though we claim that human rights imply equality for every disabled person, Keenan Malik disagrees, "Equality cannot have any meaning in the plural. Equality cannot be relative, with different meanings for different social, cultural or sexual groups. If so it ceases to be equality at all, or rather becomes equality in the way - 'equal but different' - in defending segregation" (Malik, 1998). Thus for people with disabilities to be secure, equality requires a common yardstick, or measure of judgment, not a plurality of meanings. What is clear is that we must understand disability both in its social construction and material inequalities.

In my mind, inclusion of disabled people remains an unrealized belief. I believe that social capital has the potential to engender improvements in health, education, community care, community revival, and protective employment. However, the fundamental opportunities to accrue social capital for disabled people so that their existing contributions are not undervalued.

Anita Ghai, Ph.D., is a reader at the Department of Psychology at Jesus and Mary College. She can be contacted at: J12/68 B Rajouri Garden New Delhi, 110027 India 110027. Email: anita.satyapal@gmail.com

References

ChildinIndia.org (2009). *Protecting children with disabilities from vulnerability and discrimination.* Retrieved June 17, 2009, from http://www.childlineindia.org.in/cr-disability.htm

Commission on Human Security (2003). *Human security now.* Retrieved June 17, 2009, from http://www.humansecurity-chs.org/finalreport/index.html http://www.humansecurity-chs.org/finalreport/English/FinalReport.pdf

Ghai, A. (2003) *(Dis) Embodied form: Issues of disabled women.* New Delhi, India: Har-Anand.

Government of Newfoundland and Labrador-Canada. (2005). *Building pathways to poverty reduction.* Retrieved June 17, 2009, from http://www.releases.gov.nl.ca/releases/2005/hrle/0321n22.htm

Guruswamy, M., & Abraham, R. J. (2009). *The poverty line is a starvation line.* Retrieved June 17, 2009, from http://infochangeindia.org/index2.php?option=com_content&do_pdf=1&id=5662

Infochange Agenda. (2009). *Food security.* Retrieved June 17, 2009, from http://infochangeindia.org/Agenda/Hunger-Has-Fallen-Off-The-Map/

Malik, K. (1998). Race, pluralism and the meaning of difference. *New Formation, 33.*

Mehta, M. D. (2007). *Agricultural biotechnology and social cohesion: Is the social fabric of rural communities at risk?* Retrieved June 17, 2009, from http://policynut.uwinnipeg.ca/mehta-cwss-proceedings.dochttp://www.ubcpress.ca/books/pdf/chapters/mehta/chapone.pdf

Misra, G., & Tripathi, K. N. (2001). Psychological dimensions of poverty and deprivation. In J. Pandey (Ed.), *Psychology in India revisited: Developments in the discipline: Volume 3. Applied social psychology & Organizational Psychology.* New Delhi, India: Sage Publications.

Shariff, A. (1999). *India human development report: A profile of Indian states in the 1990s.* Oxford, UK: Oxford University Press.

Times of India. (2007). *Father wants 'mercy deaths' for disabled sons.* Retrieved June 17, 2009, from http://www.disabilityindia.com/html/newsmay.html

Guest Editorial: Science and Technology, Social Cohesion, Human Security, and Disabled People

Gregor Wolbring, Ph.D.
University of Calgary, Canada

Abstract: This editorial highlights the linkage between science and technology advances, social cohesion, human security and disabled people.

Key Words: Disability Studies, science and technology, social cohesion

Introduction

Human security and social cohesion - the topic of this RDS issue - are central requisites especially for the medical and social well being of disabled people. Furthermore, a disability studies lens can crucially clarify and test the discourses of human security and social cohesion for their usefulness for disabled people and provide information about implications for the general population as well. Human security according to the Commission on Human Security (2003) is concerned with safeguarding and expanding people's vital freedoms. It requires both shielding people from acute threats and empowering people to take charge of their own lives. The Commission identified economic security, food security, health security, environmental security, personal security, community security, political security, freedom from fear, and freedom from want as primary concerns.

Social cohesion, a term first coined by Émile Durkheim in his 1893 book, *The Division of Labor in Society*, today has various definitions (Jeannotte, 2001; Office of the Deputy Prime Minister, 2004; The Canadian Cultural Research Network (CCRN), 2000; New Zealand Immigration Service, 2004; Spoonley, Peace, Butcher, & O'Neill, 2008; Salama, 2004; Jeannotte, 2000; Beauvais & Jenson, 2002). Some of the attributed characteristics of social cohesion are belonging, shared values, shared challenges, equal opportunity, sense of trust, hope, capacity

to live together in some harmony and a sense of mutual commitment (The Standing Senate Committee on Social Affairs, 1999). Additionally, how well institutions manage diversity and resolve conflicts by finding mutually satisfactory accommodation (The Standing Senate Committee on Social Affairs, 1999) and everyone having requisite access to establish basic social relationships in society e.g., work participation, family life, political participation, activities in civil society (The Standing Senate Committee on Social Affairs, 1999), are also attributed characteristics of social cohesion. Social Cohesion is linked directly to indexes, indicators and various measures of well-being (Atkinson Foundation, 2005; Bergheim, 2006; Wikipedia, 2008; Huitt, 2004; Nevis, 1983; Börjesson, 2006; Giussani, 2006; Korea National Standard Office, 2006) and to various facets of human security. Social cohesion and human security play themselves out increasingly within a globalization agenda whereby one encounters different understandings of social cohesion and human security within different cultural and political frameworks.

Social Cohesion, Human Security and Disabled People

Social Cohesion

A sense of belonging is one main aspects of social cohesion. It is important for disabled people to belong, to be part of shared values as much as it is for everyone else, but do they belong? Are they reflected in shared values? The Americans with Disabilities Act (ADA) (1990) states that "[H]istorically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such form of discrimination against individuals with disabili-

ties continue to be a serious and pervasive social problem." The United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2007) which came into force in May 2008 is another acknowledgment that disabled people are still treated as "others" worldwide and are in need of explicit legal protection. So what values of a society generate such a "we versus the others" regarding disabled people? Which characteristics of a disabled person make them the "others"?

The author submits that ableism (Wolbring, 2008a; Wolbring, 2008c; Wolbring, 2007) is one mechanism that facilitated the "we-other" dynamic. Ableism is a set of beliefs, processes and practices that, based on one's perceived abilities, produce a particular kind of understanding of oneself, one's body and one's relationship with others within one's species, to other species and one's environment. It includes being judged by others.

Ableism reflects the sentiment of certain individuals, households, communities, groups, sectors, regions, countries and cultures to cherish and promote certain abilities such as productivity and competitiveness over others such as empathy, compassion and kindness (favoritism of abilities). Ableism, in general, is the phenomenon that some decide that certain abilities are needed in order to belong to the "we" and that one is the "other" if one does not have the same abilities as defined by the "we". Ableism is used in various "we-other" dynamics (Wolbring, 2008a; Wolbring, 2008c; Wolbring, 2007). In the case of so-called disabled people, the ableism dynamic is that some "we" define certain abilities as species-typical and the exhibition of these species-typical abilities is a measure of worthiness. Variation from these are defined abilities as deviations, as a deficient state of being, labeling the "less able" people as the "other", the "impaired" (Campbell, 2001; Carlson, 2001; Overboe, 2007) often with accompanying disablism (Miller, 2004). There is often discriminatory,

oppressive, or abusive behavior against the "other", the less able.

Citizenship is one measure of belonging and shared values. "Citizenship is a status bestowed on those who are full members of a community. All who possess the status are equal with respect to the rights and duties with which the status is endowed" (Marshall, 1950). Many articles (Massie, 2006; Jayasooria, 1999; Morris, 2005; Edwards & Imrie, 2008; Rapp & Ginsburg, 2001; Das & Addlakha, 2001; Barton, 1993; Connors & Donnellan, 1993; Craig, 2004; Keyt, 2007; Meekosha & Dowse, 1997; Wallerstein, 2003) conclude that disabled people are not treated as full citizens and that disabled people's perspectives are mostly absent from debates on citizenship. In recent times, much talk concerns the obligation and the duty (Blair, 1998) (Roulstone, 2000) (Giddens,1998) one has as a citizen. That has an impact on disabled people. Could the ableism dynamic be used to demand that disabled people have the duty to become and behave as species-typical as possible and that the other citizens have only the duty to accommodate the "disabled people who can't be fixed"? The United States Supreme Court ruling on the "definition of disability" in three cases (*Murphy v. United Parcel Service, Inc, 1999; Sutton et al. v. United Air Lines, Inc. 1999; Albertson's Inc., v. Kirkingburg, 1998*) is interpreted to mean that the Americans with Disabilities Act does not cover persons with correctable impairments (National Council on Disability USA, 2000). In other words, as soon as adaptations are available, all problems must be "fixed" and no protections through civil rights laws, such as the ADA, are allowed anymore. The "we" expect no obligation towards the ones who want to be the "other" and refuse to become part of the "we," whereby the "others" are the ones with body structure related abilities not accepted by the "we."

Human Security

Human security is another obvious need. Do disabled people experience human security?

Do they have human security needs particular to them? Ability Security – that one is accepted, and is able to live one's life with whatever set of abilities one has, and that one will not be forced to have a prescribed set of abilities to live a secure life - is one aspect rarely highlighted within the human security discourse. It is a prerequisite for everyone, especially for people who are seen as not following the ability norms such as the people labeled as impaired.

Vanmala Hiranandani in this special issue makes the case that the human security discourse in general, and the food security discourse in particular, is too limited in its scope and interpretation and too limited in the variety of people covered. She especially makes the case that disabled, people particularly under the social model interpretation, are not present in the food security discourse. This lack of presence is not just confined to the governmental, industrial, and academic discourse around human security in general and food security in particular, but also includes the NGO/CSO movement involved in these issues. The role of disabled people too often seem to be confined to the medical health angle and access to buildings, health services, transportation, employment and education. Even within this confined scope of topics, it is a struggle to involve disabled people. Charles Dube talks in his piece about the lack of access of South African disabled people to primary, secondary, and higher education. This leads to education insecurity with consequent employment insecurity and economic insecurity, with their attendant insecurities such as food insecurity, health insecurity, and political insecurity. Dube makes the point that, a) education and knowledge enable disabled people to identify common problems and act in solidarity with others, b) education and information can play a significant protective role and can thus further human security, and c) this cannot be achieved without the existence of a clearly defined legislative framework and implementation structures that guide disabled people's access to and use of support services that enhances their social, political, and economic position within mainstream society.

Science and Technology, Disabled People, and Social Cohesion

How will advances in science and technology change the politics of belonging? Will it change the meaning of belonging and social cohesion fundamentally? Will it eliminate the need for belonging and social cohesion or will it just change who belongs to whom?

Science and technology (S&T) advances are often seen as essential for disabled people. Many visions exist in regards to new and emerging converging sciences and technologies and disabled people (Wolbring, 2005). However the science and technology discourse around applications and products focuses mostly on offering disabled people medical solutions (prevention or cure/normative adaptation) and might move towards transhumanist solutions (augmentation, enhancement of the human body) but rarely offers social solutions (adaptation of the environment, acceptance, societal cures of equal rights and respect) (Wolbring, 2006).

Disabled people are seen as the trailblazers for many transhumanist solutions. Many transhumanists (those who believe that the abilities of the body should be enhanced beyond species typical boundaries) (Wolbring, 2008b; World Transhumanist Association, 2002; World Transhumanist Association, 2003) are very aware of the potential to use disabled people as trailblazers for the acceptance of transhumanist ideas and products (World Transhumanist Association, 2004). James Hughes, the former executive director of the World Transhumanist Association, writes, "Although few disabled people and transhumanists realize it yet, we are allies in fighting for technological empowerment" (Hughes, 2004). The World Transhumanist Association has a specific listserv for disabled people and transhumanism. However disabled people are often used for agendas that might not reflect

what they really want and need. As the majority of "disabled people" are poor and live in low-income countries it is very unlikely that they will gain access to these "advances." As much as human enhancement technology will become an enabling technology for the few, it will become a disabling technology for the many.

Charles Dube highlights in his piece the lack of access to technologies by disabled people due to lack of affordability, and that if and when technologies are offered, they are offered by the so-called non-disabled people based on their perception of the so-called disabled people without asking the so-called disabled people what they think they need. A 2007 piece, "The Future of Disability in America" (Field & Jette, 2007) published by the Institute of Medicine of the National Academies sees the same lack of access to technology as Charles Dube describes for South Africans. Furthermore, with the ever-increasing ability of science and technology to modify the human body beyond species-typical boundaries one can expect certain powerful people to generate a new "we," making belonging and full citizenship dependent on people (the normal and impaired by today's standard) having obtained certain "upgrades" to their bodies. If not, they will be the "others," not belonging and without full citizenship. People who do not want ("Refuseniks") or for other reasons do not have access to the "required" upgrades will constitute a new social group of the "techno poor impaired and disabled" and a new "other." And this new other might compete for resources with the old other.

Conclusion

Some of the papers in this issue indicate a deficiency of the involvement of disabled people within the social cohesion and human security discourses and a biased application of science and technology advances towards the medical fixing group of disabled people. Much more research is needed to evaluate the human security and social cohesion discourses and science and technology governance and advances from a disability studies perspective locally and globally. Envisioning science and technologies and newly appearing social movements (e.g., transhumanism) and their impact on social cohesion and human security from a disability studies perspective is needed. I hope that many more papers will cover these essential areas in the future.

Gregor Wolbring, Ph.D., is an Assistant Professor at University of Calgary, Faculty of Medicine, Dept of Community Health Sciences; Program in Community Rehabilitation and Disability Studies. Webpage: http://www.bioethicsanddisability. org

Contact Info: University of Calgary, Faculty of Medicine, Dept of Community Health Sciences, Program in Community Rehabilitation and Disability Studies. 3330 Hospital Drive, NW, T2N4N1, Calgary, Alberta, Canada. E-mail: gwolbrin@ucalgary.ca

References

Albertson's, Inc. v. Kirkingburg (1998) 527 U.S. 555 (Case No. 98–591). Retrieved February 17, 2009, from http://www.supremecourtus.gov/opinions/boundvolumes/527bv.pdf http://laws.findlaw.com/us/000/98-591.html.

Americans with Disabilities Act. (1990). Sec. 2. (a)(2) Findings and Purposes Americans with Disabilities Act. Retrieved February 17, 2009, from http://www.usdoj.gov:80/crt/ada/pubs/ada.txt

Atkinson Foundation (2005). *Reality check.* Retrieved February 17, 2009, from http://www.atkinsonfoundation.ca/ciw/SkinnedFolder_1114701572952/Document_1114708094548 http://www.atkinsonfoundation.ca/ciw/RCheck_May_2005_revised_31.pdf

Barton, L. (1993). The struggle for citizenship: the case of disabled people. *Disability & Society, 8*, 235-248.

Beauvais, C., & Jenson, J. (2002). *CPRN Discussion Paper No. F|22 Research Report - Social Cohesion: Updating the State of the Research* (Rep. No. CPRN Discussion Paper No. F|22 Research Report). *Canadian Policy Research Networks*. Retrieved February 17, 2009, from http://www.cprn.org/en/doc.cfm?doc=167# http://www.cprn.org/documents/12949_en.pdf

Bergheim, S. (2006). *Measures of well-being. There is more to it than GDP.* Retrieved February 17, 2009, from http://www.dbresearch.com/PROD/DBR_INTERNET_EN-PROD/PROD0000000000202587.pdf;jsessionid=1:451222c9:87a20b23d84617b

Börjesson, M. (2006). *Maslow turned upside down?* Retrieved February 17, 2009, from http://www.futuramb.se/blog/2006-10/maslow-turned-upside-down/

Carlson, L. (2001). Cognitive ableism and disability studies: Feminist reflections on the history of mental retardation. *Hypatia, 16*, 124-146.

Campbell, F. A. K. (2001). Inciting legal fictions: 'Disability's' date with ontology and the ableist body of the law. *Griffith Law Review, 10*, 42.

Commission On Human Security. (2003). *Human security now.* Retrieved February 17, 2009, from http://www.humansecurity-chs.org/finalreport/index.html http://www.humansecurity-chs.org/finalreport/English/FinalReport.pdf

Connors, J. L., & Donnellan, A. M. (1993). Citizenship and culture: the role of disabled people in Navajo society. *Disability & Society, 8*, 265-280.

Craig, G. (2004). Citizenship, exclusion and older people. *Journal of Social Policy, 33*, 95-114.

Das, V., & Addlakha, R. (2001). Disability and domestic citizenship: Voice, gender, and the making of the subject. *Public Culture, 13*, 511-325.

Edwards, C., & Imrie, R. (2008). Disability and the implications of the wellbeing agenda: Some reflections from the United Kingdom. *Journal of Social Policy, 37*, 267-277.

Field, M. J., & Jette, A. M. (2007). *The future of disability in America*. National Academies Press (USA). Retrieved February 17, 2009, from http://books.google.ca/books?hl=en&id=Uvs8gmoUeHcC&dq=The+Future+of+Disability+in+America&printsec=frontcover&source=web&ots=_IRLiAKIin&sig=wLpzviXzoqgpz9FxwPkup05yJgY&sa=X&oi=book_result&resnum=3&ct=resulthttp://findarticles.com/p/articles/mi_qa3622/is_200801/ai_n25500133/print?tag=artBody;col1

Giussani, B. (2006). *Hierarchy of needs revisited.* Retrieved February 17, 2009, from http://giussani.typepad.com/loip/2006/02/hierarchy_of_ne.html

Hughes, J. (2004). *Battle plan to be more than well transhumanism is finally getting in gear.* Retrieved February 17, 2009, from http://transhumanism.org/index.php/th/more/509/

Huitt, W. (2004). Maslow's hierarchy of needs. *Educational Psychology Interactive*. Retrieved February 17, 2009, from http://chiron.valdosta.edu/whuitt/col/regsys/Maslow.html

Jayasooria, D. (1999). Disabled people: active or passive citizens - reflections from the Malaysian experience. *Disability & Society, 14*, 341-352.

Jeannotte, M. S. (2001). *Social cohesion around the world: An international comparison of definitions and issues.* Retrieved February 17, 2009, from http://www.phac-aspc.gc.ca/ph-sp/phdd/news2001/pdf/social_exclusion_en.pdf

Keyt, D. (2007). The good man and the upright citizen in Aristotle's Ethics and Politics. *Social Philosophy and Policy, 24*, 220-240.

Korea National Standard Office (2006). *Social indicators in Korea*. Retrieved February 17, 2009, from http://www.nso.go.kr/eng2006/e03____0000/e03a___0000/e03aa__0000/e03aaf0000/e03aaf0000.html

Marshall, T. H. (1950). *Citizenship and social class*. Cambridge: Cambridge University Press.

Massie, B. (2006). *Finding the wormhole achieving equal citizenship for disabled people.* Retrieved February 17, 2009, from http://83.137.212.42/sitearchive/drc/library/drc_speeches/bert_massie_-_finding_the_worm.html

Meekosha, H., & Dowse, L. (1997). Enabling citizenship: Gender, disability and citizenship in Australia. *Feminist Review, 57*, 49-72.

Miller, P., Parker, S., & Gillinson, S.. (2004). *Disablism. How to tackle the last prejudice* DEMOS. Retrieved February 17, 2009, from http://www.demos.co.uk/files/disablism.pdf

Morris, J. (2005). *Citizenship and disabled people: A scoping paper prepared for the disability rights commission.* Disability Studies program University of Leeds, UK. Retrieved February 17, 2009 ,from http://www.leeds.ac.uk/disability-studies/archiveuk/morris/Citizenship%20and%20disabled%20people.pdf

Murphy v. United Parcel Service, Inc. (1999). Retrieved February 17, 2009, from http://caselaw.lp.findlaw.com/cgi-bin/getcase.pl?court=US&vol=000&invol=97-1992. certiorari to the United States court of appeals for the tenth circuit No. 97-1992. Argued April 27, 1999--Decided June 22, 1999.

National Council on Disability. (2000). *Executive summary. National disability policy: A progress report.* Retrieved February 17, 2009, from http://www.ncd.gov/newsroom/publications/policy98-99.html#1 http://www.ncd.gov/newsroom/publications/2000/pdf/policy98-99.pdf

Nevis, E. C. (1983). Using an American perspective in understanding another culture: Toward a hierarchy of needs for the People's Republic of China. *Journal of Applied Behavioral Science, 19*, 249-264.

New Zealand Immigration Service (2004). *A future together: The New Zealand settlement strategy in outline.* Retrieved February 17, 2009, from http://www.immigration.govt.nz/NR/rdonlyres/7137ABC7-9569-AE-BB09-227914CECE50/0/NZImmigrationSettlementStrategyOut

Office of the Deputy Prime Minister: (2004). *Office of the deputy prime minister: Housing, planning, local government and the regions - Sixth report.* Retrieved February 17, 2009, from http://www.publications.parliament.uk/pa/cm200304/cmselect/cmodpm/45/4504.htm

Overboe, James (2007). Vitalism: Subjectivity exceeding racism, sexism, and (psychiatric) ableism. *Wagadu: A Journal of Transnational Women's and Gender Studies, 4.* Retrieved February 17, 2009, from http://web.cortland.edu/wagadu/Volume%204/Articles%20Volume%204/Chapter2.htmhttp://web.cortland.edu/wagadu/Volume%204/Vol4pdfs/Chapter%202.pdf

Rapp, R., & Ginsburg, F. (2001). Enabling disability: Rewriting kinship, reimagining citizenship. *Public Culture, 13*, 588-556.

Roulstone, A. (2000). Disability, dependency and the New Deal for disabled people. *Disability & Society, 15*, 427-443.

Salama, P. (2004). *Development of indicators for social cohesion 12 & 13 February 2004, Venice Devising a social cohesion indicator.* Retrieved February 17, 2009, from http://pagesperso-orange.fr/pierre.salama/Salamadevisingsocindicatoreng.pdf

Spoonley, P., Peace, R., Butcher, A., & O'Neill, D. (2008). Social cohesion: A policy and indicator framework for assessing immigrant and host outcomes. *Social Policy Journal of New Zealand, 24*, 85-110.

Sutton et al. v. United Air Lines, Inc. (1999). Retrieved February 17, 2009, from http://caselaw.lp.findlaw.com/cgi-bin/getcase.pl?court=US&vol=000&invol=97-1943. certiorari to the United States Court of Appeals for the Tenth Circuit No. 97-1943. Argued April 28, 1999--Decided June 22, 1999.

The Canadian Cultural Research Network (CCRN (2000). *Making connections: Culture and social cohesion in the new millennium..* Retrieved February 17, 2009, from http://www.circle-network.org/activity/edmonton2000/confreport/plenary1.htm

The Standing Senate Committee on Social Affairs, S. a. T. (1999). *Final report on social cohesion.* Government of Canada. Retrieved February 17, 2009, from http://www.parl.gc.ca/36/1/parlbus/commbus/senate/com-e/SOCI-E/rep-e/repfinaljun99-e.htm

United Nations (2007). *United Nations International Convention on the Rights of Persons with Disabilities.* United Nations. Retrieved February 17, 2009, from http://www.un.org/disabilities/convention/http://www.un.org/esa/socdev/enable/index.html

Wallerstein, I. (2003). Citizens all? Citizens some! The making of the citizen. *Comparative Studies in Society and History, 45*, 650-679.

Wikipedia (2008). *Maslow's hierarchy of needs.* Retrieved February 17, 2009, from http://en.wikipedia.org/wiki/Maslow's_hierarchy_of_needs

Wolbring, G. (2008a). Why NBIC? Why human performance enhancement? *Innovation; The European Journal of Social Science Research, 21*, 25-40.

Wolbring, G. (2008b). "Is there an end to out-able? Is there an end to the rat race for abilities?" *Journal: Media and Culture, 11:3* Retrieved February 17, 2009, from http://journal.media-culture.org.au/index.php/mcjournal/article/viewArticle/57

Wolbring, G. (2008c). The politics of ableism. *Development, 51*, 252-258.

Wolbring, G. (2007). *NBICS, other convergences, ableism and the culture of peace.* Retrieved February 17, 2009, from http://www.innovationwatch.com/choiceisyours/choiceisyours-2007-04-15.htm

Wolbring, G. (2006). *Scoping paper on nanotechnology and disabled people.* Retrieved February 17, 2009, from http://cns.asu.edu/cns-library/documents/wolbring-scoping%20CD%20final%20edit.doc

Wolbring, G. (2005). *HTA initiative #23. The triangle of enhancement medicine, disabled people, and the concept of health: A new challenge for HTA, health research, and health policy.* Alberta Heritage Foundation for Medical Research, Health Technology Assessment Unit: Edmonton, Alberta Canada. Retrieved February 17, 2009, from http://www.ihe.ca/documents/hta/HTA-FR23.pdf

World Transhumanist Association. (2004). *The physically disabled.* Retrieved from http://transhumanism.org/index.php/WTA/communities/physicallydisabled/

World Transhumanist Association (2003). The transhumanist FAQ – *A general introduction – Version 2.1.* Retrieved February 17, 2009, from http://www.transhumanism.org/index.php/WTA/faq21/46/

World Transhumanist Association. (2002). *Transhumanist declaration.* Retrieved from http://www.transhumanism.org/index.php/WTA/declaration/

Operationalizing Human Rights and Human Security Through a Dynamic Model of Health

Mary Anne Burke, M.A.
President, BIAS FREE Co-operative, Inc.

Abstract: The UN *Convention on the Rights of Persons with Disabilities* challenges nations and the global community to address the long-standing, systemic discrimination and disenfranchisement experienced by disabled people throughout the world. This can be accomplished by understanding and paying attention to the dynamics linking human security and social inclusion. A healthy and secure society is one in which the needs of individuals are met and their contributions are encouraged and recognized. It upholds the value of diversity and recognizes that the extent to which every person realizes his or her unique potential, and the capacity of society to accommodate and honor that person's contribution, is the ultimate measure of health, both for the individual and for society. This paper draws on the *Dynamic Model of Health* (Burke, Bach, Colman, McKie, & Ward Stewart, 2000) that roots health in the values of self-determination, equality, and democratization and in community processes that support social solidarity and inclusion as a framework for analyzing the existing situation of disabled peoples and the way forward. It presents work currently being undertaken in a project aimed at developing an "inclusive" Kyrgyzstan, drawing on work that operationalized the *Dynamic Model of Health* and the *BIAS FREE Framework* (Eichler & Burke, 2005; Burke & Eichler, 2006) in the context of disabled children. The paper calls into question the existing health and development model that perpetuates benefits for a few and leaves disabled peoples off the agenda. It argues that the *logic of domination* underlying all forms of discrimination and oppression is the same in all instances, although the types of discrimination are specific to a particular hierarchy –whether it is built on disability, gender, race, or other factors – and historical or cultural context.

Understanding how to "get it right" for disabled peoples will point the way to improving human security more broadly.

Key Words: health equity, human rights, social inclusion

Introduction

Violation of human rights puts human security at risk. Violation of an individual's rights puts that person into a situation of risk to his or her health and well-being. When people's rights are violated *because* they belong to a particular social group – such as disabled people – it puts the health and well-being of the entire group at risk. When violations become systemic and social machineries ensure the oppression of groups of people, the human rights and security of everyone are risked. Understanding how to undo the machineries of oppression for disabled people – among the most oppressed in every society – will point the way to undoing the machineries that oppress all others, leading to human security more broadly.

This paper examines the international human rights framework[1] as a blueprint for action. It explores the *Convention on the Rights of Persons with Disabilities'* (United Nations, 2006) call for social inclusion and participation and general promotion of human rights as essential for peaceful and equitable societies. It presents the *Dynamic Model of Health* (Burke, Bach, Colman, McKie, & Ward Stewart, 2000) that lays out the interconnections between human rights and health and well-being, and calls into question the various instruments typically used to measure health, pointing to how they have been part of the machineries of oppression. It examines how this machinery operates in the field of

child development and the detrimental effect it has on the health and well-being of disabled children. It presents a set of instruments that operationalize the *Dynamic Model* in the context of policies and programs for disabled children, but that serve as models for identifying the machineries of oppression at work more broadly. Finally, it explores the *BIAS FREE Framework*– a rights-based tool used in the development of these instruments – and an application of the Framework to the situation of disabled children in Kyrgyzstan. It can be used to embed human rights and social inclusion at each step of the research, policy, programs, service delivery processes and in everyday practices, improving the health, well-being and security of all people.

United Nations Convention on the Rights of Persons with Disabilities: A Call for Action

The United Nations (UN) *Convention on the Rights of Persons with Disabilities* challenges the global community to address the long-standing, systemic discrimination and disenfranchisement of disabled people everywhere. The *Convention* begins with the assumption that all people are equal and have inviolable rights that adhere to them because of their inherent human dignity. Human rights are essential for health and well-being (United Nations, 2006) of individuals and of communities, and as such are the foundation for secure societies.

The *Convention* stresses the need to protect the collective well-being of disabled people, as a matter of rights, not charity. The *Convention* issues a call to action for social justice and social solidarity:

> "While human rights have often been interpreted in individualistic terms in some intellectual and legal traditions… human rights guarantees also concern the collective well-being of social groups and thus can serve to articulate and focus shared claims and an assertion of collec-

tive dignity on the part of marginalized communities. In this sense, human rights principles are intimately bound up with values of solidarity and with historical struggles for the empowerment of the disadvantaged" (Solar & Irwin, 2007).

The *Convention*, as with all other instruments within the international rights framework, lays out a blueprint for action:

> "Human rights are those rights which are essential to live as human beings – basic standards without which people cannot survive and develop in dignity. They are inherent to the human person, inalienable and universal.

> The United Nations set a common standard on human rights with the adoption of the Universal Declaration of Human Rights in 1948…its acceptance by all countries around the world gives great moral weight to the fundamental principle that all human beings, rich and poor, strong and weak, male and female, of all races and religions, are to be treated equally and with respect for their natural worth as human beings.

> The United Nations has since adopted many legally binding international human rights instruments…used as a framework for discussing and applying human rights. Through these instruments, the principles and rights they outline become legal obligations on those States choosing to be bound by them. The framework also establishes legal and other mechanisms to hold governments accountable in the event they violate human rights [...]

> As part of the framework of human rights law, all human rights are indivisible, interrelated and interdependent. Understanding this framework is important to promoting, protecting and realizing […] [human] rights" (UNICEF, 2005).

The *Convention* builds on the existing international human rights framework and on the principles and policy guidelines of the *World Programme of Action Concerning Disabled Persons* and *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*. It calls for the promotion, formulation and evaluation of policies, plans, programs and actions at national, regional and international levels to further equalize opportunities for disabled persons, given the failure of existing mechanisms to do so:

> "The existing human rights system was meant to promote and protect the rights of persons with disabilities, but the existing standards and mechanisms have in fact failed to provide adequate protection to the specific cases of persons with disabilities. It is clearly time for the UN to remedy this shortcoming" (Arbour, 2007).

Social Inclusion and Respect for Human Rights Essential for Peaceful Societies

A United Nations report states that, "Groups with special needs remain marginalized in the political process, even though their participation is critical to address their concerns effectively and, generally, to promote an equitable society" (United Nations, 2005). It argues that social inclusion and participation and general promotion of human rights are essential for peaceful and equitable societies:

> "Social integration…is essential for a society that respects every individual. In many places, however, this remains a distant goal…The social ills of increasing inequality, poverty and lack of opportunities have had a forceful, negative impact on community well-being. Social integration has economic, environmental, political, human rights and security dimensions: any attempt to create peaceful societies must foster social integration based on the promotion of human rights, non-discrimination, equality of opportunity and the participation of all people... Yet, in many countries, groups with special needs remain marginalized in the political process, even though their participation is critical to address their concerns effectively and, generally, to promote an equitable society. In particular…persons with disabilities…frequently suffer discrimination and the denial of their basic human rights" (United Nations, 2005).

Structural Violence has Negative Impacts on Individual and Community Well-Being

Discrimination experienced by disabled people is a deeply rooted expression of structural violence, with profound negative impacts on the health and well-being of disabled people, their families and communities. Structural violence is defined as "social arrangements that put individuals and populations in harm's way," stopping "individuals, groups, and societies from reaching their full potential," and "is linked very closely to social injustice and the social machinery of oppression" (Farmer, Nizeye, Stulac, & Keshavjee 2006).

Power structures within a society serve to reinforce and maintain social hierarchies (Burke & Eichler, 2006) based on characteristics such as gender, age, race, class, caste and disability[2]. Society's resources are distributed according to an individual's position within a given hierarchy. The machinery of oppression is maintained by cultural, economic, political, trade, monetary, health and other systems.

Structural violence leads to interpersonal violence (sexual violence, family violence, racial violence, hate crimes, terrorism, genocide, and wars/conflicts); poverty; social exclusion; stress, shame, discrimination and denigration; deficits in community infrastructure/environ-

ments (housing, sanitation, clean water, health care services, roads, education, employment, etc.) and lack of access to the resources needed for well-being. The underlying spirit, philosophy and principles of equality, participation and inclusion embedded in the *Convention* call for concerted efforts across society to right historical, structural and systemic discrimination that perpetuates the exclusion, social disadvantage and health inequities of disabled peoples.

The *Convention* represents:

"A paradigm shift in attitudes that moves from a perception of persons with disabilities as objects of charity, medical treatment and social protection to subjects of rights, able to claim those rights as active members of society. The Convention achieves this paradigm shift by affirming that persons with disabilities hold civil, cultural, economic, political and social rights, are entitled to full protection against discrimination and by establishing monitoring mechanisms at the national and international levels to ensure that persons with disabilities are able to enforce those rights…

…disability is not considered as a medical condition as such, but rather as a result of the interaction between negative attitudes or an unwelcoming environment with the condition of particular persons. By dismantling attitudinal and environmental barriers - as opposed to treating persons with disabilities as problems to be fixed - those persons can participate as active members of society and enjoy the full range of rights" (United Nations, 2007, p. 7).

Article 3 of the Convention, sets out the general principles as follows:

"The General Principles can be grouped as follows: respect for inherent dignity, individual autonomy and independence of persons; equality of opportunity and equality between men and women; participation and inclusion; respect for difference and acceptance of human diversity; accessibility; and, respect for the evolving capacities of children with disabilities and respect for their right to preserve their identities" (United Nations 2007, p. 8).

Article 5.4 of the *Convention*, states that, "Specific measures which are necessary to accelerate of achieve de facto equality of persons shall not be considered discrimination under the terms of the present Convention" (United Nations, 2006) and:

"While all the general principles are of equal importance, the present section illustrates the relevance of three of these, namely: the principle of non-discrimination; the principle of accessibility; and the principle of participation and inclusion. First the principle of non-discrimination is one of the basic principles of international human rights law. Discrimination on the basis of disability is defined…as follows: Discrimination on the basis of disability means any distinction, exclusion or restriction on the basis of disability which has the effect of impairing or nullifying the recognition, enjoyment or exercise on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation" (United Nations, 2007, p. 8).

Principles of equality, participation and inclusion embedded in the Convention call for representation of disabled people proportionately in all aspect of social and economic life.

Linking Health and Human Rights: The Dynamic Model of Health

The *Convention* makes clear that dignity, respect, social inclusion, participation, equality, and human rights are key determinants of health – physical, mental, social and spiritual well-being – for disabled people. The social determinants of health approach (Lalonde, 1974; Epp, 1986; Jenson & Stroick, 1999; Health Canada, 1999; Novick, 1997; Romanov Report, 2001; Odom, 2000; Odom et al., 2001) stresses the importance of these:

> "…This dimension of *empowerment* is central to operationalizing the right to health and making this principle relevant to people's lives. 'A right to health based upon empowerment' implies fundamentally that 'the locus of decision-making about health shifts to the people whose health status is at issue'…the full expression of empowerment is people's effective freedom to 'decide what the meaning of their life will be'. In this light, the right to health aims at the creation of social conditions under which previously disadvantaged and disempowered groups are enabled to 'achieve the greatest possible control over … their health'. Increased control over the major factors that influence their health is an indispensable component of individuals' and communities' broader capacity to make decisions about how they wish to live" (Solar & Irwin, 2007, p. 9).

The social determinants approach aims to reduce health inequities, defined as differences in health that are "socially produced; systematic in their distribution across the population and unfair" (Dahlgren &Whitehead, 2006). Yet health typically has been measured within a paradigm that equates disability with ill health and physical, sensory, and psychosocial impairments, deficits and disorders.

Existing measures provide information on types of impairments that are used, for example, to determine eligibility for services, or to assess one's health status based on "quality of life," and variance from normative standards. Measures such as the QALYs and DALYs (Murray, 1996; Nord, Menzel, & Richardson, 2003) and related models fall into this category, assume that increments of healthy life/quality of life are lost due to impairments, and assign a value to one's life based on discounted values of life lived with disability (World Health Organization, 2007). They do not measure inclusion in various social domains, personal, family, and community skills and capacities for inclusion, and the relevant barriers to inclusion, human rights and overall health and well-being of disabled persons. Instead, they reinforce the discrimination and exclusion of disabled people.

The Dynamic Model of Health[4]

The *Dynamic Model of Health (Burke, Bach, Colman, McKie, & Ward Stewart, 2000)* begins with a broader, holistic definition of health, such as that adopted by the World Health Organization (WHO)[4] implicitly challenging the conventional distinction between "healthy" and "sick." It goes beyond the WHO definition to define health as a state of complete physical, mental, *spiritual*, and social well-being.

The *Dynamic Model* shifts from an individualized, diagnostic, and pathological model of health to one rooted in the values of *self-determination, democratization* of decision-making processes and *equality*, as articulated by The Roeher Institute's values-based health model (Roeher Institute, 1998). Put into policy and practice, these values result in equal respect for diversity, and in individuals and communities having increased control over the factors that maximize their potential and unique developmental paths, which as discussed above, are essential ingredients for peaceful and secure societies.

Self-determination refers to capacity. It recognizes that legal status and economic status effect individuals' ability to make decisions about their lives. Diminished status in either realm diminishes self-determination, with potential negative health outcomes. *Democratization* refers to process. Health is not merely a characteristic possessed by individuals, but rather is relational. Well-being has a lot to do with how we are treated by others. To the degree that individuals feel vulnerable, stereotyped, objectified, and treated without dignity, democratization is not realized. This is an essential piece of the framework because it goes to the heart of protecting the valuable diversity and difference in society. *Equality*[5] refers to equality of outcomes, rather than equality of opportunity. It recognizes that, without equality, individuals cannot enjoy their full human rights and their full potential to contribute to society and to benefit from the results of their contributions, leading to detrimental health outcomes.

The *Dynamic Model* sustains the notion that a healthy society is one in which the needs of individuals are met and their contributions are encouraged and recognized. It embodies a holistic view of health, upholds the value of diversity, and challenges restrictive concepts and definitions. It recognizes that the ability of every person to realize his or her unique potential, and the capacity of society to accommodate and honor that person's contribution, is the ultimate measure of health, both for the individual and for society.

The *Model*, presented in diagrammatic form below, is built on a number of basic principles, including that a) persons are ineffable (indefinable in words) and thus cannot ever be fully defined even by themselves, let alone by others, nor, it follows, can their health ever be fully defined by themselves or others, and b) health itself is at heart a self-defined condition and hence that indicators of health that are self-determined must be held to be prior over objective and re-

ductionist indicators by social scientists and others.

The *Model* is multidimensional, operating on different planes akin to a gyroscope, rather than the flat instrument portrayed here. Each plane represents a different dimension of health: individual, family, community, region, state, or global community. At the heart is a flexible circle representing health. Along the circumference are four nodes representing the four domains of physical, mental, spiritual and social well-being. In keeping with a holistic definition of health as a "complete state of well-being," this model does not assign priority to any node over another. Full health depends on a balance among all domains.

The nodes are connected by elastic cords calibrated to permit individuals, families, communities and states to record their self-assessed health status in each domain, and for these to be measured and compared. The shape of the circle becomes distorted if ill health in any of the domains is not counterbalanced by a countervailing support in one or more of the other domains. For example, individuals with physical impairments who have their needs fully accommodated by supports in the physical, social, spiritual and mental domains may report a state of complete health. Within the *Model,* this would lead to a strengthening of the force exerted by the connecting cords, such that equilibrium would be maintained in the center.

Encompassing and supporting the core are the environments in which people play out their lives. Thus, the shaded outer circle represents the physical, cultural, economic, social, spiritual, and other environments that affect the well-being of individuals, families, communities and states. When these environments are detrimental to health, the shaded circle compresses and puts pressure on the rest of the model, leading to disequilibrium.

The *Model* is dynamic. Just as the elastic cords between the four domains can adjust to

achieve equilibrium, so too can the different planes. If an individual with ill health is well supported by a healthy family, community and state within healthy environments, the *Model* can maintain stability. Conversely, unhealthy families, communities, environments, states and global community can destabilize the Model and lead to ill health for the individual.
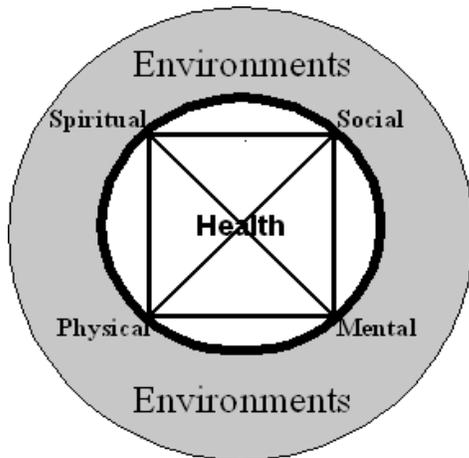
Operationalizing the Dynamic Model of Health

The *Dynamic Model* calls for new measures to understand the situation of disabled people and the interrelationships among social inclusion and the overall health, well-being and development of disabled persons. The *Dynamic Model* transcends the confines of a limited view of health and measures progress people and communities make in pursuing and achieving what constitutes for them a complete state of physical, mental, social and spiritual well-being.

It supplants the normative approach that underpins many indicators of healthy child development and educational progress. Assumptions about child development guiding the development of a public monitoring framework are not inclusive (Burke, Bach, & Crawford, 2002; Canadian Association for Community Living [CACL]., 1999). Commonly-used standards of "readiness to learn" and norms of child development define disabled children as deficits

from the outset (National Association for the Education of Young Children, 1997; Federal-Provincial-Territorial Council of Ministers, 2000; Doherty, 1997; North Carolina Ready for School Team Goal, 2000).

Families of disabled children understand the negative implications of a normative approach to healthy child development, as many have witnessed firsthand the exclusion and negative treatment which results (Burke, 2002; Canadian Association for Community Living (CACL)., 1999; Hanvey, 2002; Roeher Institute, 2000b). In contrast, inclusive family life, childcare, and education help all children to develop and grow up healthy and with dignity. Research also shows that inclusive settings result in developmental opportunities for all children as they learn about respect for difference, new forms of communication, empathy, friendship and solidarity.

A child's development is a unique, personal, familial, and community adventure shaped by developmental opportunities and outcomes (Graue, 1992; Love, Abers, & Brooks-Gunn, 1999; Pianta & Walsh, 1996.). The challenge is to maximize a child's chances to be valued, nurtured, recognized, engaged, and included in many environments.

The child development literature makes clear that children are "wired" to learn and develop (Kagan, 1999; Kagan, Moore, & Bredekamp, 1995; Meisels, 1996; Meisels, 2000; Meisels, 1999; Meisels, Atkins-Burnett, Xue, Nicholson, & Bickel, 1998; Shore, 1997; McCain & Mustard, 1999) in unique ways (Burt, 1937; Novick, 1997). Research on developmental paths has often used methods to draw "normal" patterns of development that do not account for the cultural, linguistic, communicational, and developmental diversity that children actually display (Amundson, 2000; Bernhard, 2000; Mackelprang & Salsgiver, 1999; Skrtic, 1991).

Children's development is shaped by the kinds of expectations others hold about them,

and how they are seen, recognized and known by others. They are formed in the stories written, told, and remembered by parents, families, teachers, mentors, and friends (Ricoeur, 1992; McIntyre & Caplan, 1994; Bruner, 2000; Benjamin, 1988; Polkinghorne, 1982; Lindemann-Nelson, 1997). This "intersubjective" fact of child development makes clear that the more children can be included in valuing settings and relationships with others, the more likely they are to develop a sense of self that gives them the resilience and capacity to venture into the world of education, community, civic participation, employment, and productive adulthood.

Children and their families require supports to maximize their developmental potential. The most enabling supports draw on their knowledge, are coordinated and accountable to them, meet their particular needs, strengthen their capacities, and enable transitions into inclusive educational and other environments (Allen, Cornell, Engel, & Paasche, 1998; Case, 2000; Murray, 2000; Marquis & Jackson, 2000; Roeher Institute, 2000c).

All children develop according to their own unique paths and have unique physical, emotional, intellectual, spiritual and creative capacities and multiple cognitive, kinesthetic, and communicational intelligences (Gardner, 1978; Armstrong, 1994) developed "intersubjectively" – through inclusion with others, and through spiritual development (Bronfennbrenner, 1999; Doherty, 1997; McCain & Mustard, 1999; Vygotsky, 1978). This was the essential starting point for a monitoring and accountability framework that is inclusive of all children and recognizes all paths equally – a path where one child learns to walk and another where a child learns to move by using a wheelchair – and upholds the inherent value of every child.

Towards an Inclusive Monitoring and Accountability Framework

Drawing on the *Dynamic Model of Health*, the author undertook a large body of work (Burke, 2002; Burke, Bach, & Crawford 2002; Burke, Crawford & Pegg 2002a; 2002b; 2002c) to address the failure of existing measures and indicators of health to address the needs of disabled people, their families and their communities. The work is situated within a human rights framework, and grounded in the lived experience of disabled people, their families and communities (Roeher Institute, 1998; Roeher Institute, 2000a; 2000b; 2000c; Roeher Institute, 1993). It includes a framework of inclusive indicators for monitoring child outcomes, various co-requisites of child well-being and healthy child development, and the impact of public policies on child outcomes and their co-requisites (Roeher Institute, 1999; Bach & Burke, 2002).

The framework identifies personal and interpersonal descriptors for children across seven developmental outcomes formulated to be inclusive in their conception and terminology, and consistent with the findings of research and assumptions about the uniqueness and diversity of children. The framework also identifies family, school, community and other co-requisites that play a role in shaping a child's growth and development in each of the seven outcome areas. Woven throughout the framework is a broad set of public policy decisions that have a direct or indirect impact on children.

The framework identifies the many factors that influence and shape child well-being and development, and helps us to understand and to think about these factors in a coherent way that is inclusive of all children. The framework maps out the areas where indicators are needed to monitor the effectiveness and efficiency of specific inputs, activities, outputs and outcomes in meeting developmental goals and objectives.

Individual scores on a number of measures can be aggregated to determine how individuals and subgroups are faring towards healthy development and progress in health status compared to others. In this way, systemic problems that disadvantage some groups relative to others can be identified and corrected. Communities can develop indicators that best measure the health and well-being of children within their communities.

Instruments developed to measure the inclusivity of communities, programs and services, and public policies and their impact on the overall well-being and development of children and their families (Burke, Crawford, & Pegg, 2002a; Burke, Crawford, & Pegg, 2002b; Burke, Crawford, & Pegg, 2002c) were piloted with success across Canada within the Early Child Development Sector. The results were published (Burke & Pegg, 2003a; 2003b), shared with participants, and used to facilitate a dialogue about their strengths in each domain, and where they could make improvements. In some cases, officials made an immediate commitment to improve their scores in a given domain, sometimes setting target dates for addressing identified problems.

Both the instruments and the process of consultation and feedback were critical for helping officials to see how deeply the structural barriers to inclusion were entrenched within policies, programs and service delivery. Only by identifying them could the process of dismantling the "machineries of oppression" begin.

A Case Study: Building an Inclusive Kyrgyzstan Using the *BIAS FREE* Framework

In 2007, UNICEF supported an "assessment of the situation of children with special needs in Kyrgyzstan," using instruments adapted from the Roeher research. The research findings (UNICEF, 2009) identified many violations of the rights of disabled children and their families,

and physical and social barriers that risked their health, well-being and security.

The final activity of the UNICEF project was a workshop for sharing the research findings with a broad range of stakeholders and exploring the *BIAS FREE* Framework (Eichler & Burke, 2005; Burke & Eichler 2006) and its usefulness as a tool to move towards a more inclusive Kyrgyzstan:

> "*BIAS FREE* stands for *B*uilding an *I*ntegrative *A*nalytical *S*ystem for *R*ecognizing and *E*liminating in *E*quities. The Framework is a rights-based tool for identifying and eliminating biases deriving from social hierarchies in research, policies, programs, service delivery and practices. It is premised on the equal entitlement of all people to be treated with respect and on the inviolability of human rights, understands health as a human right, and uses a rights-based model of health and well-being, as articulated in the *Dynamic Model of Health*" (Burke, Bach, Colman, McKie, & Ward Stewart, 2000).

The Framework is built on the theoretical notion that the *logic of domination* (Warren, 1987) "does not change across hierarchies, although it manifests in diverse ways across social hierarchies and contexts" (Burke & Eichler, 2006). The Framework distinguishes among a number of complex and interrelated problems, identifying the roots of the problems and points to appropriate and responsive solutions. As such, workshop participants expressed great interest in undertaking further work to improve the situation for disabled children, using the *BIAS FREE* Framework as a tool for identifying how human rights violations occur and how to eliminate them.

Consequently, UNICEF launched a follow-up project in 2008 as its priority project aimed at creating "a fully inclusive Kyrgyzstan that values, welcomes and treasures diversity and provides the conditions in which all people may

grow, develop and contribute to society to their fullest potential, enjoy equal rights within their communities and society and achieve physical, mental, social and spiritual well-being" (Pupulin & Burke, 2008). The project was supported by a decree issued from the Prime Minister's office and will be led by a national steering committee and working groups with a diverse set of community members to ensure an inclusive strategy and action plans are adopted.

While the initial entry point for the UNICEF project was disabled children, the application of the *BIAS FREE* Framework helped to broaden thinking to overall social inclusion. Revamping school systems to be free of barriers so that all children may develop and learn to their fullest potential also will benefit other children from ethnic and religious minorities and impoverished circumstances. Seeing each disabled child as unique, special and of value will open the door to seeing all children that way. If successful, the project in Kyrgyzstan will serve as a model for other countries in the region and around the world, providing a pathway to social solidarity and human security.

Conclusions

Nurturing healthy people and communities begins with their own visions, listening to disabled people, and to their understanding of what it will take to improve their overall development and well-being. Understanding the extent to which individuals, communities, and different populations are making progress along a path to healthy development that they define, and the extent to which they can make the interventions they know are essential to their well-being and their flourishing are key.

The *Dynamic Model* and the set of instruments derived from it have demonstrated their usefulness in exploring the situation of disabled children and assessing and informing the inclusivity of public policies, programs and services in a way that ensures the overall well-being and development of children, their families and communities.

The *BIAS FREE* Framework helps people to identify situations of structural violence within their own cultural and historical contexts. The Framework exposes the logic of domination faced by disabled peoples, and how it is the same for all disenfranchised communities. It thus shows the way to dismantle the machineries of oppression systematically so that societies can be transformed to be fully inclusive and ensure human rights, development and overall well-being.

Human security will always be at risk if structural violence remains embedded in our world. These are systemic problems perpetuated through the machineries of oppression that operate in research, policies, programs, service delivery and everyday practices. Dismantling these machineries will not be easy. The *Convention* provides a momentous opportunity to change the way we do business. The *BIAS FREE* Framework shows us the way. If we can "get it right" for disabled people we are well on the road to dismantling these machineries, given that the logic of oppression is the same for all social hierarchies. Ensuring human rights, health and well-being and social participation of disabled people lays the groundwork for social solidarity, peace, and improving human security more broadly.

Mary Anne Burke has published widely in the areas of public policy, social conditions and human rights. She developed Gender-based Analysis (GBA) and social inclusion tools, including the "*BIAS FREE* Framework" with Margrit Eichler. She has extensive experience as Director of Research for The Roeher Institute, and as Senior Policy Analyst and Statistician in the Canadian government for Statistics Canada; Status of Women Canada; Health Canada; and Human Resources and Social Development Canada, and internationally for UNICEF and the Global Forum for Health Research. She is an International Consultant, President of the *BIAS FREE* Co-operative, Inc. and Assistant Professor at OISE/UT.

References

Allen, K. E., Cornell, A., Engel, M., & Paasche, C. L. (1998). *Exceptional children: Inclusion in early childhood programs* (2nd Canadian ed.). International Thompson Publishing.

Amundson, R. (2000). Against normal function. *Studies in History and Philosophy of Biological and Biomedical Sciences, 31,* 33-53.

Arbour, L. *Statement by Louise Arbour, UN High Commissioner for Human Rights*

General Assembly Ad Hoc Committee. Presented at 7th session, New York. (2006, January 20). Retrieved October 12, 2007, from http://www.un.org/esa/socdev/enable/rights/ahc7stathchr.htm

Armstrong, T. (1994). *Multiple intelligences in the classroom*. VA: Association for Supervision and Curriculum Development.

Bach, M., & Burke, M. A. (2002). *Toward an inclusive approach to monitoring investments and outcomes in child development and learning*. North York, Canada: The Roeher Institute.

Benjamin, J. (1988). *The bonds of love: Psychoanalysis, feminism, and the problem of domination*. New York: Pantheon.

Bernhard, J. (2000, March). *Reconceptualizing ECE: Questioning theories and assumptions in human development.* Presentation at the Linking Research To Practice, Second Canadian Forum.

Bronfennbrenner, V. (1999). Environments in developmental perspective: Theoretical and operational models. In S. L. Friedman and T. D. Wachs (Eds.), *Measuring environments across lifespan: Emerging methods and concepts* (pp. 3-28). Washington, DC: American Psychological Association.

Bruner, J. (2000). Tot thought. *The New York Review*.

Burke, M. A., Bach, M., Colman, R., McKie, C., & Ward Stewart, G. (2000). *Dynamic Model of Health*. Retrieved (date), from http://www.cwhn.ca/resources/health_model/Dmodel.pdf.

Burke, M. A. (2002). *The construction of disability and risk in genetic counselling discourse.* North York, Canada: The Roeher Institute.

Burke, M. A., Bach, M., & Crawford, C. (2002). *Moving in unison into action: Towards a policy strategy for improving access to disability supports*. North York, Canada: The Roeher Institute.

Burke, M. A., Crawford, C., & Pegg, S. (2002a). *A tool for assessing child care/ECD programs*. North York, Canada: The Roeher Institute.

Burke, M. A., Crawford, C., & Pegg, S. (2002b). *Community profile tool: Measuring inclusivity of early childhood resources*. North York, Canada: The Roeher Institute.

Burke, M. A., Crawford, C., & Pegg, S. (2002c). *Early childhood development policy analysis tool.* North York, Canada: The Roeher Institute.

Burke, M. A., & Eichler, M. (2006). *The BIAS FREE framework. A practical tool for identifying and eliminating social biases in health research*. Global Forum for Health Research, Geneva, Switzerland.

Burke, M. A., & Pegg, S. (2003a). *Inclusivity of the Child Care Policy Environment in Canada: Much Work to Be Done.* North York, Canada: The Roeher Institute.

Burke, M. A., & Pegg, S. (2003b). *Analysis of special needs education policies in Canada using an inclusion lens.* North York, Canada: The Roeher Institute.

Burt, S. C. (1937). *The backward child.* London: University of London Press.

Canadian Association for Community Living (CACL). (1999). *Don't exclude our children: Include all Canada's children in the National Children's Agenda.* Toronto, Canada: Statement on the National Children's Agenda.

Case, S. (2000). Refocusing on the planet: What are the social issues of concern for parents of disabled children? *Disability & Society, 15,* 271-292.

Dahlgren, G., & Whitehead, M. (2006). Levelling up (part 1): a discussion paper on European strategies for tackling social inequities in health. WHO EURO.

Doherty, G. (1997). *Zero to six: The basis for school readiness.* Ottawa: Human Resources Development Canada, Applied Research Branch.

Eichler, M., & Burke, M. A. (2006). The BIAS FREE framework: A new analytical tool for global health research. *Canadian Journal of Public Health, 97*(1), 63-68.

Epp, J. (1986). *Achieving health for all: A framework for health promotion.* Ottawa: Health and Welfare Canada.

Farmer, P. E., Nizeye, B., Stulac, S., & Keshavjee, S. (2006) Structural violence and clinical medicine. *PLoS Medicine 3*(10): e449 doi:10.1371/journal.pmed.0030449

Gardner, H. (1978). *Developmental psychology: An Introduction.* London: Little, Brown, and Company.

Graue, M. E. (1992). Social interpretations of readiness for kindergarten. *Early Childhood Research Quarterly, 7,* 225-243.

Hanvey, L. (2002). Children with disabilities and their families in Canada: A discussion paper. *National Children's Alliance for the First National Roundtable on Children with Disabilities.* Retrieved (date), from http://www.nationalchildrensalliance.com/nca/pubs/2002/hanvey02.pdf

Haring, N. G., & , M. L. (1990). *Exceptional children and youth.* Columbus, OH: Merrill.

Health Canada. (1999). *Health Canada's women's health strategy.* Health Canada.

Jenson, J., & Stroick, S. M. (1999). *A policy blueprint for Canada's children.* Ottawa: Canadian Policy Research Networks.

Kagan, S. (September, 1999). Cracking the readiness myth. *Young Children.*

Kagan, S. L., Moore, E., & Bredekamp, S. (1995). *Reconsidering children's early development and learning: Towards common views and vocabulary* (Rep. 95(3)). Canada: National Education Goals Panel, Technical Planning Group.

Lalonde, M. (1974). *A new perspective on the health of Canadians.* Ottawa, Ontario, Canada: Minister of Supply and Services.

Levine, S. (2000). The Tao and Talmud of adolescence and young adulthood: Being, belonging, believing, benevolence. In L. T. F. & A. H. Esman (Vol. Eds.), *Adolescent psychiatry: developmental and clinical studies: Vol. 25. The Annals of the American Society for Adolescent Psychiatry* (pp. 45-58). Hillsdale, NJ: The Analytic Press.

Lindemann-Nelson, H. (1997). *Stories and their limits: Narrative approaches to bioethics*. New York: Routledge.

Love, J. M., Abers, J. A., & Brooks-Gunn, J. (1999). *Ready or not, here they come: Strategies for Achieving School Success for All Kansas City Children*. Ewing Marion Kauffman Foundation, Kansas City, Missouri.

Mackelprang, R., & Salsgiver, R. (1999). *Disability: A diversity model approach in human services practice*. Brooks/Cole Publishing Company.

Marquis, R., & Jackson, R. (2000). Quality of life and quality of service relationships: Experiences of people with disabilities. *Disability & Society, 15,* 411-425.

McCain, M., & Mustard, F. (1999). *Reversing the real brain drain: Early years study*. Toronto: Canadian Institute of Advanced Research.

McIntyre, R. L. & Caplan, A. L. (1994). Mapping morality: ethics and the Human Genome Project. An interview with Arthur L. Caplan, Ph.D. *Trends in Health Care Law, & Ethics, 9,* 7-12, 32.

Mead, G. H. (1972). *Mind, self and society*. Chicago: University of Chicago Press.

Meisels, S. (1996). Using work sampling in authentic assessments. *Educational Leadership, 54,* 60-65.

Meisels, S. J. (1999). Assessing readiness. In M. J. Cox & R. C. Pianta (Eds.), *The transition to kindergarten.* Baltimore, MD: Paul H. Brookes.

Meisels, S. J. (2000). On the side of the child. *Young Children*.

Meisels, S. J., Atkins-Burnett, S., Xue, Y., Nicholson, J., & Bickel, D. (1998). *Turning teachers' judgments: A validity study of curriculum-embedded performance assessment in kindergarten to grade 3* (Technical Report). Ann Arbor: University of Michigan.

Murray C. J. L. (1996). "Rethinking DALYs". In L. A. Murray & C. J. L. Murray (Series Ed.), *The global burden of disease. Global Burden of Disease and Injury Series* (pp. 1-98). Cambridge: Harvard University Press.

Murray, P. (2000). Disabled children, parents, and professionals: Partnership on whose terms? *Disability & Society, 15,* 683-698.

National Association for the Education of Young Children (1997). *Developmentally appropriate practice in early childhood programs serving children from birth through age 8*. Washington: NAEYC.

Nord, E., Menzel, P., & Richardson, J. (2003). The value of life: individual preferences and social choice. A comment to Magnus Johannesson. *Health Economics, 12*(10), 873-877.

North Carolina Ready for School Goal Team (2000). *School readiness in North Carolina: strategies for defining, measuring, and promoting success for all children*. North Carolina: State Board of Education. Retrieved (date), from http://www.fpg.unc.edu/~SchoolReadiness/SRFullReport.pdf

Novick, M. (1997). *Prospects for children: Life chances and civic society.* Toronto: Laidlaw Foundation.

Odom, S. L. (2000). Preschool inclusion: What we know and where do we go from here. *Topics in Early Childhood Special Education, 20,* 20-27.

Odom, S. L., Wolery, R., Lieber, J., Sandall, S., Hanson, M. J., Beckman, P. et al. (2001). Preschool inclusion: A review of research forthcoming from an ecological systems perspective. In M. J. Guralnick (Ed.), *Early childhood inclusion.* Baltimore, MD: Paul H. Brookes.

Pianta, P. C., & Walsh, D. J. (1996). *High risk children in schools: Constructing and sustaining relationships.* New York: Routledge.

Polkinghorne, (1982). *Narrative knowing and the human sciences.* Albany: State University of New York Press.

Ricoeur, P. (1992). *Oneself as another [Soi-meme comme un autre].* Chicago: University of Chicago Press.

Roberge, R., Berthelot, J. M., & Wolfson, M. (1995). *The health utility index: Measuring health differences in Ontario by socio-economic status. Health Reports, 17,* 25-32.

Roeher Institute (2000a). *Agenda for action: Policy directions for children with disabilities and families.* North York, Canada: Roeher Institute.

Roeher Institute (2000b). *Beyond the limits: Mothers caring for children with disabilities.* North York, Canada: Roeher Institute.

Roeher Institute (2000c). *Towards inclusion.* North York, Canada: Roeher Institute.

Roeher Institute (1999). *Towards an inclusive model for child well being and healthy development.* North York, Canada: Roeher Institute.

Roeher Institute (1998). *National evaluation of NSIPD Deinstitutionalization Initiative, final report* North York, Canada: Roeher Institute.

Roeher Institute (1993). *Social well-being.* North York, Canada: Roeher Institute.

Commission on the Future of Health Care in Canada. (2002). *Building on values: The future of health care in Canada – Final report.* Health Canada. Available at http://www.collectionscanada.gc.ca/webarchives/20071122004429/http://www.hc-sc.gc.ca/english/pdf/romanow/pdfs/hcc_final_report.pdf

Solar, O., & Irwin, A. (2007) *A conceptual framework for action on the social determinants of health.* Discussion Paper for the Commission on the Social Determinants of Health. p. 9.

Shore, R. (1997). *Rethinking the brain: New insights into early development.* New York: Families and Work Institute.

Skrtic, T. M. (1991). *Behind special education: A critical analysis of professional culture and school organization.* Denver, CO: Love Publishing Co.

Vygotsky, L. S. (1978). *Mind in society.* Cambridge, MA: Harvard University Press.

Wolbring, G. (2008) Why NBIC? Why human performance enhancement? *European Journal of Social Science Research, 21*(1), 25-40.

World Health Organization. WHO definition of health, Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946. http://www.who.int/about/definition/en/ .

World Health Organization. (2007). *Disability adjusted life years*. World Health Organization (WHO). Available at http://www.who.int/healthinfo/boddaly/en/index.html

UNICEF. (2009). *Assessment of the situation of children with disabilities in Kyrgyzstan.* Bishkek, Kyrgyzstan: UNICEF.

UNICEF. (2005) "Convention on the Rights of the Child: The human rights framework." Retrieved June 10, 2009, from http://www.unicef.org/crc/index_framework.html

United Nations. (2006) *Convention on the Rights of Persons with Disabilities.* New York: United Nations. Available: http://www.un.org/disabilities/default.asp?navid=12&pid=150

United Nations. (2005). *One United Nations: Catalyst for progress and change - How the Millennium Declaration is changing the way the UN system works.* New York: United Nations. http://www.unsystemceb.org/oneun/2/p202

United Nations Human Rights Council (2007). *Implementation of General Assembly Resolution 60/251 of 15 March 2006 Entitled "Human Rights Council" Report of the United Nations High Commissioner for Human Rights on progress of the recommendations contained in the study on the human rights of persons with disabilities.* New York: United Nations.

Endnotes

[1] The instruments of the international human rights framework are the Universal Declaration of Human Rights and the seven core human rights treaties: 1) International Covenant on Civil and Political Rights; 2) International Covenant on Economic, Social and Cultural Rights; 3) Convention on the Rights of the Child; 4) Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment; 5) International Convention on the Elimination of All Forms of Racial Discrimination; 6) Convention on the Elimination of All Forms of Discrimination against Women; and 7) Convention on the Rights of Persons with Disabilities.

[2] Wolbring argues that social hierarchies of any type are constructed on the basis of ability, with those perceived as being "more able" at the top of each hierarchy, see: http://journal.media-culture.org.au/index.php/mcjournal/article/viewArticle/46 http://journal.media-culture.org.au/index.php/mcjournal/article/viewArticle/57 Wolbring (2008) Why NBIC? Why human performance enhancement? European Journal of Social Science Research, Vol 21,No.1,pp. 25-40.

[3] This section is largely excerpted from the Dynamic Model of Health at: http://www.cwhn.ca/resources/health_model/Dmodel.pdf.

[4] The World Health Organization defines health as "a state of complete physical, mental and social well-being, not merely the absence of disease or infirmity" (World Health Organization, 1946).

[5] Throughout this article, equity is defined as the "process of being fair". Equity leads to equality, not just of opportunity, but in outcomes. Equality is defined as the outcome reached through equity. Equality means that all people enjoy equal status in society and are able to realize their full human rights and their potential to contribute to political, economic, social, personal and cultural development within their communities, and to benefit equally from them. The concept of equality includes both equality in the law — de jure equality and actual equality — de facto equality. Achieving equality ultimately means that society values equally the similarities and differences among all people and their varying roles. Equality is a goal towards which one must constantly strive.

Making Social Cohesion or Marking the Human Security Threat? Tracing Disciplines of Place in Community-Based Services for the "Developmentally Disabled"

M.S. Glennon, M.Soc.
Universiteit van Amsterdam's International School
for Humanities and Social Science

Abstract: This paper is about how human services work people into place and how places are reworked by people. As an (auto)ethnographic research on community based services for "developmental disability"—seen as technologies for making social cohesion and development—it discusses rewards and risks when tooling knowledge to make people free.

Key Words: social cohesion, community services, developmental disability

Introduction

Social Cohesion is as venerable a sociological concept as there ever was, and is defined in practice as "the ongoing process of developing a community of shared values…based on a sense of trust, hope, and reciprocity" (Dayton-Johnson, 2003). It has been used to research the effectiveness of community organizations in economic development (Borgos & Douglas, 1996), of local cultures in fostering civic volunteerism (Sharon, 2003), and the dis/integrative effects of ethnic diversity (Healy, 2007). Yet, there remains an absence of social cohesion research on community services for the "developmentally disabled" ("DD"). One aim of this paper is to address this gap.

By "DD," I mean what has been called "mental retardation," "feeblemindedness," and before that "idiocy." In the past, it included vagrancy (Foucault, 2006; Hacking, 1998). In the present, it includes also categories like autism. I say "DD" primarily because it is the signifier used by the state of Nebraska to qualify people for treatment in human service spaces, such as group homes and sheltered workshops.

Though silent on social cohesion, research on "DD" has engaged with a related concept, "social capital"—the fabric of social networks which make social cohesion possible. In journals devoted to disability studies as well as rehabilitation and integrated education, research endeavors to account for social capitals present or absent between communities and families with "DD" children (Chenoweth & Stehlik, 2004), or between "DD" students and their universities (Farmakopoulou & Watson, 2003). Elsewhere it is theoretically explicated as a tool for measuring and strategically intervening in the development of a "DD" individual's social network (Potts, 2005; Ward & Baker, 2005). The practical aim is generally to generate more opportunities for things like integrated employment (Potts, 2005; Ward & Baker, 2005), and to encourage policy makers to be more inclusive about how social capital's parameters are to be defined (Pavey, 2006).

These discussions posit an affinity between sociological discussions of social capital with the long-standing missions of deinstitutionalization, community integration and social inclusion (Bates & Davis, 2004; Partington, 2005; Potts, 2005). These texts then adapt social capital for use with an already extensive knowledge base for implementing community service systems for "DD" populations, a long standing mission of making social cohesion. "Over the past 30 years an informal network of writers… have shown how support can be provided so that people with disabilities can be employed rather than attend a sheltered workshop, live in their own home rather than in a hostel, and participate in friendships and community life with a diverse array of citizens" (Bates & Davis, 2004,

Forum on Economic Security

p. 196). Such hegemonic human service episte-mologies like Normalization/Social Role Valori-zation (SRV) do not specifically address the is-sue of social capital, but do seek to add value to roles disabled people play in society (Partington, 2005, p. 247). It must be noted that this affinity is true not only of research sympathetic to SRV, but to research from the social model of dis-ability as well (Pavey, 2006; Partington, 2005). Pavey's (2006) article in *Disability & Society argues* for the social model of disability not to refuse the concepts of social capital for its capi-talist elements, but for an inclusive definition and application. This mutual affinity to a third thing by two ideologically opposed epistemolo-gies makes sense if one is open to the possibility that Normalization is misrecognized as simply a "medical model."

While these paradigms for making inclu-sion or integration out of "DD" practically beg questions like, "What do we mean by our community?" (Partington, 2005), the position of this paper is that it may be more fruitful to ask, what do we do as we mean our community to be? Historical studies draw attention to how public policies for institutionalization of devi-ant populations in places like France, the United States, and in my case Nebraska, now rightly and broadly considered inhumane, were not in spite of a will to social cohesion but rather in the pursuit of maintaining or safeguarding notions of it (Trent, 1994; Hacking, 1998; DeKraai, 2002). Care for social cohesion became linked with control very early on in the state schools for "feebleminded" youth, says Trent (1994), and this linkage has not been severed by the ser-vice systems of today.

I use a grounded post-structuralist approach combining tools of ethnography and discourse analysis. Post-structuralist because I use analytic schemas adapted from a triad of scholars, Mi-chel Foucault, Ian Hacking, and Deleuze and Guattari, in order to trace the trajectory of two "DD" people through the state of Nebraska's community service system. Examples from Ne-braska are instructive for it is there where Nor-malization based community services for "DD" populations in the United States first came into being (Schalock, 2002). Ethnographic because this research involved three years inside Nebras-ka's community service system, first as a human service worker in 2002 and 2004; and then formally as ethnographer in 2007. In the next section I cover some recent discussion on com-munity services for "DD" before moving on to the two cases at hand. In light of these cases I will discuss how social cohesion is better under-stood as a process of struggle over its terms of constitution rather than something intrinsically reciprocating and trustworthy.

"The Group Home Problem"

A group home is a residence where three to six "DD" individuals live who are expected to "work toward independence" and who are "sup-ported and reported" by human service staff in their progress on independent living skills and maintaining good behavior (Croft, 1999; Levin-son, 2005). Recent research literature on group homes for "DD" point to paradoxes of power. Often an individual's "choices" are determined by bureaucratic contingency so that, for exam-ple, where one "chooses" to live or what house-mates to live with may be merely a factor of where there is an available bed (MacEachen & Munby, 1996). The mission to free a people and make spaces for their independence furthermore comes into tension with an impulse to impose and enforce proper models and uses of freedom and to erect restrictions around an individual in the form of "safeguards" against the risk posed to their self and to others as vulnerable and un-predictable people (Crichton, 1998; Duvdev-aney, Ben-Zur, & Ambar). Levinson's ethno-graphic paper analyses this instructively from a Neo-Foucaldian point of view as not a problem of power but rather a dilemma of freedom. A group home is not intrinsically oppressive, but is merely a technology intended for making a liberal model of citizenship work on/for a kind of people (Levinson, 2005). Unlike Levinson,

however, I would submit this work is not clinical, but colonial, as it is performed whether or not it is invited by the citizen concerned.

Group homes are then places for a discipline of development. Disciplinary power "brings together citizenship and embodied identity with perpetual observation, writing, an unclear distinction between punishment and reward, projection of the psyche, the division between normal and abnormal….and fits embodied identity together with political power" (Foucault, 2006, p. 56). Discipline is the 'anatamo-political pole of development' which "centers on the individual as a speaking, working, procreating entity" (Hacking, 2002, p. 112). Bio-politics is the other pole which "focuses on the species body…the biological processes of a population in statistical form" (Foucault, as cited in Hacking, 2002, p. 112). Community services can be considered as an example of "the whole cluster of intermediary relations which link these poles together" (Hacking, 2002, p. 112). It is with this in mind I wish now to proceed with the two cases with which this paper is concerned.

The Traces of Two Placements

I consider the following two cases as singularities within a bio-political field of social cohesion. These two cases, Merciful Black and Zero President[1], exemplify the ongoing consequences of community care, entombment/containment and interpretive development. I explain this taxonomic intervention by way of discussion. Quoted material is either speech I witnessed in the field or text from documents I encountered.

Temples of Entombment for Merciful Black

Merciful Black was in her early childhood dually diagnosed as "having mild mental retardation" and a swathe of "behavioral disorders." She resents her position in Nebraska's human service system, whose group home network she entered in 2001. She refers to her group home as "the nuthouse." She voices loudly her desire "not [to] live in a group home no more," but she

is not her own legal guardian and so has no legal authority over her processes of placement. She uses what powers are at her disposal to struggle against her placement, and these struggles are recorded onto hundreds of "incident reports" of her verbal and physical violence and aggression. These aggressions are generally directed against the property of staff or a roommate. She sometimes throws fists at their bodies, but more often throws rocks at staff's cars. Yet, for all of this she has never been reported exhibiting violent behavior in public when enjoying her "independent time in the community"—a daily four hour privilege (according to her case records this was once an 8 hour privilege, also daily).

As a regime of group home discipline, Merciful Black's can be read as processes of entombment and containment. Her placements began with a foster family in North Omaha, a low-income African-American portion of Nebraska's largest city. As a teenager she constructed a social network vested in peripheral street gang affiliations. Social service workers intervened, and her foster mother placed Merciful in a group home. From there, and over the next seven years, Merciful's placement processes drew her progressively further from the geography and culture of her community of identification—where she "was born an raiz'd in tha hood," as she describes herself to me at a barbecue.

Few of Merciful's human service workers and decision makers doubt her ability to live outside of a group home. Key decision makers on her "individual support team," however, are nervous about the kind of people she seeks for association. Merciful's guardian, a woman who lives out of state in Texas and was recommended to Merciful as a guardian by her social services case worker, advises me to stay away from Merciful's "low rent" friends. Merciful's social worker expresses similar views. In Merciful's case book it is recorded that "these friends are a bad influence on Merciful, and will take advantage of her," although the only example provided involves an

episode where Merciful takes chicken from her group home to eat it at her friend's house.

With Merciful, there are many episodes. But how her "independent time" functions in her case is telling. The following narrative is assembled and summarized from accounts in her case book as well as my own ethnographic engagement with Merciful, her friends, and her service workers.

Merciful's friends invite her to a party. Support staff are directed by her "individual service program" to drive her nowhere other than medical appointments, her guardian, or other community service settings. To use her "independent time" Merciful must "independently" access the community. By this time Merciful has been placed in a group home in West Omaha, across town from "the hood." To meet her friends Merciful must take the hour long bus ride. She does. But the bus system in Omaha is spare; with most bus lines closing early in the evening. She will need someone with a car to drive her back and her friends seldom have access to a car.

Half an hour before her independent time expires, around 11:30 pm, Merciful calls the group home to request a ride. The staff on duty cannot leave Merciful's housemates unsupervised. Merciful calls the group home manager who advises a ride home from staff is "not part of her program." Merciful misses her curfew and loses her "independent time" for a month. She becomes angry and, returning "home," cycles into breaking things, shouting, throwing rocks at a staff's car, and is eventually placed in a prone floor restraint.

Merciful is some time later invited out again. Planning ahead, she asks staff members if they will be able to drive her. The answer is programmatically "no." Merciful contacts her social worker, who reminds Merciful she is responsible for her own transport when using "independent time." Merciful offers to do extra chores to earn money for a taxi or to pay staff for gas, but she is told she must earn money from a real job or at the sheltered workshop (which pays below minimum wage). The social worker's contact record reads: "Spoke to Manager. Merciful did well at home…made the decision on her own not to go on the bus because the buses quit running at 5 pm and she would not have a way home. No physical aggression."

Merciful nominally has independent time and is nominally permitted to use it how she wishes, but a combination of contingencies - the Omaha bus lines, the location of her placement, the social identity of her friends as "bad influences" in the eyes of human service authorities - become a constellation of programmatic points which prevent her from realizing her time of independence and circulating her social capital in a manner and with a community meaningful to her. The program wants her desires to steer toward particular social capitals and models of responsible conduct. A responsible decision for Merciful, in the eyes of her social worker, is to learn docility and acceptance of her identification as being in need of a group home.

Similar episodes are repeated until one evening Merciful pins her staff to the floor while one of her housemates smashes over the worker a glass coffee table; shattering both kneecaps of the young woman concerned. Merciful is re-placed. Her new group home is in a suburb of the state capital another 60 miles west from her identified home. Merciful calls this "exile." Merciful's guardian says in the contact record, "This can be a new start." The "new start" is an ominous nine miles from the "Nebraska State Developmental Center." She loses all "independent time."

The Intepretive Development of Zero President

Zero is a much needed counter-example. He has not been placed and re-placed ever closer to the heart of human service bureaucracy and so maintained in an entombed/contained state. He has lived in the same home since 1978 more or

less adopted by a foster family, which has enabled him to claim the terms of his identity and constructively challenge the roles expected of him by Nebraska's community services system. And no shortage of support has come from his adoptive father figure, Peaceful Ruler[2]. Peaceful worked, among other things (pastor, poet, professor, activist), as an Intake Officer for Nebraska's community service system during its formative years of the late 1970s. In that capacity, he became alerted to Zero.

Zero was raised in a Polish-American working class neighborhood in South Omaha. His parents were both "DD" as well as one of his two brothers. He himself is diagnosed as having "mild mental retardation" and "ADHD," was 17 when his parents passed away. The eldest of his two brothers, "very capable," was working and trying to keep things together for his siblings, but to no avail. The house fell into severe disrepair: broken toilets, clots of trash; cockroaches crawling all about. Now Zero's other brother, also "DD," would have nothing to do with community services and as his own guardian chose to live the next ten years with "thugs" who exploited his Social Security check. Zero, still being a minor, required by law some kind of human service placement. Peaceful organized foster homes for him, but removed him from each one when he witnessed signs of entombment/containment on follow-up visits. Eventually out of foster options and afraid to move the emotionally distraught individual, Peaceful took Zero to stay in his home, at least for a few months until he was emotionally stabilized. During this time, Peaceful advocated a place for Zero at public school and taught him, among other things, how to read. By the time a few months of stabilization had passed, Zero began to call Peaceful "dad."

Peaceful says, "…It just became clear we [*he and his partner*] were having a ball parenting. So I went to child protection services and I said, 'You know, we've kind of invested a lot of time with the boy. And because he wasn't a client we weren't treating him like a client, we always treated him like a kid." Peaceful and his partner became Zero's family. Eventually Zero's "DD" brother decided to leave the "thug life" and moved in with the Peaceful family. Thirty-two years later, Zero says if Peaceful had not found him, he would have "fallen through the cracks."

Zero now works for a recycling facility built on grant money for "DD" people to have a place of employment that offers valued work in an environment of "dignity and respect." Though it is a "segregated" workplace it is not a sheltered workshop such as Merciful is compelled to attend, i.e., it is "real work for real pay." Yet, as Zero's work skills developed in this environment, it became imperative of his vocational staff to encourage him to try and seek "competitive employment in the community." After seven attempts, either sufficient support was lacking, or, as Peaceful suggests, Zero's "ADHD" proved too strong a force. In any case, Zero could not perform in the "competitive" workforce. The stream of "failures" wounded so intensely his psyche that, after its seventh repetition, he availed himself of a psychic self-healing process with a therapist which lasted several months.

Instead of trying an eighth time for competitive work, Zero began to advocate for more responsibilities at the recycling facility; not only for himself, but for his co-workers as well. A new position was carved for him to train new workers on machines. He was also taught basic word processing skills. He broadened his advocacy and began to organize an employee association so that the "DD" workers of his recycling facility might claim greater authority over the workspace and slowly take over the responsibilities of support staff. He came downstairs one day during my fieldwork, as I was dusting Peaceful's study, to share with me the progress of his work:

> "Decisions lie behind all the actions that people take….the forman (sic) coaching…described something that 'conveyed valued people from where they are to where they want to go'….but many

coaches\ forman (sic) give their followers more information than they can digest at one time….the rationale is that 'we don't have time to this in 'digestble' (sic) for" [*text breaks off*].

Here Zero rethinks "development" as something which need not be a firm application of hierarchical models for measuring workplace achievement. Work need be neither "competitive," nor "integrated" to be dignifying. Zero's experience is that social cohesion is best made where he makes not only community work, but also works an affirmative meaning of community through his labor and the application of this labor at his desired pace and toward a tangible outcome. "I don't want any landfills," he says.

A Coil of Social (In)Coherencies

My taxonomic intervention, "entombment/ containment" and "interpretive development," is adapted from A Thousand Plateaus (Deleuze & Guattari, 1987, p. 150). For clarity, I reproduce one of Deleuze & Guattari's diagrams below as Figure 1.

Figure 1: Deluezian Inspired Diagram of a Social Cohesion
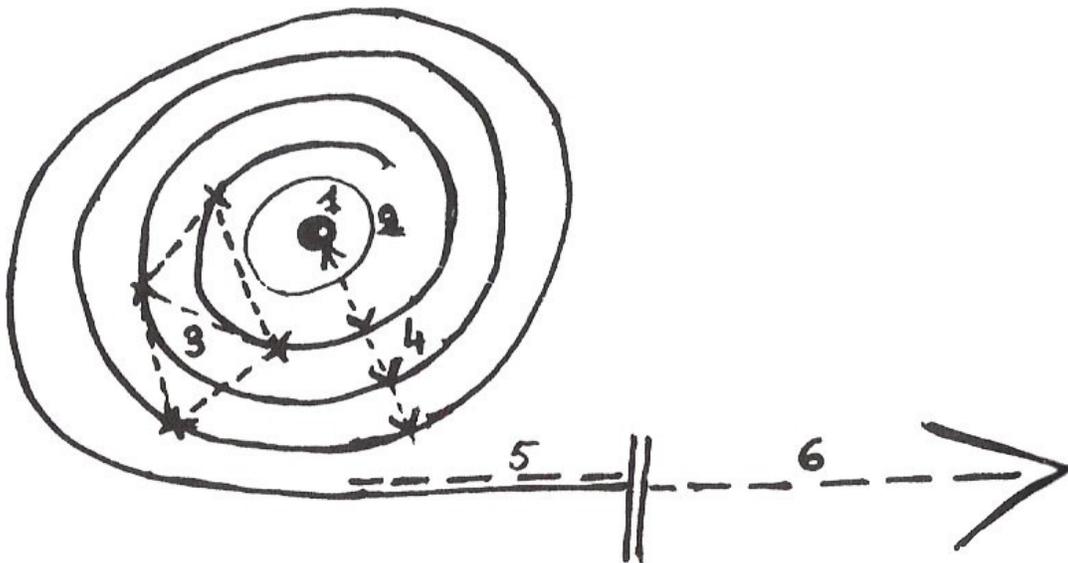
(1) "The Center or the Signifier": in this case *developmental progress*. (2) "The Temple or Palace with priests and bureaucrats": offices of health and human services, the Nebraska State Developmental Center; the direction toward which Merciful Black is being pulled. (3) "…the sign referring to other signs on the same circle or on different circles": epistemological and practical struggles over 'what community means.' (4) "The interpretive development of signifier into signified which…reimparts the signifier": Zero President moving away from the Center; Merciful Black moving toward the Center. (5) "The expiatory animal; the blocking of the line of flight": The contained element of Merciful Black, blocked from fully identifying with her community. (6) "The scapegoat or the negative sign of the line of flight": the act of escape Merciful would need to fully enter into her desired regime of coherency.

Once the mission of forging a cohesion called "community" is declared, the question must remain as to who has identified its signs and values for belonging, imputed their absence upon whom, and to what consequence? Christopher Lasch, twice in his work, *The True and Only Heaven: Progress and Its Critics* (1991), quotes a 1932 statement made by Christian ethicist, Reinold Niebuhr, "If social cohesion is impossible without coercion, and coercion is impossible without the creation of social injustice, and the destruction of injustice is impossible without the use of further coercion, are we not in an endless cycle of social conflict?" (Lasch, 1991, p. 377).

Universal Ideologies and Radical Contingencies

Although each case here is different from the other they both have in common the coil of social cohesion upon which their processes of place are manifest. Both live in spaces consequent to a Normalization movement which began Nebraska's deinstitutionalization process in 1968 with promises of the "return of the mentally retarded to society as *productive* citizens" (Terry, 1968). It was a promise of progress—the economic progress of earning independence, the cultural progress of performing the signs for valued citizenship, and the ethical progress of implementing right knowledge for practices of making-up this progressive citizenship through humanist values and a communitarian political praxis (Schalock, 2002).

Problems with Normalization-based community services in Nebraska became manifest (Schalock, 2002) when, despite the promises, the reality sunk in that not all "mentally retarded" people can or want to work in the "competitive" workplace and/or obtain the culture of independence community experts and humanists imagined as desirable for them. This compounded with the structural reality of globalization as the 1980s onward saw many of the manual labor jobs traditionally pursued by

"higher functioning DD" individuals moved out of state. Responding to this stagnation the State of Nebraska assumed tighter control over the service system to account for the dollars spent on it; to encourage people to be made to move through the system more measurably and if not moving be accounted for and treated by a form of behavioral discipline believed able to make them move. As happened with the state schools for "feebleminded" youth, "Well intentioned advocates of productivity through education became unintentionally the mediators of disabling, unproductive institutionalization" (Trent, 1994, p. 3).

Merciful's service workers do not see themselves as a conspiracy of control, but rather as agents of protection from immanent pathways into the criminal justice system. But Normalization here begets frustrating consequences in part because the articulation of its system will not affirm Merciful's work toward becoming her desired identity. There is no allowance for normalization into ghetto life. This omission becomes the commission of entombment/containment when it pathologizes not only Merciful's resistance to these blockages, but also when it actively and un/intentionally erects more blockages by pathologizing of her behavior. They should advocate for more thorough systems of mass-transit, or really teach Merciful to drive such as the social model of disability would (Oliver 1990). Yet, while the social model of disability might be more efficacious in practical terms here, theoretically it would need tweaking. The social model counts as the voices of disability those who self identify as disabled and resist structures of normalization in that name. But Merciful does not self-identify as disabled; and especially not as having "DD," the people who belong to "the nuthouse" with which she refuses to identify. When with her "non-DD" friends she actively obscures any part of her past and her identity related to her "behavioral disorder" or her "mild mental retardation." She tries, and often succeeds at "passing." In a sense she truly

pursues normalization, and with it desires the Social Role Valorization of a kind of ghetto life.

For Zero, the discipline of place was parental rather than programmatic. "You won't do your homework, then no dinner!" is one strategy Peaceful shares for how he set Zero on the trajectory of literacy. Here too is coercion, and in the eyes of some case workers I have come to know it would constitute abuse. Yet, it was this tactic of parental coercion which helped create the very conditions and skills necessary for Zero's present approach to self-advocacy—a self-advocacy he performs outside the purview of "DD peoples' parliaments" but on the very place of his community work where he now sees himself as a leader in the sense of a "monk" or a "coach." The social model of disability desires and encourages people to consider or make outcomes such as Zero's (Goodley & Lawthom, 2005). But, like Merciful's case, Zero's comes as a consequence of Nebraska's Normalization Movement. When Peaceful Ruler became Zero's paternal touchstone in 1978, he had been active as an intake officer and community advocate for Nebraska's Normalization based community services. And, in fact, Peaceful Ruler was close to key leaders of Nebraska's Normalization movement so that Zero's legal guardian is no less than the woman cited as the "silent but powerful conscience of Nebraska's Normalization movement" (Schalock, 2002). And so, the question strikes me, is there more to Normalization than a caricature of medicalization and state control?

Coda

"The recent enthusiasm for social capital," says one discussion vis-à-vis a resurgent popularity in the work of Durkheim, "Is an example of a theory whose rhetoric is often more liberating than its application" (Kishner & Sterk, 2005, p. 1142). Social cohesion paradigms tempt policy makers and research workers because its terms appear to render the desirable mechanisms of community transparent. While these tools may be useful in some cases making visible certain

needs or desires, they run always the risk of imposing a form, or rendering invisible and unaddressed that which fails forms where personhood is accounted through universals of good or bad, black or white, stagnant or developed, included or excluded, valorized or devalued.

Universal models for making social cohesion out of a "DD" population fail not only because the variables of an individual "DD" case are too multiple and contingent to fit into a single mold for making community work, but also because resilient individuals of a population which has come to be defined by its very lack of development will differentially and actively defy disservices received in the name of making through state discipline this absent thing. Another sign is needed; one less ready to point to individual villains, whether "DD," an epistemology, a state, or staff.

Seeing how community services can wind people into ever tighter networks of police, it may be time to let the coils of social cohesion unravel just a bit; to let individuals unravel it in a manner which makes sense to them—whether it is normalization into the ghetto, or rethinking the orders of valued work. Though "DD" is not madness, the wisdom may be the same. "[I]t is this circle that antipsychiatry undertakes to unravel…giving the individual the task and right of taking his madness to the limit, of taking it right to the end, in an experience to which others may contribute, but never in the name of a power conferred on them by their reason or normality" (Foucault, 2006, p. 346). Sociology just as well as human services has been down coils of social coherency many times before. Civilization is not borne of bloodless motion.

> "My consolation and my happiness are to be found in service of all that lives, because the divine essence is the sum total of all life." M. Gandhi (quoted from Peaceful Ruler's journal of daily meditations).

Michael Stephen Glennon, M.Soc., is a Research Master's student at the Universiteit van Amsterdam's International School for Humanities and Social Science. He graduated from this same institution in 2007 with a Master's in Science of Sociology concentrating in social theory and public affairs. His current research is on autistic rights awareness and engages autistic subjectivity as making spaces for cultural translation and becoming exterior to the state apparatus. It focuses specifically on (self)advocacy in virtual ethnographic spaces like Second Life and the 1960s subgenre of social science-fiction as exemplified by the writings of Philip K. Dick. Holding a Bachelor of Fine Arts in poetic composition from the University of Nebraska at Omaha. mglennon24@msn.

References

Bates, P., & Davis, F. A. (2004). Social capital, social inclusion and services for persons with learning disabilities. *Disability & Society, 19*(3), 195-207.

Borgos, S., & Douglas, S. (1996). Community organizing and civic renewal: A view from the South. *Social Policy, 27*(2), 18-28.

Chenoweth, L., & Stehlik, D. (2004). Implications of social capital for the inclusion of people with disabilities and families in community life. *International Journal of Inclusive Education, 8*(1), 59-72.

Crichton, J. (1998). Balancing restriction and freedom in the care of people with intellectual disability. *Journal of Intellectual Disability Research, 42*(2), 189-195.

Croft, S. E. (1999). Creating locales through storytelling: An ethnography of a group home for men with mental retardation. *Western Journal of Communication, 63*(3), 329-347.

Dayton-Johnson, J. (2003). Social capital, social cohesion, community. In L. Osberg (Ed.), *The economic implications of social cohesion.* Toronto: University of Toronto Press.

DeKraai, M. (2002). In the beginning: The first hundred years (1850-1950). In R. L. Schalock (Ed.), *Out of the darkness and into the light: Nebraska's experience with mental retardation* (pp. 103-122). Washington, DC: AAMR.

Deleuze, G., & Guattari, F. (1987). *A thousand plateaus: capitalism and schizophrenia.* London & New York: Continuum.

Duvdevaney, I., Ben-Zur, H., & Ambar, A. (2002). Self-determination and mental retardation: Is there an association with living arrangement and lifestyle satisfaction. *Mental Retardation, 40*(5), 379-389.

Farmakopoulou, N., & Watson, N. (2003). Motivations for entering and pathways of progression of disabled students in further education. *International Journal of Inclusive Education, 7*(3), 223-239.

Foucault, M. (2006). *Psychiatric power: Lectures at the College De France, 1973-1974.* Hampshire: Palgrave Macmillan.

Goodley, D., & Lawthom, R. (2005). Epistemological journeys in participatory action research: Alliances between community psychology and disability studies. *Disability & Society, 20*(2), 135-151.

Hacking, I. (2002). *Historical ontology.* Cambridge, MA & London: Harvard University Press.

Hacking, I. (1998). *Mad travellers.* Cambridge, MA: Harvard University Press.

Healy, E. (2007). Ethnic diversity and social cohesion in Melbourne. *People and Place, 15*(4), 49-64.

Kishner, H. I., & Sterk, C. E. (2005). The limits of social capital: Durkheim, suicide, and social cohesion. *American Journal of Public Health, 95*(7), 1139-1143.

Lasch, C. (1991). *The true and only heaven.* New York & London: W.W. Norton & Company.

Levinson, J. (2005). The group home workplace and the work of know-how. *Human Studies, 28*, 57-85.

MacEachen, E., & Munby, H. (1996). Developmentally disabled adults in community living: The significance of personal control. *Qualitative Health Research, 6*(1), 71-89.

Oliver, M. (1990). *The politics of disablement.* Basingstoke: MacMillan and St. Martin's Press.

Partington, K. (2005). What do we mean by our community? *Journal of Intellectual Disabilities, 9*(3), 241-251.

Pavey, B. (2006). Human capital, social capital, entrepreneurship and disability: An examination of some current educational trends in the UK. *Disability & Society, 21*(3), 217-229.

Potts, B. (2005). Disability and employment: Considering the importance of social capital. *Journal of Rehabilitation, 71*(3), 20-25.

Schalock, R. L. (2002). *Out of the darkness and into the light: Nebraska's experience with mental retardation.* Washington, DC: American Association on Mental Retardation.

Sharon, J. M. (2003). Singing alone? The contributon of cultural capital to social cohesion and sustainability. *International Journal of Cultural Policy, 9*(1), 35-49.

Terry, L. (Director). (1968). *Out of the darkness and into the light. A TV expose of Nebraska Beatrice State Home* [Motion Picture]. United States.

Trent, J. W. (1994). *Inventing the feeble mind: A history of mental retardation in the United States.* Berkeley: University of California Press.

Ward, A. C., & Baker, P. M. A. (2005). Disabilities and impairments: Strategies for workplace integration. *Behavioral Science and the Law, 23*, 143-160.

Endnotes

[1] Merciful Black and Zero President are pseudonyms.
[2] Peaceful Warrior is a pseudonym.

Socially Equitable Community Planning: Including Individuals with Disabilities in the Democratic Association of Place

Keith M. Christensen, MLA
Utah State University

Abstract: Individuals with disabilities need opportunities for socially equitable association, where interactions are not premised on relational social qualifications, to realize community membership. Communities of location, defined by "place" rather than "people," are a mechanism to avoid and an avenue to address the relational boundaries of communities of organization and culture for individuals with disabilities. The democratic associations of place supported by communities of location may be a significant factor in individuals with disabilities gaining membership in other types of social communities and being equal members of the community.

Key Words: equality, community, planning

People naturally come together in communities. Communities are social organizations that facilitate coordination and cooperation for mutual benefit (Putnam, 1993). These benefits are diverse but generally include security, economy, and affiliation. In particular, a strong affiliation to a community may lead to a greater sense of purpose and perceived control in dealing with an external threat (Bachrach & Zautra, 1985).

Communities are fostered through networks of organizations (e.g., family or political affiliation), culture or identity (e.g., ethnic group, disability), and location (e.g., neighborhood or region). Individuals are generally members of multiple communities, both temporarily and permanently, as a function of their perceived commonalities. Communities of organization or culture are considered to be "relational" or concerned with how similar or different an individual is to another, a sense of personal relatedness (McMillan & Chavis, 1986).

Communities of location, on the other hand, are geographically defined or defined by "place," not by people. As relational and place-based community identities are not fundamentally competitive, communities of location are often nested with or within communities of organization or culture (Tropman, Erlich, & Rothman, 2006). Indeed, a community of location may support a stronger sense of community within organization or culture (e.g., Utah Democrats, an ethnic neighborhood such as "Chinatown," or the "projects"). In addition, communities of location often cross communities of organizations or cultures. For example, residents of a neighborhood may be ethnically diverse but identify themselves as from "the neighborhood" and work closely with one another to protect the integrity of their neighborhood from a threat such as a proposed highway, big box store, or natural disaster.

The propensity of communities of location to support and cross communities of organization or culture is due in part to the difference in boundaries. All communities have membership boundaries which define who is in and who is out (McMillan & Chavis, 1986). These boundaries provide community members who are "in" with the emotional safety necessary to develop social connections (Thibaut & Kelley, 1986). As alluded to previously, the boundaries of communities of organization or culture are defined by perceptions of how similar or different individuals are to each other. Communities of organization or culture often identify deviants, individuals who depart markedly from the perceived norm, to establish strong boundaries (McMillan & Chavis, 1986). This process may be psychologically harmful for those who are so identified.

Communities of location, however, are defined not by the relatedness of the individuals but by perceived differences in places. These differences may be distinct (e.g., architectural style or natural feature) or often subtle as to be recognizable only by the residents themselves (e.g., proximity to a public park or named development). As the boundaries are defined by differences external to the individuals, defining community membership by place rather than individuals' inherent characteristics has fewer negative social affects. Further, membership in a community of location also carries very strong social role and value messages (Wolfensberger, 2000). The messages conveyed by socially valued environments have a significantly positive effect by alleviating perceived relational differences between individuals (Allen, 1997). For example, living in the "Oaks," an aesthetically pleasant upper income residential family neighborhood, carries socially valued messages. Whereas, living in the "projects" carries a socially devalued message.

Communities of location are particularly valuable for individuals with disabilities. For individuals with disabilities, social integration means, in part, increasing identification with groups not defined by disability (Ware, Hopper, Tugenberg, Dickey, & Fisher, 2007). Membership in a community of location is a mechanism to avoid, and an avenue to address, the relational boundaries of communities of organization and culture for individuals with disabilities. However, while numerous efforts have been made to facilitate individuals with disabilities living independently in the general community, comparatively little focus has been paid to understanding the communities of location which exist within the general community. Thus, even though many individuals with disabilities are now located physically within the general community, they may often still not be socially a part of their community (Ware, Hopper, Tugenberg, Dickey, & Fisher, 2007; Salzberg & Langford, 1981; Meyers, Ager, Kerr, & Myles, 1998).

When not carefully addressed, the qualities of communities of location that are especially valuable for individuals with disabilities are also those which may contribute to individuals with disabilities being "in the community, but not of it" (Ware, Hopper, Tugenberg, Dickey, & Fisher, 2007). Highly defined communities of location, which carry socially valued messages, are naturally less welcoming and tolerant toward perceived disruptions to the community definition, such as supported housing for individuals with disabilities. Opposition is typically concerned with perceived threats to property values, personal security, and neighborhood quality (Dear, 1992). These reflect members concerns for the emotional safety derived from membership in the community, and the capacity of the neighborhood to maintain those qualities by which the community is defined and perpetuated. In response to this opposition, individuals with disabilities and their advocates have tended to adopt avoidance strategies, seeking places of less resistance (Bostock & Gleeson, 2004). These "places of least resistance" are frequently either highly defined communities of location that carry socially devalued messages (e.g., low-income or declining neighborhoods) or places with less defined communities of location (e.g., residential sprawl). Either is detrimental to the social integration of individuals with disabilities.

If individuals with disabilities are to benefit from membership in communities of location, these places of greater resistance, carrying socially valued messages, should not be avoided but carefully sought. An initial disruption, evidenced by some opposition, initiates a process where the social sense of community is maintained but not without accepting the membership of individuals with disabilities (Wilton, 1998). Prolonged proximity challenges peoples' perceptions of their personal relatedness with others (Dear, Wilton, Gaber, Takahashi, 1997).

However, to be successful this process must be thoughtfully undertaken based on an understanding of how communities of location de-

velop. Some communities of location naturally develop over time as peoples' perception of the place becomes endowed with meaning through experience. Natural features, continuous development patterns, and local establishments may serve as a sustaining catalyst for this "sense of place." These places are identifiable by, and identified with, the "locals" who are members of a particularly strong community of location. This shared experience with a place supports democratic association, or interactions, which are not premised on relational social qualifications (Oldenburg & Brissett, 1980).

Other communities of location are developed through careful planning of the environment by professionals in the planning fields. The goal of planning professionals is the creation of communities where sharing, bonding, and learning can occur in a safe yet stimulating environment (Lynch & Hack, 1984). Often these efforts are intended to create the same catalysts, which sustain historic communities of location. The community planner will plan for opportunities to share experiences by providing places that support purposeful behavior and affiliation (e.g., the neighborhood pub, skatepark, community center, or playground). Further, the community planner will plan environments that support social mobility, or places with opportunities to expand social boundaries through democratic associations (e.g., parks, pedestrian-friendly streets, residential neighborhoods with a mix of housing types, or a community gathering place). Ideally, to support democratic associations these places must equitably assess the costs in individual expenditures of time, resources, and energy necessary for social participation for each participant. Particularly for individuals with disabilities, the cost of social participation is often not equitably assessed by the environment (Hahn, 1985).

Historically, community planning efforts pertaining to equality focused on race, ethnicity, and economic issues. Issues with respect to individuals with disabilities were undertaken as a subsidiary aspect of community health and not necessarily a matter of equality (So & Getzels, 1988). This emphasis leads to practices where the needs of individuals with disabilities are addressed during the detail design and construction processes (e.g. curb-cuts or sidewalk widths) as reasonable accommodations. Under reasonable accommodation the intent, at least in practice, is to minimize the costs in time, resources, and energy to provide a minimal level of access for individuals with disabilities. Whether the level of access is considered reasonable is generally determined by the cost, resulting in a proportional system of separate but equal. In essence, some of the capital costs for development are transferred as social costs to the individual with a disability. This practice creates situations where it is disproportionately expensive socially for individuals with disabilities to participate in the democratic associations of communities of location. Such planning practices are untenable in terms of equality of access where the intent is to equitably assess the cost in individual expenditures of time, resources, and energy to participate in the community. Fairness in the planning process requires that steps be taken to redress the imbalance (So & Getzels, 1988) so the social cost is equal to the expenditure of other individuals. However, only relatively recently has the planning profession begun to more widely recognize and address individuals with disabilities in terms of social equality.

To include individuals with disabilities as equal members of the community, this shift must continue. An important step toward socially equitable community planning practices is the inclusion of individuals with disabilities in the process at the policy level.

In addition to advocating for a continued shift toward socially equitable planning practices, which include individuals with disabilities, both individuals with disabilities and advocates need to give greater attention to communities of location. While often taken for granted, communities of location are especially important for

individuals with disabilities to be equal members of the community. Membership in the community does not result from merely being present in the physical community. Physical exposure is a necessary but not a sufficient condition to create a sense of community, and may instead create a sense of alienation (Cummins & Lau, 2003). Great care must be taken to recognize the various communities of location and the places, which support them.

For example, is the neighborhood primarily defined by place (e.g., the "woods" or the "cottages") or is the neighborhood defined primarily by the homogeneous characteristics of the residents (e.g., the wealthy neighborhood)? The latter is a community of identity where democratic association is unlikely to occur. Is the available housing for individuals with disabilities located in areas of residential "sprawl," which are characterized by undifferentiated housing without a sense of neighborhood or community? Is the neighborhood hangout, where democratic association takes place, physically accessible without significant effort on the part of the individual with disabilities? Are the places where individuals with disabilities are employed found within the general community's employment places? Are the organizations that provide services for individuals with disabilities found with the organizations that provide services for community members in general?

Recognizing and understanding the communities of location that exist in the physical community is complex. There are ample opportunities for greater advocacy, research, and emphasis in the disability and planning fields. The democratic associations of place, which support communities of location, may be a significant factor in individuals with disabilities gaining membership in other types of social communities and being equal members of the community. Not only does familiarity tend to increase acceptance, but connectedness with members through one community may facilitate acceptance in additional communities through shared affiliations. Indeed, for individuals with disabilities to realize community membership, there needs to be opportunities for socially equitable democratic association. For individuals with disabilities, the benefits of the democratic association of place through communities of location may be significant and should not be taken for granted.

Keith Christensen, MLA, is an assistant professor in the Department of Landscape Architecture and Environmental Planning, and a senior research scientist with the Center for Persons with Disabilities, at Utah State University. Keith's research emphasizes the planning and design of socially inclusive environments.

Acknowledgements

References

Allen, C. (1997). The policy and implementation of the housing role in community care - a constructionist theoretical perspective. *Housing Studies 12*(1), 85-111.

Bachrach, K. M., & Zautra, A. J. (1985). Coping with a community stressor: The threat of a hazardous waste facility. *Journal of Health and Social Behavior, 26*, 127-141.

Bostock, L., & Gleeson, B. (2004). Contested housing landscapes? Social inclusion, deinstitutionalization and housing policy in Australia. *Australian Journal of Social Issues, 39*(1), 41-62.

Cummins, R. A., & Lau, A. L. D. (2003). Community integration or community exposure? A review and discussion in relation to people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 16,* 145-157.

Dear, M. (1992). Understanding and overcoming the NIMBY syndrome. *Journal of the American Planning Association, 58*(3), 288-301.

Dear, M., Wilton R., Gaber S. L., & Takahashi, L. (1997). Seeing people differently: the sociospatial construction of disability. *Environment and Planning D: Society and Space, 15*(4), 455-480.

Hahn, H. (1985). Disability policy and the problem of discrimination. *American Behavioral Scientist, (28)*3, 293-318.

Lynch, K., & Hack, G. (1984). *Site planning.* MIT Press: Cambridge, MA.

McMillan, D. W., & Chavis, D. M. (1986). Sense of community: A definition and theory. *American Journal of Community Psychology, 14*(1), 6-23.

Meyers, F., Ager, A., Kerr, P., & Myles, S. (1998). Outside looking in? Studies of the community integration of people with learning disabilities. *Disability and Society, 13,* 389-413.

Oldenburg, R., & Brissett, D. (1980). The essential hangout. *Psychology Today*, pp. 82-84.

Putnam, R. D. (1993). The prosperous community: Social capital and public life. *The American Prospect 4*(13), 35-42.

Salzberg, C. L., & Langford, C. A. (1981). Community integration of mentally retarded adults through leisure activity. *Mental Retardation, 19*, 127-131.

So, F. S., & Getzels, J. (1988). *The practice of local government planning.* Washington, DC: . International City/County Management Association (ICMA).

Thibaut, J., & Kelley, H. (1986). *The social psychology of groups.* New York: Wiley.

Tropman, J. E., Erlich, J. L., & Rothman, J. (2006). *Tactics and techniques of community intervention.* Itasca, IL: F. E. Peacock Publishers, Inc.

Ware, N. C., Hopper, K., Tugenberg, T., Dickey, B., & Fisher, D. (2007). Connectedness and citizenship: Redefining social integration. *Psychiatric Services, 58*(4), 469-474.

Wilton, R. D. (1998). The constitution of difference: Space and psyche in landscapes of exclusion. *Geoforum, 29*(2), 173-185.

Wolfensberger, W. (2000). A brief overview of social role valorization. *Mental Retardation, 38*(2), 105-123.

Appropriateness and Consciousness in Community Based Rehabilitation through Participatory Action Research

Tavee Cheausuwantavee, Ph.D.
Mahidol University, Thailand

Abstract: Community-based rehabilitation (CBR) in Phuttamonthon District, Nakhonpathom Province, one of the metropolitan areas located in central Thailand, was examined in terms of factors influencing existence of CBR and movement of CBR participants through Participatory Action Research (PAR). The results showed some factors and consciousness or intentionality within the CBR phenomena, which could effect the sustainability of CBR. Thus, WHO's concept of CBR may be redefined: CBR is not only a static strategy but also dynamic consciousness within a community.

Key Words: Thailand, community-based rehabilitation, consciousness

Introduction

The main problems of persons with disabilities (PWDs) in rural areas, particularly in developing countries and the Third World, are limitations of resources and available rehabilitation services. Community based rehabilitation (CBR) has been introduced as a possible approach to increase the coverage of services in these countries, to address not only the need of governments with limited resources, but also the needs for equalization of opportunity for PWDs (ILO, UNESCO,UNICEF, WHO, 2002; Thomas and Thomas, 1999). Ideally, the core concepts of CBR are in the following assumptions: (1) PWDs are empowered to maximize their physical and mental abilities through self-awareness and promotion of human rights; (2) cooperative efforts or collectivity among PWDs and their communities are crucial for providing them resources and opportunities; and (3) the "insiders' or all members of the community have to be responsible for running and maintaining their CBR projects.

Although CBR as an ideal concept has been explicitly declared and implemented since 1994 by the WHO (1994) and other international agencies, there have been some problems and controversies occurring in CBR as the standard practice. Focusing on Thailand, lack of financial supports for CBR projects, lack of knowledge and skills by CBR workers, and negative attitudes toward PWDs by communities as well as a lack of the community participation, have been the main problems for CBR sustainability (Tawornkit, 1995; Sasad, 1998; Souysuwan, 2000; Cheasuwantavee, 2005). Furthermore, CBR projects are usually run by international NGOs (Non-government Organizations), GOs (Government Organizations, and researchers who are outsiders to such communities. Thus, the implication is that the concerns and participation of community members with their own perspectives and experiences are crucial indicators for the effectiveness and sustainability of CBR. In the meanwhile, there are no other studies to comprehensively examine community concerns and participation. The study of the movement of community members for establishment of CBR needs to be conducted in terms of both process and outcome, including the development of participation, assessment and diagnosis of problems, and active planning for problem solving.

Therefore, participatory action research (PAR) was conducted in order to challenge PWDs and other community members to actively examine together the features of the existing community context and any assistance resources for persons with disabilities (PWDs), in order to modify and improve them. The results of this study may help us expand our perspectives on CBR with definitions different from the traditional WHO concept. Additionally,

because it has illustrated CBR through community insiders with their own experiences and perspectives, transformative and emancipatory learning (Freire, 1970; Mezirow et al., 1990) will be provided both to these particular CBR participants and to individuals who will be involved in CBR in the future.

In short, the objectives of this study are to provide PWDs, community members and stakeholders in the community an opportunity to critically examine: 1) The features of an existing community context in terms of supports or rehabilitation services for PWDs and the movement of some of the community members for establishment of their own CBR, 2) The factors influencing the success or failure of CBR, 3) The features of an appropriate master plan of CBR within this particular context, and 4) the consciousness or intentionality of CBR participants/workers for being a CBR as such.

Methods

Research Design

This study chronicles participatory action research (PAR) conducted in Puttamonthon District, Nakhonpathom Province, Thailand. PAR is ideally conducted by local people or community members. It is designed to address specific local issues and results are directly applied to the problems at hand (Aimers, 1999; Wikipedia Foundation, 2008). For this study, PAR is divided into four steps as follows: 1) developing a basis for participation, 2) data collection and analysis, 3) planning, and 4) action and evaluation (Figure 1). In the beginning phase or first step, the researcher was a leader. In the second through fourth steps, the researcher became a facilitator.

Participants

The 15 participants were volunteers, invited to join the CBR project supported by the Thai Research Fund (TRF). Hence, they were select-

Figure 1: Steps of Participatory Action Research (PAR) on CBR
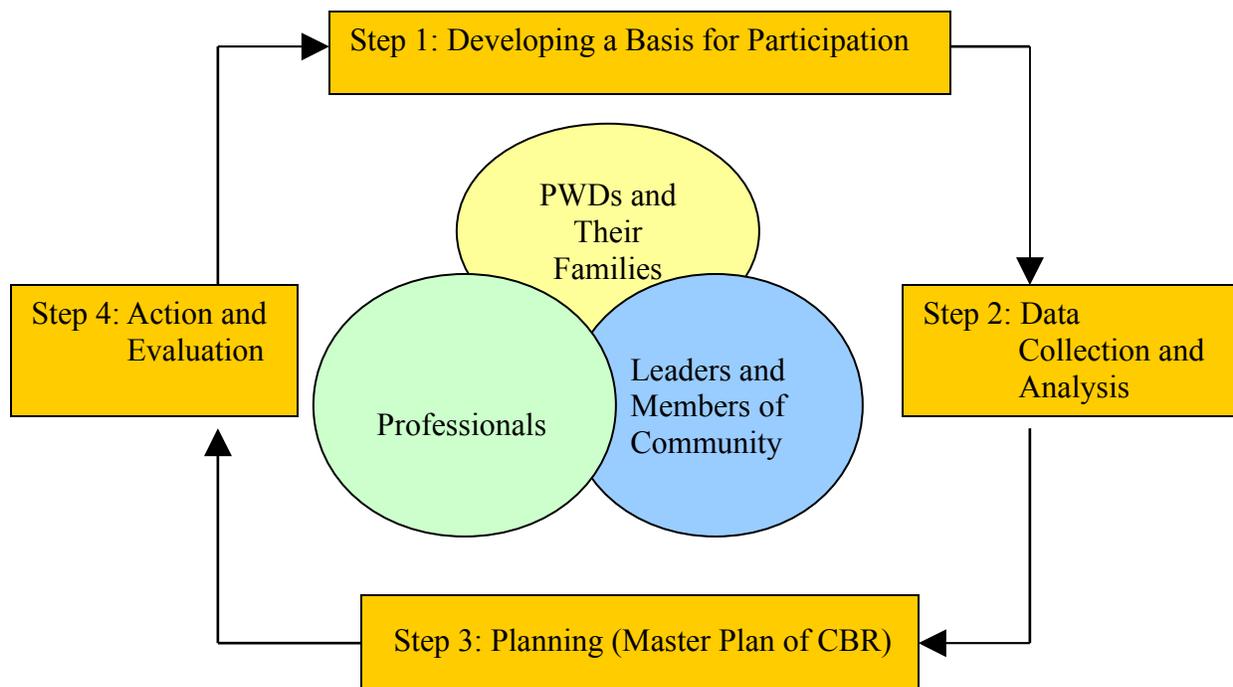
Adapted from Aimers (1999)

54

ed through purposive and criterion sampling as sectors and roles for development and implementation of CBR as suggested by one of the UN bodies, the Economic and Social Commission for Asia and the Pacific or ESCAP (1997). Those participants were 4 PWDs, 4 neighbors or community members, 3 community leaders, and 4 professionals including a nurse, a teacher, a researcher and a secretary of the CBR project (Table 1).

Instruments

Due to the nature of PAR itself, a researcher is a crucial instrument for participatory action, participatory observation and interpretation. However, tape recordings of the participant meetings and discussions, researcher guidelines for in-depth interviews, and field notes were also used for gathering data.

Data Analysis

Quantitative analysis such as frequency and percentage, as well as qualitative analysis in the typology and interpretation for constructing a coding frame and meaning, were conducted on the transcriptions. In terms of qualitative analysis, all transcriptions from participant meetings and discussions, in-depth interviews and field notes were paraphrased and then were reduced related to theoretical concepts or key words such as stigma, empowerment, collectivism, etc. For this step, transcriptions, paraphrases and theoretical concepts/key words were categorized in column 1,2,3 respectively. After that, the data was decoded by their relations, coherences, similarity and dissimilarity in to meaning, consciousness and story.

Results

The Features of Community Context, the Existing Rehabilitation Services for PWDs and the Movement of CBR Participants

Puttamonthon District is located in Nakhonpathom Province, in central Thailand. The population is about 24,000, most of whom are involved in agriculture. As its metropolitan area is about 18 kilometers from Bangkok, the capital, it has been influenced by industrialization and modernization. In particular, there are many well-known governmental and non-governmental organizations in Thailand located in this community, such as Mahidol University, Mahidol Witayanusorn for excellent science students, the Training Center for Delinquent Youth, the School for Occupational Training and the Kantana Movie Studio. However, both the general population and PWDs in this community tend to be neglected and unable to access the services of organizations. There were no empirical clues or documents confirming that PWDs in this area were provided rehabilitation services.

Fortunately, in 1997, an outreach or mobile clinic for registration and health care services for PWDs in Phuttamonthon community was provided in cooperation with the provincial disabled people's club and the Department of Provincial Public Assistance of Nakhonpathom Province. This was an essential turning point for rehabilitation services, a transformation from traditional services provided by only governmental organizations and professionals to collaborative services provided by both governmental organization (GO) and the disabled people's organization (DPO). Then, in 1997-1999, researchers and colleagues at Ratchasuda College - one of the faculties of Mahidol University providing disability and rehabilitation study and research - conducted projects to deliver counseling services and basic supports for PWDs and their families as "an outreach."

In 2000, this project developed within the framework of the CBR approach, by having some participants from the community become more involved. This included PWDs, community leaders and a local nurse. Although this project tended to be CBR in approach with some evidence showing greater contributions in terms of early detection, registration, and enhanced quality of life of PWDs, as well as promoting positive societal attitudes toward PWDs, there

were at least three obstacles to CBR. First, the CBR project was mainly run by a researcher and colleagues who were community outsiders. Thus, it could not be launched after the withdrawal of a researcher or an author. Second, needs assessment, problem diagnosis and problem solutions were explicitly proposed from a researcher perspective rather than by PWDs and community members. Third, there were no additional concerns, participation, or sharing of budgets and resources from the majority of the community and local government. These obstacles were quite influential on the development and sustainability for CBR at that time.

Preliminary data illustrated that CBR sustainability was heavily dependent upon participation and awareness of PWDs and other individuals in the community. Thus, understanding and learning according to their own perspectives, values, beliefs and direct experiences regarding disability, rehabilitation and CBR needed to be promoted.

In 2004, the role of the researcher gradually shifted from instructor and leader to a facilitator and partner. A learning process began as participatory action research (PAR) was conducted. PAR consisted of 4 steps including: (a) developing a basis for participation, (b) data collection and analysis, (c) planning, and (d) action and evaluation.

The first step was developing a basis for participation. The researcher had visited, established a relationship and shared ideas with people in the community including PWDs and their families, neighbors, and members and leaders of the community for promoting awareness about the problems of PWDs. The researcher also searched for the potential participants, set up a working group, then studied available data, formulated the research question, wrote a proposal together with those participants and submitted this to the Thai Research Fund (TRF).

At the end of the first step, there were 15 participants in this working group including 4

PWDs, 4 neighbors or community members, 3 community leaders, 4 professionals, namely a nurse, a teacher, a researcher as well as a secretary of this project. Of the 15 participants, 9 were male (60%), with a mean age of 48.2 years, 11 were community members and leaders as insiders (73%), and 8 graduated under grade 12 or less than a high school education (53%) (Table 1).

The second step was data collection and analysis. One year later, in 2005, our proposal was considered and received funding from TRF, we - the working group and researcher - became the CBR participants that engaged ourselves and other community members in a variety of activities for direct experience and data collection. The problems and needs of the majority of PWDs and their families in the community were assessed by field visits, interviews, public hearings and study from other available secondary data. CBR participants also had weekly meetings for critical discussion, mutual sharing and analyzing data together. At the end of the second step, the problems and needs of PWDs and their families were identified according to priority and need in order of greater to lesser concerns by CBR participants and community members with their own perspectives with regard to the following issues: 1) medical rehabilitation, 2) occupational rehabilitation, 3) educational rehabilitation, 4) accommodations and sanitation system, 5) inclusion and 6) citizenship and political rights.

The third step was planning. Eventually, a master plan including appropriate solutions corresponding to the six problems articulated above as well as to the needs of PWDs in the community was mutually established by CBR participants and other stakeholders. In addition, it included six areas for enhancement of quality of life of all PWDs in the community. It was disseminated to the local governments, namely to the sub-district administrative organizations (SAOs) and other agencies that had been involved in CBR.

Table 1. Characteristics of CBR Participants

No.	Assumed Name	Gender	Age (Years)	Address (District)	Occupation/ Position	Education	Others
1.	Somsak	Male	66	Phuttamonthon	Retirement (Official)	Diploma	CM
2.	Anan	Male	58	Phuttamonthon	Retirement	Grade 12	CM
3.	Path	Male	73	Phuttamonthon	Retirement	Grade 4	CM
4.	Wanna	Female	68	Phuttamonthon	Retirement	Grade 9	CM
5.	Sutin	Male	55	Phuttamonthon	Head of Village	Grade 4	CL
6.	Chalong	Male	66	Phuttamonthon	Deputy Head of Village	Grade 4	CL
7.	Sopa	Female	39	Phuttamonthon	Deputy Head of SAO	Master Degree	CL
8.	Wipa	Female	48	Phuttmonthon	Unemployment	Grade 10	PWDs/CM (Arthritis)
9	Preumjit	Female	39	Phuttmonthon	Unemployment	Grade 9	PWDs/CM (Clubfoot)
10.	Pana	Male	35	Phuttmonthon	Unemployment	Grade 9	PWDs/CM (Head injury and Partial Paralysis)
11.	Saksun	Male	32	Phuttmonthon	Unemployment	Grade 9	PWDs/CM (Spinal Cord Injury and Quadripegia)
12.	Sum	Male	43	Phuttmonthon	Teacher of Informal School of Phuttamonton	Bachelor Degree	P
13.	Sopita	Female	38	Sampran	Nurse of Public Hospital of Phuttamonthon	Bachelor Degree	P
14.	Nid	Female	24	Sampran	Research Assistant	Bachelor Degree	P
15.	Tavee	Male	39	Thaweewatana	Professor/ Researcher	Doctoral Degree	P

Key: CM = Community member, CL = Community leader, SAO = Sub-district administrative

The fourth step was action and evaluation. The master plan was implemented and evaluated by CBR participants and community stakeholders in order to develop a better, more appropriate approach in the next cycle. However, due to time constraints (sixteen months) and the funding level from TRF, this step could not be fully monitored and data was not fully collected.

The Factors Influencing the Success and Failure of CBR

During the 16 months of CBR conducted through PAR, we provided 15 field visits, in-depth interviews with over 50 PWDs and their families in the community, and 2 public hearings among PWDs, families, community members, leaders and professionals in the local area. There were over 179 PWDs identified and registered by CBR participants. The six problems and needs of PWDs in the community were critically identified and reasonably ordered for establishing comprehensive solutions within a master plan by the 15 CBR participants and other community members as revealed earlier.

Drawing upon the knowledge and experience of CBR participants, the four explicit positive aspects regarded as factors influencing the success and contributions of CBR were also reflected in the team's own perspectives. First, CBR was considered a transformative learning or consciousness raising of CBR participants. Second, CBR was an example of collectivity and social justice. Third, CBR participants who lived in this community perceived the CBR researcher as a partner and ally rather than as a suspicious outsider and protagonist. Fourth, strong cohesion and relationships have formed among CBR participants. Although we had to deal with many obstacles, we have still maintained bonds and networks. These rich relationships constitute social capital that has been established not only within the CBR context, but also through life histories within the community context. For instance, "Somsak" (assumed name) - a community member who was one of the CBR participants - has been a folk healer taking care of many children and adults in this community for about forty years. In addition, most of the CBR participants who were neighbors or community members were friends and relations as well as from the same family. Therefore, social capital as community cohesion and relationships were still a positive factor which provided deep-rooted support for the disability rights movement and rehabilitation services including CBR within this community, which have not been highlighted in the extant mainstream discourse.

By contrast, there were also three explicit negative aspects - factors threatening the success of CBR. First, stigma and negative attitudes of the majority of people in the community toward PWDs were manifested. These dehumanizing community values were displayed through a variety of expressions and actions including ignorance, neglect and oppression of families, disregard of the welfare of PWDs by community leaders and lack of broader participation in CBR by community members.

Second, the CBR participants as well as the community members not only lacked knowledge and skills regarding CBR and disabilities, but also were uncertain about their abilities to run a CBR project themselves. Because CBR has been an approach transforming the paradigm from a medical model to a social model that requires more responsibilities from the community in participation, planning, intervention and program management, it has generated a large number of burdens upon the community. Additionally, there is complexity of the power structures and the hierarchy of social class within the community. Disability issues and CBR were classified as the last priority of local policies.

Third, CBR was difficult to advance without financial supports. TFR was the principal support for this project, but it did not cover the wages of CBR participants. Having CBR workers continuously deliver services for PWDs in the community was important for the project to be effective. Besides our small team of 15 CBR

participants, no one else participated in the project, despite the researcher and other participants trying to convince community members to join the project throughout its sixteen-month research period. The main reason was that there were no benefits for CBR participants while other jobs could provide workers salaries and money to address their personal interests and sustenance. Thus, it is implied that capitalism in the form of individual vested interest has influenced not only the mainstream society, but also the Puttamonthon District. In short, CBR will really be sustained only by cooperation of the stakeholders rather than volunteers who devote themselves without any benefits.

The Features of an Appropriate Master Plan of CBR Within this Particular Context

According to the particular problems and needs of PWDs and their families as well as factors influencing the success and failure of CBR, in the second step of PAR, perspectives were critically identified through direct experiences among stakeholders, not only from CBR participants but also from community leaders and members with their own perspectives. Data collection and analysis including 15 field visits, in-depth interviews with over 50 PWDs and their families in the community, and 2 public hearings among participants were undertaken. Therefore, in the third step, "An appropriate master plan of rehabilitation services and development for PWDs in Phuttamonthon District" was mutually established by those participants. This master plan simply consisted of the six strategies corresponding to the crucial problems and needs of PWDs as well as the factors which were previously identified and ranked from greater to lesser concerns by community members with their own perspectives as follows: (1) the promotion of health and mental health, (2) the promotion of economic security and income, (3) the promotion of education, (4) the promotion of barrier-free environment and social integration, (5) the promotion of positive attitudes toward PWDs, and (6) the promotion of human and political rights, respectively.

The Basis of Consciousness Among the CBR Participants/Workers for CBR

Within the CBR phenomenon, there was not only a "static product" as the master plan established, but also a "dynamic process" presented as consciousness raising and meaning construction by the CBR participants. Some kinds of consciousness have tended to be internally driven or rooted in explicit support for a variety of movements and actions. The following examples are evidence which supports such assumptions.

Consciousness of Empowerment

Much of what we have gained through CBR has been a transformative learning or consciousness raising both for the population at large and for PWDs involved in CBR. Cooperative work among various sectors and those having a variety of roles among the CBR participants, particularly PWDs and other people, helped to expand more positive attitudes and learning from each other as well. Stigma or labeling values toward PWDs were shifted to empowerment perspectives.

"Pruemjit"(assumed name), one of CBR the participants and a women with a congenital physical impairment, said that:

> " I had never thought I was OK because I have been a PWD myself. After I joined this project, I see other PWDs…they are worse than me. I think that I have to help them. When I see and visit them, I realize how I should help them to have opportunities to go and live in society not only in their houses but also…outside. I usually talk to and encourage other people, other agencies to visit and help them."

"Somsak," a CBR participant and community member, also reflected his awareness and experience when he had to invite PWDs and

their families to participate in a public hearing held by CBR participants:

> " …I told them [PWDs] that they have to present themselves to the society, don't close themselves or only stay at home because I have known one PWD who lives in another village; he is a leader of a sub-district organization (local government). I showed them… he was a good role model, PWDs could be elected and become politicians. I encouraged them to join our meeting. I believe that this meeting will help them to have more opportunities in society."

Consciousness of Collectivity

CBR was also manifested as collectivity and social justice. The public consciousness and awareness of the group interest of individuals involved in CBR supported it as a social movement. "Chalong" (assumed name), a CBR participant and a community member, reflected his perspective on these issues as follows:

> "I feel in my mind…nobody can help her (a girl with severe cerebral palsy in community) except her grandfather. I realize that it is questionable how she would be able to survive if her grandfather died. These are our concerns. PWDs are so pitiful."

The collective and public consciousness also tended to be rooted in empathy, compassion philanthropy, and religion, particularly the Buddhist principle of karma. "Anan" (assumed name), a CBR participant and community member, reflected that:

> "As human being, I believe that …whenever we are ill, money can only help us to go a hospital…whenever we die, our families can only help us go to a grave. The existing and long lasting things are only the goodness and the merit that we made. Thus, the purpose of my participation in this CBR is to perform the good-

ness or the merit that will support and help me to be happy and healthy in my next birth."

Consciousness of Broadened Minds

Ideally, CBR has been proposed as an appropriate approach in developing countries which have limited resources. However, this movement tends to be the product of the efforts of international organizations such as the UN and its constitutive bodies such as the WHO, ILO and UNESCAP. It is usually also run by NGOs and professionals who are community outsiders. This tacitly implies that CBR is a discourse, a foreign kind of knowledge that may be easily rejected by community insiders.

The efficacy and integrity of CBR was challenged by this community. The community had many questions about the effectiveness and success rate of CBR, as well as the personal stance of and hidden benefits to the researcher as an outsider. Fortunately, these initial suspicions have gradually become mutual understandings. However, the researcher and CBR participants needed to have additional discussions and reflections in several of our "public sphere" meetings. Ultimately, CBR participants who lived in the community perceived the CBR approach and researcher as a partnership and an alliance rather than as a suspicious form of knowledge and hostility. "Somsak" reflected upon his argument in favor of allowing a researcher to run the CBR project as a partnership and an alliance:

> "At first, my friends warned me that I might be deceived by Tavee [a researcher] only into helping him to achieve his academic work and then withdrawing himself from the project. But I don't care whether I will really be deceived or whether CBR will be a success. I only know that Tavee and this project helped me to learn and experience more about PWDs. My friends and I were both encouraged to learn and more bewared of the suffering of PWDs than I have ever

known and realized before, although I have lived here over sixty years. This valuable information and his contribution are much more than enough for me and our community to have any [suspicious] questions…I think."

Discussion

Having a sense of social movement and consciousness of collectivity within the CBR phenomena in Phuttamonthon District, implies that civil society exists there. CBR as a manifestation of civil society also has roots in the communitarian ideal and the utopianism that emphasizes group interest, cooperation and interdependence (Kamenka, 1982). Although of course, a utopian society has never existed, its philosophy is valuable to promoting and advocating harmonious living. The cooperative efforts and mutual relationships among CBR participants including PWDs, community members, leaders and professionals helped them to have more positive understandings and attitudes toward each other. The consciousness of empowerment of PWDs was gradually promoted. Thus CBR became a field of discursive practice in the public sphere for transformative learning and consciousness raising of those involved (Mezirow et al., 1990; Frieze, 1970; Goffman, 1963). CBR itself is a social cohesion approach and an alternative for the establishment of human security and harmonious living within the current stressful world.

Regarding demographic characteristics of CBR participants, particularly persons without disabilities who created civil society and social cohesion, they were generally middle aged or older, with a mean age of 48.2 years. They were mostly of low education and middle class, but with enough basic supports and attainments through their lives to provide a sufficient standard of living; good, healthy, warm and successful families. These demographics may imply that personal fulfillment and the wisdom of individuals accumulated through their lifelong

experience, rather than wealth and extensive formal education, are sufficient for creating collective and public disability consciousness.

Nowadays, rehabilitation services with programs of philanthropy and public assistance have been usually rejected as oppressive and inappropriate. Nevertheless, this study points out that there have been at least two contradictions within CBR, between the WHO's concept and actual practice.

First, its outcome pursues empowerment of PWDs that places emphasis on "individualism," while its process pursues social cohesion that places emphasis on "collectivity." Second, individualism in the pursuit of empowerment places emphasis on civil rights and equality, leading to a social model, while collectivity in the pursuit of public consciousness obviously places emphasis on empathy, compassion and a religious, particularly Buddhist, model, leading to a philanthropic orientation. These discrepancies may indicate to us some arguments for rethinking CBR given the WHO's traditional concept that has been taken for granted for over ten years. On the other hand, an empowerment approach under capitalism has probably not been sufficient to enhance the quality of life for PWDs. The moral and public consciousness of society must also be considered (Cheausuwantavee, 2005). Hence, it may suggest that the values of compassion and philanthropy might appeal to the positive side of human nature to provide, when available, the necessary resources to establish social cohesion and a social safety net. Then social cohesion leads to social justice and resource mobilization rather than to oppression (Iatridis, 1994). The consciousness of broadened minds, of unity and social empowerment (Wiber, 1997; Freire, 1970) should be of greater concern in a CBR approach.

The phases of CBR through PAR - including developing a basis for participation, data collection and analysis, and planning, as well as action and evaluation - might explicitly show

a dynamic and a holistic feature of CBR in contrast to earlier research findings (Sangsorn, 1988, Tawornkit, 1995; Sasad, 1998; Souysuwan, 2000; Cheasuwantavee, 2005). These apparent contradictions, as well as the factors influencing the success or failure of CBR on both an individual and group or a community basis, help us to know that CBR is more difficult to do and understand than indicated in theory, but it is not absolutely impossible that it can be implemented in actual practice. Discursive and hidden meanings of CBR must also be accounted for (Gordon, 1980; Hacking, 2004). In sum, to understand and extend what exists beneath the apparent contradictions of CBR, individuals need to use another lens and look beyond CBR to investigate its covert assumptions.

Based on our experiences stemming from this research, we - the CBR participants - have learned more than we expected from our experiences and about how we should proceed within conditions of mutual sharing, critical reflection and participatory action. Although some problems could not be radically solved, the way we think about them has changed. This experience might be called "transformative learning" or "conscientization" (Mezirow, et al., 1990; Friere, 1970). Additionally, we learned that the essential qualifications of CBR participants/workers are also "C" "B" "R": "Creation" of alternative solutions, "Broadened mind" for accepting individual differences and "Resistance" to the "usual" obstacles. Finally, the new CBR can be defined as *the homogeneity of the diversity of levels of consciousness of the community, in the service of an emancipatory and equal life for powerless and oppressed persons within an unequal daily life world (that I want to highlight and critique).*

Conclusions

We suggest the following:

1. Philanthropic, medical and social models of disability can be integrated into a CBR approach, corresponding to the particular community context.

2. Further studies of the implicit meanings of CBR within particular contexts must be done in order to gain greater understanding and expand the body of knowledge of CBR and disabilities.

Acknowledgement

Tavee Cheausuwantavee, Ph.D., is an assistant professor and director of the Master Degree of Art Program in Rehabilitation Science. He has worked at Ratchasuda College, Mahidol University, Thailand. He graduated with a doctoral degree in Social Administration. His academic work and specialty focus on social welfare and policy, rehabilitation administration, rehabilitation counseling and community based rehabilitation (CBR). He may be contacted at: tavee98@yahoo.com or rstcs@mahidol.ac.th

References

Aimers, J. (1999). Using participatory action research in a local government setting. In I. Hughes (Ed.), *Action research electronic reader*. Australia: The University of Sydney.

Cheausuwantavee, T. (2005). Community based rehabilitation in Thailand: Current situation and development. *Asia Pacific Disability Rehabilitation Journal, 15*(20), 50-66.

Economic and Social Commission for Asia and the Pacific (ESCAP). (1997). *Understanding Community Based Rehabilitation.* Bangkok, Thailand: United Nations.

Freire, P. (1970). *Pedagogy of the oppressed.* New York, NY: The Continuum Publishing Corporation.

Goffman, E. (1963). *Stigma: Note on the management of spoiled identity.* NJ: Prentice-Hall, Inc.

Gordon, C. (Ed). (1980).*Power/ Knowledge: Selected Interviews and Other Writings 1972-1977* by Michel Foucault. Hetfordshire: Harvester Wheatsheaf.

Hacking, I. (2004). Between Michel Foucault and Ervin Goffman: Between discourse in the abstract and face-to-face interaction. *Economy and Society 33*(3), 277-302.

Iatridis, D. (1994). *Social policy: institutional context of social development and human services.* CA: Brooks/ Cole Publishing Company.

ILO, UNESCO, UNICEF, & WHO. (2002). *Community based rehabilitation: CBR with and for people with disabilities.* Draft joint position paper. Geneva: WHO.

Kamenka, E. (Ed.). (1982). *Community as a social ideal.* UK: Edward Arnold Ltd.

Mezirow, J. et al. (1990). *Fostering critical reflection in adulthood: A guide to transformative and emancipatory learning.* San Francisco, CA: Jossey-Bass Inc.

Sasad, A. (1998). *Expectation in community based rehabilitation of physically disabled persons: Case study Bandung District, Udonthani Province.* Unpublished master's thesis, Mahidol University, Thailand.

Souysuwan, K. (2000). *Community based rehabilitation for the blind CBR.* In Council of disabled people organization in Thailand, Center of the 10th special education, Foundation for disabled children. Seminar Report: CBR dream to real. Ubonratchatanee Province, Thailand.

Tawornkit, K. (1995). *Study of knowledge performance regarding CBR and attitudes toward disabled persons of personnel who worked in public social welfare sector.* Unpublished master's thesis, Thammasat University, Thailand.

Thomas, M., & Thomas, J. M. (1999). A Discussion on the relevance of research in the evolution of community based rehabilitation concepts in South Asia. *Saudi Journal of Disability and Rehabilitation, 5*(1), 21-24.

Wikipedia Foundation (2008). *Participatory action research.* Retrieved May 3, 2008, from http://en.wikipedia.org/wiki/Participatory_action_research

Wilber, K. (1997). An integral theory of consciousness. *Journal of Consciousness Studies. 2*, 71-92.

World Health Organization (WHO). (1994). *Community based rehabilitation and the health care referral services: A guide for programme managers.* Geneva, Switzerland.

Illiteracy is Insecurity: Education, Technology and Disability in South Africa

Charles Dube, M. Sc.
University of Fort Hare, South Africa

Forum on Economic Security

Abstract: This treatise argues that illiteracy is insecurity and, in South Africa, education has eluded the majority of disabled people. A technology divide is intensifying the able-disabled divide that has always existed in South Africa, thus creating a "cartel of satraps" that plunges the disabled into marginalization.

Key Words: technology, social cohesion, security

Introduction

In South Africa, access to primary and secondary, let alone higher education among disabled people has remained slim. Disabled students who have managed to enroll at higher education institutions have encountered a number of problems associated with unfavorable social and technological environments. Their disadvantaged position in relation to access to education has had cumulative effects. With limited professional expertise, disabled people have found it very difficult to penetrate the job market, thus plunging them into economic insecurity, with its attendant insecurities such as food insecurity, and health insecurity. It is estimated that more than 80% of South Africa's 2.5 million disabled people are unemployed (Statistics South Africa, 2005). The Commission on Human Security (CHS) defines human security in the following fashion:

> "Human security is concerned with safeguarding and expanding people's vital freedoms. It requires both shielding people from acute threats and empowering people to take charge of their own lives. Needed are integrated policies that focus on people's survival, livelihood and

dignity, during downturns as well as in prosperity" (CHS, 2003, p. iv).

The above definition highlights that human security is multifaceted. In addition to these conventional forms of human security, Gregor Wolbring (2006), founder of the International Centre for Bioethics, Culture and Disability, adds ability security as well as self-identity security.

The over-arching argument of this paper is that illiteracy is insecurity. As is noted by the CHS, education can give people freedom to promote their human security and that of others. It is also education and knowledge that enables disabled people to identify common problems and act in solidarity with others. By making people effectively vocal, education and information can play a significant protective role and can thus further human security. This, however, cannot be achieved without the existence of a clearly defined legislative framework that opens disabled people's access to and use of support services that enhances their social, political and economic position within mainstream society.

Both education and appropriate technology have eluded the majority of disabled people in South Africa. Where technology has been used in higher education institutions as a means of support services to people with disabilities, it has been used within the medical model of disability, with its attendant assumption that disabled persons are objects of professional intervention, a burden for themselves and their families, and dependent on other people's charity. The medical model of disability is a model by which illness or disability is the result of a physical condition, is intrinsic to the individual (it is part of that individual's own body), may reduce the

individual's quality of life, and causes clear disadvantages to the individual. In South African higher education institutions such as technical institutions, technology, however perceived and used (that is, whether within the social model or the medical model of disability), has been least provided to people with disabilities. Issues of targeting in the production and provision of technology have meant that those who are able to pay for the technical services are offered such services. This has created a technology divide between the financially muscular and the financially challenged. Where attempts have been made to provide technology to disabled people, little consultation has been made with them to ascertain their needs.

Closely related to the issue of financial targeting is lip service paid by the government to the practice of higher education transformation to cater for the needs of disabled students. As the paper argues, education transformation is a discourse that has not been turned into full practice. Because of this, South Africa has remained, as C. V. McClain (personal communication, June 14, 2002) points out, "A country of three nations." Not only is it divided along racial lines (that is, between blacks and whites), but also along the ability-disability divide. People with disabilities still face unacceptable social and economic exclusion, with the disabled people being among the poorest of the poor and more likely than able-bodied peers to be uneducated. Thus disabled people have come to constitute the third nation in the sense that the country is already divided along white-black divide, a divide which also determines differential access to socio-politico-economic resources (McCain, personal communication, June 14, 2002).

Against this background, this paper argues that a socially cohesive society becomes necessary. While disabled people's movements in general and disabled students in higher education in particular can unite and fight for inclusion within society, holistic social unity requires that government, civil society organizations, and dis-

abled people's movements understand the need for such unity and collectively strive for a division-free society within education institutions. This is beneficial not only to disabled people, but also to the non-disabled people (Disabled Peoples' International North America and the Caribbean, 2008). The argument is that constructing "special" academic institutions for people with disabilities can intensify stigmatization of this group of people. Where such schools are constructed, for example, among Deaf people, questions relating to the social rather than technical need to do so have to be considered.

In this paper, the future of technology is examined; whether it will be invented with issues of its implications for human security in mind; whether it will increase personal freedom or lock the human being within itself (technology); whether it will become a means to an end or an end in itself; whether it will adapt to the human being or the human being adapt to technology; in a nutshell, whether it will be invented within the medical circles of disability or aligned to the social model and understanding of disability. For instance, this relates to whether a wheelchair is provided to enhance human beings or as a device that is used just as a bicycle is used by non-disabled people.

It is also important to note that while this paper focuses more on educational insecurity than other insecurities, it acknowledges the multifaceted nature of human security and also makes reference to other forms of security. The treatise also simultaneously addresses and proposes the way forward vis-à-vis existing gaps in human security and social cohesion in relation to higher education.

Developing a Person's Security: Illiteracy as Insecurity

Human security entails the removal of depriving contingencies to accessing education. According to the Commission on Human Security (CHS), "Educational deprivations are par-

ticularly serious for human security. Without education, men and especially women are disadvantaged as productive workers, as fathers and mothers, as citizens capable of social change" (CHS, 2003, p.14). From this statement, it emerges that governments have to prioritize education the same way as they do other forms of security such as economic security, environmental security, and national political security.

In South Africa's higher education institutions, broadly defined rights of disabled students to access education as well as support services within educational institutions have not been very helpful to them, especially for the most marginalized black disabled people. A charity-based approach to the provision of education and support services has meant that the rights of disabled people are not clearly defined. This section provides a brief historical and current account of this state of marginalization with the goal of analyzing how this has contributed to the educational insecurity of the majority of disabled people in general and of students in particular.

Racial inequalities between blacks and whites characterized apartheid education in South Africa's 36 public higher education institutions (Howell, 2006). The majority of black disabled people of school-going age were highly insecure in relation to access to both lower and higher education. With increased attempts to democratize (however defined) the country from 1994 onwards, the government focused more on increasing participation of black disadvantaged students in higher education institutions than on disability rights, hence the peripheral status issues of disability rights occupied during this period. Matshedisho (2007) notes this when he says that the path towards disability rights and their relevance for support services for disabled students in South Africa has been overshadowed by struggles against apartheid. He observes that, " While disabled students in some developed countries fought for their rights and access to higher education, South African students were

generally fighting for political rights and access to exclusively white higher education institutions" (Matshedisho, 2007, p. 694). Although he did not specify which students were fighting for political rights, it is almost clear that the majority, if not all, of these were blacks. To date, despite attempts to increase participation of blacks, limited attention has been placed on addressing issues of access and participation for students categorized by the government's National Plan for Higher Education (NPHE) as "non-traditional students," among which are disabled students (Department of Education, 2001a, p. 28).

Because of this exclusion, many disabled people have not been able to access education, with 70% of disabled people of school-going age being estimated to be outside the general education and training system (Office of the Deputy President, 1997). For those who have been able to access higher education, the socio-technological environment has not always welcomed them. Depending on the institution, the provision of support services for the disabled students is between slim and zero. Research carried out by the Department of Education (DoE) (2001), through its Council on Higher Education, revealed that Technical institutions are least positioned to provide support services for disabled students, mainly because they offer career-specific qualifications, which might have prevented disabled people from participating in an already discriminatory recruitment and labor process (DoE, 2001). Those few institutions that have been able to provide support services for disabled students have done so with a medical perception of disability rather than a social one. For instance, within the medical model of disability, wheelchairs are provided to "correct" a "defective" body. This has not helped much in changing the perception of disability in society. As Riddell (1998) notes, while the provision of necessary assistive devices such as a Brailling machine may be necessary for some students, using that technology without understanding "the social context" will not bring about the changes

that are needed (Riddell, 1998, p. 217), namely adapting the social environment to understand the needs of disabled people, not vice versa.

Feeding into this discriminatory system is the lower education schooling system, with its lackluster approach to the provision of advice to disabled students vis-à-vis subjects that prepare them for higher education. Odendaal-Magwaza and Farman, (1997) note that in higher education, disabled students have reported being denied access to certain courses because they are believed to be unable – due to impairment – to meet the course requirements. Examples include courses involving fieldwork or practical professional development in off-campus facilities; courses that entail the studying of visual material or the use of particular types of equipment; and courses which require extensive interaction with the public. All this has meant that those who have managed, and those trying, to enroll at higher education institutions live in insecurity of: whether they will fit into the general institutional environment or not; whether the wheelchair users will find conducive pavements to travel on or otherwise; whether the visually impaired will be provided with Braille; whether for those who are visually impaired, books in large print will be provided that enable them to read and to find information found in other small print sources; and whether disabled students will be able to complete their studies whether or the conditions will not permit them to do so.

A person's level of education can either increase or reduce their employment status, and the ability to use available technical, social and political resources to increase his or her freedom, choices and control over his or her life. With the intensification of the use of science and technology to "enhance" and "perfect" the human being, there is need for disabled people to stay abreast of the local, regional as well as global trends in technological research and developments. This will help discern its utility for the intended beneficiaries. This can only be done if the disabled are educationally empow-

ered to discern the negative and positive impacts of emerging technologies. People's security and quality of life are put at stake if they are unable to read and write. This is so because "illiteracy and innumeracy are themselves insecurities" (CHS, 2003, 14).

While much has been said by the government about educational transformation to cater for the needs of the disabled students, very little has been done to effect this. There is over-reliance on the discourse of transformation, which is not accompanied by the practice of such transformation by the government and higher education institutions. Evidence of such lip service to transformation is found in government documents such as, "The National Plan for Higher Education" (NPHE) (2001), formulated by the Ministry of Education to set down guidelines on the transformation of higher education in South Africa. The NPHE recommends the development of regional strategies to support disabled students. After acknowledging a lack of data on students with disabilities, the paper concludes in the following fashion:

> "The Ministry recognizes that it may not be possible for every institution to provide the full array of infrastructure needed to service the specific educational needs of disabled students. This provides an opportunity for institutions within each region to develop regional strategies, which would ensure that disabled students are catered for within the region. However, at a minimum, all institutions should have the basic infrastructure to allow access to the campus for disabled parents and members of the community more generally" (Ministry of Education, 2001, p. 41).

As sound as such propositions are, very little, if anything, has been done to see to it that basic infrastructure has been provided in institutions to allow access to the campus for disabled students and members of the community, let

alone providing opportunities for institutions to devise regional strategies to cater to people with disabilities. The government and higher institutions of learning, therefore, recognize the need for cohesive policies within the disability circles but have very relaxed follow-up mettle. One of the reasons for this lip service to the provision of support services has been a lack of adequate funds to provide them, hence the "Education White Paper 6 on Special Education," released by the Department of Education in July 2001, acknowledged the need to establish these support services, however, on a minimum basis because, "It will not be possible to provide relatively expensive equipment and other resources, particularly for blind and deaf students, at all higher education institutions" (DoE, 2001, p. 31).

With such a "vague commitment" (Howell & Lazarus, 2000, p. 1) towards addressing the concerns of disabled people, little attempt has been made in the process of policy implementation to address the barriers in the education system, which continue to exclude learners with disabilities from higher education institutions and/or from the process of teaching and learning. Similarly, to date, initiatives to accommodate diversity and the building of equity have failed to specify mechanisms towards addressing the full spectrum of learning needs among the learner population (Howell & Lazarus, 2000, p. 1).

Science & Technology and Targeting (S & T)

Issues of affordability, accessibility, availability, usability, and utility of current and emerging S & T need to be considered from disabled people's perspectives. There is a need to question whether technology increases the independence of its user, both the disabled and the non-disabled and most importantly, whether the technology is provided within the social model view of how such technology is to benefit disabled people. Independence has to be defined by the

intended beneficiary of such technology, not by the service provider. When it comes to the production of technology perceived to benefit disabled people, there has always been little, if any, consultation with disabled people. The expert bias that pervades research and development means that disabled people are relegated to the status of users only.

The invention of technology is not always influenced by altruism. While genuine grounds to help may exist on the part of those who invent a particular technology, there is almost always the business aspect of such inventions. Concerning S & T, the World Council of Churches (WCC) notes that science and technology applications are not value-neutral. The intentions, purposes, and actions that shape the direction, advances, and policies for science and technology use, research and development embody the perspectives, purposes, prejudices, particular objectives, and cultural economic, ethical, moral, spiritual, and political frameworks of different social groups and society at large (WCC, 2005, p. 57).

For disabled people who have been able to get education in South Africa, this has been viewed as an act of goodwill rather than viewing it as a right. Consequently, even services to cater for them, especially in institutions of higher learning, are very limited. Matshedisho (2007) notes this when he says that the provision of support for disabled students in South Africa finds itself in a contradictory position of espousing disability rights and the social model of disability, yet being embedded in the practice and legacy of benevolence. A lack of political will on the part of government and higher education management structures to provide disability support services is testimony to this benevolence.

Against this background, groups that fight for the integration and inclusion of disabled people become more needed than ever. Because social cohesion involves a definition of who is "in" and who is not (Beauvais & Jenson, 2002),

disabled people need to strengthen their fight for representation, inclusion, and participation through a united front.

The question of targeting also accounts for the availability of very limited means of public transport for disabled people. In Morocco, Sarah Touahri chronicles the difficulties faced by disabled people in accessing public transport. She narrates the story of Raja Fatini, 25, who lost both her legs in a terrible automobile accident seven years ago and how this shattered her dreams of becoming a doctor. "I got over the distress of my disability," she says, "But my broken dreams still haunt me." The synopsis of her story is as follows:

> "I was prepared to catch the bus with my wheelchair. However, public transport does not provide access for people like me, just the same as public buildings. My future was destroyed not because of the accident, but rather because disabled people are marginalized by the state" (R, Fatini, personal communication, April 25, 2008).

The above story highlights that education is also dependent on accessibility issues. It is because of this perception that the Union of the Physically Impaired Against Segregation (1976, p. 4) defines disability as:

> "The disadvantage or restriction of activity caused by contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream social activities. Disability is therefore a particular form of social oppression" (Union of the Physically Impaired Against Segregation, 1976, p. 4).

Fatini thinks that the Moroccan government should be responsible for integrating disabled people into society and the labor market.

These sentiments echoed by Fatini also pervade the minds of many disabled across the globe.

Reflecting on Social Cohesion

Against this background of charity-based approach vis-à-vis provision of support services to disabled people, there is need for an integrated stance by people with disabilities to fight for access to such services. Social cohesion becomes crucial for the attainment of such services. Through social capital, social networks can be established that, subsequently, will lead to a cohesive front on the part of disabled people. Although attempts have been made to credit L. J. Hanifan with the first use of the concept of social capital (Putnam, 2000), the first direct mainstream use of the concept was by John Dewey (Farr, 2004). As Farr notes, Dewey used the very term "social capital" in four different publications (1900, 1909, 1915, and 1934), three of which preceded Hanifan's usage. Social capital appears in Dewey's writings for the first time in The Elementary School Record. Hanifan clearly read and prominently cited Dewey in the bibliography of his 1920 book on the community center, a topic upon which Dewey had famously spoken much earlier. However, Hanifan did not cite Dewey in his original Annals essay of 1916 (Farr, 2004). Developing on Dewey's writings, Hanifan, in 1916, argued the importance of community involvement for successful schools and invoked the idea of "social capital" to explain why. For Hanifan, social capital referred to:

> "Those tangible substances [that] count for most in the daily lives of people: namely good will, fellowship, sympathy, and social intercourse among the individuals and families who make up a social unit...The individual is helpless socially, if left to himself...If he comes into contact with his neighbor, and they with other neighbors, there will be an accumulation of social capital, which may immediately satisfy his social needs and which may

bear a social potentiality sufficient to the substantial improvement of living conditions in the whole community. The community as a whole will benefit by the cooperation of all its parts, while the individual will find in his associations the advantages of the help, the sympathy, and the fellowship of his neighbors" (as cited in Putnam, 2000).

From then on the concept of social capital gained popularity among social scientists and has continued to gain usage in more or less the same meaning (Putnam, 2000; Portes, 1998; Salisbury, 1969). As defined by Berkman (1984), social networks occupy an important position in the fulfillment of a number of basic needs such as intimacy, self-worth, a sense of belonging, and the satisfaction of both giving and receiving help. Among the disabled South Africans in higher education institutions, the formation of self-help groups helps them deal with isolation and enables them to develop their potential. As they gather in these self-help groups, disabled students share experiences with other disabled students in a way that will enable them to help each other. In such groups, the disabled students gain socio-politico-economic empowerment while at the same time boosting their self-confidence. Students also share information and experiences that will strengthen one another. Perhaps the most effective way of empowering people with disabilities is to provide them with the means to come together to benefit from the liberating effect of sharing common experiences (Ellis, 1993).

It is also important, however, to note the dark side of social capital. Portes (1998), for instance, identified four negative consequences of social capital: exclusion of outsiders; excessive claims on group members; restrictions on individual freedom; and downward leveling norms. At the same time, such negative consequences have been associated with "bonding," as opposed to "bridging," social capital.

Beauvais and Jenson (2002) have combined an interest in social cohesion with social capital to show the interactive elements of the two. With its emphasis on the importance of relationships (Field, 2003), the twining of social cohesion and social capital also point to the importance of a strong sense of belonging and a concrete experience of social networks in building communities. This calls for more than the work of disability movements in building such cohesive communities. The term social cohesion has been subjected to a diversity of definitions from the time it was coined by Emile Durkheim at the end of the 19th century. Theoretical and ideological orientations have influenced such definitions. As Jeanotte notes:

> "The OECD (Organization for Economic Co-operation and Development) had the narrowest implicit definition of social cohesion, focusing almost exclusively on the economic and material aspects of the concept. The Council of Europe, on the other hand, had an extremely broad definition of cohesion – so broad, in fact, that it had separated cohesion into three inter-related categories – democratic cohesion, social cohesion and cultural cohesion. The European Union has characterized its approach to social cohesion as being consistent with "the European model of society", founded on a notion of solidarity which is embodied in universal systems of social protection, regulation to correct market failure and systems of dialogue" (Jeanotte, 2000, p. 2).

Because of the absence of a single definition of social cohesion, it is still debated whether social cohesion is a cause or a consequence of other aspects of social, economic and political life (Beauvais & Jenson, 2002).

As a form of social cohesion, mainstreaming is also important in education. Within the education discourse, mainstreaming is the idea that students with disabilities can and should

be educated alongside students without disabilities (DPINAC, 2008). In view of this, higher education institutions should not be separated into "special" and "ordinary" institutions. More often than not, this separation has meant a subsequent differential and unequal allocation of resources to "special" institutions. When financial resources are scarce on the part of the government, it is these "special" classes that attract secondary attention. The positive impacts of mainstreaming in education are illustrated in the following fashion:

"Segregating students in separate special education classes isolates and stigmatizes them, and often fails to maximize their academic potential. By placing students with special needs into a regular classroom, they are able to learn from, develop friendships with, and model their behavior after students without disabilities. Students with disabilities aren't the only ones who benefit from this arrangement; students without disabilities benefit as well…They learn that persons with disabilities are capable of achieving much more than that which most people generally give them credit for. They learn that all people deserve to be treated equally, with dignity and respect" (DPINAC, 2008, p. 14).

However, when and where separation is done, it has to be based on thorough assessments of the need to do so. For instance, some disabilities may require that such "special" schools be provided, for example, among the deaf. Because of the sign language they use, they may need to work in institutions outside conventional institutional settings. In such circumstances, provisions have to be made to ensure the availability of relevant support services and the training of personnel to work in such institutions. At the same time, it is in these institutions that 'special' technological inventions first find their way, where they are 'tested' to assess their efficacy in 'enhancing' personal ability. This means that in such institutions, the other dimension of human security, i.e., personal security, is put at stake (Linton, 1998). It should also be noted that some advocates of inclusive education are critical of a divisive sign language education that targets only the deaf, advocating for universal instruction in sign language (Linton, 1998).

Conclusion

This paper has highlighted that illiteracy is insecurity, the neglecting of which can lead to other cumulative forms of insecurity. The treatise is that for the majority of the disabled people in South Africa a lot still needs to be done to enable them to access higher education. Some negative developments in relation to the structuring of education in general and higher education in particular have also been brought to light. This structuring manifests itself in the construction of "special" and "ordinary" schools for the disabled and nondisabled people respectively, a feature that reinforces discrimination against the disabled people in higher education. It is in view of such structuring that the author has argued for mainstreaming in education to help clear the ability-disability divide within higher education institutions. The "altruistic" tendency guiding the provision of technology has also been deconstructed, especially in view of cost-benefit drives that direct such production and provision. In view of the market-oriented motives that govern the production and provision of technology, the exposition emphasized the point that targeting becomes the norm rather than the exception, where those who can financially afford technology are targeted in its production. The analysis also revealed that where technological provisions have reached the disabled, this, more often than not, has been done within the medical, rather than social, model of disability. This has not helped clear the negative societal perception towards disability.

Charles Dube, M. Sc., in Sociology and Social Anthropology is currently pursuing a Master of Social Science in Development Studies with the

University of Fort Hare, South Africa. Charles is also an Associate Editor, International Journal of Interdisciplinary Social Sciences, Australia (www.charlesdube.cgpublisher.com). His research focuses on disability rights and technology.

References

Beauvais, C., & Jenson, J. (2002). *Social cohesion: Updating the state of research.* Ottawa: Canadian Heritage.

Berkman, L. (1984). Social networks, social support, and physical health. *Annual Review of Public Health, 5*, 413-432.

Commission on Human Security. (2003). *Human Security Now.* Commission on Human Security.

Department of Education. (2001). *Education white paper 6: Special needs education: Building an inclusive education and training system.* Pretoria, South Africa: Department of Education.

Disabled Peoples' International North America and the Caribbean. (2008). *Equal opportunities for all. Respecting the rights of persons with disabilities.* Disabled Peoples' International North America and the Caribbean.

Ellis, K. (1993). *Squaring the circle: User and care participation in needs assessment.* London: Joseph Rowntree Foundation.

Farr, J. (2004). Social capital: A conceptual history. *Political Theory, 32*, 6-33.

Field, J. (2003). *Social capital.* London: Routledge.

Howell, C., & Lazarus, S. (2000) *Building an inclusive education and training system: the challenges for higher education in South Africa.* Paper presented at the International Special Education Congress, University of Manchester, July 24–28, 2000.

Howell, C. (2006). Disabled students and higher education in South Africa. In B. Watermeyer, L. Swartz, T. Lorenzo, M. Schneider, & M. Priestley (Eds.), *Disability and social change: A South African agenda.* Cape Town: HSRC Press.

Jeanotte, M. S. (2000). *Social cohesion around the world: An international comparison of definitions and issues, strategic research and analysis.* Ottawa: Canadian Heritage.

Linton, S. (1998). *Claiming disability: Knowledge and identity.* New York: New York University Press.

Matshedisho, K. R. (2007). Access to higher education for disabled students in South Africa: A contradictory conjuncture of benevolence, rights and the social model of disability. *Disability & Society, 22*(7), 685-699.

Ministry of Education. (2001). *National plan for higher education.* Pretoria, South Africa: Department of Education.

Odendaal-Magwaza, M., & Farman, R. (1997). *Draft white paper 3: A programme for higher education transformation.* Submission for public hearing at the National Assembly, Parliament, Cape Town, South Africa.

Office of the Deputy President. (1997). *White paper on an integrated national disability strategy.* Pretoria, South Africa: Office of the Deputy President.

Portes, A. (1998). Social capital: Its origins and applications in modern sociology. *Annual Review of Sociology, 24*, 1-24.

Putnam, R. (2000). *Bowling alone: The collapse and revival of American community.* New York: Simon and Schuster.

Riddell, S. (1998). Chipping away at the mountain: Disabled students' experience of higher education. *International Studies in Sociology of Education, 8*, 217-228.

Salisbury, R. (1969). An exchange theory of interest groups. *Midwest Journal of Political Science.*

Union of the Physically Impaired Against Segregation. (1976). *Fundamental principles of disability.* London: Union of the Physically Impaired Against Segregation.

Wolbring, G. (2006). *Human security and NBICS.* Retrieved June, 4, 2009, from http://www.innovationwatch.com/choiceisyours/choiceisyours.2006.12.30.htm

Disability, Poverty and Food Sovereignty: Advancing the Human Security Agenda

Vanmala Hiranandani, Ph.D.
Dalhousie University, Canada

Abstract: This essay furthers the human security discourse using the lenses of disability and food studies. The human security agenda must embrace the principle of food sovereignty that counteracts neo-liberal notions on food security. Since poverty, food insecurity, and disability are manifestations of similar development processes, horizontal alliances are imperative for systemic change.

Key Words: human security, food sovereignty, poverty

Introduction

Food is one of the vital elements of human existence. Food consumption is the single most important determinant of good health (WHO, 1998). It is pivotal to human security, which has been defined as:

> "Protect[ing] the vital core of all human lives in ways that enhance human freedoms and human fulfillment. Human security…means protecting people from critical and pervasive threats and situations…It means creating political, social, environmental, economic, military and cultural systems that together give people the building blocks of survival, livelihood and dignity" (Commission on Human Security, 2003, p. 4).

Human security is thus broadly understood as freedom from fear and want, and as protecting and empowering the world's most vulnerable people – it encompasses safety from chronic threats, such as hunger, disease and political repression, and protection from sudden and hurtful disruptions, such as war and violence. Attaining food security is viewed as crucial for ensuring safety from both chronic threats and sudden disruptions (Stoett, 2000; Yoshikawa, 2007).

However, several decades of research and efforts to achieve food security have been unsuccessful in finding sustainable solutions to hunger around the globe. Despite the modernization of food production and distribution, the politics of food systems and economic restructuring have increased hunger and malnutrition that threaten the well-being of millions of people worldwide. Jean Ziegler, UN rapporteur for food, reported that in 1990, 20% of the world's population suffered from extreme under-nutrition; by 1999, this had increased by 19% (Ziegler, 2004). In 2000-2002, the Food and Agricultural Organization estimated that 852 million people worldwide were undernourished (FAO, 2004a). This figure includes 815 million in "developing countries," 28 million in countries in transition, and 9 million in "developed countries".[1] The continuing reality of hunger, exacerbated by the rising food prices of 2008 (see Grebmer, Fritschel, Nestorova, Olofinbiyi, Pandya-Lorch, & Yohannes, 2008), is a grave threat to human security; yet this aspect has been overlooked in public policies of many countries.

Furthermore, most literature on food security has lacked a disability perspective. Extant studies on disability and food security have been limited to the fields of medicine and nutrition that largely view "disability" from a medical model as a deficit or a problem inherent in the individual. While this health science perspective is significant to understand the interrelations between chronic illness, impairment and malnutrition, it is inadequate to address the wider socio-economic disparities that affect the livelihoods, opportunities and self-determination of disabled persons.

The purpose of this essay is to further the agenda of human security using the lenses of disability rights and food studies. The notion of "food security" within the concept of human security will be further elaborated, followed by a brief review of the literature on the relationships between food security, disability and poverty. Using the social model of disability, the paper contends that since disability is a social construction, it is imperative to examine and address societal structures that cause disability in the first place. Similarly, it is argued that poverty does not exist as an *a priori* condition – rather, it signifies socio-political and economic processes in the development agenda, which emanate from the hegemony of neo-liberal ideology that believes in unfettered economic growth. Further, the essay makes a case for expanding the idea of human security to include the principle of food sovereignty, which provides a sound alternative to the neo-liberal idolatry that belies the discourse on food security. It is contended that food sovereignty is imperative to attain freedom from hunger and indignity, particularly from the perspective of disabled people[2,] the majority of whom reside in rural areas in "developing countries." Finally, the paper suggests some ways ahead for the human security agenda making a case for the disability movement to ally with grassroots movements of other marginalized groups because poverty, disability, and various forms of social exclusion are symptoms of similar processes.

Food Security and Human Security

The most commonly used definition, first put forth by the Rome Declaration on World Food Security and the World Food Summit, describes food security as "a situation in which all people at all times have physical and economic access to sufficient, safe and nutritious food to meet their dietary needs and food preferences for an active and healthy life" (FAO, 1996). The significance of food security is evident from the fact that malnutrition remains the world's most serious health problem and the single biggest contributor to child and maternal mortality. Six million children under the age of five die each year because of hunger (FAO, 2000). Nearly one-third of children in the "developing world" are either underweight or stunted (World Bank, 2006). Many malnourished children suffer from lifelong physical and cognitive impairments.

The prevalence of hunger and malnutrition around the globe continues to foster discussions and research on food security and poverty. In recent years, poverty reduction work has been guided by the Millennium Development Goals (MDGs) published by the United Nations (2000). The first MDG is to reduce by half, between 1990 and 2015, the proportion of people whose income is less than one dollar a day. The second target is to halve, between 1990 and 2015, the proportion of people who suffer from hunger. Clearly, the issue of food security remains central to the attainment of MDGs.

While food security studies have gathered momentum in recent decades (see Hiranandani, 2008), most research on disability and access to food is restricted to disease and impairment effects of undernourishment (e.g., Gordeuk & Boelaert, 2002; Kadiyala & Gillespie, 2004). Malnutrition is viewed as a major cause of disability. For instance, Helander (1993) underscores that one way to prevent disability is to ensure adequate nutrition. However, this contention does not address socio-economic inequalities that lead to malnutrition in the first place. Most studies assume that "disability" is a limitation within the individual and that food insecurity is a result of material hardships and income poverty due to the disabled person's functional limitations that prevent or hinder their participation in the economy (see Armour & Pitts, 2006; Canadian Council on Social Development, 2003). This paper turns next to a discussion of the nexus between disability and poverty that has been the focus of much mainstream disability and development literature.

Disability, Poverty and Development Work

Disability and poverty are said to be inextricably linked. In developed and developing countries alike, people with disabilities are more likely to be poor than their non-disabled counterparts (FAO, 2004b). As Albert, McBride, & Seddon (2002) illustrate, poor people are much more likely to live in unhealthy conditions and to have inadequate access to clean water, sufficient nutrition and affordable health care. Conversely, impairment can lead to poverty and social exclusion and foster financial dependency on handouts, the state and the extended family. Thus, the relationship between poverty and disability has been posited as a vicious circle.

This poverty-disability axis adopted by most studies views food insecurity as a result of poverty, cutbacks to income assistance, inadequate wages, unemployment etc, but fails to address employment barriers, inaccessible services, social organization and attitudes that restrict opportunities and livelihoods of disabled persons. While it is true that "disability" is a major cause of global poverty on par with gender discrimination and the denial of human rights (Durham, 2002), societal factors such as prejudice and discrimination are more significant in eliminating poverty than a limited focus on the individual's functional limitations and economic capabilities. In "developing countries," people with physical and cognitive variations are often seen as most disadvantaged by others in their local communities. A survey of literature by Elwan (1999) shows that being "disabled" was ranked at the top of a list of fourteen "ill-being" criteria in Asia and Africa – becoming widowed and lacking land were ranked as second and third respectively. Individuals with disabilities are often the victims of negative attitudes and are subject to stigmatization, neglect, deterioration of physical condition or onset of secondary conditions, and even starvation (see Mander, 2008 for a poignant study). Exclusion and marginalization reduce their opportunities to contribute to the household and community thereby augmenting the risk of poverty.

Enhancing equity for people with disabilities and changing society's attitudes is imperative to end the poverty-disability cycle and enhance food and human security. Disability studies and the social model of disability have major implications for poverty reduction work. As Yeo (2005) states, "[I]f the problem emanates from society itself then what is needed is to change society not the individual. If society were constructed in a more egalitarian, inclusive manner then both poverty and the exclusion of disabled people could be addressed" (p. 6). The social model, thus, offers a powerful framework for comprehending and tackling the complex issues of disability and poverty. It posits disability as a crosscutting societal theme necessitating policy focus on reducing social exclusion.

The Need for Alternative Conceptions of Poverty

Just as disability is not simply a matter of bodily variations but is caused by social exclusion, poverty too is not merely a matter of incomes that are inadequate to meet basic needs. The Poverty Assessment Study Report (1995) mentions that:

> "Poverty is above all a symptom of imbedded structural imbalances, which manifest themselves in all domains of human existence. As such, poverty is highly correlated with social exclusion, marginalization, vulnerability, powerlessness, isolation and other economic, political, social and cultural dimensions of deprivation…It results from limited or no access to basic infrastructure and services, and is further compounded by people's lack of access to land, credit, technology and institutions and to other productive assets and resources needed to ensure sustainable livelihoods" (as cited in Dube & Charowa, 2005, p. 9).

It is clear, then, that poverty is not separate from the rest of society; it is an inevitable consequence of the way society is organized. However, hitherto most anti-poverty work has occurred within the framework of explaining poverty as a lack of something – this prevents altering socio-political and economic processes that produce and reproduce poverty. Green & Hulme (2005) observe that recommendations for reducing or eliminating poverty remain focused on the poor who must increase their incomes or be incorporated through inclusion policies. Poverty is conceptualized in terms of how "institutions" work or not to reduce poverty, rather than questioning their underlying ethos that cause poverty.

The larger issue, from the perspective of disabled people, is their exclusion from the development agenda and the paradigm of *economic growth* and free market economy that drive the development agenda. Yet, the world's most powerful countries have routinely held that the complex problem of poverty can be solved only by economic growth. We are taught to believe that growth and development are virtually synonymous - that economic growth will "trickle down" and automatically lead to greater prosperity for all (Gershman & Irwin, 2000). Such consensus prevails although this assumption has been disproven even in the USA, where relatively robust economic growth until recently occurred alongside a flagrant erosion of the quality of life for many citizens.

The indicators of economic growth include Gross National Product (GNP) and Gross Domestic Product (GDP), which are accounting procedures used to assess the value of goods and services produced in an economy (Gershman & Irwin, 2000). However, these measures tell us nothing about the distribution of wealth - that is, whether the benefits of growth are shared widely among the population or are restricted to a few elite. Furthermore, both the GNP and the GDP register products only if they are sold, not if they are distributed without charge (Yeo, 2005). For instance, privatization of water

places a monetary value on water and therefore raises GNP, yet it renders water unaffordable to the poorest, including disabled people.

Following the fall of the Soviet Union, a neoliberal orthodoxy asserted itself in policy circles that led to the identification of development with economic growth under free market conditions. Neo-liberalism believes that state intervention is an obstacle to economic growth because it creates inefficiency and market distortions. Therefore, government expenditures should be reduced, allowing provision of services through the private sector that is more efficient due to profit incentives (Gershman & Irwin, 2000). These principles have lead to privatization of health and social services, education, transport and, increasingly, water and food provision in many parts of the world. Neo-liberalism undergirds most national and international development work around the world, particularly that espoused by the World Bank.

Neo-liberalism has major implications for disabled persons. For instance, Yeo (2005) cites the example of Chile that has been called the "social laboratory" of neo-liberal policies of free market economy and cutbacks to government expenditures. Disability rights occupy a backseat in Chile – indeed, Yeo (2005) informs us that for 25 years disabled children have been portrayed in pathetic ways to appeal for donations in annual telethon media shows. Multinational corporations, such as Nestle and McDonalds, sponsor the telethons that are viewed as the country's most important effort for disabled children. While this boosts the image and sales of corporations, it reinforces the pity/charity model and does nothing to improve the rights of disabled people.

Even the Human Security Report does not question the paradigm of neo-liberalism: it views markets and economic growth as imperative for human security, while espousing safeguards to ensure more equitable distribution of the benefits of market economy (see Commission on

Human Security, 2003). This perspective overlooks the irrefutable evidence that land, water and environmental degradation is caused by unbridled neo-liberalism (Gershman & Irwin, 2000) - the brunt of these costs is borne by poor people and disabled people in the "developing world."

Neo-Liberalism and Food (In)security

The paradigm of market economy views food as a commodity, rather than a right. Millions of people are excluded from consuming this "commodity" simply because they lack the purchasing power to buy it. Recent worldwide hikes in prices of basic foods have spiraled hunger and malnutrition and led to food riots in several countries resulting in political instability (EPW, 2008). According to the Commission on Human Security (2003), people's access to food is affected by inequitable distribution of food, environmental degradation, natural disasters and conflicts. However, the Commission's report overlooks that food security is closely associated with the state of agriculture. The pivotal importance of agriculture in the fight against hunger and poverty lies in the fact that around 2.5 billion people around the globe rely on agriculture as their primary source of income (Egziabher, 2003; IATP, 2005). In India, roughly 700 million of the country's one billion people depend on the agricultural sector for their livelihood (Coleman, 2003). Because agricultural resources play an indispensable role for the livelihoods of the majority in developing countries, any changes in agricultural policies can trigger an impact on rural livelihoods and food security.

In several countries that gained independence from colonialism, food security was a central objective of economic planning. However, in recent decades neo-liberal globalization in the form of international rules that encompass trade liberalization, privatization, and the use of genetically engineered seeds have transformed agricultural practices and rural livelihoods everywhere (Desmarais, 2002; Madeley, 2002; Rosset,

2006).[3] Trade and seed patenting policies, such as the Agreement on Agriculture (AoA) and the Trade-related Aspects of Intellectual Property Rights (TRIPs) have forced "developing countries" to open their agricultural sector to global agribusinesses and to replace traditional farm-saved seeds with genetically engineered seeds (which are non-renewable and thus require repurchase for each growing season). Trade treaties have caused cheap and subsidized food to flood international markets, thereby devastating local small-scale farmers (IATP, 2006, Madeley, 2002; Rosset, 2006). In India, evidence suggests that tens of thousands of small-scale and subsistence farmers have been pushed off the land (Sharma, 2000). Besides, with the decline in rural credit by nationalized banks, farmers are forced to borrow loans at exorbitant interest rates from private moneylenders (Hardikar, 2006). Countries such as India have witnessed an epidemic of farmer suicides since 1997 (Jeromi, 2007; Sainath, 2007a, 2007b).

Furthermore, a handful of transnational companies have gained increasing control over global food and water supplies, yet there is no system to ensure their accountability (FAO, 2004a). Agri-food corporations Cargill and Pepsico now control 70 percent of the world food trade. Cargill itself accounts for 60 percent of the world trade in grains (Shiva, 2004a). Smallholders, including disabled farmers, who cannot compete with huge corporations fail to get access to the global marketplace and thereby face the risk of being excluded from the food system both as producers and consumers. FAO (2004b) notes that disabled farmers increasingly have inadequate access to means of production such as land, water, inputs and improved seeds, appropriate technologies and farm credit. Yet, the Commission on Human Security (2003, p. 78) promotes international trade as a crucial tool for development, although it acknowledges the inherent double standards of the global trade system that allows "developed countries" to maintain their subsidies for local producers

while demanding that "developing countries" dismantle their protections.

Moving Beyond Neo-liberalism: Towards Food Sovereignty

The current concept of human security maintains that it is concerned with "safeguarding and expanding people's vital freedoms" (Commission on Human Security, 2003, p. iv). Yet, people's freedom to save seeds and grow their own food is being taken away through international trade treaties. The existing denotation of "food security" is indifferent to questions such as who produces food, how and under what conditions. As Patel, Balakrishnan, and Narayan (2007) argue, the most commonly used definition of food security put forth by the Rome Declaration on World Food Security (FAO, 1996) is compatible with an economy in which everyone eats McDonalds' burgers, while the fast food chain extinguishes small-scale farmers and ravages the planet by its ecological footprint – and yet, is perceived to contribute to "economic growth." Food security, perceived solely in terms of access to food, is congruent with neo-liberal policies that militate against basic human rights.

In 1996, Via Campesina, the largest international farmers' association, put forth the concept of *food sovereignty* in reaction to the increasing (mis)use of the term "food security." *Food sovereignty* is in stark contrast to the neo-liberal approach that argues the best way to achieve food security in "developing countries" is to import cheap food from "developed countries," rather than producing locally. Via Campesina argues that cross-border agricultural trade only contributes to more poverty, marginalization and hunger (Starr, 2005). Food sovereignty defies the neo-liberal approach and focuses on local autonomy, local markets and community action. Via Campesina insists family farmers in the global South and North do not need access to global markets; all they need is access to their local markets (Desmarais, 2002). To this end, the most important step to attain food sover-

eignty is to protect farmers against trade treaties that benefit only multinational corporations that control the World Trade Organization and trade agreements in its ambit. Food sovereignty advocates an alternative trade model where national policies enable farmers to access their local markets and to trade only the surplus food (that too bilaterally) rather than producing primarily for export. Via Campesina calls upon governments to protect the access of peasants and landless people to land, water, seeds, and credit. Food sovereignty, therefore, emphasizes the need for land reforms, removing restrictions on the use of farm-saved seeds, and safeguarding water as a public good to be sustainably distributed. Food sovereignty brings together farmers of "developing" and "developed" countries by linking social struggles of millions of rural people who have been driven off their land by corporate control of the food chain. It insists on agriculture whose central concern is human beings, rather than profit. Thus, food sovereignty is a solid alternative to mainstream thinking on food security.

However, disability issues have been overlooked even within the food sovereignty paradigm. Organizers of conferences on food studies rarely consider accessibility issues for disabled people. Via Campesina has instituted women's forums (Desmarais, 2002), but deliberations on disability are lacking. Nonetheless, disability and food sovereignty movements have the potential to inform each other. Both food sovereignty and disability studies/social model call for systemic change – both embody humanist principles of dignity, individual and community sovereignty, and self-determination.

Imagining Alternative Futures

Neo-liberalism, with its tenets of economic growth and market economy, has significant implications for disabled persons; however, this is a largely neglected area of investigation. To date, there are few studies on disability in rural areas where the vast majority of poor and disabled farmers reside. Thus, there is negligible informa-

tion about the impact of recent food crises and increase in food prices on this subpopulation. Critiques of global and national food and agricultural policies have neglected the concerns of disabled people.

It is imperative to examine the global political economy of food from disability rights perspective because 85-90% of the global population of people with disabilities reside in "developing countries," where 70% of the total population depends on agro-food systems for their livelihoods. The World Food Summit of 1996 recognized the contributions to food security by disabled farmers in rural areas, noting that a large proportion of disabled people were farmers with the responsibility of ensuring enough food for their households (FAO, 1996). In order to attain human security for all, it is essential to overhaul the dominant anti-poverty perspective on food security and shift towards the combined approaches of food sovereignty and disability rights to understand the socio-economic implications of global agri-food systems for the entirety of humankind that embodies a range of physical and cognitive abilities.

People with physical and cognitive variations have been largely marginalized from the economic growth agenda for years. Instead of advocating alternatives, even the disability movement has rallied for inclusion in the dominant economic growth model (Yeo, 2005). Consequently, while many other grassroots movements are campaigning against international financial institutions and the World Bank's "poverty reduction" strategies on the grounds that the Bank's approach perpetuates poverty, disability activists are fighting for inclusion within the Bank's policies. Instead of sham inclusion in the idolatry of economic growth (with its concomitant environmental and human costs), meaningful change can be attained by building horizontal alliances with other social movements such as peasant mobilization, ecological movements, labor organizations, coalitions of racialized peoples and indigenous

populations, progressive media as well as with larger endeavors for global peace and justice. It is true that other social movements may not be always inclusive of disability, and advocacy may be required in order to gain recognition within these groups. However, as Yeo (2005) surmises, disabled people can ally with other grassroots social movements that believe in transformative politics and systemic change or get co-opted by "half-hearted invitations for inclusion in the very agenda that causes poverty and disables people" (p. 26).

Concluding Remarks

This essay has brought together several arguments. While food security is one of the cornerstones of human security, this paper has contended that a limited focus on food security in terms of economic access to food is problematic. Expanding the notion of human security to include food sovereignty is both necessary and desirable. Food sovereignty interrogates the social and economic relations of food production, distribution and consumption – it resists processes of neo-liberal globalization that is transforming the diversity of localized food systems into a more homogenous world system controlled by a few large corporations and trade agreements.

Food security, poverty and disability are inherently political issues. While individual experiences of living with pain, illness or impairment cannot be discounted, disability is much more than a question of health or illness - it is primarily a social construction, where people with bodily variations live under certain social arrangements that are exclusionary in nature. Likewise, poverty cannot be abolished until the very system of economic growth and neo-liberalism that lavishes a few and impoverishes the masses is brought under scrutiny.

Furthermore, this essay has called for re-imagining disability activism by recognizing common ground with resistance movements of other disenfranchised peoples. The processes

that affect disabled people are similar to those that marginalize many others. Alliances with other progressive movements are crucial for broad-based changes to address the underlying causes of food insecurity, poverty, and disablism. Unless structural and societal causes of deprivation and discrimination are addressed, progress towards human security remains a pipedream.

Vanmala Hiranandani, Ph.D., is Assistant Professor at Dalhousie University School of Social Work, Canada, with prior teaching appointments at York University, Toronto and University of Northern Iowa, USA. She worked in India previously as a medical social worker and on research projects concerning women, health, development and indigenous populations. Her research encompasses health consequences of development policies and economic globalization; food sovereignty; disability studies; anti-racist and anti-colonial thought; and participatory research.

References

Albert, B., McBride, R., & Seddon, D. (2002, September). *Perspectives on disability, poverty & technology - A report to Healthlink Worldwide and GIC Ltd.* Norwich, UK: Overseas Development Group, University of East Anglia.

Armour, B. S. & Pitts, M. (2006). *Food for thought: Food stamps, food insecurity and disability*. Paper presented at the annual meeting of the Economics of Population Health: Inaugural Conference of the American Society of Health Economists, Madison, WI, USA. Retrieved February 15, 2008, from http://www.allacademic.com/meta/p93440_index.html

Canadian Council on Social Development. (2003). *Two themes: Workplace issues and personal security.* Retrieved April 6, 2008, from http://www.ccsd.ca/drip/research/dis10/index.htm

Coleman, W. D. (2003). *Globality and transnational policy-making in agriculture: Complexity, contradictions, and conflict.* Working Paper Series. Hamilton, ON: McMaster University Institute on Globalization and the Human Condition.

Commission on Human Security. (2003). *Human security now.* New York: Author. Retrieved May 20, 2008, from http://www.humansecurity-chs.org/finalreport/English/FinalReport.pdf

Desmarais, A. A. (2002). The Via Campesina: Consolidating an international peasant and farm movement. *Journal of Peasant Studies, 29*(2), 91-124.

Dube, A.K. & Charowa, G. (2005). *Are disabled peoples' voices from both south and north being heard in the development process?* Retrieved May 20, 2008, from http://www.disabilitykar.net/research/thematic_voices.html

Durham, M. (2002). *Poverty, disability and impairment in the developing world.* Retrieved April 7, 2008, from http://www.disabilitykar.net/pdfs/odg-summary.pdf

EPW. (2008, June 14). Editorial: Right to food versus right to profit. (2008, June 14) *Economic and Political Weekly*, p. 7.

Egziabher, T. B. (2003). How (not) to feed Africa. *New Internationalist, 353*, 14-15.

Elwan, A. (1999, December). Poverty and disability: A survey of the literature. *Social Protection Discussion Paper Series.* Washington, DC: The World Bank.

Escobar, A. (1995). *Encountering development: The making and unmaking of the Third World.* Princeton, New Jersey: Princeton University Press.

FAO. (1996, November 13-17). *World Food Summit*. Rome, Italy: Author.

FAO. (2000). *The state of food insecurity in the world 2000*. Geneva: Author.

FAO (Food and Agriculture Organization). (2004a). *The state of food insecurity in the world*. Rome, Italy: Author. Retrieved February 28, 2008, from ftp://ftp.fao.org/docrep/fao/007/y5650e/y5650e00.pdf

FAO. (2004b). *FAO's input to the proposal of the UN Ad Hoc Committee on a 'Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities.'* Retrieved May 4, 2008, from http://www.un.org/esa/socdev/enable/rights/uncontrib-fao.htm

Gershman, J., & Irwin, A. (2000). Getting a grip on the global economy. In J. Y. Kim, J. V. Millen, & A. Irwin (Eds.), *Dying for growth: Global inequality and the health of the poor* (pp. 11-43). Monroe, Maine: Common Courage Press.

Grebmer, K. V., Fritschel, H., Nestorova, B., Olofinbiyi, T., Pandya-Lorch, R., Yohannes, Y. (2008). *Global hunger index: The challenge of hunger 2008*. Washington, DC: International Food Policy Research Institute.

Green, M. & Hulme, D. (2005). From correlates and characteristics to causes: Thinking about poverty from a chronic poverty perspective. *World Development, 33*(6), 867-880.

Gordeuk, V. R., & Boelaert, J. R. (2002). Protein energy malnutrition and risk of tuberculosis infection. *The Lancet, 360*, 1102.

Hardikar, J. (2006, January 18). *Farming and indebtedness: Loan after loan*. Retrieved June 7, 2007, from http://www.indiatogether.org/2006/jan/agr-landloans.htm

Helander, E. (1993) *Prejudice and dignity: An introduction to community-based rehabilitation.* New York: United Nations Development Program.

Hiranandani, V. S. (2008). Food security as a social movement in neo-liberal times: Envisaging a role for social sciences. *The International Journal of Interdisciplinary Social Sciences, 2*(5), 39-48.

IATP (Institute for Agriculture and Trade Policy). (2006). *WTO Agreement on Agriculture: A decade of dumping: US dumping on agricultural markets*. Minnesota: Author.

IATP. (2005). *Planting the rights seed: A human rights perspective on agricultural trade and the WTO*. Minneapolis, MN: Author.

Jeromi, P. D. (2007, August 4). Farmers' indebtedness and suicides: Impact of agricultural trade liberalization in Kerala. *Economic and Political Weekly*, 3241-3247.

Kadiyala, S., & Gillespie, S. (2004). Rethinking food aid to fight AIDS. *Food and Nutrition Bulletin, 25*(3), 271-282.

Madeley, J. (2002). *Food for all*. London: Zed Books.

Mander, H. (2008, April 26). Living with hunger: deprivation among the aged, single women and people with disability. *Economic & Political Weekly*, 87-98.

Patel, R., Balakrishnan, R., & Narayan, U. (2007). Explorations on human rights. *Feminist Economics, 13*(1), 87-116.

Rosset, P. M. (2006). *Food is different: Why we must get the WTO out of agriculture.* Halifax, NS: Fernwood.

Sainath, P. (2007a, February 25). *1400 suicides in one region alone last year. Two million in 'maximum distress.'* Counterpunch. Retrieved April 20, 2007, from http://www.counterpunch.org/sainath02242007.html

Sainath, P. (2007b, April 07). *And meanwhile in Vidarbha.* Retrieved April 20, 2007, from http://www.indiatogether.org/2007/apr/psa-meanwhile.htm

Sharma, D. (2000). Selling out: The cost of free trade for India's food security. In J. Madeley (Ed.), *Trade and hunger: An overview of case studies on the impact of trade liberalization on food security.* Stockholm, Sweden: Forum Syd.

Shiva, V. (2004a). Stolen harvest: The hijacking of global food supply. In M. Fort, M. A. Mercer, & O. Gish (Eds.), *Sickness and wealth: The corporate assault on global health* (pp. 107-117). Cambridge, MA: South End Press.

Shiva, V. (2004b). The future of food: Countering globalization and recolonization of Indian agriculture. *Futures, 36.* 715-732.

Starr, A. (2005). *Global revolt: A guide to the movements against globalization.* London & New York: Zed.

Stoett, P. (2000). *Human and global security: An exploration of terms.* Toronto: University of Toronto Press.

Tucker, V. (1999). The myth of development: A critique of a Euro-centric discourse. In R. Munck & D. O'Hearn (Eds.), *Critical development theory: Contributions to a new paradigm* (pp. 1-26). London and New York: Zed Books.

United Nations. (2000). *United Nations Millennium Declaration.* United Nations General Assembly Resolution 2 session 55. Retrieved January 20, 2008, from http://www.un.org/millennium/declaration/ares552e.htm

World Bank. (2006). *Repositioning nutrition as central to development: A strategy for large-scale action.* Washington, DC: Author.

WHO. (1998). *World Health Report.* Geneva: Author.

Yeo, R. (2005). *Disability, poverty, and the new development agenda.* Retrieved April 7, 2008, from http://www.disabilitykar.net/research/red_new.html

Yoshikawa, N. (2007). *Human security in practice: Food security in North Korea.* Paper presented at the annual meeting of the International Studies Association 48th Annual Convention, Hilton Chicago, IL, USA, February 28, 2007. Retrieved June 19, 2008, from http://www.allacademic.com/meta/p179005_index.html

Ziegler, J. (2004). *Economic, social and cultural rights - The right to food.* Report submitted to the Commission on Human Rights. Retrieved April 20, 2007, from http://www.landaction.org/gallery/Zieglerpaper.pdf

Endnotes

[1] Given the arguments advanced by several critical development theorists about the contested nature of 'development' (e.g., Escobar, 1995; Tucker, 1999), I prefer to use the terms developing countries and developed countries in quotes in order to rupture the essentialist nature of the terminology that not only presupposes a fixed and universal trajectory of development but also fails to account for geo-political power inequities and interests involved in defining countries as the "First World" or the "Third World."

[2] In this paper, the terms "disabled" and "disability" are used to underscore the social exclusion that "disabled persons" or "people with disabilities" face in a disabling society. Where bodily realities are alluded to, the term physical and cognitive variations or impairment is used.

[3] The term "liberalization" refers to "reducing barriers to the free flow of trade and investment, as well as reducing or eliminating government subsidies that keeps the prices of certain essential goods low" (Gershman & Irwin, 2000, p. 23)

A FOCUS on **The United Nations Convention on the Rights of Persons with Disabilities** with specific emphasis on eradicating poverty through education and employment

Special keynotes include: Michael Stein, Executive Director, Harvard Law School Project on Disability, and Cabell Research Professor, William & Mary School of Law.

Please contact Charmaine Crockett at *cccrocke@hawaii.edu* or (808) 956-7539 for more information on how to submit proposals and be a part of the dialogue.

In developing countries, 80% to 90% of persons with disabilities of working age are unemployed, whereas in industrialized countries the figure is between 50% and 70%.

Ninety per cent of children with disabilities in developing countries do not attend school, says UNESCO

The Center on Disability Studies presents:

PacificRim InternationalForum

A pre-conference event

April 10 & 11, 2010

Hilton Hawaiian Village
Honolulu

A focus on the Convention on Rights of Persons with Disabilities

With special attention to education and employment

www.pacrim.hawaii.edu/internationalforum
stodden@hawaii.edu • cccrocke@hawaii.edu

Co-sponsored with the William S. Richardson School of Law.

Is the "Rights Model of Disability" Valid in Post-conflict Lebanon? A Participatory Pilot Survey in Beirut

Nawaf Kabbara, Ph.D.
University of Balamand, Lebanon
&
Kozue Kay Nagata, Ph.D.[1]
United Nations
Development Cooperation Branch

Abstract: This paper views the process and outcome of constructing a "rights model of disability," which is culturally specific to a war-torn, middle-income Arab country, Lebanon. The analysis was made from the perspective of human security and postconflict recovery and rehabilitation in a war-torn Arab country. The objective of this participatory research is to triangulate and co-validate the proposed rights model of disability through analysis of the collective views of Lebanese disabled people who took part in the participatory and interactive focus group, which took place in Beirut in August, 2007, after the civil conflict of Lebanon and partial destruction of Beirut and other towns/villages. The disabled participants were asked to express their individual views about several contentious issues, such as the social model vs. medical model debate, the diversity existing among different categories of disabled persons, the issue of tension and/or coalition among single-impairment and cross-impairment groups, the effectiveness of the current disability policy in Lebanon and the particularity in war-torn transitional Lebanon. The rights-based approach to disability inclusive development (cooperation) advocated by the co-authors are field-tested and co-validated and proved to be among the most appropriate approaches, through the personal disability experiences of Lebanese people.

Key Words: Lebanon, development, rights

Background of the Study

A variety of models have been promoted to explain disability and disabled persons, which may be expressed in the opposed binary of the medical model vs. the social model. The former model views "disability" as a problem of the individual, caused by impairment (including disease and trauma), so that the management of disability requires medical intervention and/or rehabilitation of the individual. Rehabilitation and daily living skills training are viewed as the main intervention, and the principle political response is often reform of the rehabilitation or health care system. On the other hand, the social model presents a drastic paradigmatic shift in the discourse of disability. This new paradigm considers disability as a variation of society. It forms a real part of any social formation. The social model of disability views the issue mainly as social barriers (e.g. negative attitudes, physical barriers, institutional and legal barriers, etc.), which were created by the environment, and thus it is collective social responsibility to make the environment barrier-free. The social model is becoming widely accepted by many in academic circles as well as within the community of both developed and developing countries. Nowadays, however, a growing number of people may refer to the social model of disability in a much more dynamic manner, which may be alien even to the original radical version. For example, Hurst (2001) summarizes the social rights model of disability in the following way: "The radical social model of disability provides us with the insight to describe the way in which society is constructed to make people with disabilities disabled" (Hurst, 2001).

The authors are in the position to echo the view that the social model of disability helped us to understand the importance of protecting

and promoting the human rights of disabled persons and their civil rights at the country level (Greater London Action on Disability (GLAD), 2000). We see the value of supporting a more balanced, dynamic, updated version of the social model, which may be called the "human rights model of disability," where the right to be different is respected, diversity among disabilities is well recognized, and disabled citizens can claim their access to rehabilitation, medical service, and other social services as their basic human (social) right.[1]

In designing an appropriate national policy and legislation on "disability and development," the first step is to make an evidence-based field assessment of the emerging challenges that disabled persons are facing in a given community, and invite their own voice concerning the most appropriate disability approach and policy, through their own disability experiences. Social norms, values, religious beliefs and practices may influence the attitudes of non-disabled persons towards various categories of disabled people. The Lebanese case is very rich in this regard. A war-torn, middle-income Arab country, it is witnessing a vivid disability movement with slow response and change at both the societal and political levels.

Historically a war-torn country and very fragile, Lebanon is among the most advanced democracies in the Arab region, with active participation of civil society groups, such as professional organizations, press associations, consumer groups, and women's groups. Lebanon is a very unique case.

Most recently, the kidnap of two Israeli soldiers by Hezbollah on July 12, 2006 triggered a disproportionately devastating military response from Israel and catastrophic damage to Lebanon and ordinary people's lives, not only in the Hezbollah-controlled south, but the entire country. Many victims, including women and children, were treated for injuries from cluster bomb explosions. The fighting is over, but it caused devastation in the country. In addition to the damaged buildings, and the estimated million pieces of explosive ordnance littering South Lebanon, sad personal stories of permanent injury, disfigurement, trauma and disability are heard (Christian Aid, 2006).

Aims of the Study

The Lebanese case is no doubt a very unique experience from many angles. Lebanon enjoys a very vivid and lively disability movement, including the Lebanese Council of Disabled People (LCDP), a coalition of about twelve disabled people's organizations and Lebanon's chapter of Disabled Persons International (DPI). Lebanon also hosts the headquarters of the Arab Organization of Disabled People, which, together with the League of the Arab States, is mandated as an official (but civil society) regional implementation mechanism of the Arab Decade of Disabled Persons (2004-2013). It is unusual for any civil society entity to be given such a prominent role in the Arab region. Other disabled people's organizations (DPOs) are also active in the country. A country of conflict, yet, Lebanon has the most advanced comprehensive law on disability in the region (Lebanon, Law No. 220/200, 2000).

This small participatory pilot study is aimed at collecting evidence on the current level of social barriers towards disability, as well as to invite Lebanese disabled persons to identify the gap between the challenges they are facing now in the reconstruction stage (after Israel's latest military intervention and the subsequent civil unrest in 2006-2007) and the current level of services available in the country.

Methodology and Results

The aims of this study necessitated the use of a participatory quality method, similar to the so-called participatory rural appraisal (PRA). The data were collected using a semi-structured group interview, focus group discussions and a few individual interviews. The personal net-

work (this particular "wasta"[2]) of the primary author (Kabbara, 2005; 2007) in Lebanon was used, and he arranged to invite representatives of different categories of disabled people[3] and their family members to the focus groups. Thus the sample selection is based on the so-called "convenience sampling methodology." Interviews/sessions were conducted mainly in Arabic supplemented by English, and the most appropriate forms of assisted communication (e.g. Lebanese sign language, parents-guided communication, written communication, etc.) were used for deaf, hard-of-hearing, and intellectually disabled participants. All interviews and discussions were transcribed verbatim for accuracy, after the full consent of the interviewees. Four group interviews and focus groups were conducted by co-authors at AOD's office in Beirut for deaf people, blind people, physically disabled people and people with intellectual disabilities in addition to a parents' group. Thus there were a total of 29 participants in this study, with 17 women and 12 men. The sample distribution is illustrated in Table 1.

ability," or an alternative to the existing models? Does the process of changing attitudes start with disabled persons first or with society at large? Who initiates the change?

The social model activists are in favor of forming a single cross-impairment organization as a unified group of "the oppressed" to lobby for their rights and advance a positive attitude towards disabled persons. How much unity, however, can people with different impairments maintain as a single disability group? How much diversity exists among different types of impaired persons? Branfield (1999) argues that the disability movement must consist of, be led by and present all kinds of impairment groups, to fight against the institutionalized discrimination that all disabled people are facing. Is this argument applicable in Lebanon?

The range of opinions within each focus group discussion was noted as each individual commented on their own disability experience, needs priorities and their own definition of human rights. In short, generally the collective

Table1: Disability-type and gender distribution of participants (N=29)

	Male	Female	Total
Blind Persons	2	2	4
Deaf Persons and Hard of Hearing	1	6	7
Physically Disabled Persons	5	2	7
Parents	2	6	8
Persons with Intellectual Disabilities	1	1	2
A Survivor of Psychiatry	1	0	1
Total	12	17	29

The Disability Model Debate

Over the past decades, there have been heated debates on the language of disability and its definition, which reflect a dynamic philosophy towards and conceptions of the term disability and about the dynamism of discrimination and prejudice. Which model of disability do Lebanese disabled people prefer? Is it the "medical model of disability" or "social model of dis-

opinion expressed by the focus groups supported the social model of disability and the rights-based approach to disability over the medical model. The needs, priorities and rights include employment and income security, social integration, access to education particularly higher education, communication, physical accessibility, medical service, and antidiscrimination legislation.

"I suppose in Lebanon disability is still based on the outdated medical model, as the majority of non-disabled people regard disability as charity or women's stuff. But we don't need this individual model, and we need a model that ensures us our rights, both socio-economic and political rights. The rights-based model is excellent, as that will allow us to claim not only civil-political rights but also socio-economic rights, including schooling, medical service, and rehabilitation. Yes, we need the entire package" (Ahmed[4], a blind middle-aged man).

"The most humiliating expression towards us in Arabic language is "Haram" (meaning the forbidden). Are we Haram, forbidden people, a defect created by God? We must be treated as humans before we can claim our human rights" (Nada, a physically disabled young woman).

"I do not expect our economic rights to be properly met in this war- torn troubled society. The state is barely managing to provide employment and services even to other [able-bodied] members of society. We want to see the legal employment quota practiced, as our society is far behind other richer countries. I can choose 'charity' if it means income security. We cannot afford waiting for social change. Of course, we need a full package of human rights, but more so for socio-economic rights. We need money" (Antoine, a physically disabled young man).

Diversity of Persons with Disabilities

The Convention on the Rights of Persons with Disabilities (United Nations, 2007) to which Lebanon became a signatory in 2007, stipulates in its preamble the importance of "recognizing further diversity of persons with disabilities," as well as "recognizing the need to promote and protect the human rights of all

persons with disabilities, including those who require more intensive support."

Similarly, the findings of this study indicate that a wide diversity exists among different categories of disabled persons in Lebanon. The human rights of persons with disabilities, particularly those with intellectual impairments, disabled women, and people with psychosocial impairments (including survivors) are violated in daily life. The attitudes of the non-disabled towards these most marginalized groups are particularly negative in the Arab World in general and in Lebanon.

According to the collective opinions of the focus groups, there appeared to be more different opinions among the disabled population than similarities in Lebanon. Also, the findings suggested that trust among disabled groups was no deeper than that between them and mainstream society, or than the very fragile trust among Lebanese people in general. For instance, a group of deaf people, particularly the group with exclusive sign-language users (congenitally deaf people) has mixed feeling about their own disability identity--similar to the findings in many other countries:

"Am I disabled or not? We have a problem of communication. We have a linguistic problem. But sometimes, I feel that I am disabled, too. Our disability is not so visible, and others don't find me as disabled until I try to communicate. I think deaf people are less discriminated against in Lebanon than other categories with more visible disability. Lebanese people attach a significant value to physical beauty and perfection. I do enjoy being with non-disabled people too, but I prefer socializing with my deaf friends, as we share sign language. I don't have many friends with other disabilities, though I respect them. Does 'Deaf Culture' exist in Lebanon? Perhaps yes. At least I do enjoy being with my deaf friends. I find

it more relaxing and cozy" (Mona, a deaf woman and sign language user).

Nevertheless, the participants in the focus groups fully understand both the tension among different impairments and the politics of coalition:

"I think we shall unite as a cross-impairment group, working together with other impairment groups, with our common goal of promoting human rights of the disabled. Why? Three major reasons I can think of. First of all, we must deliver as one, because our society defines us as the disabled. It is not our own choice but society decided so. Thus, to a degree disability is a social construct, which was defined and imposed by our society. We must live with it whether we like it or not. Second, we must act as a single cross-impairment group for political campaigning to promote human rights and nondiscrimination, as our Law 202/2000 covers all of us, as its beneficiaries. We are equally covered by the law. It is a matter of legal definition. It is the legal scope under which groups all of us are covered as a single entity. If we can advocate our rights as one, it will echo our collective voice more effectively. That is the politics of coalition, typical in Lebanon. As we live in such a sectarian society, we are used to this dual mechanism and we can manage it" (Riad, a disability activist in a wheelchair and, Amal, a woman who is hard-of-hearing).

Historically, Lebanese people are very political, and thus, they pointed out the importance of the politics of coalition through representing as a cross-impairment group, if necessary, putting aside the tension among the groups for a while:

"There is no such thing as a 'disability culture' but there are a growing number of disability subcultures in Lebanon (e.g.

deaf culture, veteran culture, elite disability group, etc). But we can gang up together against our common enemy, the suppressor, the right-wingers and ruthless businessmen when necessary. This society has been always so fragmented and sectarian, but we act together, too. For us, this is not a new coping mechanism; indeed we have been using it for so many years" (Walid, a young physically disabled student).

Arab women with disabilities claim that they are another category that are facing double or even triple discrimination. Many disabled Lebanese women are discriminated against simply because they are also women. Having a disability and being poor compounds this gender-based prejudice. The following testimony of an English-speaking young Lebanese woman with mild developmental disability vividly illustrates this problem:

"I was born in Canada. Our family came back to Lebanon, and we have settled in Beirut. I am an overseas Lebanese. In my view, Lebanese attitudes towards intellectually disabled women are so negative. It is cultural. Disabled women are facing double discrimination based on gender and disability, and intellectually disabled women are facing triple discrimination in this country. I am enrolled in a junior college now, and I even presented our views at the UN forum in New York, during the last session of the Ad Hoc Committee on the Convention. You know, I regained my courage and confidence there, in New York. In our society where women are judged based on physical appearance and perfection, other people tend to see us as non-marriageable, useless. I am facing a serious problem in developing a relationship" (Josephine, a young woman with developmental delay).

However, sometimes, parents' view is different:

> "Sexuality is not a priority for our children; it is not a priority in Lebanon at all. Employment is a priority. Sexuality is a western idea" (Umayma, a mother).

> "Lebanese women with disabilities are denied the most fundamental human rights including the right to love and be loved. Our society in general and our male disability activists too often fail to recognize our sexuality, and they discourage the expression of it. See, many disabled men will marry non-disabled women, by their choice, but for us, marriage is not even an option. Our parents tend to over-protect us from our aspirations, as they think they will not be achieved, and pity us. I don't think our male disability activists can represent our voice in this regard, as they are equally insensitive" (a collective voice of disabled women).

Sectarian cultural difference was expressed, too:

> "I think we are very different from those living in Hezbollah areas, by all means, with disability or without, men or women" (Christine, a young mildly physically disabled woman).

Diversity among different categories of disability was noted. The voice of intellectually disabled people may not be well represented by the cross-impairment groups. Mousa, a Shiite Lebanese leader, who is a medical doctor by profession, and a father of two children with severe mental disability, articulates this:

> "The diversity among different disabilities which exists in Lebanon is very wide. I am not certain whether the trust among disabled groups is higher than that between the mainstream society and the 'disability group'. In Lebanon, I am a pioneer and founder of a self-help group of parents of intellectually challenged children, but I have often faced a hidden tension in coalition with cross-impairment self-help groups (often dominated by a group of physically disabled men). Sometimes they don't see us, the parents' groups, as a full-fledged self-help group. But our children need parental support. Isn't it obvious? Who will help them otherwise? Those children with severe intellectual disability like my kids cannot raise their own voice. We are a self-help group, too."

The gap existed between urban elites and rural grass-roots people, too:

> "Generally, the gap often exists between the grassroots organizations (often run by less-educated persons) and the national leaders of the disability movement in Lebanon (often Western educated and/or English/French speaking individuals) who have access to the international community and donor agencies. Sometimes, the combination of limited political space of operation available to the self-help groups within their own organizations and weak grass-roots support have led to a peculiar practice of democracy. Given the absence of full transparency and accountability in the performance of the leaders, and the lack of popular participation and control from the grassroots, the authoritarian Arab leadership pattern has extended to the disability movement, thus creating the wide gap between two groups" (Said, a physically disabled leader of DPI).

Antidiscrimination through Public Education, Empowerment of Persons with Disabilities and Legislation

The Convention on the Rights of Persons with Disabilities was proclaimed in December 2006 and entered into force in May 2008, and Lebanon has already signed the Convention.

Lebanon already signed the Optional Protocol of the Convention and is in the process towards ratification. The national law of 220/2000 on disability, which is comprehensive and rights-based, was passed 7 years ago. However, its implementation is very slow and there is no monitoring and enforcing mechanism to monitor the progress of the Law and accountability is weak. The negative attitudes of non-disabled persons, including both direct and indirect discrimination, are among the most serious barriers to full participation and integration. Generally, to rectify the negative attitudes and combat discrimination, there are two different yet related approaches. One is a reactive and enforcing approach, through legislation (anti-discrimination law) and its enforcement agency, preferably an independent third party mechanism. This mechanism is not available in Lebanon yet. Another approach is a proactive one, through public education and raising awareness with the aim of making society "inclusive." Their preference for these two options was asked of participants:

> "People can be influenced by legislation; that is so vital. Just like Lebanon now, a society without enforcement of laws is lawless and chaotic. The enforcement of laws is essential for Lebanon to claim itself as a civilized society. Wasta, wasta, wasta, it is all over in Lebanon and sadly, it is becoming a social norm. Right wing Lebanese people and ruthless businessmen are fundamentally flawed, and they must be prevented from transgressing through coercion and antidiscrimination law and its enforcing mechanism. Punishment, levy, 'yes'; 'soft measures' are not effective in Beirut. Lebanon needs an anti-discrimination law. Otherwise, Lebanese people will continue to mock our defenseless children and the only way to improve the perpetuation of this institutional discrimination is through law enforcement" (a collective voice of the parents' group).

> "We need both. Lebanese people can be influenced too, but antidiscrimination legislation is vital. Even in our society, an oriental society, such laws need not be viewed as an instrument of scrutinizing; they are fundamental values of a democratic civic society. An oriental society can be dynamic too. In the years to come, antidiscrimination law shall be a major objective of us, the 'pan-disability' group's advocacy" (Issa, a physically disabled university student).

Disability and Civil Conflict in Lebanon

The fighting between Hezbollah and the Israeli army is over, but the scars of the devastation caused in Lebanon may not heal quickly. The fighting also caused political instability, igniting the already existing tensions between different sectarian groups of Lebanon. According to the report by the Lebanese government, 50 schools were totally destroyed and 300 were damaged by the conflict with the reconstruction costs estimated at over two billion dollars all over Lebanon. A study conducted by Kabbara following the war on 116 disabled persons living in the war affected zones showed clearly that most of these people suffered tremendously from the conflict. Most disabled people were not properly looked after in terms of evacuation and in taking care of their needs, both medical and financial (Kabbara, 2007). The same study revealed that many disability service institutions were directly hit and destroyed keeping the disability community more vulnerable and insecure.

Lebanon is a country that has been occupied by a foreign power for a long time, and devastated by the subsequent political instability and civil conflict. Negative perceptions towards physical disability were changed during the civil conflicts. The issue of disability has become an important political agenda all of a sudden. The conflict increased the number of disabled persons including those with a serious mental trauma. Traditionally, disability was a mere stigma,

and now it has become heroic, at least as a symbol of active resistance. However, this new focus diverted attention away from Lebanese women with disabilities who have been most discriminated against traditionally. This "veteran culture" of Lebanon created a new classification system and hierarchy among disabilities. Aerial, land and sea attacks targeted mainly Southern cities of Lebanon, the Hezbollah controlled areas, and the devastated infrastructure forced almost a million people away from their home territories. Many of them are still forced to live in shelters without accessibility and mobility. This war-torn situation brought a new dimension to disability in Lebanon.

The following testimonies are insightful:

"The infrastructure damage and political instability (the tension among sectarian societies) caused severe economic stagnation and a high unemployment rate, with foreign investment migrating away from Lebanon to a neighboring country. Our major challenge now is employment. We cannot depend on the legal employment quota; so we must acquire a set of marketable skills so that we can survive in the private sector. We need an equal access to credit and the market, if our option is to start entrepreneurship, which may be the only viable choice now. Who is going to choose a disabled applicant with so many over-qualified jobless candidates, in this employers' labor market?" (Issa, a young physically disabled university student).

"In Hezbollah-controlled areas, one can say that disability is now, to a degree, perceived as martyrdom where men sacrificed their lives to live in wheelchairs, or say, unfortunate children stepped on land-mines to live with prosthetics. We are well taken care of by our Hezbollah leaders. We may be better off than others. But there is a significant difference between its (Hezbollah) members and non-members,

regarding the level of social services and rehabilitation offered. We are lucky ones" (Abdel Aziz, a young Shiite Moslem Man, a member of Hezbollah with amputation).

"Yes, disability is becoming a political agenda now. People see it as a human rights issue, as recently our civil conflicts have increased the scope of disability in this country. But people are not yet interested in us, disabled women or those with congenital disability. Particularly women with intellectual disability are so marginalized" (Amina, a female NGO staff with mild physical disability).

"I think that the majority of disabled people, we, were politically sacrificed in favor for this minority of disabled martyrs. Our society tends to see us, the congenitally disabled people, less, and as not worthy even for charity and rehabilitation, institutionalizing and segregating us" (Antoine, a young physically disabled man).

Furthermore, the issue of invisible disability is often forgotten in a war-torn country. In war-torn Lebanon, the difference between the disabled and the non-disabled is getting mixed up, without clear cut distinction, and in many instances, disability is temporary (such as long-lasting injuries) and in some cases, it is less than permanent or is recurrent (e.g. people with psycho-social disability and survivors). Indeed, the war and violence-causing trauma have a significant impact on the mental health of the entire population and particularly youth and children. Indeed, psychological trauma itself is the most widespread disability resulting from the repeated civil wars and armed conflicts. According to a study conducted in 1992, among the samples collected in some 20 countries such as Israel, Korea, etc, the Lebanese people were the most depressed people of the nationalities surveyed (Karam, 1998). The findings of this study revealed that psychosocial disability is still treated

as a purely medical issue in Lebanon. This category is not covered by the law, and they are not recognized as a disability group by either the non-disabled or their disabled peers.

However, the findings also informed us of a new opportunity in the transition from emergency to development:

> "In our areas in the South, we have started repairing the damaged infrastructure and schools by replacing broken windows and plastering walls, and we have converted some school toilets into accessible ones and added wheelchair ramps for inclusive education. We have no accessibility policy yet, in the Hezbollah controlled areas, but the authority is concerned about accessibility, and foreign donors are helping us in this regard, too" (Abdallah, a Shiite man with amputation).

> "In the challenging condition of reconstruction and rehabilitation of war-torn Lebanon, disabled persons organizations (DPO) may be seen as a new horizon, a vanguard of innovative practices, effectively using social service delivery networks, engaging in development work and promoting disability mainstreaming, campaigning for the rights-based approach, managing knowledge, with the aim to bring about democratic social change in Lebanese society. The disability movement may become a pioneer as a social movement in war-torn Lebanon. After all, Lebanon is the only democracy in the region, isn't it?" (Ahmed, an activist who uses a wheelchair).

The transition from relief to development in Lebanon may be providing them with both challenges and new opportunities to create a new inclusive Lebanese society, in the near future.

Discussion

The findings of this study revealed several important concerns in Lebanon, including (1) significance of the mutual and dynamic interaction between a disabled individual and his/her social environment (e.g. social barriers, war-torn condition, negative attitudes, etc.); (2) the diversity existing among different types of disabled persons (e.g. impairment type, gender, social status, religion, rural-urban, etc.), and (3) the importance attached to universal human rights, domestic antidiscrimination law and proactive measures including awareness-raising and public education. Culturally, overall social attitudes towards disabled persons, particularly towards disabled women and those with intellectual and/or psychosocial disability are very negative in Lebanon. Thus, when we seek the right set of strategies for disability mainstreaming, we must consider environmental factors, particularly the transition and reconstruction of Lebanon within the framework of the mutual dynamics between disabled individuals and the surrounding society. There is a new scope of mainstreaming disability in the reconstruction stage, such as introducing the concept of universal design. Finally, the majority of people who participated in the focus groups supported the co-authors' human rights-based approach to disability inclusive development as a viable theoretical framework, and they reiterated the importance of an effective monitoring and enforcement mechanism of implementation of the disability legislation in Lebanon. Models of disability are to be constructed so that an object can be looked at in dynamic ways and under different socio-economic, political and cultural conditions. In the field of development cooperation (e.g. official development assistance: ODA, NGO support, etc.), such a model shall be flexible enough to permit all sorts of intervention. For instance, if a disabled person is unemployed, the solution shall be flexible with many developmental intervention options, ranging from the enacting an antidiscriminatory

labor law or making the work place fully accessible (both targeting the society) to the provision of skills training (targeting the individual).

Nawaf Kabbara, Ph.D., is a professor of political science at the University of Balamand, Lebanon and he is a prominent disability activist and leader in Lebanon and the Arab region. He is among the founders of the Arab Decade of Disabled Persons (2004-2013).

Kozue Kay Nagata, Ph.D., is a currently a senior economic affairs officer in charge of development cooperation policy of the United Nations at the Office of ECOSOC Support and Coordination, New York. Prior to her current position, she served as a focal point for disability matters, from 1988 to 2002, at the United Nations Economic and Social Commission for Western Asia (ESCWA) in Beirut, Amman, and Baghdad, and from 2003 to 2006, at the United Nations Economic and Social Commission for Asia and the Pacific (ESCAP) in Bangkok. However the views expressed in this article are those of the co-authors and do not necessarily reflect the views of the United Nations.

References

Branfield, F. (1999). The disability measurement: A movement of disabled people: A response to Paul S. Duckett. *Disability & Society 14*(3), 399-403.

Christian Aid (2006). Lebanon's new disabled, report of (2006, October 18). *Electronic Lebanon.* Available at http://electronicintifada.net/v2/article5856.shtml

Greater London Action on Disability (GLAD) (2000, February). *Reclaiming Social Model of Disability Conference,* London, UK.

Hurst, R. (2001). International Classification of Functioning, Disability and Health, *Disability Tribune*, September.

Kabbara, N. (2006). *Disability situation in Lebanon and the Arab World.* Paper included in the annex 5 of the Japan International Cooperation Agency (JICA) sponsored study on disability approach in the Arab Islamic Country. http://www.jica.go.jp/branch/ific/jigyo/report/kyakuin/200506_01.html

Kabbara, N. (2007, March). *Monitoring implementation of the Arab Decade of Disabled Persons 2004-2013 in the ESCWA Region.* Paper submitted to the United Nations ESCWA, for the Committee on Social Development, 6th session, Amman, Jordan.

Karam, E. (1998). *The grapes of wrath*, Institute for Development Research and Applied Care (IDRAC) Mental Health Research Programme 1996-1998.

Lebanon (2000), *Law on Disabled Persons (220/2000) dated 25/9/2000*, available in Arabic language only. Informal English version is available from Kabbara upon request.

United Nations (2006). *General Assembly Resolution A/RES/61/106, Convention on the Rights of Persons with Disabilities, and its Optional Protocol.* United Nations. Retrieved January, 2008, from http://www.un.org/esa/socdev/enable/rights/convtexte.htm

United Nations (2007), *Convention on the Rights of Persons with Disabilities, and its Optional Protocol, the List of Status of Signatories.* United Nations. Retrieved January, 2008, from http://www.un.org/esa/socdev/enable/conventionsign.htm

Endnotes

[1] Kozue Kay Nagata, Ph.D. is a senior UN development economist; however the views expressed in this article are those of the co-authors and do not necessarily represent the views of the United Nations.

[2] This definition is a slightly modified version from the new definition of the social model, by GLAD at the international conference held in February 2000. For further detail, refer to GLAD (2000).
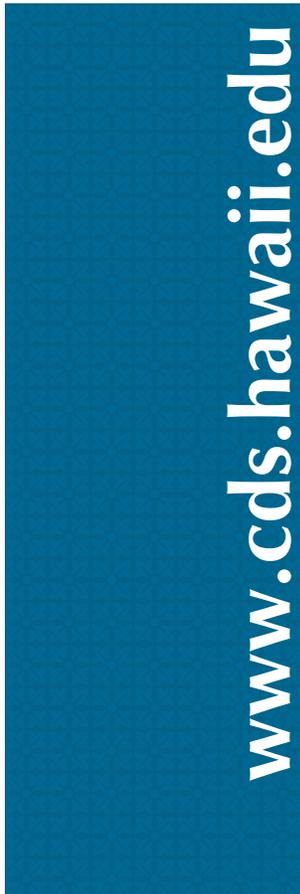
[3] In Arabic language, "Wasta" means personal connection or contact, which is a very influential factor for achieving success in the society. However, herein, the term was used positively for the purpose of assuring the right mixture and representation of the participants.

[4] People with different impairments, representing both single impairment organizations (e.g., deaf organization) and a cross-impairment organization (DPI Lebanon). Fully recognizing the potential tension between family groups and self-help groups of people with intellectual disabilities in any society, the parents are invited too as the coauthors recognized the vital role of family in Lebanese society, particularly in transition from crisis to development.

[5] All personal names used in this paper are "pseudonyms" to protect the confidentiality of information.

Book Reviews

Title: *Vital Questions Facing Disability Studies in Education*

Editors: Scot Danforth and Susan L. Gabel

Publisher: New York: Peter Lang, 2006

Paperback, ISBN: 978-0-8204-7824-0, 383 pages

Cost: $36.95 USD

Reviewer: Steven E. Brown, Ph.D.

Editors Danforth and Gabel facilitated an excellent collection of 20 essays in 10 categories following their own "Introduction," which itself comes on the heels of a brief Foreword by long-time disability studies educator Steven J. Taylor discussing disability studies in education prior to being named as such. Each editor also has an essay of his or her own in the collection. Danforth discusses "Learning from Our Historical Evasions: Disability Studies and Schooling in a Liberal Democracy." This essay, paired with Deborah J. Gallagher's "The Natural Hierarchy Undone: Disability Studies' Contributions to Contemporary Debates in Education," falls under the category, "How Can Disability Studies Inform Our Understanding of Contemporary Political Debates in Education, Particularly in their Relevance to Disabled Students?"

These essays follow a section about "Language and Representation of Disability," which includes Phil Smith's creative, "Split-----ing the ROCK of {speci [ES]al} e.ducation: FLOWers of lang[ue]age in >DIS<ability studies," which in addition to its content displays a form many will find challenging, just as many students with various disabilities do with our current educational practices and formats.

I particularly liked Gabel's dissection of "Applying Disability Theory in Educational Policy: NIDRR's "New Paradigm of Disability as a Cautionary Tale," in the section, "In What Ways is Disability Studies (Ir)Relevant to Local, State, and National Policy?" How does disability studies interact with institutionalized policy and bureaucracy and, maybe more importantly, how can, or will it, influence progressive changes in the future?

Other sections address demographic populations, such as schools, teachers, families, culturally and linguistically diverse populations, and communities. Still others address subjects like technology, international education and why teach disability studies in education.

Disability Studies in Education is a plentiful smorgasbord of appetizing forays into disability studies in education. As soon as I finished reading the book I began using it in the class I was teaching. It belongs in any disability studies library.

Steven E. Brown, Ph.D., is an Associate Professor at the University of Hawai'i Center on Disability Studies and an RDS Editor.

Title: *Playing By the Rules: A Story About Autism*

Author: Dena Fox Luchsinger

Publisher: Bethesda, MD: Woodbine House, 2007

Cloth, ISBN: 978-1-890627-83-6, 32 pages

Cost: $16.95 USD

Reviewer: Landry Fukunaga

A child with autism often takes center stage in the lives of family members trying to cope with the specific needs of their son or daughter. Siblings and family members are important in the lives of children with autism, despite a tendency to focus on the disability, interventions, and coping responses. Dena Fox Luchsinger's book *Playing By the Rules: A Story About Autism* focuses on the perspective of a sister during the course of an evening at home with her brother, mother and visiting aunt. This book is targeted

toward children (ages 4-8 years) and is comprised of 32 pages of colorfully illustrated text.

From the viewpoint of a sibling, the amount of attention given to a child with autism can be irritating and often necessitates mediation through explanations for unusual behavior. Three major themes addressed by this book include social behavior, rigid rules, and the lack of verbal communication experienced by individuals with autism. This book adequately addresses these issues through interactions between Josh, a boy with autism, his visiting aunt, and his sister Jody.

Josh exhibits atypical social behaviors such as a lack of eye contact, walking away when someone is talking to him, and unfriendliness to unfamiliar people. His sister Jody explains to their aunt reasons why Josh might walk away (he only likes animal games) and the story also explains to the reader why Josh might be unfriendly (new people rub him the wrong way) however the lack of eye contact is never directly explained to the reader. Jody also addresses Josh's rigid play routines in this story and this explanation of Josh's rules is appropriate for young children. Jody acts as the facilitator in this story when explaining the use of communication tools to her visiting aunt who is unfamiliar with Josh's special way of interacting with new people. Adequate examples that demonstrate a lack of verbal communication skills in concrete ways appropriate for children include the use of *PECS* (Picture Exchange Communication System) and Josh's use of physical prompting for desired items.

Playing By the Rules demonstrates how a sibling can help facilitate interactions through communication tools and an increased understanding of the need for sameness and routines experienced by many individuals with autism. Interestingly, this book also illustrates how a sibling can use the attention directed towards a brother with autism to her own benefit which may not be the message intended by the author, such as when Jody gets a lollipop because

her aunt took too long with her brother. Additionally, this book uses several examples that require the reader to interpret the mental states of others, which may not be appropriate for a child with autism. Overall, this book's merits outweigh the weaknesses as it addresses issues important for a sibling of a child with autism to understand. *Playing By the Rules* uses an interesting perspective to teach siblings how important they are in helping others understand their brother or sister with autism. Ideally, this book is most worthwhile if an adult explains the situations that may be difficult to understand and helps the sibling come to conclusions about which of Jody's behaviors were morally right or wrong. Additionally, the colorful illustrations should make the book appealing to young children and worthwhile for parents.

Landry Fukunaga, M.A., Evaluation Specialist, Center on Disability Studies, University of Hawai'i at Manoa worked as a direct support worker and therapist for individuals with autism for five years in the state of Hawai'i. Research interests include program evaluation, disability studies, non-verbal communication, and social interactions for people with autism. She can be contacted at lfukunag@hawaii.edu.

Title: *Make the Day Matter! Promoting Typical Lifestyles for Adults with Significant Disabilities*

Editors: Pamela M. Walker and Patricia Rogan

Publisher: Baltimore, MD: Paul H. Brookes Publishing Co., 2007

Paperback, ISBN: 978-1-55766713-7, 162 pages

Cost: $26.95 USD

Reviewer: Courtney E. Rice

Make the Day Matter! Promoting Typical Lifestyles for Adults with Significant Disabilities is a comprehensive book detailing the history of special education and rehabilitation for people with significant disabilities, and outlin-

ing policies, strategies, and programs for parents and professionals to inform the reader about navigating the process of providing individuals with disabilities self-direction. The conceptual framework revolves around the following five concepts: community presence, choice, community participation, respect, and competence. The book has 12 contributors, academic professionals specializing in the fields of special education and disability studies, research associates, and program directors prominent within the disability community.

The book begins with a chapter chronicling the history of special education and rehabilitation, which spans the era of institutionalization (1800-1960) to the self-advocacy movement (1980s-present). The work also highlights major disability legislation and the Olmstead Decision, the Supreme Court case that "affirmed the right of individuals with disabilities 'to live in the most integrated setting'" (p. 9).

Following the historical background, *Make the Day Matter!* sequentially moves through an individual's developmental lifecycle from preschool to postsecondary education, eventually addressing the elderly years, in regards to discussing person-centered avenues for self-determination. Throughout the work, the authors provide poignant case examples within each period of an individual's lifespan, in which successful strategies for societal inclusion were attained. Frequently, suggestions are made about transition planning beginning at a young age, and recommend inclusive education geared toward an individual leading a meaningful adult life. Many planning tools such as, Person-centered Approach to Habilitation (PATH) and personal futures planning, are discussed in the book to provide readers with examples to assist in transition planning. In addition, two options for transition services for youth ages 18 to 21 are also described providing parents and professionals various examples of appropriate supported transition programs for individuals of this age group.

Make the Day Matter! presents readers with a thorough concept of person-centered planning for individuals with significant disabilities. For the interested reader, the work focuses on three major areas of an individual's life: education, employment, and social and leisure opportunities. The contributors suggest purposeful transition planning, inclusive education, and a person-centered approach could benefit individuals with significant disabilities to lead fulfilling and rewarding lives.

Although this book was written for parents and professionals, a theme within this work proposes developing an individual's self-advocacy skills to increase independence and self-determination. For example, information about self-advocacy groups (i.e., Self Advocates Becoming Empowered (SABE), ADAPT (formerly American Disabled for Attendant Programs Today), and Grassroots Regional Organizing Program (GROP) are provided as well as helpful suggestions; such as, encouraging self-advocacy work as a volunteer to eventually gain employment in this area. *Make the Day Matter!* instills in the reader a paradigm shift that includes the individual with a significant disability as an active participant in the planning of his or her life.

Make the Day Matter! is well organized and detailed in its presentation, which allows the reader to utilize this work as a reference tool when working with adults with significant disabilities. It appears to be a valuable resource for parents, service providers, advocates, and educators who wish to increase their knowledge of appropriate avenues for assisting individuals with significant disabilities to create satisfying and active lives within their community.

Courtney E. Rice, M.A., is completing her doctoral degree in clinical psychology at The American School of Professional Psychology at Argosy University, Hawai'i.

Title: *End-of-Life Issues and Persons With Disabilities*

Editors: Timothy H. Lillie and James L. Werth, Jr.

Publisher: Austin, TX: PRO-ED, Inc., 2007

Paperback, ISBN: 1-4164-0263-2, 200 pages

Cost: $39.00 USD

Reviewer: Mark F. Romoser

This is a collection of scholarly articles originally published as a special series in the *Journal of Disability Policy Studies*. As such, it makes no claim to give a neutral presentation of the issues surrounding the end of life as it pertains to people with disabilities, particularly physician-assisted suicide (PAS). Rather, prominent opponents of PAS, such as Paul Longmore and Ron Amundson, professors at San Francisco State University and the University of Hawai'i at Hilo respectively contribute the bulk of the articles. Longmore analyzes the issue within the context of the larger disability rights movement (pp. 144-155), while Amundson, along with Hilo resident Gayle Taira, offers a more personal perspective (pp. 73-78).

The most frequent contributor from the pro-PAS position is Karen Hwang of Kessler Medical Rehabilitation and Research in New Jersey, who gets in some interesting points: "supporters of PAD [physician-assisted death, as opposed to "suicide"] assert that emphasizing vulnerability contradicts the goals of the independent-living movement by promoting the image of people with disabilities as a weak class incapable of full self-determination" (p. 20), and "a lot of us were left wondering why so much attention was being paid to the (Terri) Schiavo story when there are around 400,000 *thinking, feeling* citizens with disabilities under 65 languishing in nursing homes" (p. 183; emphasis hers).

Dr. Richard Radtke addresses an issue frequently mentioned by PAS proponents, that of unmanageable pain. Dr. Radtke describes his experience with trigeminal neuralgia, an excruciatingly painful condition that can accompany MS. For nearly a year, he was unable to eat solid food or even speak (p. 82). Yet, he emphatically rejects the notion that pain alone can cause life not to be worth living. He recalls a friend telling him, "If you can feel pain, you sure as hell can feel pleasure" (p. 82).

Other articles cover a broad spectrum of specific end-of-life issues ranging from dementia (pp. 124-134) to AIDS (pp. 113-123). There are discussions about withholding treatment and the emerging notion of "futile care" (pp. 39-50), and even a piece dealing with something called "chronic sorrow" (pp. 100-112). Of interest here is a first-person account from the caregiver's point of view, told by Marsha Saxton (pp. 84-93).

The book closes with two pieces about the last disability-related end-of-life case to capture the popular imagination, that of Terri Schiavo. Obviously, the Schiavo case does not involve PAS directly, since someone in a persistent vegetative state such as Schiavo's cannot give consent. Rather, the pieces focus respectively on the images of Schiavo and other people with disabilities portrayed during the extensive national media coverage of the case (pp. 167-182), and on the relationship between right-to-life and disability rights advocates, who found themselves in agreement that Schiavo's feeding tube should not be removed, but on little else (pp. 183-184).

The link to the abortion debate in the Schiavo case tends to highlight the similarly shrill emotional tone of the debate over PAS. This collection offers a way to step back and examine the issue from a reasoned, scholarly perspective, something not often found when the subject is as emotionally charged as PAS.

At its steep price, this book is not for a general audience, but certainly for those with an abiding interest in the subject, and for libraries

and other institutions wishing to build a collection of topical works in the disability field.

Mark Romoser is the Policy and Program Analyst at Hawaii Centers for Independent Living in Honolulu. He may be contacted at: markr@pacificil.org

Title: *Behavioral Support, 2ⁿᵈ Edition*

Series: *Teachers' Guides to Inclusive Practices*

Editors: Rachel Janney and Martha E. Snell

Publisher: Baltimore, MD: Paul H. Brookes, 2008

Paperback, ISBN: 1-55766-911-2, 192 pages

Cost: $26.95 USD

Reviewer: Mary Shaughnessy

Behavioral Support, 2ⁿᵈ Edition, is the latest in a series of books in the "Teachers' Guides to Inclusive Practices" series. Rachel Janney and Martha E. Snell's affordable guidebook provides educators with realistic and concise ways to implement effective behavioral support, both in the classroom and throughout the entire school.

The book starts with an explanation of the rationale for and the success behind the strategy of "positive behavior support" (PBS). It goes on to include information on how teachers can run school wide or universal interventions; how they can also do selected interventions with specific learners who are exhibiting risky behaviors; and how staff may need to intervene in more specialized ways with students who require intensive, one-to-one help.

Behavioral Support includes ready-to-use strategies, and includes many helpful worksheets. One such worksheet outlines sample behavior expectations for different areas of the school, such as hallways, cafeterias, and assemblies. Implementing these tips should help students to improve their communication skills and their self-control skills. Staff can also en-courage at-risk students to form better relationships with their peers and teachers by following the authors' suggestions on how to involve students in the community lives of their schools.

There are only five chapters in this easy-to-read text. These chapters use case studies from real students and real teachers, from the composite "Mountain View Elementary" school. Particularly helpful are the "Student Snapshots," which give the reader a look at the possible predictors of problem behaviors as well as at the confusion that can arise when classroom expectations are inconsistent.

The book concludes with a lengthy reference list, perhaps useful if one wishes to do further study in the area of behavioral support. The authors also provide appendices with blank forms and resources on behavioral support, so that educators can put the suggested templates to use straight away in their own classrooms.

Janney and Snell use simple language and utilize real-life examples, making their new book a perfect one for teachers and support staff who are beginning to work with students with challenging behaviors. Since the authors urge the creation of school wide support teams, it should also prove to be a good reference book for principals and administrators.

Mary Shaughnessy is an Instructor and Faculty Liaison at the Faculty of Education at Queen's University, in Kingston, Ontario. She is currently working towards her Ed.D. from Athabasca University in Alberta. She may be contacted at: mary.shaughnesssy@queensu.ca.

Disability Studies Dissertation Abstracts

Attitudes and willingness of California community college public safety (Police, fire and emergency medical services) faculty to provide accommodations for students with learning disabilities. Malangko, Mark C.. Proquest Dissertations And Theses 2008. Section 0035, Part 0514 136 pages; [Ed.D. dissertation].United States -- California: University of California, Santa Barbara; 2008. Publication Number: AAT 3323700.

Cultural worlds of d/Deaf children in school. Valente, Joseph Michael. Proquest Dissertations And Theses 2008. Section 0010, Part 0518 172 pages; [Ph.D. dissertation].United States -- Arizona: Arizona State University; 2008. Publication Number: AAT 3321177.

Can a therapeutic summer camp program improve school performance and behavioral outcomes for students with EBD. Boone-Thornton, Michelle. Proquest Dissertations And Theses 2008. Section 1058, Part 0525 165 pages; [Ed.D. dissertation].United States -- Virginia: Regent University; 2008. Publication Number: AAT 3326832.

The supervision experience and process through the eyes of the hearing supervisor, deaf counselor-in-training, and the sign language interpreter: A case study. Hanks, Brooks Bastian. Proquest Dissertations And Theses 2008. Section 0320, Part 0519 218 pages; [Ph.D. dissertation].United States -- Idaho: Idaho State University; 2008. Publication Number: AAT 3322825.

Exploration of siblings' explanatory models of Autism. Carter, Faye Isobel. Proquest Dissertations And Theses 2008. Section 0031, Part 0529 202 pages; [Ph.D. dissertation].United States -- California: University of California, Los Angeles; 2008. Publication Number: AAT 3322093.

Disproportionate representation of preschool-aged children with disabilities. Morrier, Michael Joseph. Proquest Dissertations And Theses 2008. Section 0079, Part 0518 290 pages; [Ph.D. dissertation].United States -- Georgia: Georgia State University; 2008. Publication Number: AAT 3323226.

Learning to be Deaf. Garrett, Barbara Donelle. Proquest Dissertations And Theses 2008. Section 0993, Part 0326 229 pages; [Ph.D. dissertation].United States -- California: School of Intercultural Studies, Biola University; 2008. Publication Number: AAT 3322812.

Public policy analysis about the services provided to special needs students. Montanez Concepcion, Isabel Cristina. Proquest Dissertations And Theses 2008. Section 0281, Part 0452 256 pages; [Ph.D. dissertation].United States -- Puerto Rico: University of Puerto Rico, Rio Piedras (Puerto Rico); 2008. Publication Number: AAT 3319567.

Marital quality and self-efficacy: Influence on disease management among individuals with rheumatoid arthritis. Tewary, Sweta. Proquest Dissertations And Theses 2008. Section 0202, Part 0452 137 pages; [Ph.D. dissertation].United States -- South Carolina: University of South Carolina; 2008. Publication Number: AAT 3321442.

The lived experience of parenting children with Tourette's Syndrome: A phenomenological study. Sasnett, Roger H.. Proquest Dissertations And Theses 2008. Section 0168, Part 0622 152 pages; [Ph.D. dissertation].United States -- Ohio: The Ohio State University; 2008. Publication Number: AAT 3321350.

The drinking pattern of deaf college students. Kalellis, Mickey James. Proquest Dissertations And Theses 2008. Section 1443, Part 0622 172 pages; [Ph.D. dissertation].United States -- Arizona: Northcentral University; 2008. Publication Number: AAT 3323776.

A sibling support group for siblings of children with autism. Perez, Tracy. Proquest Dissertations And Theses 2008. Section 1355, Part 0622 125 pages; [Psy.D. dissertation].United States -- Florida: Carlos Albizu University; 2008. Publication Number: AAT 3319751.

Perceptions of sibling relationship quality: Differences between deaf- hearing dyads and hearing-hearing dyads. Dardeen, Kelly Renee. Proquest Dissertations And Theses 2008. Section 0094, Part 0451 81 pages; [Ph.D. dissertation].United States -- Indiana: Indiana State University; 2008. Publication Number: AAT 3322202.

Information for Advertisers

The Review of Disability Studies, published by the Center on Disability Studies at the University of Hawai'i at Manoa, invites advertisements from (a) publishers of books, films, videos, and music, (b) employers with position announcements, and (c) producers and distributors of products and services. For questions or to advertise with RDS, please email rdsj@hawaii.edu or call 808-956-5688.

Why Advertise With RDS?

The Review of Disability Studies is the ideal vehicle for reaching an international audience in the field of disability studies. We have and are pursuing affiliations with other major organizations in the field.

Subscribers are academics, advocates, and libraries. It is a highly receptive audience for appropriately targeted advertising. Research shows that specialty journals such as the Review of Disability Studies are cited by professionals as the most useful source of information for the purchase of products and services, more so than conferences, direct mail, and direct sales.

Copy Requirements and Cost

Advertisements must be submitted in an electronic format - preferably a PDF file with fonts embedded or as a Microsoft Word file - in an email attachment sent to rdsj@hawaii.edu.

Dimensions for a half page are 7 x 4 inches at a cost of $300. Dimensions for a full page are 7 x 8 inches at a cost of $500.

Discounts:

10% discount for 3, 4 or 5 insertions

20% discount for 6 or more insertions

10% publishers discount

10% discount for first time advertisers

Please note: Only one type of discount will be applied to each booking. Combinations of discounts are not accepted.

Frequency and Length

RDS is published four times a year and runs approximately 50 pages.

Terms and Conditions

1. All advertisements submitted are subject to editorial approval. We reserve the right to refuse or to remove advertisements at our discretion.

2. A confirmation of your order will be supplied upon acceptance.

3. We cannot make any guarantees as to publication dates. While we will make every effort to ensure that your advertisement will be published, the Review of Disability Studies may run ahead or behind schedule.

4. All advertisements are accepted on a space available basis. On rare occasions it may not be possible to accommodate a particular advertisement. Should this be the case, a refund or substitute issue will be offered.

5. No liability is accepted by the Center on Disability Studies or the University of Hawai'i for the content of any advertisements or quality of any products, materials, or services advertised.

6. The Center on Disability Studies and the University of Hawai'i do not accept any liability for loss or damage arising from the use of any products or materials purchased as a result of advertisement publication.

7. Invoices for all advertisements must be settled within 30 days of receipt from the date as postmarked.

8. All advertisement prices are subject to sales tax, general equity tax, value added tax, or any similar tax if chargeable and at the current rate.

9. Prices are correct at the time of publication. The Center on Disability Studies, at the University of Hawaiʻi at Manoa, reserves the right to increase advertisement rates at any time.

About the Center On Disability Studies

The mission of the Center on Disability Studies (CDS), at the University of Hawaiʻi at Manoa, is to support the quality of life, community integration, and self- determination of all persons accomplished through training, service, research, demonstration, evaluation, and dissemination activities in Hawaiʻi, the Pacific Region, and the mainland United States.

The Center on Disability Studies is the umbrella for some 25 funded projects. It originated as the Hawaiʻi University Affiliated Program (UAP) funded by the Administration on Developmental Disabilities of the U.S. Department of Health and Human Services. It was established in 1988 as part of a network of over 60 UAP's in the United States. It is now a University Center for Excellence in Disability Education, Research, and Service.

Although core funding for the Center is provided by the Administration on Developmental Disabilities, other federal and state funds are provided by the Maternal and Child Health Bureau of the U.S. Department of Education, various other programs in the U.S. Department of Education, the University of Hawaiʻi, and the State Planning Council on Developmental Disabilities.

The activities of the Center for Disability Studies extend throughout the state of Hawaiʻi, the mainland United States, and the Pacific region with funded projects in several initiative areas including intercultural relations and disability, mental health, special health needs, Pacific outreach, employment, and school and community inclusion.

The Center provides a structure and process to support and maintain internal professional development, collegiality, and cooperation, reflecting an organizational commitment to excellence. Center activities reflect a commitment to best practice and interdisciplinary cooperation within an academic, community, and family context. Activities are culturally sensitive and demonstrate honor and respect for individual differences in behavior, attitudes, beliefs, and interpersonal styles.

SUBSCRIPTION FORM

Subscription period is for one year (4 issues) and includes a print and electronic version.

Please enter a one-year subscription of the Review of Disability Studies for:

Name of Subscriber: _____

Address: _____

_____

_____

Email: _____

Phone: _____

Please Select:

__Personal $50.00 (personal check only)

__Libraries and Institutions $100.00 (check or purchase order)

__Student $25.00 (please provide a photocopy of a photo ID or other proof of status)

__Additional $15.00 for first class mail outside the U.S. and Canada

__This subscription is being sponsored by _____

Address of Sponsor: _____

Email of Sponsor: _____

**Sponsors will receive one free copy of RDS and their name will be listed on our sponsor list.

Amount enclosed by check or purchase order $_____

(Please make payable to RCUH 2144)

Credit Card #_____Exp Date_____

VO#_____

Please select if you would like an alternative format to the print version:

__Braille   __Large Print   __Audio Cassette

Subscribe online at www.rds.hawaii.edu/subscribe/

Email form and payment information to velina@hawaii.edu or mail to:

The Review of Disability Studies

Center on Disability Studies

1776 University Avenue, UA 4-6, Honolulu HI, 96822

For questions please email rdsj@hawaii.edu or phone 808-956-5688

RDS