

Guest Editorial: Human Security, Social Cohesion, and Disability
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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, prenatal 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.

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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

¹The 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).

²If 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.

³An 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.

