Disability and Global Health

In This Issue....
by Debjani Mukherjee, Ph.D.
Associate Director, Donnelley Family Disability Ethics Program

It has been approximately a year since I returned to RIC from a 10 month leave of absence to be a Fulbright Scholar in India. The ensuing year has given me some perspective on what I learned and has reinforced the fact that each of us live in a tiny part of the world. While we can never know other parts as intimately as we do our own, exposure to different ways of thinking, living, thriving and surviving not only broadens our understanding of human experience but provides alternatives for creative solutions to global and local problems. Before I describe the theme and contents of this issue, I want to take this opportunity to mourn the loss of our dear friend and benefactor Strachan Donnelley, Ph.D. His philosophical work on “Humans and Nature” reminds us that we are all interconnected and that each of us has the opportunity to make an impact on the lives around us. A special issue in the Spring will include more about his life and work.

This issue of Ethics Matters is devoted to “Disability and Global Health,” which was also the title of a course that I taught to undergraduates at Northwestern University (NU) in the Spring of 08. The objectives of the course were to examine cultural conceptions of disability, explore stigma and its effects on people with disabilities, consider the impact of biological diversity on global health, appreciate various models of disability including medical and social, and discuss western and non-western notions of health, disability and human rights.

In this issue, I summarize my experience examining social and ethical dimensions of long-term adjustment to Traumatic Brain Injury in Kolkata, India. We introduce our newest staff member and the themes of our program. NU students Emery Mathieson, Vivian Leung and Anna Tygesson share the information that they presented in a poster session for Global Health (GH) 390. Their posters were chosen as the top 3 by RIC judges Joanne Garces, Teresa Savage and Teresa Moro. Two of the presentations involve China, a country that has had the focus of the world as the host of the Summer Olympics, and one focuses on Nicaragua. The undergraduate teaching assistant for GH390, Margaret Emmott, summarizes her lecture on the historical context of eugenics and disability. Next we go to Australia, where NU student Ashwin Kotwal, provides an analysis of disability themes in the film Shine. Rebecca DeBoer, a medical student and candidate for a masters in Medical Humanities and Bioethics at NU, just returned from an intensive research project in Mumbai, India and she shares her thoughts on cancer and global health. Staff members Teresa Moro and Carmen Cicchetti contribute a summary of the latest guidelines on premature infants in Europe and on the UN convention on disability rights. Finally, Kristi Kirschner reflects on her participation in the Rehabilitation International Conference held in August of this year. Disability and global health is an enormous area, and we hope this sampling of topics piques your interest.
Brain Injury in West Bengal, India
by Debjani Mukherjee, Ph.D.

Debjani Mukherjee, Ph.D., in front of the Taj Mahal, Agra, India.

The human brain is an amazing organ and damage to it can impact the full range of human functioning from how you organize your thoughts and what you feel to how you walk and talk. All around the world, brains are damaged due to traffic accidents, violence, falls, and disease processes. Traumatic Brain Injury (TBI) is an international public health problem and as a purely medical phenomenon it is similar around the world, but the responses of individual, family, and social systems vary. How do our notions of responsibility, productivity, life-satisfaction, and personal identity influence outcomes? In the long-term, after the intensity of medical treatment has subsided and the initial adjustment to the injury has occurred, what do people with TBI report about their lives and what aspects help them tackle the changes that often occur? With these questions in mind, I set off to Kolkata (formerly Calcutta) India to study the social, cultural and ethical aspects of long-term adjustment to TBI.

Conducting cross-cultural or international research had its challenges. While I am bilingual and of Bengali origin, the dramatic differences in cultural norms and bureaucracies as well as translating between the US and Indian systems (for example going through Institutional Review Boards) took longer than anticipated. Nonetheless, the Fulbright Scholars Program afforded me a unique opportunity to live, learn, teach and research in India. I had great collaborators. Dr. Sandip Chatterjee, a neurosurgeon at the Park Clinic, facilitated access to his patients. Dr. Jayanti Basu, an applied psychologist at the University of Calcutta, advised me on social science norms and helped translate measures and methods. And Kamalika Ray, a masters student, assisted with data collection. At the end of my nine month scholarship, I had collected qualitative and quantitative data on 15 persons who had lived with TBI for approximately 5 years or more and 9 of their family members. Additional sources of data included immersion in the cultural context and field notes.

I am still wading through my data, but I will share five noteworthy findings. The first is that in Kolkata, the doctor-patient relationship is fundamentally different, and physicians are often literally referred to as God (Rebecca DeBoer whose article also appears in this issue found the same phenomenon in her work with cancer patients in Mumbai). This faith in healers is a source of strength and comfort. The second is that family networks afford a greater variety of outcomes. While the healthcare and government infrastructure is often lacking, families fill in the gaps. For families without economic resources, this can cause a great burden, but with no other options, the network assumes the responsibility. The third is that in my small sample, people often returned to paid employment, a finding that is unlike the situation in the U.S. (cont. on p. 3)

Street scene of Kolkata, India
http://www.pbase.com/prantik/image/58399438

Traffic in Kolkata, India
http://www.pbase.com/prantik/image/58398625
The fourth finding is that without formal rehabilitation medicine services (a specialty that did not exist in Kolkata when I was there), acute care physicians do the follow-up, and informal rehabilitation occurs in the community through trial and error. The fifth is that participants with brain injury were slightly less satisfied with their lives (according to the subjective well-being scale) than participants without brain injury, but overall they were satisfied and found meaning and purpose in their situations.

As I think about brain injury and global health in India, road safety is a glaring aspect. The erratic traffic patterns and chaos in Kolkata are well-known, yet the use of helmets and seatbelts are not as widespread. Most of my participants had been involved in traffic accidents; one person had fallen off of a scooter transporting 3 people. In some ways, we are all naive to the potentials for injury and brain damage, yet education about prevention seems paramount, in addition to appropriate services post-injury.

Finally, journeying to a location that is dramatically different from Chicago and connecting with health care providers, persons with TBI, family members and others opened up new ways of thinking about injuries, recovery and adaptation. I can’t wait for my next opportunity to learn more!

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**Donnelley Family Disability Ethics Program News**

**Introducing Teresa Moro, A.M., LSW**
**Our Newest Member**

Teresa Moro is the newest member of the Donnelley Family Disability Ethics Program. As a clinical educator, Teresa will be spearheading our initiatives at developing educational programs and materials for healthcare providers.

Teresa is the project director for the “Life Support Decisions for Extremely Premature Infants” study. This study is currently being conducted at the University of Illinois-Chicago. Dr. Karen Kavanaugh is the principal investigator and Dr. Teresa A. Savage (from RIC) is a co-investigator. This study explores life support decisions that are made for women at risk of delivering between 22 and 25 weeks gestational age.

Currently, Teresa is also a doctoral student in the School of Social Service Administration at the University of Chicago. For her dissertation she is looking at shared decision-making and the prenatal encounter between mothers at risk of delivering prematurely and their physicians.

Teresa’s background is in medical social work with a particular interest in issues surrounding chronic illness and disability. In the last few years, Teresa has become increasingly interested in the area of end-of-life and palliative care. She has co-authored several articles on grief and perinatal and neonatal end-of-life care.

**Donnelley Family Disability Ethics Program Themes**

**Our Projects Revolve around 5 themes:**

1. Medical Uncertainty
2. Access and Integration
3. Health Care Professional Practices
4. Global Health/Human Rights
5. Representations of Disability in the Arts and Society
Epilepsy in China
by Emery Mathieson

The stigmatization faced by people with epilepsy in China is immense. Over time, this stigmatization has grown to punish people for the label of the condition rather than for the condition itself. Such stigmatization is based upon long-standing thoughts and attitudes and is a result of the perception of the condition. This stigmatization and ostracism pervades every aspect of life including marriage, employment and education. Marriage prospects are diminished, as potential spouses do not wish to take on the responsibility of caring for a person with epilepsy. This limits choices and causes some to hide their condition. Chinese people with epilepsy also encounter hardships in finding employment. Employers are reluctant to hire them for fear of accidents or poor work. This forces people with epilepsy into typically low paying jobs, leaving them unable to afford adequate medical treatment. Children are subjected to stigmatization as well and are impeded in their social development and educational pursuits. By ostracizing children at a young age, they have difficulty becoming full participants in Chinese society. By avoiding medical treatment, people with epilepsy risk premature mortality, a risk that is already four times higher than that of the general Chinese population.

Stigmatization is based upon the social label given to people with epilepsy rather than the medical condition itself. Chinese culture labels these people with a social black mark extending from a combination of past and present misconceptions of the conditions. Once so tagged, people with epilepsy face a lifetime of stigmatization from the label itself rather than the condition.


Abandonment of Disabled Children in China
by Vivian Leung

An estimated 100,000 children in China are abandoned each year, most of whom are children with disabilities or girls (UNICEF). In a developing country dealing with the challenges of population growth and the effects of rapid economic growth, the reasons for disabled children being orphaned and abandoned are many. Stigma and poverty are at the center of these causes, and an examination of these issues in the context of China’s cultural, social, and political history reveals the challenges associated with orphaned children with disabilities in China. Stigma arises from deep-rooted values of familial duty, karma, and productivity from China’s Confucian, Buddhist, and communist cultures. Lack of support for families with disabled children compels many to abandon their child or place him or her on the streets to beg.

Preventing abandonment and protecting these orphans are on China’s national agenda, though the country’s top-down approach is often ineffective in rural areas where local governments are often corrupt and laws are not fully enforced. China needs community-based initiatives to fight the root causes of child abandonment and deinstitutionalized, and specialized care for orphans with disabilities. Currently, China’s disabled orphans rely heavily on foreign aid and adoption. As China continues to change, the burdens and best solutions to problems associated with these children will also evolve.

- “can fei”: crippled and useless
- Confucian ideals: familial duty
  - Care for parents
  - Carry on family line
- Buddhist beliefs: Karma
  - Congenital disability is karmic retribution
  - Children with disabilities indicates a past sin
- Communist values: productivity
  - Contribution to community
  - Ability to work and help build a stronger nation

The Fate of Abandoned Children with Disabilities

- Child Welfare Institutes (CWIs)
  - State-run orphans
  - Extremely poor conditions
- Street children
  - Begging – may become part of begging rings
  - Picked up by government officials, detained, returned to families unable to support them
- Private orphans and homes
  - International donors
  - Adoption


Children with Cleft Palates in Nicaragua: Social, Economic, and Political Factors that Shape Everyday Life

by Anna Tygesson

Social, economic, and political factors shape the perception and treatment of children with cleft palates in Nicaragua. A cleft palate is a fairly common congenital facial deformity, occurring when the palatal plates on the roof of the mouth fail to fuse properly during early prenatal life. Although the origin of this physical disability remains unclear, it can manifest itself in varying degrees of severity. Along with producing physical abnormalities, this disability also results in serious complications such as malnutrition, breathing difficulties, speech impediments, and nose, ear, and sinus infections. Cleft palates occur in elevated rates among certain ethnic backgrounds as well. Nicaragua, for example, has a high prevalence of cleft palates. In Nicaragua, various cultural aspects impact the daily lives of children with this disability. Although families are usually accepting of these children, peers often ostracize and humiliate them. They experience behavioral, affective, and cognitive stigma, damaging their sense of self-worth and limiting their roles within society. Due to the extreme poverty in this country, parents often turn to organizations such as Operation Smile and Interplast in order to obtain free surgery and treatment for their children with cleft palates. Even though the motivations and practices of these charities have been put into question, they continue to help thousands of children in need as well as empower and educate Nicaraguans. Although some children receive medical attention from these charities, they are as a whole ignored or forgotten by the Nicaraguan government. The government needs to implement a coherent, effective plan to address the needs of children with cleft palates, along with the entire Nicaraguan population with disabilities, in order to provide them with the basic human rights and respect that they deserve.


Key Facts: According to Nicaragua’s National Institute of Statistics and Census (INEC), 12.5% of Nicaragua’s population of 5.4 million, or 675,000 people, have some type of disability. Others, such as the National Technological Institute, place the figure at 15%, or 810,000 people. http://www.cinterfor.org.uy/public/english/region/ampro/cinterfor/ifp/inatec/index.htm
Genetics, Eugenics and Disability: A Historical Approach
by Margaret Emmott

On May 15, 2008, students enrolled in “Disability and Global Health” considered the history of eugenics movements. The approach was grounded in a study of the historic origins of eugenics movements. Students then learned about contemporary examples of eugenics, genetic testing and the effects of such movements on the disability community.

Eugenics, or the encouragement of reproduction of preferred individuals, has existed since ancient times. In Plato’s Republic, written in the fifth century BC, rulers decided who would bear children and enforced the hiding of imperfect offspring. The Roman belief that legislators were responsible for purifying the state persisted in many societies and in diverse literature for the next two centuries (Searle, 1976). Theories supporting controlled human breeding gained their greatest strength with modern statistical and evolutionary theory in the 19th century.

The Eugenics movement, which flourished in Britain and the U.S. in the 19th and early 20th centuries (Dikotter, 1998), was born out of the marriage of emerging genetic science and the interests of particular social groups. Francis Galton, the cousin of Charles Darwin and father of modern eugenics, proposed in 1865 that humans take charge of their own evolution through controlled breeding. In Galton’s unpublished utopian fantasy, Kantsayehere, citizens reproduced according to quotas determined by physical and mental ranking (Paul, 1995). Breeding by citizens determined unfit was banned. Eugenics societies became popular in both Britain and the U.S. in the early 20th century. These organizations trained and dispensed eugenics field-workers who investigated family traits, identified “feeble-minded” families and promoted sterilization of people considered high risk or unfit for reproduction (MacKenzie, 1996). Workers were pressured to find genetic links among family members and to defend theories of social inheritance. Eugenics societies published their findings in regularly printed journals. The involuntary sterilization of persons with mental and physical disabilities was written into U.S. law, giving the state the right to remove children from parents with low IQ scores or to have persons with mental illness or delayed mental development sterilized. People with disabilities were to be segregated and sterilized for the betterment of society (Paul, 1995).

Eugenics became most infamous in Nazi Germany. In tandem with promoting the proliferation of Aryan Germans, the Nazi regime supported the sterilization of 400,000 people with disabilities, extensive experimentation on live human beings to test genetic theories, and the calculated killing of tens of thousands of institutionalized persons. The technology and techniques employed in this eugenics program were later translated to the systematic killing of other populations deemed unfit by the Nazi regime, including homosexuals, Jews and gypsies. Awareness and criticism of eugenics movements rose out of the actions of Nazi Germany.

Contemporary genetic counseling continues to feed the ethical debate surrounding genetics, eugenics and disability (Doyle, 2004). Cultural concerns, healthcare costs and technological advancements further complicate the debate. Sex-selective abortions, most common in China and India, suggest that female gender may be seen as a social disability (Bennett, 1983). Other developing and emerging economies grapple with the challenges of high healthcare costs and changing social networks that have eliminated community support for individuals with disabilities (Knudsen, 2006). In many developed countries, legislators and disability rights activists are faced with ethical challenges created by amniocentesis and other genetic tests (Baker, 2002). Different countries take unique approaches to the debate. In Australia, extensive psychological counseling goes hand-in-hand with genetic counseling in order to fully support parents (Turnbull, 2000). In Brazil, there is a strong movement to defend parents with cognitive disabilities in asserting their sexual and reproductive rights (Block, 2002). Genetic testing and counseling remain popular practices in the U.S., Britain and Israel, where amniocentesis is regularly performed on expecting mothers over the age of 35.

After reviewing the extensive and complex history of eugenics movements and the modern-day counterparts, students had a roundtable discussion of ethical dilemmas that the subject poses. They discussed the place of individual and societal rights, the place of the state in determining and defending those rights, as well as differing cultural approaches to the debate.

Perspectives on Mental Illness in the Movie Shine
by Ashwin Kotwal

In the critically acclaimed Australian film, *Shine*, director Scott Hicks presents the rise of the career of piano prodigy David Helfgott and his life after a mental breakdown. The movie, which is based on a true story, has been highly controversial; some claim it is an inspiring story of overcoming obstacles, whereas others find it patronizing or factually inaccurate. Analysis of representations in *Shine* can reveal stereotypes and themes surrounding mental illness in Australian culture, and serve as the means for a discussion of alternate methods of framing David’s story which are more sensitive to the disability community.

The movie begins with David Helfgott, a quiet and socially awkward kid, who is forced to practice constantly by his controlling father. David soon wins a scholarship to study in London, and despite his father’s violent abuse and a threat that if he leaves he will “no longer have a father,” David accepts the scholarship. In London, he plays the “Rach 3” for a piano competition, and although he wins, the combined physical and mental strain of the piece causes him to collapse at the completion of the performance and have a mental breakdown. After time at a mental institution and with the help of his second wife, Gillian, he begins to perform music again. The movie concludes with him receiving a standing ovation at the end of a sold-out piano performance in Australia.

Australian films originally centered on masculine and rugged stories, and *Shine* is part of an increasing national trend to include the topic of disability in mainstream films (Rosen et al., 1997). Whereas Australian “psychiatric” films were originally more non-conformist and straightforward, *Shine* attempts to send a more inspirational message. For instance, the portrayal of David shows how people with mental illness can find a place in the world, and how people in general can triumph over adversity.

However, Scott Hicks, the director, often relies on stereotypes and sensationalism in the quest to tell an entertaining story. For example, Margaret Helfgott, David’s sister, has vehemently disputed the representation of David’s father, Peter Helfgott, as an abusive tyrant, stating that Peter was supportive, never abused David, and stayed in contact with him even after he left home (Helfgott, 1998). The film representation may tarnish the memory of David’s father and propagate the myth that families are to blame for mental illnesses (Rosen & Walter, 2000). The misconception that mental illness results from “a genius gone mad” is also advanced in the film; it appears that David’s devotion to and brilliant performance of the “Rach 3” ultimately drives him insane (Welch, 2007). Such a stereotype creates a simple cause and effect relationship for mental illness, and the association of mental illness and fallen genius may put unneeded pressure on individuals to accomplish something extraordinary to fit back into society.

David is also portrayed as a helpless child whose conversations are meant to be humorous. David’s second wife is represented as his savior and a pseudo-maternal figure, ignoring much of the independent time the real David had after his breakdown, like the years he spent in a half-way house (Rosen & Walter, 2000). Such an exaggerated portrayal reinforces paternalistic notions in Australia that individuals with mental illnesses are incapable of being self-reliant.

Although the film is Australian, the “rags to riches” theme and its heavy marketing in the United States make, “this Australian film ... in fact very Euro-American” (Lapointe, 1997), showing a need for both Hollywood and the Australian film industry to improve their representations of individuals with disabilities. Disability activist Jack Nelson, for instance, argues that films should “neither deny nor emphasize the disability portrayed” (Nelson, 1994, p.15). In the case of *Shine*, David could have been depicted as living and growing with his mental illness instead of battling it. Similar to films such as Sling Blade and The Best Years of Our Lives, instead of focusing on “childish incompetence,” the film could have also shown that prejudice and paternalism inherent in society were the main barriers to performing piano again (Riley, 2005, p.82-83). *Shine* is therefore an important step in raising consciousness about conditions of disability in Australia, but it is critical that future films avoid the stereotypes and misconceptions surrounding mental illness inherent in this film.

A majority of the world’s cancer patients live in developing countries, and the number will grow as populations increase, age, and adopt lifestyles and habits associated with modernity. The burden of cancer in these countries is compounded by a severe shortage of resources needed for cancer prevention, detection, and especially treatment. Meanwhile, pharmaceutical companies from the West are outsourcing more and more oncology trials to the developing world in order to save time and money. This trend has sparked concern over the ethics of human research in countries such as India, which has become a leading site for trials. Despite the flurry of concern, however, there has been little effort to empirically examine the Indian cultural context underlying research. This context must be accurately understood in order to identify the most pressing ethical issues and implement appropriate solutions.

With this objective in mind and the methods of cultural anthropology at hand, I spent the summer in Mumbai (Bombay) at Tata Memorial Centre, the foremost cancer institute in India. In collaboration with Dr. Rakesh Jalali, my interpreter, Mrunal Marathe, and I interviewed 80 cancer patients and 20 oncologists. We asked our participants to share their beliefs about various indicators of the context underlying cancer treatment research: the cause of cancer, the source of trust in treatment, the doctor-patient relationship, medical decision-making including the decision to participate in research, and the increasing number of trials in India.

Although we are still analyzing the data, a few preliminary conclusions can be drawn. It is clear, for example, that the safeguards designed to protect human subjects in the West, such as written informed consent, are currently inadequate in the Indian context. Social and cultural factors, such as low literacy and widespread poverty, immense faith and reverence toward doctors, a norm of acceptance rather than questioning, and a diminished or absent sense of individual rights, create a context in which patients cannot be expected to be true medical decision-makers. Doctors usually end up deciding whether their patients participate in trials, even when an optimal informed consent process is in place, so efforts to improve ethical conduct must be tailored accordingly.

Furthermore, efforts must also be directed toward the less sensational but equally important need for investigator-initiated research that stretches far beyond the drug development craze. As the burden of cancer grows in India, quality research is essential to understand the epidemiological realities and pathological variants of cancer in India; to assess the safety, efficacy, and cost-effectiveness of treatments in the Indian population. Although investigators have made strides toward achieving these goals, they continue to face obstacles such as insufficient funding. Addressing these obstacles and facilitating quality investigator-initiated research is an essential part of fulfilling our ethical obligation to the cancer patients of India.
Threatened Preterm Delivery: 
A Brief Overview
by Teresa Moro, AM, LSW
Clinical Educator, Donnelley Family Disability Ethics Program

Preterm births are relatively common occurrences around the world. About 12.5% of all births in the U.S. are preterm (IOM, 2006). A full-term pregnancy is 40 weeks gestational age and infants born between 22 and 25 weeks are considered extremely premature and at the “margin of viability.” This means that the infant’s chance of survival is less than infants born at later gestational ages (Hack & Fanaroff, 2000). While survival has improved, extremely premature infants are at risk for several short and long-term medical issues, such as initial breathing problems from immature lungs and later chronic lung changes from oxygen and ventilator use. Some extremely premature infants show impairments or disabilities as they develop, while some do not. This article will provide a brief synopsis of treatment guidelines in the U.S. and internationally and consider how personal and cultural values may affect medical decision-making.

In the U.S., there is currently no legislation mandating physicians’ medical management of mothers at risk of delivering between 22 and 25 weeks, or how their babies should be treated at birth. While the American Academy of Pediatrics (McDonald, 2002) and the American College of Obstetricians and Gynecologists (2002) offer management guidelines, there is no official consensus regarding treatment. This being said, there is some evidence to indicate that the majority of neonatologists in the U.S. will treat infants ≥25 weeks and will not institute resuscitative efforts for babies ≤22 weeks (Meadow, 2006).

This practice is consistent with the current standards outlined by medical societies in many industrialized countries (Pignotti & Donzelli, 2008). Specifically, in a review of existing guidelines put forth by medical societies in several countries including the U.S., Canada, the U.K. and Switzerland, there appears to be a general consensus that 22 0/7 to 22 6/7 weeks gestational age appears to be the “cutoff of human viability.” Thus, professional societies recommend only offering compassionate care at this gestation. There was also agreement that at ≥25 0/7 weeks gestation antenatal steroids, prenatal transport, and caesarean section, if indicated, are all recommended and that resuscitation is offered to all infants without a fetal anomaly.

Guidelines aside, there is also some evidence to suggest that physician’s personal or cultural values may impact their decision making. The EURONIC study was developed in order to explore physician practices in 142 Neonatal Intensive Care Units across ten European countries (Cuttini et al., 2000). Of the 1,391 physicians surveyed, most of them, regardless of country, responded that an outcome of severe mental disability was a result equal to or worse than death. There was not as great a consensus among physicians regarding severe physical impairment. The belief in the “sanctity of life” vs. the “quality-of-life” as a basis for treatment or non-treatment varied within and across countries. Personal attitudes towards resuscitation were significantly associated with physicians’ practices of setting treatment limits based on poor neurological prognosis, e.g., physicians who were more likely to set treatment limitations based on quality-of-life concerns were less likely to agree that all infants should be resuscitated. Physicians in many countries noted that a limitation of treatment was a “slippery slope” (Rebagliato et al., 2000, pp. 2454).

While there is no consensus on guidelines for treatment protocol in the U.S., based on the finding in the EURONIC study, it is possible that physician attitudes and values may impact the decisions made for babies born extremely prematurely. Before being able to draw similar conclusions for the physicians in the U.S., additional research needs to be conducted.


The United Nations Convention on the Rights of Persons with Disabilities
by Carmen A. Cicchetti, M.A., M.Ed
Business Support Manager,
Donnelley Family Disability Ethics Program

The World Health Organization (WHO) estimates that there are 600 million persons with disabilities, or roughly 25 percent of the world’s population. These persons are frequently denied human rights and are typically marginalized. On May 3, 2008, the U.N. Convention on the Rights of Persons with Disabilities and its accompanying Protocol received the necessary number of signatures by member states to become an international legal document. The U.N. General Assembly is expected to adopt the treaty at its next session, which started in September, 2008. The U.S. has not signed the Convention.

The Convention is a legally binding international human rights treaty. The countries which ratify this Convention commit themselves to eliminating discrimination on the basis of disability.

The principle of non-discrimination is the fundamental principle of human rights law. Other treaties such as the International Convention on the Elimination of All Forms of Racial Discrimination and the Convention on the Elimination of All Forms of Discrimination against Women are also based on this principle.

Since the focus is protection against discrimination, the Convention doesn’t create any new rights but simply identifies the specific actions that countries must take to protect against discrimination on the basis of disability. Human rights law protects against direct discrimination such as legislation or socio-cultural practices like refusing to admit a child with a disability into a school on the basis of a disability, or refusing to hire a person because they or their child has a disability. It also protects against indirect discrimination which is typically very subtle, such as providing medical services readily accessible to a person without a disability but inaccessible for a person with a disability.

The Convention marks a paradigm shift because it affirms that people with disabilities should not be viewed as "objects" of charity, medical treatment or social protection. Rather, like their counterparts, they are "subjects." They have rights and are capable of exercising their rights and making decisions based on their free and informed consent. Countries which ratify the Convention commit themselves to incorporating people with disabilities as full and active members of their societies.

The Convention has eight guiding principles:

1. Respect for an individual’s inherent dignity, autonomy, and independence
2. Non-discrimination
3. Complete and effective inclusion in society
4. Respect for human diversity and the perception of persons with disabilities as representative of that diversity
5. Equal opportunity
6. Accessibility
7. Equality between men and women
8. Respect for both the evolving capacities of children with disabilities as well as their right to maintain their identities

The Convention is a rich document and the first human rights treaty in the 21st century. For more information about the Convention, you can go to www.un.org/disabilities, www.ohchr.org, or to enable@un.org.
The 21st Rehabilitation International World Congress
by Kristi L. Kirschner, M.D.
Director, Donnelley Family Disability Ethics Program

I had the pleasure of representing RIC at the recent 21st Rehabilitation International (RI) World Congress which took place in Quebec, Canada from August 25-27. It was my first time attending the meeting, and quite an interesting experience. For those of you who haven’t heard of RI, it “is a global and diverse organization bringing together expertise from different sectors in the disability field, advancing and implementing the rights and inclusion of persons with disabilities.” Representatives from developed and developing countries across the globe attended and participated in the congress whose theme was “Disability Rights and Social Inclusion: Ensuring a Society for All.” I had a chance to meet and network with disability activists, leaders of independent living movements, policy makers, and health care and rehabilitation professionals. Locally, Marca Bristo, President of Access Living of Metropolitan Chicago and RIC Board member attended, playing a leadership role as the Vice President for North America of Rehabilitation International (RI), and President of the U.S. International Council on Disabilities. Also from Access Living were Daisy Feldt and Amber Smock. Karen Tamley represented the Chicago Mayor’s Office for People with Disabilities.

The hundreds of participants who attended the meeting shared information and experiences about topics ranging from the International Classification of Functioning, Disability and Health (ICF) with a particular focus on social participation and how to measure it, to education, employment, the disproportionate impact of war, violence and natural disasters on people with disabilities, and women’s health (there was a concomitant two day global summit on the Rights of Women with Disabilities). Pulsating as a unifying theme throughout the congress was the United Nations Convention on the Rights of People with Disabilities, a major human right document (see p. 11). Thus far there have been over 100 signatories to the treaty, not including the US. In an increasing global world, I believe that efforts to include the US as a signatory to this important document will clearly be important and you can bet there are a lot of discussions on-going about this issue, particularly in the current election year environment. So stayed tuned!

In short, it was a meeting I felt honored to attend, and we will continue to look for opportunities to foster international conversations on disability and human rights, which is one of major goals of the RIC Donnelley Family Disability Ethics Program.

Rehabilitation International logo and picture, courtesy of RI. The webpage for RI can be found at http://www.riglobal.org. RI works to promote the rights and inclusion of persons with disabilities in all parts of the world through advocacy, training and direct services.
Ethics Resources for RIC Staff

Currently located on the South Mezzanine level of RIC, the Donnelley Family Disability Ethics Program houses a library, periodical section, and VHS/DVD collection.

**Library.** The Ethics Library now houses over 700 volumes and 171 videos/DVDs, all focusing on some aspect of disability. These are available for staff to check out.

**Periodicals.** We currently subscribe to twenty-four periodicals. Among these are *The American Journal of Bioethics*, *Journal of Disability Policy Studies*, *The Journal of Clinical Ethics*, *The Hastings Center Report*, *Disability and Society*, and *Neuroethics*.

**Film Series.** Once each month, we show a film from our library collection. The film is always shown at noon, but the day varies to enable a variety of staff to attend.

**Educational Seminars.** Ethics Program Staff routinely present educational seminars on ethical issues which are requested by RIC staff.

**Ethics Scholars Program.** Staff teach a one-year program open to all members of the RIC community, providing training and professional development in ethics. Applications for our next Scholars Program will be available in February of 2009 and will be available online at http://www.ric.org/conditions/community/ethics

**Ethics Consultations.** Ethics consultations are available upon request by calling 312-238-1119.

Just two of the resources from our library on disability and global health.

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**Upcoming Events For RIC Staff**

**Film Series:**
- Fri, Oct. 24th: *Walk This Way*
- Tues., Nov. 18th: *Beyond Disability: The Fefe Stories*

**Educational Seminars:**
- Each month the Donnelley Family Disability Ethics Staff conduct an educational seminar for RIC staff.
- For information about times and locations of either our films or our educational seminars please contact Carmen Cicchetti at 8-1119 or ccicchetti@ric.org

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