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Editor's Forum

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This issue of *Health Ethics Today* is the first to appear after a series of major transitions at the John Dossetor Health Ethics Centre (JDHEC) during 2006. The *Oxford English Dictionary* defines transition as “passing or change from one place, state, condition etc. to another” and our experience this year fits the definition well.

In July Prof. Dick Sobsey was appointed as the new JDHEC Director replacing Dr. Paul Byrne as Interim Director. Prof. Sobsey has a distinguished career at the University of Alberta, in the Faculty of Education and as Director of the J. P. Das Developmental Disabilities Centre, and is widely recognized for his writing and advocacy for people with disabilities. We look forward to development of our teaching and research programs at JDHEC under Dick’s leadership.

A second transition saw the appointment of Dr. Brendan Leier to the JDHEC faculty and as Clinical Ethicist at the University of Alberta and Stollery Children’s Hospitals, replacing Dr. Barbara Russell who moved to the Centre for Addiction and Mental Health, Toronto. Brendan had been a Postdoctoral Fellow at JDHEC for the past two years.

The papers to follow reflect transitions in how health care is perceived and presented, in how practitioners view ethics, and in how the health records we keep are changing. Dick Sobsey draws attention to the gap between the public stance on

the rights of the disabled to health care in Canada and our day to day clinical practice. He argues that we do not in practice live up to the standard that we preach, and he challenges us to face up to this inconsistency as a matter of ethics upon which we should not remain silent.

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When teaching ethics to health care students and professionals we are often told that Bioethics is an ivory tower intellectual exercise focused on ethical rules and esoteric cases.

Brendan Leier's paper is an excellent answer to this charge. Brendan takes a famous statement from the political theorist, Hannah Arendt, on "the banality of evil" and applies it to the place of ethics in health care. He presents ethics as an everyday essential to being a good practitioner.

Eleanor Stewart describes a new development in how therapy may be presented as an 'already patented package' with a market driven approach. She asks us how we should respond ethically to this approach in our single payer system where patented therapies may be offered as 'special' and not available without direct charges to patients. She suggests that our re-

sponses will determine the future of our professional identity as health care providers.

The old standard paper medical record or chart is rapidly becoming obsolete as we move into the sophisticated electronic health record (EHR). The ability to gain access to information about patients electronically gives enormous advantages in continuity of care across different health facilities. Common worries about EHR refer to privacy, confidentiality, tampering and depersonalizing communication (whatever happened to the phone call referral between practitioners?). Mary Marshall and Joan Roch highlight a new concern; the need for good governance of the EHR. They state that good governance is as essential as good technology for EHR success because it allows custodians to have confidence in the robustness of the EHR. ■

Canadian Bioethics and The United Nations Convention on the Rights of the Child

Dick Sobsey, EdD

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The United Nations Convention on the Rights of the Child came into force on September 2, 1990 (U.N. General Assembly Document A/RES/44/25). As of May 8, 2006, 190 countries, including Canada, which ratified the Convention on December 13, 1991, have agreed to terms of the convention, making the Convention the most universally ratified human rights treaty in history. With the ratification by Alberta in March of 1999, all Canadian Provinces have also added their own commitments to support the agreement.

The Convention has important implications for bioethics, but 16 years after the Convention took force, there has been relatively little discussion of these implications in the Canadian bioethics community. While many of the 54 articles of the convention have important implications for bioethics, a few stand out as having profound implications.

Article 6, The Right to Life and Survival, and *Article 24, The Right to the Highest Attainable Standard of Health Care*, are two of the most obvious. *Article 1*, which defines a child as "every human being below

the age of eighteen years unless under the law applicable to the child, majority is attained earlier," and *Article 2*, which prohibits discrimination on the basis of disability (among other attributes), may have even more powerful implications. *Article 23, The Special Rights of Children with Disabilities*, requires that special assistance be provided to children with disabilities, including enhanced medical treatment and health care.

One of the most obvious implications for bioethics is related to the selective non-treatment of infants with severe disabilities (Sobsey, in press). Under the Convention, once born, a child's right to survival is absolute and inviolable. Potential quality of life rationale for denying this right stemming from a child's disability are prohibited as discriminatory, and parental consent or even parental demands to withhold life-saving treatment become irrelevant because parents have no authority to deprive their children of their universal rights. In addition, *Article 23* requires special efforts be made to ensure the survival of children with disabilities. In short, any failure to provide

the best available medical treatment based on the nature or extent of a child's disability appears to be clearly prohibited under the Convention.

Europe has reacted to the bioethical implications of the Convention in at least two significant ways. First, the *1995 Resolution on respect for human rights in the European Union* cites the Convention in framing its prohibitions on euthanasia and withholding life-saving treatment. Sections 17 and 18 of the resolution state:

that the right of life includes the right to medical treatment, and that this right must be afforded to all persons irrespective of status, health condition, sex, race, ethnic origin, colour, age, religion, or convictions;

and

calls for a ban on euthanasia to the detriment of the disabled, patients in long-term coma, disabled new-born infants and the elderly.

In one of the few attempts to reconcile the commonly held principles of bioethics and requirements of the Convention, UNESCO (2001) convened an international symposium "Bioethics and the Rights of the Child" in Monaco in April, 2000. Although the 200 delegates failed to reach complete consensus on many essential issues, general agreement was reached regarding the requirements of the Convention on protection of the survival of children with disabilities:

A child's disability, whatever the degree, should never be considered as a liability...

When interests [of the parent and child] differ, the child's best interest should, in principle, prevail over that of the adult...

Under no circumstances should the sole interest of society prevail over that of the child.

Protection of rights must be reinforced if the child is disabled...

The North American bioethics community, however, has been virtually silent. One of the few organizations to break this silence has been Yale University's Interdisciplinary Center for Bioethics, which ran a series of seven lecture and discussion meetings on the implications of the Convention during the 2005-2006 academic year (*The Rights of Children, 2005-2006*). It is both commendable and ironic that an American



University has taken the lead on this dialogue since the United States is one of the few nations that has failed to ratify the Convention (Mason, 2005). By contrast, Canada appears to have signed the Convention but ignored its obligations under the pact. The Canadian Bioethics and health care communities have a responsibility to promote these rights and to respect these obligations, or else refute them. Simply ignoring them does not seem like an "ethical" response to the Convention. ■

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On the Banality of Ethics

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In 1961, the philosopher Hannah Arendt visited Jerusalem to cover the trial of the Nazi SS Officer Adolph Eichmann who was responsible for much of the planning of the holocaust. Arendt's conclusions on the trial appeared in her book, *Eichmann in Jerusalem: A Report on the Banality of Evil*. Two general opinions about Eichmann emerged during the trials. The first, characterized in Eichmann's defense, claimed that Eichmann had a primary duty to follow orders and could not be found guilty for carrying out orders from higher command. The second opinion held that Eichmann shared the same anti-Semitic psychopathy as his Nazi superiors and this hatred fueled his passion for the holocaust. Arendt, however, suggested a third description of Eichmann, calling him "the embodiment of the banality of evil". Arendt makes a remarkable point in dismissing both Eichmann's claim of innocence and the explanation of Eichmann's actions as pathologically motivated or spurred through pure hatred. What she introduces is the notion that a more or less unremarkable, ordinary person can act in the most grotesque fashion under appropriate influences and conditions.

I play on Arendt's title to demonstrate a point about ethics following her point about evil. It was important for many survivors of World War Two, to make sense of Hitler's rise to power as an anomalous historical occurrence wherein the world bore witness to evil incarnate. However, Arendt argues that a close examination of the orchestrators and executors who carried out the holocaust, admits no common thread of hatred or psychopathy. On the contrary, almost all were ordinary people in every sense. If this so, then the vilification of the orchestrators and executors of the holocaust served to mask an essential truth about the potential behaviour of all 'ordinary' people.

In 1963, American psychologist Stanley Milgram provided 'empirical evidence' in support of Arendt's thesis. Motivated by the Nuremberg trials, Milgram devised a cunning experiment to determine to what extent an authority figure could motivate an experimental subject to perform acts contrary to his or her own conscience. Experimental subjects were told that they would be participating as a 'teacher' in a study on memory and learning. Other members of Milgram's team were given the role of 'learner'.

Experimental subjects were lead to believe that the 'learner' was another study recruit. (it is interesting to speculate if this research would get research ethics approval today)

The subject 'teacher' witnessed the 'learner' being placed in a chair with arm restraints and fitted with electrodes for the purpose of supposedly administering electrical shocks during the experiment. The subject 'teacher' was then taken to an adjacent room and seated before a large buzzing panel with a series of switches labeled from 15 to 450 volts. The switches were also labeled with descriptions that ranged from 'Mild Shock' to 'XXX Danger Severe Shock'. When the experiment began, the 'teacher' asked the 'learner' to respond to a set of word pairs. When the 'learner' gave a correct answer, the 'teacher' moved to the next pair. When the 'learner' gave an incorrect answer, the 'teacher' was instructed to give a shock by flipping a switch. After every wrong answer, the voltage was increased one increment. Though the 'teacher' was not aware that no actual shock was given, the 'learner', would respond as if a shock was felt. The responses ranged from grunts, to loud complaining, to pleas for release, to screams of agony, and finally with no response at all after high voltage shocks (this was to lead the 'teacher' to believe that the 'learner' was unconscious or worse). Whenever the 'teacher' hesitated, a man in a white coat (supposedly the scientist in charge) would command the 'teacher' to continue. The 'white coat' was responsible for pushing the 'teacher' to continue and used several strategies to do so including taking responsibility for the well-being of the 'learner' and aggressively demanding that the 'teacher' continue even when the 'learner' became unresponsive.

The results of the Milgram study rank among the most remarkable in social science. Over 65% of subjects were motivated to complete the task, which meant that all the switches from 15 to 450 volts had been thrown. Few subjects did this willingly and almost all displayed signs of moderate to severe psychological distress. But under the watchful eye of the authority figure, a large majority of the 'teachers' complied with their experimental expectations. To Milgram, the findings left little doubt that, given the appropriate social situation and motivation, ordinary

individuals have the capacity to perform acts they themselves find unconscionable.

These uncomfortable conclusions seem to penetrate to the heart of human nature, especially when considering what form of care we can expect from our own social group. If the scope of evil extends to the broadest reaches of our social realm, I argue that our moral theory must follow. If social situations and hierarchical structures have such a profound impact on the behaviour of individuals, what impact does this have on how we form ethical expectations and standards for individuals working in healthcare?

A common impression of ethics is that its role lies in the margins, in the ethereal realm of values, in the executive board-room, in the scientific laboratory, in the high court of law, in the military prison, on the cusp of life and death. Bioethics, when reaching the public eye, does nothing to disavow the impression that its role is grappling with the fantastical future (stem cell research, human cloning, designer DNA) or the calamitous present (exotic cases, pandemic planning, terrorist attacks).

If ethical practice in the form of adherence to norms, seeking education, or increasing one's moral attunement, has the potential to mitigate the occurrence of everyday evil, then the status and role of ethics needs to be reconsidered. If evil can so commonly



dwel among us then so too must morality. As such, ethical status and sphere of interest must become a matter of the banal, the everyday. Practically speaking, my own interest lies in the potential of 'everyday ethics' finding its home in the hospital, the examination room, the outpatient clinic, in the extended-care facility, in all the places where people gather to care and be cared for. One might wonder if this is even a legitimate concern; whether caring professionals working together toward a common goal could ever be influenced to harm instead of help. Unfortunately, as clinicians themselves attest, all the features of the Milgram experiment are present in the delivery of healthcare today. Healthcare in the Western world is delivered inside a

system increasingly organized along hierarchical corporate models. As well, although the 'team-approach' to care is now widely practiced, the composition and activity of the healthcare team demonstrates strict hierarchical structure. This residue of centuries of medical tradition is seen in the persistence of the language of 'doctor's orders'. Both organizational structure and the 'culture of medicine' provide the influence necessary for the Milgram effect. Finally, the provision of modern healthcare bears witness to a growing fragmentation of patient care. This fragmentation is beneficial in that it allows for patients to be seen by a variety of specialists. However, the

fragmentation of care unfortunately may result in a fragmentation of the perception of patients as persons. If clinicians are only responsible for particular aspects of individual patient care, attention to the interests of the patient as a whole will suffer. This fragmentation also allows clinicians to avoid ethical responsibility for the long-term implications of specialized care. Again, this mechanism to ‘cast-off’ moral responsibility is an organizational feature identified by Milgram as essential in compliant behaviour.

Fortunately, for the conscientious caregiver, there are several ways to mitigate the occurrence of the types of harms identified above. Many caregivers over time, and through modeling trusted mentors, learn to identify and incorporate a kind of ‘mindful virtue’ into their clinical practice. My first suggestion simply involves the recognition of the Milgram effect itself, particularly, that great harm and suffering does not necessarily rely on malevolent motivations or intentions. I suggest that thoughtlessness alone is more than enough to create the necessary gap between clinician and patient that allows for lack of care and resulting harms.

Ethics is often associated with the application of principles or rules to guide behaviour or actions. I do not wish to diminish the necessary function of rules that help prevent patient harm, but such rules often embrace negative obligations, i.e., actions and behaviors to avoid. My second suggestion is that in transcending the limitations of rule-based approaches to ethics, the clinician must learn the ‘practice’ of ethics in the form of the exemplification of moral virtues.

The first of these virtues is the virtue of mindfulness. As a clinician you are morally attuned to your patient only insofar as you are mindful of the clinician - patient relationship as it develops. This type of mindfulness can be best understood as being

‘present with’ or ‘there for’ patients as they express their concerns. Most people have had the experience of being with someone who is not ‘present for you’ while you ‘tell your story’ and we recall how this lack of presence made us feel. It is the practice of this ‘presence’ that connects the clinician to the patient as a person, not as a statistic on a chart, or the third of five patients to be seen. This is also the extraordinary process in which the clinician - patient relationship is forged. In reflecting on my own experience interviewing patients about perceptions of quality of care, it is the nature of this experience (the presence) that influences, even more than medical outcomes, their subjective experience of quality of care. For the critic, subjective experiences of care may seem to be irrelevant as criteria for assessing what objectively appears to be a good outcome. However from an ethics perspective this ‘presence’ is the very ground of the healing disciplines, it is the essence of care. Mindfulness is a skill like any other that must be practiced to be perfected. The benefits are recognizable for both patient and clinician. The greater extend to which you are ‘present’ for your patient will inevitably open up richer avenues of understanding and self reflection in addition to their therapeutic value.

To conclude, for the clinician, the important lesson from thinkers like Arendt and Milgram is that the difference between the best and the worst ethical standards of care is not as momentous as we once might have thought. In recognizing the ‘banality of ethics’ we commit to use each moment we spend with a patient to forge a respectful relationship essential to the provision of good care. ■

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To Market, To Market: Changing Service Delivery to Children with Autism

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Children with Autism Spectrum Disorder (ASD) represent an increasing number of the children with communication disorders served by speech-language pathologists (SLP). One in 200 children will be affected by this neurodevelopmental disorder (Fombonne, 2003). This group of children has garnered the attention of clinicians, researchers, funding agencies, and law and policy makers. As is often the case in the field of intervention for children with disabilities, a plethora of interventions aiming to make positive differences in the lives of children with ASD is available.

Recently I attended a conference session hosted by Relationship Development Intervention® about a “unique treatment program” for children with ASD. I offer the following story of a change in the context of service delivery to children with ASD that may adversely impact the nature of the SLP’s relationship with these children and families. This change will also require the profession’s notions of moral identity and agency to be examined.

The presentation felt vaguely like an infomercial. The SLP presenter noted that she was among a group of less than 10 Canadian clinicians certified to deliver the U.S. based program. There was very limited information about how this program differed from familiar approaches to ASD since the intervention was trademarked; access to methods and content was restricted to program enrolled parents of children with ASD, certified program clinicians, or program clinical trainees. However, the material presented was familiar to the SLP audience but appeared to be re-packaged in a new form, using new vocabulary developed by the program’s authors (Gutstein and Sheely, 2002). Supporting effectiveness research evidence was scant with only preliminary unpublished research results presented. This type of conference presentation is not unusual in early intervention practice, except that this particular intervention program was already trademarked and had gone to market with this SLP appearing to be its “agent”.

In her paper entitled “Care and the extension of markets”, (Held, 2002) outlines the progression toward marketization of what was previously seen as social goods in areas such as healthcare, education, and

childcare. For some time, Held states, public health care and education have been presented as inefficient, costly, and unsustainable while market solutions are proposed to solve these ills. When a service is eventually taken to market, Held states that the values that underpin the activity shift so that the primary norm is maximizing profit. The extra market norms, such as caring, which previously guided the activity, are displaced in importance.

In Alberta, funding for children with ASD remains in public hands to the extent that provincial governments allocate funding to enable families to purchase services from a range of providers. As services to children with disabilities such as ASD are increasingly out sourced, the opportunities for private practice have expanded (personal communication).

This trend has resulted in services for children with ASD being commodified for some time. As my example illustrates however, the potential for competition among providers is being set up in a way that SLPs have not seen before. With the advent of trademarked programs for ASD, a more complicated picture is developing of how SLPs and families will choose interventions.

In the future, it may not be sufficient to be a qualified licensed SLP to be successful in providing services to clients. Clinicians with years of experience and knowledge will compete with ‘specialist’ clinicians who offer access to unique trademarked intervention programs aimed at specific conditions like ASD. In a more crowded market driven system, without evaluation of services offered, this program training may well give a false impression of clinical superiority to clients. Further, following Held’s (2002) argument, there is also the risk that when self-interest is the motivating force as it is in markets, clinicians may be less inclined to share information and knowledge that gives them a competitive edge.

Newer clinicians are perhaps more attuned to the market model of providing clinical services. In a recent discussion with graduate trainees from rehabilitative medicine programs, I noted that the majority expressed interest in establishing their own private practice upon graduation, rather than working in publicly



funded and delivered clinical services. Children with ASD are a population large enough in number and with sufficient funds to sustain a specialized private practice at least in urban areas in Canada. I suspect that new SLPs lacking in experience, may be attracted to trademarked programs as a way to boost their marketability and “competitive edge”.

This change in service delivery also leads me to wonder about notions such as professional moral

identity and moral agency of health care providers. If we change the structure of delivery, we are likely tampering with other aspects of the clinical practice. Moral identity has been found to be a predictor of moral action (Damon and Gregory, cited in Doane, 2004). As practitioners we define ourselves and our agency in accordance with what we believe is right and why. The social process of professional moral identity formation is extended over time and contexts through engagement in the activities that are constituent of clinical practice (Doane, 2004). If I move from the public to the private and then to the corporate sector, how is my professional moral identity changed?

As clinicians engage in new forms of market driven clinical practice, their roles and relationships will change and possibly new moral identities will be formed. While it is true that all clinicians are seeking to improve their patient’s health and to earn a living, the guiding principle when labour is marketized is economic gain. The risk is that profit becomes the priority over such non-market values as caring for or promoting the flourishing of others.

This new trend may displace ethical norms traditionally associated with SLP practice in favour of market driven norms. SLPs will be challenged to reconsider and clarify their professional moral values and to reconstruct their identities in order to work in the new market. As a profession intimately involved in the care of children with ASD and other disabilities, we need to seek this clarity now. ■

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Governance of the Electronic Health Record

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The health system is information intense. It is estimated that there are over 3 million health related transactions per day in Canada (Health Canada, 2001); transactions that require documentation and that flow from one part of the circle of care to another. Electronic health record (EHR) systems are increasingly being used to document the transactions and support the information flow.

By definition, the EHR is a secure and private life-time record of an individual's key health history and care within the health system. The record is to be made available electronically to authorized health care providers and the individual patient anywhere, anytime in support of quality care (Canada Health Infoway, 2003). In essence, the EHR is being created to facilitate the sharing of key pieces of health information between multiple authorized custodians across the continuum of care, across healthcare delivery organizations and across geographies, to support the provision of optimal care. In an EHR environment, custodians within the circle of care must have confidence that the systems in which the data are held will meet certain levels of service.

Custodians must have confidence that:

- the systems will be available when they are needed during the day, night or on weekends,
- the integrity of the information will be maintained as it flows between custodians,
- the data will be properly protected, kept secure and confidential in each part of the system,
- the storage and communication systems will be protected from intrusion, and
- the data will be properly managed and handled by each custodian.

Custodians must also have confidence that only authorized individuals will have access to the data, and that the data will only be used for authorized purposes; such assurances do not exist in many of the current paper systems.

Governance embodies the rules by which a system or organization will function. Those involved in the de-



velopment of the EHR system have noted the need for an organized approach to overall governance of both the system and the information held by the multiple custodians, to ensure reliable, effective, seamless operation of a system that is trusted and used by health care providers (Canada Health Infoway, 2006).

Legislation and professional rules of conduct prescribe many rules for custodians. However, in neither case do the rules extend to matters of operation that need to be addressed in an interoperable EHR system. For example, current legislation and professional rules of conduct would not identify who would be responsible for handling system operations such as back-up procedures or problems; or who would be responsible for determining what data are to flow into the EHR, or who would be authorized to view or change the data. The Pan-Canadian Health Informa-

tion Privacy and Confidentiality Framework (2005) released by the Advisory Committee on Infostructure and Emerging Technology provided some additional guidance, but the EHR requires agreement on a precise set of rules to address overall EHR governance and data stewardship matters. It also requires a body to approve, maintain and oversee these rules (Pharmaceutical Information Network, 2002).

Governance is as essential as technology to the success of the interoperable EHR initiative (Canada Health Infoway, 2005). A number of jurisdictions are already tackling the issue. Governance in the EHR context is a new area of health information management that will affect all jurisdictions as well as pan-Canadian interoperability. As such, Canada Health

Infoway is also studying the topic with an aim to increasing awareness of the important role governance plays in the effective functioning of the EHR. ■

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Upcoming Events

Dossetor Centre Health Ethics Seminars:

Please check the John Dossetor Health Ethics Centre website at www.ualberta.ca/BIOETHICS/ for an updated seminar schedule.

Edmonton Aging Symposium:

The John Dossetor Health Ethics Centre is very pleased to sponsor Dr. Daniel Callahan from the Hastings Center, as a symposium feature speaker for the Edmonton Aging Symposium, 30-31 March 2007, Bernard Snell Hall, Walter Mackenzie Health Sciences Centre.

For more information: <http://www.edmontonagingsymposium.com/>

Bioethics Week 2007:

Bioethics Week will take place from 5 – 11 March 2007. More information available at: <http://www.phen.ab.ca/bioethicsweek/>

AVAILABLE NOW!

Ethics in Health Care Research Five Video Scenarios

The videos portray realistic situations which raise ethical issues about the treatment of human subjects in health care research. The researchers' dilemmas are left unresolved so that viewers can suggest possibly appropriate actions.



Video 1 Turning a Blind Eye (10 minutes)

- touches on reporting medical errors observed in the course of a research project, the limits of research subjects' right to confidentiality, and the risks involved in reporting.



Video 2 Michael's Journey (12 minutes)

- highlights subjects' rights to change or withdraw data they have provided, concerns over subject anonymity, and whether persons about whom subjects have provided data have any rights to that information.



Video 3 The Almighty Dollar (9 minutes)

- focuses on difficulties researchers face in acquiring subjects, such as accessing other clinicians' clients, how closely to follow inclusion criteria, and concern over subjects who are not able to give informed consent.



Video 4 A Line in the Sand (11 minutes)

- explores the rights of funders to influence the course of research and presentation of findings, including feedback to subjects on adverse events which occur during the course of a study.



Video 5 The Ties that Unbind (10 minutes)

- raises issues about the use of electronic data files for secondary analysis, including protection of subject privacy when names are attached, whether consent should be obtained, and special circumstances when potentially vulnerable.

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