

**John Dossetor
Health Ethics
Centre**



**John Dossetor Health Ethics Centre
Annual Report
1 April 2007 – 31 March 2008**



UNIVERSITY OF
ALBERTA

• **CONTENTS**

Introduction	page 3
Mission Statement	page 3
John Dossetor Health Ethics Centre Operational Overview	page 3
Core Activities	page 4
Operating Budget 2007-2008	page 5
Faculty Research Funding	page 6 - 7
Teaching	page 7 - 8
Supervision of Graduate Students and Postdoctoral Fellows	page 8 - 10
Presentations	page 11 - 14
Publications	page 15 - 17
Faculty, University and Community Committees and Membership	page 17 - 19
Health Ethics Consultation Service	page 19 - 20
Library Resources	page 20
Media Requests	page 21 - 22

• INTRODUCTION

The John Dossetor Health Ethics Centre is committed to excellence in health care ethics through scholarship, discovery learning and community engagement. In 2007-2008 the John Dossetor Health Ethics Centre (JDHEC) maintained this commitment. Ongoing, established events such as Health Ethics Seminars, Grand Rounds, Health Ethics Week, publication of the newsletter *Health Ethics Today*, and Clinical Ethics Committee Education Day, continued over different parts of the year. In addition, over the year major efforts were implemented to develop a 5-year (2008-2013) Strategic Plan for the Centre.

• MISSION STATEMENT

The John Dossetor Health Ethics Centre endeavors to promote ethical engagement, mutual respect and critical reflection on matters of moral concern in health care. We aim for excellence in four interdependent domains of activity: interdisciplinary scholarship, clinical ethics, health policy consultation, and professional and public health ethics education. Compassion and social justice are cross-cutting themes in all that we do.

• JOHN DOSSETOR HEALTH ETHICS CENTRE OPERATIONAL OVERVIEW

Director

Dick Sobsey, EdD
Professor
Faculty of Education

Faculty

Wendy Austin, RN, PhD Canada Research Chair Professor Faculty of Nursing	Paul Byrne, MB, ChB, FRCPC Clinical Professor Faculty of Medicine & Dentistry	Glenn Griener, PhD Associate Professor School of Public Health Faculty of Arts
Brendan Leier, PhD Assistant Clinical Professor Faculty of Medicine & Dentistry	Laura Shanner, PhD Associate Professor School of Public Health	

Staff

Carol Nahorniak, BSc Centre Administrator	Stacy Cabral, BA Information Officer	Edna Cunningham Liley Information Officer
--	---	--

Adjunct Faculty

Dr. Eric Blyth University of Huddersfield Huddersfield, England	Dr. Ronald Damant Pulmonary Medicine University of Alberta	Dr. Patricia Marck Faculty of Nursing University of Alberta
Ms. Lisa Shields Edmonton, Alberta	Dr. Derek Truscott Faculty of Education University of Alberta	

• **CORE ACTIVITIES**

Since its conception in 1985 the John Dossetor Health Ethics Centre has provided scholarly excellence in health care ethics research, education and community service to students, faculty and staff at the University of Alberta, members of Capital Health, other health care agencies and the general public.

Graduate courses taught were INT D 570 (Health Care Ethics), INT D 670 (Research Ethics) and PHS 543 (Public Health Ethics, Law and Policy).

Research continued in the areas of: Clinical Practice, Compassion, Disability Ethics, Emerging Technologies, Gender Issues, Health Policy, Human Rights, Mental Health, Moral Distress, Neonatal-Perinatal Ethics, Public Health, Relational Ethics, Risk and Reproductive Ethics.

Service took place as:

- Clinical consultation
- Participation/Membership on
 - Ethics Committees in the Capital Health region
 - International Academy of Law and Mental Health
- Providing Health Policy Consultation in Assisted Reproduction, CACL Task Force, CHA Home Care, Disclosure, End of Life, Stem Cell, Organizational Ethics, Pandemic and UNICEF
- Health Ethics Today (newsletter)
- Health Ethics Seminar Series
- Health Ethics Week
- Clinical Ethics Grand Rounds
- Media requests

• **JOHN DOSSETOR HEALTH ETHICS CENTRE OPERATING
BUDGET 2007-2008**

REVENUE

Faculty of Medicine & Dentistry	\$74,445.00
Health Sciences Council	\$53,500.00
External Revenue – Other Internal Revenue (Capital Health)	\$15,694.00
External Revenue – Other Internal Revenue (UAH Foundation)	\$3,148.00
External Revenue – Symposium Non-Credit Fees	\$1,285.72
Ethics Research Videos	\$198.12
Trustholder Extraordinary Expenses Fund (TEEF) Reimbursement	\$26,546.58

TOTAL REVENUE **\$174,817.42**

EXPENDITURES

Support Staff Salaries	\$100,564.45
Benefits	\$19,943.27
Supplies, Services & Sundries	\$12,425.26
Utilities	\$0.00
Communications	\$7,338.22
Travel/Hosting	\$1,717.82
Repairs & Maintenance	\$180.88
Credit Card Fees/Discount Fees	\$98.85
Rentals & Leases	\$2,216.34
Capital Equipment, Collections & Construction	\$0.00

TOTAL EXPENDITURES **\$144,485.09**

Academic Salaries:

Wendy Austin	1.0 FTE Nursing
Paul Byrne	0.2 FTE Medicine & Dentistry
Brendan Leier	0.3 FTE Medicine & Dentistry
Glenn Griener	0.6 FTE School of Public Health, 0.2 FTE Philosophy, 0.2 FTE Nursing
Laura Shanner	1.0 FTE School of Public Health
Dick Sobsey	0.5 FTE Faculty of Education, 0.5 FTE Health Sciences Council

• FACULTY RESEARCH FUNDING

Research Funding and Awards to Faculty of the John Dossetor Health Ethics Centre

Name	Principal / Co-Investigator	Recent Awards / Research Grants	Amount	Research	Date
W. Austin		Canada Research Chair	\$500,000	Relational Ethics in Health Care	2003-2008
	Principal	Social Sciences and Humanities Research Council	\$155,000	“Compassion Fatigue” As Experienced By Canadian Health Professionals	2007-2010
	Principal	Canadian Institutes of Health Research	\$146,726	The Experience and Resolution of Moral Distress in Pediatric Intensive Care Teams	2007-2010
	Co-Investigator	Canadian Institutes of Health Research	\$49,838	Ethical Issues in Transplantations and Research with Deceased Individuals	2007-2009
	Co-Investigator	Canadian Institutes of Health Research	\$24,340	Community Consultation to Design an Intervention to Reduce AIDS Stigma	2006-2007
	Principal	World Health Collaborating Centre in Nursing and Mental Health	\$25,000	Promoting and Supporting Ethical Mental Health Care: An International Initiative	2007
	Principal	The Caritas Health Group	\$4,997.33	Compassion Fatigue: The Experience of Nurses	2006-2007
	Principal	The Canada Foundation for Innovation	\$55,328	Relational Ethics in Healthcare Research Centre	2004 - 2009
	Principal	Social Sciences and Humanities Research Council	\$65,000	Ethical Relationships in Forensic Settings	2004 - 2007
	Principal	Capital Care Foundation	\$20,000	Supporting Relationships Between Family and the Healthcare Team in Traditional Continuing Care Settings	2004 - 2007
	Principal	Canadian Institutes of Health Research	\$247,613	Risks to Participants in Qualitative Interviews: Perspectives of Researchers, Participants, and Research Ethics Boards	2003 - 2008
	Co-Investigator	Canadian Institutes of Health Research	\$1,759,868	EQUIPP: A Training Program to Enhance Qualitative Understanding of Illness Processes and Prevention	2003 – 2009
P. Byrne	Principal	Stollery Children’s Hospital Foundation	\$8,100	Treatment Choice for Hypoplastic Left Heart Syndrome: A Question of Ethics	2005-2008
	Principal	Social Sciences and Humanities Research Council	\$37,840	Giving and Receiving Unexpected News Following Prenatal Ultrasound Examination	1998 - 2007
	Co-Investigator	The Caritas Health Group	\$4,997.33	Compassion Fatigue: The Experience of Nurses	2006-2007

Faculty Research Funding continued:

Name	Principal / Co-Investigator	Recent Awards / Research Grants	Amount	Research	Date
B. Leier	Co-Investigator	Stollery Children's Hospital Foundation	\$8,100	Treatment Choice for Hypoplastic Left Heart Syndrome: A Question of Ethics	2005-2008
	Co-Investigator	The Caritas Health Group	\$4,997.33	Compassion Fatigue: The Experience of Nurses	2006-2007
D. Sobsey	Principal	Social Sciences and Humanities Research Council	\$38,865	Defining Disability Ethics	2008-2010
	Co-Investigator	Alberta Centre for Child, Family, and Community Research	\$100,000	Sustainable Support Services for Families of Children with Severe Disabilities	2008-2010
	Co-Investigator	From Archives to Activism. Community-University	\$20,000	Proposal Development Grant	2008

- **TEACHING**

AUSTIN:

- INT D 570 Healthcare Ethics - Spring 2007

GRIENER:

- INT D 670 Research Ethics - Winter 2008

SHANNER:

- PHS 543 Public Health Ethics, Law and Policy - Winter 2008

Incidental Guest Lectures:

- Pharmacy 212
- Fetal Physiology 513
- INT D 600 Maternal-Fetal Medicine

Course Development:

- Updated PHS 543 Public Health Ethics, Law and Policy
- Created integrated curriculum across 5 core courses for Master's Public Health programs in School of Public Health
- Updating PHS 709 Ethics in Health Care Organizations

Mentor and Educator:

- Maternal-Fetal-Newborn Health Strategic Training Program

SOBSEY:**Incidental Guest Lectures:**

- EDPY 597 Integrative Health Care Education
- MED 526 Patient-Centred Care Part II - Winter 2007
- DDS 520 Patient-Centred Care - Winter 2007

Teaching continued:**SOBSEY:****Course Development:**

Worked with Continuing Medical Education Department, Faculty of Medicine and Dentistry to develop a joint Faculty of Education – Faculty of Medicine Master’s Degree Program in Medical Education.

- **SUPERVISION OF GRADUATE STUDENTS AND POSTDOCTORAL FELLOWS**

AUSTIN:***Supervision, Doctoral Degrees******In progress:******Supervisor***

Diane Kunyk, Nursing, 2007 - (Supervisor) *Nurses’ Experience of Addictions*

Nicole Snow, Nursing, 2006 - (Supervisor) *Community Mental Health Ethics*

Michele McIntosh, Nursing, 2005 - (Supervisor) *Risks to Participants in Qualitative Research*

Cheryl Webster, Nursing, 2003 - (Supervisor) *Depictions of Psychiatric Nursing in Film*

Cindy Peternelj-Taylor, Nursing, 2002 - (Supervisor) *Ethics, Engagement & Forensic Nursing*

Co-Supervisor

Jocelyn Dye-Grech, Nursing, 2003 - (Co-Supervisor) *The Lived Experience of IVF & Selective Reduction/ Abortion of Infertile Couples*

Julija Kelecevic, Forensic Anthropology, 2001 - (Co-Supervisor) *Situating Forensic Anthropology: Ethical and Professional Issues*

Anne Marie Creamer, Nursing, 2002 - (Co-Supervisor) *Stigma*

Supervisory Committee Member

Lisa Adams, 2006 - (Supervisory Committee)

Catherine Thibeault, Nursing, (McGill University), 2005 - (Supervisory Committee) *The Relational Experience of Hospitalized Persons with Acute Mental Illness and their Nurses*

Danielle Leigh Fullerton, Educational Psychology, 2004 - (Supervisory Committee) *Well-Being of Female Academics*

Michelle Vandergrind, Educational Psychology, 2004 - (Supervisory Committee) *An Interpretive Inquiry of Adolescent Sibling Sexual Offenders’ Experience of Counselling*

Rebecca Porter, Nursing, (University of Iowa), 2003 - (Supervisory Committee) *Futility*

Examining Committee Member

Shelley Raffin, Nursing, 1998 - (Examining Committee for Proposal Defence)

Mentoring

Kertchok, Ratchaneekorn, Nursing, 2005 - *Relational Ethics*

AUSTIN continued:**Completed:**

Bashir Jiwani, Public Health Medicine, 2004 - 2008 (Examining Committee for Proposal Defence)

Yu-Ri Kim, Educational Psychology, 2003 - 2008 (Examining Committee for Candidacy Exam) *Personal-Safety Vocabulary for Children with Disabilities*

Marion Healy-Ogden, Nursing, 2001 - 2007 (Supervisor) *The Lived Experience of Well-Being*

Gerri Lasiuk, Nursing, 2001 - 2007 (Co-Supervisor) *The Lived Experience of Pregnancy and Birth of Women with Histories of Childhood Sexual Abuse*

Susan Ray, Nursing, 2004 - 2007 (Supervisory Committee) *The Lived Experience of Peace-Keepers*

Don Rose, Nursing, (University of Toronto) 2007 (External Examiner) *Exploring the Concept of Respect in Forensic Psychiatric Nursing: A Focused Ethnography*

Supervision, Masters Degrees**In progress:****Supervisor**

Dawn Kocuper, Nursing, 2005 - (Supervisor) *Ethical Decision Making*

Duncan (Stewart) MacLennan, Nursing, 2005 - (Supervisor) *Care Relationships with Incarcerated Youths*

Monica Whitehead, Nursing, 2004 - (Supervisor) *Spirituality*

Co-Supervisor

Kathryn Fisher, (Co-supervisor), *Aboriginal families with a child in PICU*

Pepper, Dawn, Nursing, 2006 - (Co-supervisor) *Ethical Decision Making for Parents in the NICU*

Completed:

Gillian Lemermeyer, Nursing, 2002 - 2007 (Supervisor) *Relational Ethics in the NICU*

Gwen Thompson, Nursing, 2004 - 2007 (Supervisory Committee) *Nurses' First Experience of Death in the ICU*

BYRNE:**Supervision, Doctoral Degrees****In progress:****Co-Supervisor**

Jocelyn Dye-Grech, Nursing, 2003 - (Co-Supervisor) *The Lived Experience of IVF & Selective Reduction/ Abortion of Infertile Couples*

Supervision, Masters Degrees**Completed:**

Gillian Lemermeyer, Nursing, 2002 – 2007 (Supervisory Committee) *Relational Ethics in the NICU*

**Supervision of Graduate Students and Postdoctoral Fellows continued:
SOBSEY:**

Supervision, Doctoral Degrees

In progress:

Supervisor

Robert Cey, Educational Psychology, (Supervisor) *Changes in Sexual Preferences*
Wanapa Intaprasert, Educational Psychology, (Supervisor) *Families of Children with
Developmental Disabilities*
Tim Weinkauff, Educational Psychology, (Supervisor) *Ambivalence Amplification Theory
& People with Disabilities*
Jocelyn Wilkie, Educational Psychology, (Supervisor) *PRN Orders and Dementia*

Supervisory Committee Member

Kent Cameron, Educational Psychology, (Supervisory Committee) *Relaxation Carrels
for Children with Behavior Disorders*
Sandra Hodgetts, Educational Psychology, (Supervisory Committee) *Weighted Vests and
Autism*
Keith Johnston, Physical Education, (Supervisory Committee)
Krista Pierce, Educational Psychology, (Supervisory Committee)

Examiner

Kim Adams, Rehabilitation Medicine

Completed:

Ursula Gardynik, Educational Psychology, (Supervisory Committee) *Resilience in
University Students with Learning Disabilities*
Kathryn Holleran, Educational Psychology, (Supervisory Committee)
Yu-Ri Kim, Educational Psychology, 2003 - 2008 (Supervisor) *Abuse Prevention
Training Vocabulary*
Shelley Watson, Educational Psychology, (Supervisor) *Parents of Children with
Disabilities & Differential Diagnosis*

Supervision, Masters Degrees

In progress:

Supervisor

Michaella Jellen, Educational Psychology, (Supervisor) *Teaching Empathy*
Lorna Sutherland, Educational Psychology, (Supervisor) *Inclusive Friendships*

Supervisory Committee Member

Katie McGillivray, Physical Education, (Supervisory Committee) *Empowerment of PWD
through Activity*

• PRESENTATIONS

Health Ethics Seminars:

The Health Ethics Seminar series is open to all faculty, staff and students at the University of Alberta, as well as Capital Health staff and the public.

21 September 2007, *Normal versus Healthy Paradigms within Schizophrenia.*

Austin A. Mardon, CM Order of Canada

19 October 2007, *Politics of the Dead: Ownership of the Image*

Erika Goble, MA

Research Project Coordinator, Faculty of Nursing, University of Alberta

16 November 2007, *An Ethical Analysis of Growth Attenuation in Children with Developmental Disabilities*

Dick Sobsey, EdD

Director, John Dossetor Health Ethics Centre, John Dossetor Health Ethics Centre, University of Alberta

15 February 2008, *Withdrawal of Care in the Neonatal Intensive Care Unit: A Philosophical Discussion*

Sara Calderón, MN Student, Faculty of Nursing, University of Alberta

7 March 2008, *The Earth Charter: Values and Principles for Sustaining Life on Earth*

Colin Soskolne, PhD

Professor, School of Public Health University of Alberta

Presentation also part of Health Ethics Week

Health Ethics Week 2008:

4 March 2008, *When Healthcare Providers Experience Distress: The Importance of Moral Space*

Leonard Fleck, PhD

Center for Ethics and Humanities in the Life Sciences, College of Human Medicine, Michigan State University

Presentation in collaboration with University of Alberta and Stollery Children's Hospitals Clinical Ethics Committee and the Provincial Health Ethics Network

4 March 2008, *The Waterdance: Film & Discussion*

Hosted by John Dossetor Health Ethics Centre, University of Alberta

Edmonton Room, Stanley A. Milner Library

Presentations continued:**Grand Rounds:**

18 September 2007, *On the Ethics of Human Flourishing: Can an Old Idea Inform the New Model of Healthcare? (Part 1)*

Brendan Leier, PhD

Clinical Ethicist, University of Alberta and Stollery Children's Hospitals
Assistant Clinical Professor, John Dossetor Health Ethics Centre, University of Alberta

22 January 2008, *On the Ethics of Human Flourishing: Can an Old Idea Inform the New Model of Healthcare? (Part 2)*

Brendan Leier, PhD

Clinical Ethicist, University of Alberta and Stollery Children's Hospitals
Assistant Clinical Professor, John Dossetor Health Ethics Centre, University of Alberta

1 April 2008, *Towards a Pragmatic Definition of Death*

Brendan Leier, PhD

Clinical Ethicist, University of Alberta and Stollery Children's Hospitals
Assistant Clinical Professor, John Dossetor Health Ethics Centre, University of Alberta

Faculty Presentations:**AUSTIN:**

Relational ethics in health care. (Austin, W.) *Distance Education Course 2007: An Introduction to Bioethics*. Provincial Health Ethics Network, Red Deer, AB, May 3, 2007 (Invited presentation)

Moral distress in healthcare ethics: A relational perspective. (Austin, W.) *Cancer Care Network*. Canmore, AB, May 4, 2007.

Barriers to ethical practice in mental health care settings. (Austin, W.). *Education Series: Ethics in Mental Health*. Alberta Hospital Edmonton, Edmonton, AB, May 30th, 2007.

Austin, W. (2007, July). Engagement with Persons who have Committed "Evil" Acts: An Aspect of Professional Practice in Forensic Psychiatric Settings. In *the International Congress of the Academy of Law and Mental Health*. Padua, Italy, June 22-30, 2007, p. 179.

Relational Ethics in Health Care. (Austin, W.). *Darlana University at Falun*. Falun, Sweden, September 3, 2007. (Invited Speaker)

Relational Ethics in Health Care. (Austin, W.). *Faculty of Health Sciences, University of Malmo*. Malmo, Sweden September 5, 2007. (Invited Speaker)

AUSTIN continued:

The Possibility of Phenomenology: Is it of Real Use to Clinical Practice. (Austin, W.). *Qualitative Health Research*. International Institute of Qualitative Methodology, Banff, AB, September 20-24, 2007.

Nurses' Experience of Compassion Fatigue. (Austin, W., Leier, B., Byrne, P., Goble, E.). *Towards Professional Wisdom*. Edinburgh, UK, March 27, 2008.

BYRNE:

(Byrne, P.). *Ethics Medical Education - End of Life*. Room 626, Medical Sciences Building, University of Alberta, Edmonton, AB, April 02, 2007.

(Byrne, P.). *ICU Ethics Education Teaching Neonatal / Pediatric Critical Care Staff*. Stollery Children's Hospital, Edmonton, AB, May 22, 2007.

(Byrne, P.). *NICU in NICU Rounds – Pulmonary Haemorrhage*. David Schiff Neonatal Intensive Care Unit, Stollery Children's Hospital, Edmonton, AB, October 11, 2007.

Is NICU Care Ethical? (Byrne, P.). *Neonatal Fellows Retreat*. Jasper Park Lodge, Jasper AB, November 2-4, 2007.

WIT Film Screening-HBO Film: Part of Ethical Question & Answer. (Byrne, P.). *Good Medicine Film Series*. Discussion Panel. Stanley A Milner Theatre, Edmonton Public Library, Edmonton, AB, February 16, 2008.

LEIER:

On the Ethics of Human Flourishing: Can an Old Idea Inform the New Model of Healthcare? (Part 1). (Leier, B.). *UAH/SCH Clinical Ethics Committee Grand Rounds*. University of Alberta, Edmonton, AB, September 18, 2007.

On the Ethics of Human Flourishing: Can an Old Idea Inform the New Model of Healthcare? (Part 2). (Leier, B.). *UAH/SCH Clinical Ethics Committee Grand Rounds*. University of Alberta, Edmonton, AB, January 22, 2008.

Reflects on the Difficult Patient. (Leier, B.). *Health Ethics Week, Provincial Health Ethics Network*. Peter Lougheed Centre, Calgary, AB., Rockyview General Hospital, Calgary, AB., Foothills Medical Centre, Calgary, AB., March 4, 2008.

When Your Work Gets You Down: Addressing Moral Distress Among Health Professionals. (Leier, B.). *Health Ethics Week, Provincial Health Ethics Network*. Red Deer Regional Hospital, Red Deer, AB., Claresholm Centre for Mental Health & Addictions, Claresholm, AB., Chinook Regional Hospital, Lethbridge, AB., Medicine Hat, AB., Tom Baker Cancer Centre Auditorium, Calgary, AB., March 3-5, 2008.

LEIER continued:

An Ethic of Human Flourishing: Towards a Clinical Framework. (Leier, B.). *Health Ethics Week, Provincial Health Ethics Network*. Rockyview General Hospital, Calgary, AB., March 5, 2008.

Working Towards Shared Decision-Making: The Human Flourishing Model. (Leier, B.). *Health Ethics Week, Provincial Health Ethics Network*. Cross Cancer Institute, Edmonton, AB., March 11, 2008.

SHANNER:

Nobody's Child...*Anybody's* Ethics? Ethics of Donor Anonymity. (Shanner, L.). *Nobody's Child: International conference on donor conception*. Nanaimo, BC., May 29-June 2, 2007. (Invited Speaker).

U.S. Medicare Part D: What NOT to do in Canadian Pharmacare. (Shanner, L.). *Canadian Bioethics Society Annual Conference*. Toronto ON, May 30, 2007.

(Shanner, L.). *Ethics Review for Stem Cell Research, Canadian Institutes of Health, Stem Cell Network AGM*, Montreal, Quebec, November 7, 2007.

Ethics in Public Health: Emerging Landmarks and Uncharted Waters. (Shanner, L.). *Public Health Symposium*. University of Alberta, November 15-16 2007. (Poster Presentation).

Ethical Principles for Canadian Pharmacare. (Shanner, L.). *Western Canada Health Policy Summit*. Calgary, AB., December 5, 2007. (Invited Speaker).

SOBSEY:

Guardianship and its alternatives. (Baggs, A., Sobsey, D., and Others). *International AutComm Conference*. Edmonton, AB., October, 2007

Families of children with autism. (Sobsey, D.). *Autism Today Conference*. Edmonton, AB., October 2007.

An ethical analysis of growth attenuation of children with severe disabilities. (Sobsey, D.). *John Dossetor Health Ethics Seminar*. University of Alberta, November 16, 2007.

The Latimer Case: Implications for Canadians with Disabilities. (Sobsey, D.). *Disability Issues Group*. University of Alberta, March, 2008.

Inclusion and Autism. (Sobsey, D.). *Southwest Region Children's Services, Family Supports for Children with Disabilities*. March, 2008.

• PUBLICATIONS

John Dossetor Health Ethics Centre:

The newsletter, *Health Ethics Today*, has a circulation of approximately 7,500, which includes Alberta physicians and health care professionals, academics, members of the Canadian Bioethics Society, the Provincial Health Ethics Network and friends of the Dossetor Centre. In addition, issues of *Health Ethics Today* are posted on the Dossetor Centre's website: (<http://www.ualberta.ca/BIOETHICS/>).

Health Ethics Today, 2007, Volume 17, Number 1

Faculty Publications:

AUSTIN:

Books

Austin, W. & Boyd, M.A. (Eds.), (2008). *Psychiatric Nursing for Canadian Practice*. PA: Lippincott, Williams, & Wilkins, Inc.

Peer-Reviewed Journal Articles

Morse, J., Niehaus, L., Varnhagen, S., **Austin, W.**, & McIntosh, M. (in press). Qualitative Researchers' Conceptualizations of the Risks Inherent in Qualitative Interviews. *The International Review of Qualitative Research*.

Austin, W. (in press). Ethics in a time of contagion: A relational ethics perspective. *CJNR: Canadian Journal of Nursing Research*.

Austin, W., Park, C., & Goble, E. (2008). From interdisciplinary to transdisciplinary research: A case study. *Qualitative Health Research*, 18(4), 557-564.

Austin, W., Kagan, L., Rankel, M., & Bergum, V. (2008). The balancing act: Psychiatrists' experience of moral distress. *Medicine, Health Care and Philosophy*, 11, 89-97.

Abstracts and Non-peer Reviewed Articles

Austin, W., Goble, E., & Kulyk, D. (in press). Global Ethics in Mental Health Research Network. *Canadian Bioethics Society Newsletter*.

Austin, W., Kulyk, D., Carmago, P. (in press). Pan American Health Organization/World Health Organization Collaborating Centre for Nursing and Mental Health hosts Global Mental Health Ethics: A Nursing Research Perspective Symposium. *Nursing & Midwifery Links*.

Austin, W. (in press). Relational Ethics. In L. Given (Ed.), *The SAGE Encyclopedia of Qualitative Research Methods*. Thousand Oaks, CA: SAGE.

Austin continued:

Austin, W. (2007, July). Engagement with Persons who have Committed “Evil” Acts: An Aspect of Professional Practice in Forensic Psychiatric Settings. In *Proceedings of the XXXth International Congress of the Academy of Law and Mental Health*, Padua, Italy, June 22-30th, 2007, p. 179.

BYRNE:**Abstracts and Non-peer Reviewed Articles**

Byrne, P. (2007). Editors Forum. *Health Ethics Today* 17(1), 1-2.

Byrne, P. (2007). Neonatal Drug Screening; Is It Justified in Babies of Drug Abusing Mothers? *Health Ethics Today*, 17(1), 5-8.

LEIER:**Assessment & Teaching Materials**

Sobsey, D., Leier, B., & Bailey, T. (2008). Web-based instructional module on abortion for incompetent individuals. *Royal College of Physicians and Surgeons of Canada*.

SHANNER:**Peer-Reviewed Journal Articles**

Maksymowych, W.P., Gladman, D., Rahman, P., Boonen, A., Bykerk, V., Choquette, D., Dimond, S., Fortin, P., Karsh, J., Klinkhoff, A.V., Mosher, D., Mulholland, K., Olszynski, W.P., Russell, A.S., Savage, L., **Shanner, L.**, Shojania, K., Starr, M., Thomson, G., Zummer, M., & Inman, R. The Canadian Rheumatology Association/ Spondyloarthritis Research Consortium of Canada treatment recommendations for the management of spondyloarthritis: a national multidisciplinary stakeholder project. *Journal of Rheumatology*, 34(11), 2273-84.

SOBSEY:**Books and Book Chapters**

Sobsey, D., & Truscott, D. (in press). Ethical considerations in the treatment of chronic pain. In S. Rashiq, S. Schopflocher, & P. Taenzer, (Eds.), *Chronic pain: A health policy perspective* (pp. 51-57). Weinheim, Germany, Wiley-VCH.

Peer-Reviewed Journal Articles

Hansen, N., Janz, H., & **Sobsey, D.** (in press). Eugenics in the 21st Century: Deconstructing Darwinism. *Lancet*.

Encyclopedia Entries

Sobsey, D. (in press). Violence. In *Encyclopedia of American Disability History*. New York: Facts on File.

Sobsey, D. (in press). Barbara Waxman-Fiduccia. In *Encyclopedia of American Disability History*. New York: Facts on File.

SOBSEY continued:

Sobsey, D. (in press). Dale Evans. In *Encyclopedia of American Disability History*. New York: Facts on File.

General Audience Publications

Sobsey, D. (2007). Perspectives. In J. Canfield, M.V. Hansen, H. McNamara, & K. Simmons (Ed.), *Chicken soup or the soul: Children with special needs: Stories of love and understanding for those who care for children with disabilities* (pp. 140-141). Deerfield Beach, FL: Health Communications, Inc.

Assessment & Teaching Materials

Sobsey, D., Leier, B., & Bailey, T. (2008). Web-based instructional module on abortion for incompetent individuals. *Royal College of Physicians and Surgeons of Canada*.

• **FACULTY, UNIVERSITY AND COMMUNITY COMMITTEES AND MEMBERSHIP**

AUSTIN:**Professional, University and Community Service Activities:**

Member, International Editorial Review Board, *Journal of Ethics in Mental Health*

Member, Ethics Advisory Group, Aboriginal Capacity and Developmental Research Environment Network (ACADRE) (2002-)

Board Member, Health Law Institute, University of Alberta

Research reviewer for Social Sciences and Humanities Research Council of Canada (2007)

Member of the Leadership Committee, Mental Health Research Institute (U of A) (2006-)

Member of the Canadian Association for Nursing Research (2006-)

Member of the Editorial Review Board: *Advances in Nursing Science* (1999-)

Member of the Editorial Review Board: *Journal of Ethics in Mental Health* (2005-2007)

Peer Consultant, University Teaching Service (1990-)

Membership in Professional Organizations:

Alberta Association for Registered Nurses

Canadian Psychological Association

Canadian Nurses Association

International Academy of Law and Mental Health

Canadian Association for Nursing Research

Reviewer:

International Journal of Offender Therapy and Comparative Criminology (2007-)

Canadian Public Policy (2005-)

Social Science and Medicine (2005-)

Nursing Ethics (2004-)

International Nursing Review (2001-)

Qualitative Health Research (2000-)

Journal of Psychiatric and Mental Health Nursing (1996-)

AUSTIN continued:

Clinical Nursing Research (1995-)
Western Journal of Nursing Research (1995-)

BYRNE:

Professional, University and Community Service Activities:

Committee Member, University of Alberta and Stollery Children's Hospitals' Clinical Ethics (1995-)
Bioethics Consultant, Research Ethics Board, University of Alberta/Capital Health/ Caritas (1998-)
Ethical Consultant, Pediatric Advisory Team, Province Wide Service, Provincial Advisory Group (1998-)
Member, Canadian Bioethics Society (1993-)
Member, Catholic Bioethics Interest-Group, St. Joseph's College (1994-)

Membership in Professional Organizations:

Canadian Pediatric Society

Reviewer:

Medical Research Council of Canada
American Journal of Obstetrics & Gynecology
The Physicians' Services Incorporated Foundation
Health Sciences Center Foundation

GRIENER:

Professional, University and Community Service Activities:

Chair, Health Research Ethics Board – Social & Behavioural Panel (2004-)
Member, Health Research Ethics Board – Social & Behavioural Panel (1999-)
Biosafety Committee (1999-)
EMR Data Stewardship and Standard Committee, Capital Health (2006-)
Out-of-Country Health Services Appeals Panel, Alberta Health & Wellness (1995-)
Alberta Advisory Committee on AIDS, Alberta Health and Wellness (2002-)
Electronic Health Record Data Stewardship Committee, Alberta Health and Wellness (2003-)
Public Member & Member of Research Task Group
Acting Chair - Canadian General Standards Board (CGSB) Committee on Research Ethics Boards Reviewing Clinical Trials (2007-)

Membership in Professional Organizations:

Past President, National Council on Ethics in Human Research (2007-2008)
Council Member, National Council on Ethics in Human Research (2005-)
Special Working Committee, Interagency Advisory Panel on Research Ethics, Social Sciences and Humanities Research Ethics (2003-)
Peer Review Committee, Canadian Institutes for Health Research Ethics, Law and Humanities (2003-)
Canadian Patient Safety Institute (2005-)

LEIER:

Professional, University and Community Service Activities:

Committee Member, University of Alberta and Stollery Children's Hospitals' Clinical Ethics (2006-)

Research Ethics Review Committee, College of Physicians and Surgeons of Alberta (2006-)

Member, Capital Region Health Ethics Coordinating Council (2006-)

SHANNER:

Professional, University and Community Service Activities:

Research Ethics Committee Member, Stem Cell Oversight Committee, Canadian Institutes of Health Research (2006-)

Membership in Professional Organizations

Editorial Board Member, International Journal of Feminist Approaches to Bioethics

SOBSEY:

Professional, University and Community Service Activities:

Steering Committee Member, Alberta Consortium on the History of Eugenics

Committee Member, Canadian Institutes of Health Research, Research Integrity

University Representative, A Canada Fit for Children in A World Fit for Children

Reviewer:

Adapted Physical Activity Quarterly

American Journal on Mental Retardation

Developmental Disabilities Bulletin

Exceptionality Education Canada

Intellectual and Developmental Disabilities

Paul H. Brookes Publishing Company

NAHORNIAK:

Professional, University and Community Service Activities:

Secretariat, University of Alberta and Stollery Children's Hospitals' Clinical Ethics Committee (2004-)

CABRAL:

Professional, University and Community Service Activities:

Committee Member, University of Alberta and Stollery Children's Hospitals' Clinical Ethics Committee (2007-)

• **HEALTH ETHICS CONSULTATION SERVICE**

Administrative support for the consultation service of the University of Alberta and Stollery Children's Hospitals Ethics Committee is provided by the John Dossetor Health Ethics Centre. Requests for ethics consultation by patients, family and healthcare professionals are received and coordinated by the Centre. Coordination involves obtaining the information and then forwarding it to the Clinical Ethicist and may involve

assembling a team from the UAH ethics committee to respond to the request. On average the committee receives 7-8 detailed ethics consultations per month in addition to many telephone and 'corridor' consultations.

• **LIBRARY RESOURCES**

The Library in the John Dossetor Health Ethics Centre contains a wide range of books and journals in the area of health ethics including, clinical ethics, end-of-life issues, women's issues (feminist bioethics), philosophy, psychology, technology and ethics, law and medicine, transplantation, ethics education, reproductive issues, relational ethics, nursing ethics, and ethical theory. In addition, the Library has a variety of health ethics video tapes. University faculty members, students, Capital Health staff, as well as the public are welcome to utilize the facility by appointment.

Some of the more current journals available:

ACTA Bioethica (2000-2001)

Alberta Association of Registered Nurses (1997)

Bioetica Informa (1999-2002)

Bioethics Examiner (1997-2008)

Bioethics Research Notes (1993-2003)

Bulletin of Medical Ethics (1988-2006)

Cambridge Quarterly of Healthcare Ethics (1992-2008)

Ethics and Intellectual Disability (1995-2006)

Hastings Center Report (1973-2008)

Health Law Journal (1993-2007)

Health Law Review (1991-2008)

HEC Forum (1998-2005)

IRB: A Review of Human Subjects Research (1989-2008)

Journal of Clinical Ethics (1990-2008)

Journal of Medical Ethics (1989-2007)

Journal of Medical Humanities (1992-2006)

Journal of Medicine and Philosophy (1976-2004)

Kennedy Institute of Ethics Journal (1992-2004)

Medical Principles and Practice (1994-2002)

National Council on Ethics in Human Research Communiqué (1990-2000)

Nursing Ethics (1997-2003)

• MEDIA REQUESTS

The faculty of the John Dossetor Health Ethics Centre responded to requests, as well as had feature articles in local and national media on a variety of health ethics issues. Some examples:

SHANNER:

Babies made from blueprints / Ethics of Procreation. Vicki Swann. *Nanaimo Daily News*, May 15, 2007, p. A1.

CBC Radio: blocking growth hormone in children with disabilities. Interviewed by Laurie Fagen (Ottawa) June 19, 2007.

CTV The Verdict. Live interview on donor anonymity. July 14, 2007.

Crisis of trust over sperm bank errors. Alison Motluk. *New Scientist*, August 11, 2007 p. 6-7.

CBC Ideas "Brave New Family". 2-part program on assisted conception. interviewed by Alison Motluk and aired repeatedly (1st air dates Oct 15 and 22, 2007).

SOBSEY:

Disabled locked away. Monaghan, R. *Herald News* [Joliet, IL], p. A.7. Discusses research by Sobsey, October 5, 2007.

Lacking Speech, they gain a voice. Henderson, H. *Toronto Star*. p. L.3. Discusses research by Sobsey, November 3, 2007.

Pratap, V. *Global Edmonton Television News*. Interview on violence against people with disabilities, January, 2008.

Disabled vulnerable to violence, prof says; Police continue hunt for aboriginal man who attacked woman with cerebral palsy. *Edmonton Journal*. p. B.3. Discusses research by Sobsey, January 31, 2008.

Children's rights must be universal and yet special. *UNICEF Canada*. "Halfway There: A Canada fit for Children in a World Fit for Children". (pp. 6-7). Ottawa: UNICEF Canada & Canadian Heritage. [Also published in French as À mi-chemin: Un Canada digne des enfants dans un monde digne des enfants.]

Vulnerability of disabled ignored in Latimer reaction, activists say. Henderson, H. *The Record*. Kitchner-Waterloo. p. D.11. Discusses advocacy work by Sobsey, February 29, 2008.

Support for Latimer puts disabled at risk: critics. *The Spectator*. Henderson, H. (Hamilton, Ont). p. A.14. Discusses advocacy work by Sobsey, February 29, 2008.

SOBSEY continued:

Latimer ruling 'slippery slope,' disabled say; Advocates fear appearance of leniency puts vulnerable at risk. Henderson, H. *Toronto Star*. [ONT Edition], p. A.15. Discusses advocacy work by Sobsey, February 29, 2008.

Tracy Latimer's legacy; What of other children with disabilities? What of aging parents with dementia? Janz. H.L. *Edmonton Journal*. p. A.19. Discusses work by Sobsey, March 15, 2008.

People with Intellectual Disabilities & Sexual Violence. Davis, L.A. *Daily Local News*. West Chester, PA, pp. 3-15. Discusses research by Sobsey, March 27, 2008.

U.S. author shares his combination for success; Once you find the key, it works every time, says writer of the *Chicken Soup for the Soul* series of books. MacDonald, J. *Edmonton Journal*. p. D. 5. Discusses essay by Sobsey, 5 October 2007.

Public Policy Consultation & Expert Opinion

Dick Sobsey acted as an expert on disability issues for courts in Canada, The United States, and New Zealand this year.