



**John Dossetor Health Ethics Centre**

# **ANNUAL REPORT**

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**April 1, 2008 – March 31, 2009**



**UNIVERSITY OF  
ALBERTA**

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## • INTRODUCTION

We are pleased to present the annual report for the John Dossetor Health Ethics Centre 2008-2009 fiscal year. From its conception the faculty and staff of the John Dossetor Health Ethics Centre have been committed to excellence in health care ethics through scholarship, discovery learning and community engagement. The John Dossetor Health Ethics Centre (JDHEC) successfully maintained this commitment last year. Among our many activities some of JDHEC's highlights were: 1) in Spring 2008 JDHEC hosted its fifth annual, successful Health Ethics Symposium, *Getting Lost in "Doing Good"*; 2) to commemorate the University's Centenary in the fall of 2008 JDHEC organized the visit of AHFMR Visiting Lecturer, Dr. Carl Elliott from the Center for Bioethics, University of Minnesota; and 3) Professor Simo Vehmas from the Department of Special Education, University of Jyväskylä, Finland presented a seminar in our Health Ethics Seminar series. Ongoing, established events such as Health Ethics Seminars, Grand Rounds, and Health Ethics Week continued over different parts of the year.

The John Dossetor Health Ethics Centre has 5 core faculty members with highly regarded credentials and expertise who are committed to addressing and promoting health care ethics. Their many accomplishments and contributions are reported within this document.

The John Dossetor Health Ethics Centre's goal is to continue to uphold and cultivate our commitment of academic excellence in health care ethics through established and ongoing development of support, collaborations, and linkages.

## • 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

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

### Staff

<b>Carol Nahorniak, BSc</b> Centre Administrator	<b>Stacy Cabral, BA</b> Information Officer	<b>Edna Cunningham Liley</b> Information Officer (on leave)
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## • CORE ACTIVITIES

From John Dossetor Health Ethics Centre's beginning in 1985 it has provided scholarly excellence in health care ethics research, education and community service to students, faculty and staff at the University of Alberta, health care practitioners and members of Alberta Health Services (Capital Health), other health care agencies and the general public.

**Graduate courses** taught in the 2008-2009 calendar year were INT D 570 (Health Care Ethics), PHS 709 (Ethics & Health Care Organizations) 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 with Alberta Health Services (Capital Health)
  - International Academy of Law and Mental Health

**Core Activities continued:**

- 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
- Health Ethics Symposium
- Clinical Ethics Grand Rounds
- Media requests

• **JOHN DOSSETOR HEALTH ETHICS CENTRE OPERATING  
BUDGET 2008-2009**

**REVENUE**

Faculty of Medicine & Dentistry	\$77,593.00
Health Sciences Council	\$53,500.00
External Revenue – Other Internal Revenue (Capital Health)	\$15,694.00
External Revenue – Symposium Non-Credit Fees	\$9,380.95
AHFMR Visiting Lecturer Grant	\$1,000.00
U of A Conference Fund	\$1,200.00
Leier Grant Account	\$9,101.00
Ethics Research Videos	\$66.67

**TOTAL REVENUE****\$167,535.62****EXPENDITURES**

Support Staff Salaries	\$84,446.31
Benefits	\$15,157.76
Supplies, Services & Sundries	\$4,962.32
Consultant & Professional Services	\$8,678.27
Utilities	\$0.00
Communications	\$3,811.59
Course Registrations	\$460.00
Travel/Hosting	\$1,337.09
Credit Card Fees/Discount Fees	\$167.08
Rentals & Leases	\$2,172.36
Capital Equipment, Collections & Construction	\$5,082.54

**TOTAL EXPENDITURES****\$126,275.32****Academic Salaries:**

Wendy Austin - 1.0 FTE Nursing

Paul Byrne - 0.2 FTE Medicine &amp; Dentistry

Brendan Leier - 0.3 FTE Medicine &amp; Dentistry

Laura Shanner - 1.0 FTE School of Public Health

Dick Sobsey - 0.5 FTE Faculty of Education, 0.5 FTE Health Sciences Council

## • GRANT FUNDING

### Funding to the John Dossetor Health Ethics Centre

Name	Principal / Co-Investigator	Award / Research Grant	Amount	Research	Date
<b>R. Sobsey</b>	Principal	University of Alberta Conference Fund	\$1,200	Health Ethics Symposium May 2008	2008-2009
<b>R. Sobsey</b>	Principal	AHFMR Visiting Lecturer Grant	\$1,000	AHFMR Visiting Lecturer, Dr. Carl Elliott	2008-2009

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

Name	Principal / Co-Investigator	Award / Research Grant	Amount	Research	Date
<b>W. Austin</b>		Canada Research Chair	\$500,000	Relational Ethics in Health Care	2008-2013
	Co-Investigator	Alberta Centre for Child, Family, & Community Research	\$9,972.30	Hospital Transfer – Parents' Experience of the Transfer of their Baby	2009-2011
	Principal	Social Sciences and Humanities Research Council of Canada	\$155,000	"Compassion Fatigue" As Experienced By Canadian Health Professionals	2007-2010
	Principal	Canadian Institutes of Health Research (CIHR)	\$146,726	The Experience and Resolution of Moral Distress in Pediatric Intensive Care Teams	2007-2010
	Co-Investigator	Canadian Institutes of Health Research (CIHR)	\$49,838	Ethical Issues in Transplantations and Research with Deceased Individuals: The Views of Recent Immigrants and Healthcare Professionals	2007-2009
	Project Leader	The Canada Foundation for Innovation	\$55,328	Relational Ethics in Healthcare Research Centre	2004 - 2009
	Principal	Social Sciences and Humanities Research Council of Canada	\$65,000	Ethical Relationships in Forensic Settings	2004 - 2008
	Principal	Canadian Institutes of Health Research (CIHR)	\$247,613	Risks to Participants in Qualitative Interviews: Perspectives of Researchers, Participants, and Research Ethics Boards	2003 - 2008
	Co-Investigator/Mentor	Canadian Institutes of Health Research (CIHR)	\$1,759,868	EQUIPP: A Training Program to Enhance Qualitative Understanding of Illness Processes and Prevention	2003 – 2009
<b>P. Byrne</b>	Principal	Alberta Centre for Child, Family, & Community Research	\$9,972.30	Hospital Transfer – Parents' Experience of the Transfer of their Baby	2009-2011
	Principal	Stollery Children's Hospital Foundation	\$8,100	Treatment Choice for Hypoplastic Left Heart Syndrome: A Question of Ethics	2005-2008
<b>B. Leier</b>	Co-Investigator	Stollery Children's Hospital Foundation	\$8,100	Treatment Choice for Hypoplastic Left Heart Syndrome: A Question of Ethics	2005-2008

**Faculty Research Funding continued:**

<b>Name</b>	<b>Principal / Co- Investigator</b>	<b>Recent Awards / Research Grants</b>	<b>Amount</b>	<b>Research</b>	<b>Date</b>
<b>B. Leier</b>	Co-Investigator	Social Sciences and Humanities Research Council of Canada	\$155,000	“Compassion Fatigue” As Experienced By Canadian Health Professionals	2007-2010
<b>L. Shanner</b>	Co-Investigator	Canadian Institutes of Health Research (CIHR)	\$1,852,500	Strategic Training Program in Maternal-Fetal-Newborn Health	2003-2009
	Principal	Alberta Heritage Foundation for Medical Research	\$350,000	Ethics, Law and Policy in Health Care	2007-2008
<b>D. Sobsey</b>	Co-Investigator	Social Sciences and Humanities Research Council of Canada	\$199,604	Sustainable family care for children with severe or profound disabilities	2009-2011
	Co-Investigator	From Archives to Activism. Community-University Research Alliance Program	\$12,000	Proposal Development Grant	2009
	Principal	University of Manitoba Canadian Institutes of Health Research (CIHR) Sub-Grant	\$13,500	End of Life Care and Vulnerable Populations	2008-2009
	Principal	Social Sciences and Humanities Research Council of Canada	\$38,865	Defining Disability Ethics	2008-2010
	Principal	Canadian Institutes of Health Research (CIHR), Health Services and Policy Research	\$81,122	Ethics Catalyst Grant	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 Research Alliance Program	\$20,000	Proposal Development Grant	2008

## • 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 health care practitioners, clinical ethics committee members and the general public.

26 September 2008, *GARDASIL, Girls and God: To Vaccinate or Not To Vaccinate*

Doris M. Kieser, PhD, Assistant Professor of Theology

St. Joseph's College

University of Alberta

**Presentations continued:****Health Ethics Seminars:**

22 October 2008, *Disability, Harm, and the Origins of Limited Opportunities*

Simo Vehmas, PhD  
 Department of Special Education  
 University of Jyväskylä, Finland

21 November 2008, *Nobody's Child: Impoverished Ethics and Bad Law in Assisted Conception*

Laura Shanner, PhD  
 Associate Professor & Director  
 School of Public Health and John Dossetor Health Ethics Centre

23 January 2009, *Where Do Ideas About Human Variation Come From? Disability and Sub-Normalcy in Health and Medicine*

Rob Wilson, PhD  
 Professor & Team Organizer, What Sorts Network  
 Department of Philosophy, University of Alberta

13 February 2009, *Is It Time to Ration Acute Care Hospital Beds?*

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

3 March 2009, *Apology Legislation and Health Care: Is this in the Best Interests of Patients?*

Tracey Bailey, BA, LLB  
 Executive Director Health Law Institute  
 University of Alberta

**UNIVERSITY OF ALBERTA CENTENARY EVENT:**

7 October 2008, *White Coat, Black Hat: Subverting Medicine for Fun and Profit*

AHFMR Visiting Lecturer  
 Carl Elliott, MD, PhD  
 Professor, Pediatrics and Philosophy  
 Centre for Bioethics, University of Minnesota

With his research expertise, experience, and extensive list of publications, Carl Elliott has established himself as one of the leading scholars in bioethics in the areas of enhancement technologies, research ethics, and the philosophy of psychiatry. Carl Elliott's visit provided a unique opportunity to further explore these areas. In addition it was a wonderful means to celebrate the University of Alberta's centennial year by expanding knowledge of health ethics.



**Presentations continued:**

**HEALTH ETHICS SYMPOSIUM, *GETTING LOST IN “DOING GOOD”*,  
1 May 2008:**

This one-day symposium hosted by the John Dossetor Health Ethics Centre, included presentations which were interdisciplinary and examined the essential place of ethics in health care practice.

*Feeling Lost at Home*

Brendan Leier, PhD  
Clinical Ethicist, University of Alberta and Stollery Children’s Hospitals  
Clinical Assistant Professor, John Dossetor Health Ethics Centre

*Lost Babies: Technology Driven Perinatal Care*

Paul Byrne, MB, ChB, FRCPC  
Staff Neonatologist, Stollery Children’s Hospital  
Clinical Professor, Faculty of Medicine and Dentistry

*“What Were They Thinking?” How Appalling Acts Can Spring From Good Intentions*

Wendy Austin, RN, PhD  
Canada Research Chair  
Professor, Faculty of Nursing and John Dossetor Health Ethics Centre

*“Lost in the Details” The Unintended Harms of Protection*

Richard Sobsey, EdD  
Professor, Faculty of Education and Director, John Dossetor Health Ethics Centre

*Lost in the Crowd: Individuals in Public Health and Health Policy*

Laura Shanner, PhD  
Associate Professor, School of Public Health and John Dossetor Health Ethics Centre

*I Once Was Lost: Confessions of an Ethics Bureaucrat*

Glenn Griener, PhD  
Associate Professor, School of Public Health and Faculty of Arts

**HEALTH ETHICS WEEK 2009:**

2 March 2009, *Without Walls Selling Murder: The Killing Films of the Third Reich:  
Film & Discussion*

Hosted by the John Dossetor Health Ethics Centre  
Presented in collaboration with the Arts & Humanities in Health & Medicine Program, the History of Medicine Program, and What Sorts of People Should There Be Network

## **Presentations continued:**

### **Health Ethics Week:**

3 March 2009, *Apology Legislation and Health Care: Is this in the Best Interests of Patients?*

Tracey Bailey, BA, LLB  
Executive Director Health Law Institute  
University of Alberta

6 March 2009, Poetry Session: Poetry by medical professionals that raises ethical issues will be used to evoke memories and experiences. An opportunity for writing, sharing and discussion was provided.

Shirley Serviss, Literary Artist  
Artists on the Wards program  
University of Alberta Hospital

### **GRAND ROUNDS:**

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

19 December 2008, *Can We Refuse to Care for Transplant Tourists?*

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

### **FACULTY PRESENTATIONS:**

#### **AUSTIN:**

What were they thinking? How appalling acts can spring from good intentions.

(Austin, W.) *Getting Lost in "Doing Good"*. John Dossetor Health Ethics Symposium, University of Alberta, Edmonton, AB, May 1, 2008. (Invited Speaker)

Speak No Evil? Dark Thoughts About One's Patients in Forensic Psychiatry.

(Austin, W.) *Secret Transgression*: Sociology Graduate Students Conference, May 10, 2008. (Keynote)

Oversight, Surveillance, and the Ethical Researcher. (Austin, W.) *4th International Congress of Qualitative Inquiry*, Center for Qualitative Inquiry, Institute of Communications Research, Urbana-Champaign, Chicago, IL, May 16, 2008.

**Presentations continued:****Austin:**

The Flashlight & the Hammer: Tools and Metaphors for Grappling with Moral Distress.

(Austin, W.) *Between a Rock and Hard Place: When Healthcare Providers Experience Moral Distress*. Provincial Health Ethics Network/ College and Association of Registered Nursing of Alberta, Calgary, AB, May 23, 2008. (Invited)

Relational Ethics as an Approach to Fostering Ethical Mental Health Care. (Austin, W.) *Mental Health Forum: Bringing the Stigma Out of the Shadows*, Edmonton, AB, May 29, 2008 (Invited)

Maybe I Can't Do This Anymore: The Impact of Moral Distress on One's Career. (Austin, W.) Clinical Nurse Educators, Alberta Hospital Edmonton, Edmonton, AB, June 10, 2008. (Invited)

Relational Ethics in Health Care. (Austin, W.) Faculty of Nursing, St Francis Xavier University, Antigonish, NS, June 16, 2008. (Keynote)

The Tragedy of Good Intentions in Health Care & Research: Learning from the Past to Save the Future. (Austin, W.) *Research Challenges in the Global Health Care Community*. Chulalongkorn University & the University of Alberta, Bangkok, Thailand, June 24, 2008. (Keynote)

Supporting Relationships Between Family and the Healthcare Team in Traditional Continuing Care Settings: A Participatory Action Research Project. (Austin, W.) *Healthy People for a Healthy World*, Bangkok, Thailand. June 25 to 27, 2008.

Is Ethical Engagement with Patients and Families at Risk in Today's Health Care System? (Austin, W.) Myrtle Crawford Memorial Lectureship, University of Saskatchewan, Saskatoon, SK. November 2, 2008. (Keynote)

Notions of Evil: A Fit Topic for a Relational Ethicist? (Austin, W.) Myrtle Crawford Memorial Lectureship, University of Saskatchewan, Saskatoon, SK. October 31, 2008. (Keynote)

Moral Distress and the Health Professional. (Austin, W.) Myrtle Crawford Memorial Lectureship, University of Saskatchewan, Saskatoon, SK. October 29, 2008. (Keynote)

Using Research to Support Ethical Practice. (Austin, W.) Alberta Health Services: 4<sup>th</sup> Annual Nursing Research Day, Edmonton, AB. March 11, 2009. (Invited)

**Presentations continued:****BYRNE:**

Lost Babies: Technology Driven Perinatal Care. (Byrne, P.) *Getting Lost in “Doing Good”*. John Dossetor Health Ethics Symposium, University of Alberta, Edmonton, AB, May 1, 2008. (Invited Speaker)

Debate “On the Edge of Viability”...What Should We Do? *NICU Rounds*. University of Alberta Hospital, Edmonton, AB, May 15 2008. (Moderator)

**LEIER:**

Towards a Pragmatic Definition of Death. (Leier, B.) UAH/SCH Clinical Ethics Committee Grand Rounds. University of Alberta, Edmonton, AB, April 1, 2008.

Feeling Lost at Home. (Leier, B.) *Getting Lost in “Doing Good”*. John Dossetor Health Ethics Symposium, University of Alberta, Edmonton, AB, May 1, 2008. (Invited Speaker)

Towards a Pragmatic Definition of Death. International Symposium for the Definition of Death, Veradero, CU, May 2008.

Can We Refuse to Care for Transplant Tourists? (Leier, B.) UAH/SCH Clinical Ethics Committee Grand Rounds. University of Alberta, Edmonton, AB, December 19, 2008.

*Ethics of Human Flourishing*. 8<sup>th</sup> Annual Ethics at the Bedside and in the Clinic Workshop, Lakehead University, Thunder Bay, ON, February 20, 2009. (Keynote)

Resource Scarcity and Ethical Responsibility. (Leier, B.) *Alberta Health Services Lunchtime Ethics Series 2009*. Royal Alexandra Hospital, Edmonton, AB, February 5, 2009. (Invited Speaker)

Is It Time to Ration Acute Care Hospital Beds? (Leier, B.) John Dossetor Health Ethics Seminar. University of Alberta, Edmonton, AB, February 13, 2009. (Invited Speaker)

Definitions of Death in DCD Protocols. (Leier, B.) Canadian Society for Transplantation Scientific Meeting, Banff, AB, March 2009.

When my Heart Stops Beating, Am I Really Dead? (Leier, B.) Lakehead University Centre for Bioethics Annual Symposium. Thunder Bay, ON, March 2009.

**Presentations continued:****SHANNER:**

Stem Cell Contributions to the Health of Canadians: Introductory Questions. (Shanner, L.) CIHR Stem Cell Oversight Committee. Ottawa, ON, April 14, 2008. (Invited Speaker)

Lost in the Crowd: Individuals in Public Health and Health Policy. (Shanner, L.) *Getting Lost in "Doing Good"*. John Dossetor Health Ethics Symposium, University of Alberta, Edmonton, AB, May 1, 2008. (Invited Speaker)

Searching in the Ether: Internet Connections in Donor Conception. (Shanner, L.) *Who Am I? Best Interest and Rights of Children of Assisted Reproduction* International Conference, Calgary, AB, June 14, 2008.

Global Citizenship: Ethics and Public Health Perspectives. (Shanner, L.) *International Conference: Global Citizenship Education and Post Secondary Institutions: Policies, Practices and Possibilities*. Global Citizenship Conference, Edmonton, AB, October 24, 2008.

Nobody's Child: Impoverished Ethics and Bad Law in Assisted Conception. (Shanner, L.) John Dossetor Health Ethics Seminar. University of Alberta, Edmonton, AB, November 21 2008. (Invited Speaker)

**SOBSEY:**

"Lost in the Details" The Unintended Harms of Protection. (Sobsey, R.) *Getting Lost in "Doing Good"*. John Dossetor Health Ethics Symposium, University of Alberta, Edmonton, AB, May 1, 2008. (Invited Speaker)

Disability Ethics: The Ultimate Border Crossing. (Sobsey, R. and Janz, H.) Annual Conference of the Canadian Disability Studies Association, University of British Columbia, Vancouver, BC, June 5, 2008.

Controversies in Growth Attenuation of Children with Severe Disabilities. (Sobsey, R.) Pediatric Grand Rounds. University of Alberta, Edmonton, AB, June, 2008.

Eugenic practices: Past, Present, & Future. (Sobsey, R.) *Families and Memory*. Public Workshop, Edmonton, AB, October, 2008.

Varieties of Eugenic Experience in the 21st Century. (Sobsey, R.) *Special Symposium, Philosophy, Eugenics, and Disability in Alberta and Places North* (with additional presentations by S. Vehmas, S.M. Tweedale, & R. Wilson). 45<sup>th</sup> Annual Meeting of the Western Canadian Philosophical Association, Edmonton, AB, October 25, 2008.

**Presentations continued:****Sobsey:**

Canadian Association on Community Living, Values & Ethics Task Force. (Sobsey, R.)  
Public Symposium: *The Pursuit of Perfection*. Edmonton, AB, October, 2008.  
(Panelist & Discussant)

The Role of Family Degeneracy Studies in Shaping the Eugenics Movement. (Sobsey,  
R.) History of Medicine, Public Symposium, University of Alberta, Edmonton,  
AB, November, 2008.

- **PUBLICATIONS**

**FACULTY PUBLICATIONS:****AUSTIN:****Chapters**

**Austin, W.** (in press). Ethical nursing practice: It's All about relationships. In P. Cowan  
& S. Moorhead (Eds.). *Current Issues in Nursing*, 8<sup>th</sup> Ed., St. Louis, MO: Mosby  
Inc.

**Austin, W.** (2008). On being ethical in a global community: What is a nurse to do? In V.  
Tschudin (Ed), *The Globalization of Nursing: Ethical, legal and political issues*.  
Oxford, U.K.: Radcliffe Publishing Ltd.

Morse, J., Niehaus, L., Varnhagen, S., **Austin, W.**, & McIntosh, M. (2008). Qualitative  
Researchers' Conceptualizations of the Risks Inherent in Qualitative Interviews. In  
N.K. Denzin & M.D. Giardina's (eds.) *Qualitative Inquiry and the Politics of  
Evidence*. (pp. 195-217). Walnut Creek, California: Left Coast Press.

**Peer-Reviewed Journal Articles**

Mill, J., **Austin, W.**, Edwards, N., Jackson, R., MacLean, L., & Reintjes, F. (in review).  
Wherein lies the stigma? Accessing health services while living with HIV. *AIDS  
and Behavior*.

Whitty-Rogers, J., Alex, M., MacDonald, C., Pierrynowski, G., **Austin, W.** (in press).  
Hearing voice fostering choice: Working with children in end-of-life decision  
making – A Relational Ethics perspective to autonomy. *Nursing Ethics*, 16(6).

**Austin, W.**, Goble, E., Kelecevic, J. (in press). The Ethics of Forensic Psychiatry:  
Moving from Principles to a Relational Ethics Approach. *Journal of Forensic  
Psychology and Psychiatry*.

**Austin, W.**, Strang, V., Goble, E., Mitchell, A., Thompson, E., Lantz, H., Balt, L.,  
Lemermeyer, G., Vass, K. (in press). Supporting relationships between family and  
the healthcare team in continuing care settings. *Journal of Family Nursing* 15(4).

**Publications continued:****Austin:**

Mill, J., Edwards, N., Jackson, R., **Austin, W.**, MacLean, L. & Reintjes, F. (in press). Accessing health services while living with HIV: Intersections of stigma. *Canadian Journal of Nursing Research*.

Snow, N., **Austin, W.** (in press). Community Treatment Orders: The ethical balancing act in community mental health. *Journal of Psychiatric & Mental Health Nursing*.

**Austin, W.**, Kelecevic, J., Goble, E., & Mekechuk, J. (2008). Moral distress and the Pediatric Intensive Care team: Seeking resolution through sharing narratives. *Nursing Ethics*, 16(1), 57-68.

Wall, S., **Austin, W.** (2008). The influence of teams, supervisors, and organizations on healthcare practitioners' ability to practice ethically. *Canadian Journal of Nursing Leadership*. 21(4), 85-99

Morse, J., Niehaus, L., Varnhagen, S., **Austin, W.**, & McIntosh, M. (2008). Qualitative researchers' conceptualizations of the risks inherent in qualitative interviews. *The International Review of Qualitative Research*. 1(2), 195-215

**Austin, W.** (2008). Ethics in a time of contagion: A relational ethics perspective. *CJNR: Canadian Journal of Nursing Research*.

**Abstracts and Non-peer Reviewed Articles**

**Austin, W.**, Kunyk, D., Carmago, P. (2008). 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.** (2008). Relational Ethics. In L. Given (Ed.), *The SAGE Encyclopedia of Qualitative Research Methods*. Thousand Oaks, CA: SAGE.

**Austin, W.**, Byrne, P., Leier, B., Goble, E. (2008). Compassion fatigue: The experience of nurses. *Caritas Research*, 11, 11-12.

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

Austin, W., **Byrne, P.**, Leier, B., Goble, E. (2008). Compassion fatigue: The experience of nurses. *Caritas Research*, 11, 11-12.

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

Austin, W., Byrne, P., **Leier, B.**, Goble, E. (2008). Compassion fatigue: The experience of nurses. *Caritas Research*, 11, 11-12.

**Publications continued:****Leier:**

**Leier, B.** (in press). Preventing Sex Selection in Therapeutic Abortion. *Journal of the Society of Obstetricians and Gynecologists Canada.*

**SHANNER:****Chapters**

**Shanner, L.** (2008). Bioethics and health law: Theoretical foundations and moral points of view. In B.L. Gervais (Ed), *Canadian Health Law Practice Manual*, Markham, ON: Lexis-Nexis.

**SOBSEY:****Chapters**

**Sobsey, D.** (2009). Foreword. *Combating abuse of people with disabilities: A call to action.* Baltimore: Paul H. Brookes Publishing Co.

**Peer-Reviewed Journal Articles**

Wilgosh, L., Scorgie, K, **Sobsey, D.**, & Cey, R. (in press). Quality of life and empowerment issues for post-secondary students with physical and learning disabilities. *Developmental Disabilities Bulletin.*

Hansen, N., Janz, H., & **Sobsey, D.** (2008). 21<sup>st</sup> century eugenics? *The Lancet*, 372, S104-107.

Wilgosh, L., **Sobsey, D.**, Cey, R. & Scorgie, K. (2008). Life management of post-secondary students with disabilities. *Developmental Disabilities Bulletin*, 36, 199-224.

**Sobsey, D.** and Cameron, K. (2008). A brief history of the J.P. Das Developmental Disabilities Centre. *Developmental Disabilities Bulletin*, 36, 251-265.

**Other**

Calder, P., **Sobsey, D.**, & Jacobs, P. (2008). The costs of mental health and mental illness in education. Edmonton: Institute of Health Economics.

**Web Publication**

Drake, S. & **Sobsey, D.** (2009, March 27). Let's put this pet theory to sleep. MercatorNet.

**icad** *International Coalition on Abuse & Disability*, <http://icad.wordpress.com/> 240  
 Authored posts with more than 160,000 page views.

*What Sorts of People Should There Be?* <http://whatsortsofpeople.wordpress.com/> 45  
 Authored posts with more than 14,000 page views.



## • TEACHING

### **AUSTIN:**

- INT D 570 Healthcare Ethics - Spring 2008

### **BYRNE:**

- Clinical Teaching on medical ethics at undergraduate, graduate and post-graduate levels for FoMD

### **LEIER:**

- Clinical Teaching on medical ethics at undergraduate, graduate and post-graduate levels for FoMD and Nursing
- Ethics Education for Alberta Health Services, Caritas and Provincial Health Ethics Network

### **SHANNER:**

- PHS 543 Public Health Ethics, Law and Policy - Winter 2009
- PHS 709 Ethics in Health Care Organizations – Fall 2008
- Incidental Guest Lectures:**
- PHS 541 Population Health (Soc Determ)
- PHS 510 – Chemistry, Partitioning and Transformation of Environmental Contaminants
- MED 515 – Community Health
- HPS 501 – Social & Behavioral Foundations in Promoting Health
- Occupational Medicine Ethics Half-Days (residency program)
- PHS 500- Introduction Health Systems and Policy
- PHS 596 – Epidemiology Methods 1 (2 sections)
- PHS 505 – Fundamentals of Public Health (Intro PH)
- PHS 696 – Advanced Epidemiology
- PHS 631 – Program Eval
- Lunch and Learn: Ethics Across Cultures

### **SOBSEY:**

#### **Incidental Guest Lectures:**

- MED 526 Patient-Centred Care Part II – Fall 2008
- DDS 520 Patient-Centred Care – Fall 2008
- PThER 525 Professional Issues (Physical Therapy)
- PHARM 326 Laws and Ethics
- EDPY 456 Collaboration and Consultation in 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*

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 with Paul Byrne) *The Lived Experience of IVF & Selective Reduction/ Abortion of Infertile Couples*

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

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

##### *Supervisory Committee Member*

Jodie Oosman, Medicine, (University of Calgary), 2006 - (Supervisory Committee) *Community Treatment Orders*

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)

#### *Supervision, Masters Degrees*

##### *In progress:*

##### *Supervisor*

Sara Calderon, Nursing, 2006 - (Supervisor)

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

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

**Supervision of Graduate Students and Postdoctoral Fellows continued:****Austin:*****Co-Supervisor***

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

Katherine Fisher, Nursing, 2007 - (Co-Supervisor) *Aboriginal Families with a child in PICU*

***Completed:***

Carla Petker, Educational Psychology, 2009 - (Examining Committee Member)  
*Psychologists and Self Care*

Monica Whitehead, Nursing, 2004 - 2008 - (Supervisor) *Pediatric Nurses' Perspectives of Spirituality and Spiritual Care Within Nurse-Patient Relationships: An Interpretive Description*

***Supervision, Research Training***

Dana Glorieux (Faculty of Nursing Health Professional Research Summer Student Internship), *Ethical Issues in Organ Donation & Transplantation*, May – August 2008

Theo Di Castri (AHFMR Undergraduate Research Internship), *Experience and Resolution of Moral Distress in PICU Teams*, July – August 2008

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

Katherine Duthie, School of Public Health, - (Supervisor)

***Committee Member***

Christopher Michell-Viret, School of Public Health, - (Committee Member)

**SOBSEY:*****Post-Doctoral Research Fellow******In progress:******Supervisor***

Heidi Janz, Educational Psychology, - (Supervisor) *Disability Ethics*

***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*

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

Tim Weinkauff, Educational Psychology, - (Supervisor) *Ambivalence Amplification Theory & People with Disabilities*

Jocelyn Wilkie, Educational Psychology, - (Supervisor) *PRN Orders and Dementia*

***Co-Supervisor***

Shin-Yi Wang, Educational Psychology, - (Co-Supervisor) *Meta-Analysis, effect size in single-case research*

***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 and Recreation, - (Supervisory Committee) *Dignity in Sports for individuals with disabilities*

Stuart Morris, Educational Psychology, - (Supervisory Committee) *Deafness education*

Shane Lynch, Educational Psychology, - (Supervisory Committee) *Intrinsic and Extrinsic Motivation in Autism*

Krista Pierce, Educational Psychology, - (Supervisory Committee) *Transformational Experiences of Post Secondary Education Students and Instructors Involved with Students with Significant Disabilities who are Receiving Inclusive Post Secondary Education Supports*

Cheryl Webster, Nursing, - (Supervisory Committee) *Depictions of Psychiatric Nursing In Film*

***Examining Committee Member***

Kim Adams, Rehabilitation Medicine, - (Examining Committee Member) *The use of robots in detaching math skills to students with disabilities*

***Completed:***

Lise Belzile, Educational Psychology, 2008 - (Examining Committee Member)

*A Foucauldian Interrogation of Teacher's Discourse of Inclusion*

Paula Cook, Education (University of Manitoba), 2009 - (Examining Committee Member)

*Neurologically-based behavior*

Sandra N. Thompson, Psychology, (University of Manitoba), 2009 - (Examining

Committee Member) *Parental Perception of Family Adjustment in Childhood*

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

Lorna Sutherland, Educational Psychology, - (Supervisor) *Inclusive Friendships*

***Co-Supervisor***

Michaella Jellen, Educational Psychology, - (Co-Supervisor) *Teaching Empathy*

**Supervision of Graduate Students and Postdoctoral Fellows continued:****Sobsey:*****Supervisory Committee Member***

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

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

**AUSTIN:**

Peer Consultant – University Teaching Services

Member of the Editorial Board – Journal of Mental Health Nursing

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

Member of the Ethics Advisory Group, Aboriginal Capacity and Developmental Research Environment Network (ACADRE)

Member of the Board of the Health Law Institute

Member of the Board International Academy of Law and Mental Health (2001-2009)

Member of the International Scientific Committee, International Academy of Law and Mental Health (1999 - 2009)

**BYRNE:**

Committee Member, University of Alberta and Stollery Children's Hospitals' Clinical Ethics (1995- )

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- )

Member, Canadian Pediatric Society

**LEIER:**

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:**

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

Editorial Board Member, Philosophy, Ethics and Humanities in Medicine

## **Faculty, University and Community Committees and Membership continued:**

### **SOBSEY:**

Elected Fellow, American Association on Intellectual and Developmental Disabilities  
(1994- )

Canadian Bioethics Society

Canadian Disability Studies Association

Committee Member, Canadian Institutes of Health Research: Research Integrity  
Committee

TASH: Equal Opportunity & Inclusion for People with Disabilities

### **NAHORNIAK:**

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

### **CABRAL:**

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 and CDs. University faculty members, students, Alberta Health Services 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)

**Library Resources continued:**

Bioethics Examiner (1997-2007)  
 Bioethics Research Notes (1993-2003)  
 Bulletin of Medical Ethics (1988-2006)  
 Cambridge Quarterly of Healthcare Ethics (1992-2009)  
 Ethics and Intellectual Disability (1995-2006)  
 Hastings Center Report (1973-2009)  
 Health Law Journal (1993-2008)  
 Health Law Review (1991-2009)  
 HEC Forum (1998-2005)  
 IRB: A Review of Human Subjects Research (1989-2009)  
 Journal of Clinical Ethics (1990-2009)  
 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:

**LEIER:**

*The Current*, CBC Radio, April 3, 2008.

**SOBSEY:**

Developmental Disabilities; New developmental disabilities findings from California State University described. *Biotech Week*, September 10, 2008. p. 774.

Jodie Sinnema. Walk to Remember honours parents' loss; Memories of stillborn, lost pregnancies shared. *Edmonton Journal*. October, 2008. p. B.1.

Voiceless and abused, DNA evidence in rape points to 'caregiver' woman may have been attacked before. *Seattle Post-Intelligencer*, (WA), November 11, 2008.

**Media requests continued:****Sobsey:**

Interview on filicide. *CBC-Radio* Canada International, January, 2009.

Carolyn Abraham. Disturbed parents who kill their children may feel they are acting out of love. *The Globe and Mail*. (Toronto, ON), January 5, 2009. p. A.4.

Andrew Chung. Mother charged with murdering her 3 kids, aiding husband's suicide  
*Waterloo Region Record*. January 6, 2009. p. A.3.

There is very little help for parents suffering from depression; Mental illness is common among people who kill their own children. *The Gazette*. (Montreal, PQ) January 7, 2009. p. A.13.

Andrew Chung. 'Illness kills, not individual'; Experts help explain what may drive parents to take children's lives. *Toronto Star*, January 11, 2009. p. A.7.

Janet Bagnall. Warning signs, risks often ignored before parents kill. *Times – Colonist*, (Victoria, BC), January 13, 2009. p. A.10.

M. Stephenson. How could she have done it? *The Chronicle-Herald*, January 31, 2009.

Montreal Couple Suing Hospital, *The Current*, CBC Radio, March 18, 2009.

Abuse At Texas Institutions Is Beyond 'Fight Club' (US), *National Public Radio*, Morning Edition, 18 March 2009.

The R-word isn't just hurtful, it's hate speech. *Daily Local News* (West Chester, PA), March 26, 2009.

Against Euthanasia, *The Western Confucian* (US), March 29, 2009.