ANNUAL REPORT April 2009 – March 2010



John Dossetor Health Ethics Centre





John Dossetor Health Ethics Centre 5-16 University Terrace Edmonton, AB, T6G 2T4 Phone: (780) 492-6676 Fax: (780) 492-0673 www.ualberta.ca/BIOETHICS/



OUR MISSION

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.







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OPENING MESSAGE

Welcome to the John Dossetor Health Ethics Centre's 2009-2010 Annual Report.

The John Dossetor Health Ethics Centre is an interdisciplinary centre at the University of Alberta committed to work in health ethics. In 2009-2010 the Centre made many contributions in discovery, interpretation and dissemination of knowledge in the area of health ethics. We reached out to scholars, students, health care practitioners, clinical ethics committee members, health care administrators, patients and their families, media and the general public.

This past year was particularly busy. Among our many activities some of our achievements were: 1) hosting a sixth annual, successful Health Ethics Symposium, *ETHICS EDUCATION: Minding the Gaps*; 2) hosting two successful Health Ethics Workshops on the *New Adult Guardianship and Trusteeship Act*; and 3) continuing with established events such the Health Ethics Seminar Series, Health Ethics Week and publishing the newsletter, *Health Ethics Today*. Our health ethics seminars, workshops and symposia were presented to full capacity attendance.

The John Dossetor Health Ethics Centre has 5 core faculty members with highly esteemed qualifications and expertise who are committed to addressing and promoting health care ethics. Their many accomplishments and contributions in health ethics teaching, research and community engagement 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.

The John Dossetor Health Ethics Centre would like to thank everyone who supports the Centre. We are extremely grateful for this support which shows the importance of promoting health care ethics in academia, the health care system and community.



STAFF



Director



Dick Sobsey, EdD Professor Faculty of Education

Faculty



Wendy Austin, RN, PhD Canada Research Chair Professor Faculty of Nursing

Dr. Sobsey is a Professor of Educational Psychology and serves as Director of the John Dossetor Health Ethics Centre, and Associate Director of the J.P. Das Developmental Disabilities Centre at the University of Alberta. Dr. Sobsey has worked to improve health care, educational opportunities, and social conditions for people with disabilities and their families since 1968. He is particularly interested in human rights and violence prevention. His current research areas include positive changes in families of children with disabilities, long-term outcomes for babies born to mothers who experience severe trauma during against people pregnancy, crimes with developmental disabilities, and historical research on the eugenic family studies.

Dr. Austin is Professor in the Faculty of Nursing with a joint appointment to the John Dossetor Health Ethics Centre, University of Alberta. Dr. Austin holds a Canada Research Chair in Relational Ethics in Health Care. She is an Adjunct Foreign Professor with the University of Malmö, Sweden and serves on the Boards of the Health Law Institute, University of Alberta and the International Academy of Law and Mental Health. She is a former Senior Scientist with the International Institute of Qualitative Methodology and a former member of the Canadian Nurses Association Ethics Committee. A founding Co-Director of the University of Alberta's PAHO/WHO Collaborating Centre in Nursing and Mental Health, she has been an advisor in mental health to the International Council of Nurses and the president of the Canadian Federation of Mental Health Nurses. Her research encompasses identifying and exploring relational ethics issues in mental health care, developing a relational ethics perspective on research ethics, and exploring ways to better prepare healthcare practitioners and researchers for ethical practice.





Paul Byrne, MB, ChB, FRCPC Clinical Professor Faculty of Medicine & Dentistry

Brendan Leier, PhD Assistant Clinical Professor Faculty of Medicine & Dentistry

Dr. Byrne was born in Ireland and attended medical school at University College in Dublin, receiving his MB, ChB degree in 1976. He immigrated to Kingston, Ontario in 1981 for further Pediatric training, receiving his FRCP and FAAP in Paediatrics in 1983 and completed a Neonatal Fellowship in London, Ontario. In 1985 he joined the University of Alberta's Department of Paediatrics and Neonatal Intensive Care Unit (NICU) and was NICU Director 1988 -1997. Dr. Byrne was Co-Director of the John Dossetor Health Ethics Centre 1997-1999 and Interim Director 2002-2006. Dr Byrne teaches clinical ethics to health care professionals and students, undertakes ethics consultations at the University of Alberta and Stollery Children's Hospitals and has ongoing research projects focusing on ethical decision-making in perinatal care.

Dr. Leier earned his PhD from the Department of Philosophy, University of Alberta in 2002. He is currently the Clinical Ethicist for the University of Alberta Hospital, Stollery Children's Hospital and Mazankowski Alberta Heart Institute, and Clinical Assistant Professor in the Faculty of Medicine and Dentistry. Dr. Leier is presently doing research in collaboration with Drs. Paul Byrne and Wendy Austin on the topics of pediatric best interest, moral distress, end-of-life decisionmaking, transplant ethics, compassion in the practice of medicine, risk and decision-making.





Laura Shanner, PhD Associate Professor School of Public Health Dr. Shanner is an Associate Professor of Health Ethics at the School of Public Health and John Dossetor Health Ethics Centre at the University of Alberta. Her primary interests include ethical issues in reproduction and genetics, public health ethics, gender issues in health, and ethical assessment of health policy and law. Currently a board member of the Alberta Public Health Association, a member of the Alberta Provincial Advisory Committee on Tobacco, and a member of the Stem Cell Advisory Committee for the Canadian Institutes for Health Research, she has also served as an expert consultant to multiple Health Canada policy development committees and the Canadian Biotechnology Advisory Committee. Dr. Shanner is a former co-chair of the International Network for Feminist Approaches to Bioethics, a former board member of Friends of Medicare (Alberta), and has worked in the U.K., Australia and the U.S. as well as Canada. Before coming to Alberta, Dr. Shanner held the I'Anson Assistant Professorship in Interdisciplinary Studies (Bioethics) at the University of Toronto, and has taught bioethics at the Johns Hopkins University and Georgetown University. She earned her Ph.D. in Philosophy-Bioethics from Georgetown University and the Kennedy Institute for Ethics (1994). Her publications have spanned books and journals in philosophy, women's studies, law, comparative theology, and experimental sciences.

Staff Carol Nahorniak, BSc Centre Administrator

Stacy Cabral, BA Information Officer

Postdoctoral Fellow *Heidi Janz*, PhD Post-Doctoral Fellow

Research Assistant *Wanapa Intaprasert* **Graduate Students** *Katherine Duthie*, MA *Michael van Manen*, MD, FRCPC



CORE ACTIVITIES

Since its beginnings 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, health care practitioners and members of Alberta Health Services, other health care agencies and the general public.

Graduate courses taught in the 2009-2010 calendar year were INT D 570 (Health Care Ethics), PHS 709 (Ethics in 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
- Health Ethics Today (newsletter)
- Health Ethics Seminar Series
- Health Ethics Week
- Health Ethics Symposium
- Health Ethics Workshops
- Clinical Ethics Grand Rounds
- Media requests
- Participation/Membership on
 - Ethics Committees with Alberta Health Services
 - o 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



OPERATING **BUDGET** 2009 - 2010



REVENUE

Faculty of Medicine & Dentistry	\$84,266.00
Health Sciences Council	\$53,500.00
External Revenue – Other Internal Revenue (Alberta Health Services)	\$15,794.00
External Revenue – Symposium Non-Credit Fees	\$2,333.34
UofA Conference Fund	\$1,000.00
UAH Hospital Foundation (2008-2009 allocation)	\$3,408.00
UAH Hospital Foundation (2009-2010 allocation)	\$2,189.00
Ethics Research Videos	\$66.67
Buy out for Director (currently between HSC and Educational Psychology)	\$44,000.00

TOTAL REVENUE

\$206,557.01

EXPENDITURES

Benefits \$15,635.6
Supplies, Services & Sundries \$11,668.8
Health Ethics Today Newsletter (publishing, printing & distribution) \$8,986.8
Communications \$3,754.9
Course Registrations \$1,279.5
Travel & Associated Expenses \$3,669.4
Credit Card Fees/Discount Fees \$160.0
Repairs & Maintenance \$134.4
Rentals & Leases \$2,172.4
Capital Equipment (computers, printers, HDTV) \$6,858.8
Buy out for Director (currently between HSC and Educational Psychology) \$44,000.0

TOTAL EXPENDITURES

\$188,479.50



RESEARCH FUNDING



Funding to the John Dossetor Health Ethics Centre

University of Alberta Conference Fund, *Health Ethics Symposium – Ethics Education: Minding the Gaps –* \$1,000 (2009)

Principal Investigator: **Dick Sobsey**, John Dossetor Health Ethics Centre, University of Alberta.

<u>Research Funding and Awards to Faculty of the John Dossetor Health Ethics</u> <u>Centre</u>

Community-University Research Alliance Program – From Archives to Activism – \$1,000,000 (2010 – 2015)

Principal Investigator: Rob Wilson, University of Alberta, Co-Investigator: **Dick Sobsey**, John Dossetor Health Ethics Centre, University of Alberta.

Social Sciences and Humanities Research Council of Canada (SSHRC), Research Grant – Defining Disability Ethics Sustainable Family Care for Children with Severe or Profound Disabilities – \$199,604 (2009 – 2011)

Principal Investigator: David McConnell University of Alberta, Co-Investigator: **Dick Sobsey**, John Dossetor Health Ethics Centre, University of Alberta.

Alberta Centre for Child, Family, & Community Research, Investigator Driven Small Grant – Hospital Transfer – Parents' Experience of the Transfer of their Baby – \$9,972.30 (2009 – 2010)

Principal Investigator: **Michael van Manen**, Department of Pediatrics, University of Alberta and Co-Investigators: **Wendy Austin**, Faculty of Nursing, University of Alberta and **Paul Byrne**, Department of Pediatrics, University of Alberta.



Canadian Institutes of Health Research (CIHR) – Addressing Disparities in Maternal Health Care in Pakistan: Gender, Class and Exclusion – \$452,000 (2009-2014)

Principal Investigator: Zubia Mumtaz, University of Alberta, Co-Investigators: S. Hamid, L. Laing, University of Alberta, S. Salway, **Laura Shanner**, School of Public Health, University of Alberta and S. Zaman.

Canadian Institutes of Health Research (CIHR), Health Services and Policy – *Ethics Catalyst Grant* – \$81,122 (2008 – 2012)

Principal Investigator: **Dick Sobsey**, John Dossetor Health Ethics Centre, University of Alberta.

Social Sciences and Humanities Research Council of Canada (SSHRC), Research Development Initiative Grant – *Defining Disability Ethics* – \$38,865 (2008 – 2011)

Principal Investigator: **Dick Sobsey**, John Dossetor Health Ethics Centre, University of Alberta.

Social Sciences and Humanities Research Council of Canada (SSHRC), Standard Research Grant – "Compassion Fatigue" As Experienced By Canadian Health Professionals – \$155,000 (2007 – 2011)

Principal Investigator: **Wendy Austin**, Faculty of Nursing, University of Alberta and Co-Investigator: **Brendan Leier**, John Dossetor Health Ethics Centre, University of Alberta.

Canadian Institutes of Health Research (CIHR), Operating Grant – Experience and Resolution of Moral Distress in Pediatric Intensive Care Teams: A Canadian Perspective – \$146,726 (2007 – 2011) Principal Investigator: Wendy Austin, Faculty of Nursing, University of Alberta.

Alberta Centre for Child, Family, & Community Research – Sustainable Support Services for Families of Children with Severe Disabilities – \$100,000 (2008 – 2010)

Co-Investigator: **Dick Sobsey**, John Dossetor Health Ethics Centre, University of Alberta.



AWARDS

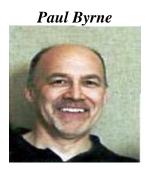


Wendy Austin



Canada Research Chair in Relational Ethics in Health Care (2008 – 2013)

"Dr. Austin's research program centers on exploring the core elements of relational ethics and their application in particular healthcare environments. The aims of this research program include identifying and exploring relational ethics issues in mental health care (including from a global perspective); developing a relational ethics perspective on research ethics; exploring ways to better prepare healthcare practitioners and researchers for ethical practice; and advancing the theoretical basis of relational ethics."



Faculty of Medicine & Dentistry Excellence in Humanism Award (2009)

"Dr. Byrne is widely recognized and respected as a clinical educator, particularly with respect to modeling excellent end-of-life decision-making and communication skills in the NICU environment."





Tanis Doe Award for Canadian Disability Study and Culture (2010)

Dr. Janz was selected by the Canadian Disability Studies Association to be the recipient of the 2010 Tanis Doe Award for Canadian Disability Study and Culture. According to the Canadian Disability Studies Association:

"This award honours an individual who dares to "speak the unspeakable" in advancing the study and culture of disability, and who has enriched through research, teaching, or activism, the lives of Canadians with disabilities."







JOHN DOSSETOR HEALTH ETHICS CENTRE

Health Ethics Today, 2009, Volume 18(1)



The newsletter, Health Ethics Today, has a circulation of approximately 9,000, which includes distribution to all medical doctors across Alberta, health care professionals, scholars, students, members of the Canadian Bioethics Society, Provincial Health Ethics Network and friends of the Dossetor Centre. *Health Ethics Today* is posted on the Dossetor Centre's website (http://www.ualberta.ca/BIOETHICS).

STAFF PUBLICATIONS

Wendy Austin

Books

Austin, W. & Boyd. M.A. (Eds.) (2010). *Psychiatric and Mental Health Nursing for Canadian Practice* (2nd ed.). Philadelphia, PA: Lippincott, Williams, & Wilkins, Inc.

Chapters

Austin, W. & Healey-Ogden, M. (2010). Mental health in the workplace. In W. Austin & Boyd, M.A. (Eds.), *Psychiatric and Mental Health Nursing for Canadian Practice* (2nd ed.) (pp. 56-68). Philadelphia, PA: Lippincott, Williams, & Wilkins, Inc.

Yonge, O. & **Austin, W.** (2010). Contemporary psychiatric and mental health nursing practice. In W. Austin & Boyd, M.A. (Eds.), *Psychiatric and Mental Health Nursing for Canadian Practice* (2nd ed.) (pp. 71-82). Philadelphia, PA: Lippincott, Williams, & Wilkins, Inc.



Austin, W. (2010). Ethical psychiatric and mental health nursing practice. In W. Austin & Boyd, M.A. (Eds.), *Psychiatric and Mental Health Nursing for Canadian Practice* (2nd ed.) (pp. 83-100). Philadelphia, PA: Lippincott, Williams, & Wilkins, Inc.

Austin, W. (2010). Cognitive behavioural therapy. In W. Austin & Boyd, M.A. (Eds.), *Psychiatric and Mental Health Nursing for Canadian Practice* (2nd ed.) (pp. 261-274). Philadelphia, PA: Lippincott, Williams, & Wilkins, Inc.

Austin, W. (2010). Mental health promotion with children and adolescents. In W. Austin & Boyd, M.A. (Eds.), *Psychiatric and Mental Health Nursing for Canadian Practice* (2nd ed.) (pp. 631-650). Philadelphia, PA: Lippincott, Williams, & Wilkins, Inc.

Austin, W. (2010). Mental health assessment of children and adolescents. In W. Austin & Boyd, M.A. (Eds.), *Psychiatric and Mental Health Nursing for Canadian Practice* (2nd ed.) (pp. 651-677). Philadelphia, PA: Lippincott, Williams, & Wilkins, Inc.

Austin, W. (2010). Ethical nursing practice: It's all about relationships. In P. Cowan & S. Moorhead (Eds.), *Current Issues in Nursing* (8th ed.). St. Louis, MO: Mosby Inc.

Peer-Reviewed Journal Articles

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

Pepper, D., Rempel, G., Austin, W., Ceci, C., & Hendson, L. (in press). Parents'

Perspective of Decision-Making in the Neonatal Intensive Care Unit at the Extremes of Prematurity.

<u>Olmstead, D.</u>, Scott, S. & **Austin, W.** (in press). Unresolved pain in children: An ethical perspective. *Nursing Ethics*.

<u>Healey-Ogden, M</u>. & **Austin, W.** (in press). Uncovering the Mystery of the Lived Experience of Well-Being. *Qualitative Health Research*.

Beattie, O., **Austin, W.**, Kelecevic, J. & Goble, E. (2010). Ethical issues in resolving the organ shortage: The views of recent immigrants and health professionals. *Health Law Review*, *18*(2), 25-30.

Snow, N., **Austin, W**. (2009). Community Treatment Orders: The ethical balancing act in community mental health. *Journal of Psychiatric & Mental Health Nursing, 16*, 177-186.



Austin, W., Goble, E., Kelecevic, J. (2009). The Ethics of Forensic Psychiatry: Moving from Principles to a Relational Ethics Approach. *Journal of Forensic Psychology and Psychiatry*, 20(6), 835-850.

Austin, W., Strang, V., Goble, E., Mitchell, A., Thompson, E., Lantz, H., Balt, L., Lemermeyer, G., Vass, K. (2009). Supporting relationships between family and the healthcare team in continuing care settings. *Journal of Family Nursing* 15(3), 360-383.

Whitty-Rogers, J., Alex, M, MacDonald, C., Pierrynowski, G., **Austin, W.** (2009). Hearing voice fostering choice: Working with children in end-of-life decision making – A Relational Ethics perspective to autonomy. *Nursing Ethics*, *16*(6), 743-758.

Mill, J., Edwards, N., Jackson, R., **Austin, W.**, MacLean, L. and Reintjes, F. (2009). Accessing health services while living with HIV: Intersections of stigma. *Canadian Journal of Nursing Research*, 6(1), 1-18.

Austin, W., Goble, E., Leier, B. & Byrne, P. (2009). Compassion fatigue: The experience of nurses. *Ethics and Social Welfare*, *3*(2),195-214.

Abstracts and Non-peer Reviewed Articles

Austin, W. (2009, May). Ethical Issues in Organ Donation in Canada: Views of Recent Immigrants and Health Professionals. In *Proceedings of the VIth World Conference on Bioethics*, Gijon, Spain, May 18-21st, 2009, p. 233-234.

Austin, W. (2009). "What Were They Thinking?": How Appalling Acts can Spring from Good Intentions. *Health Ethics Today*, *18*(1), 4-6.

Paul Byrne

Peer-Reviewed Journal Articles

Austin, W., Goble, E., Leier, B. & **Byrne, P.** (2009). Compassion fatigue: The experience of nurses. *Ethics and Social Welfare, 3*(2), 195-214.

Non-peer Reviewed Articles

Byrne, P. (2009). Can We Do It? – Yes We Can! – (but Ought We?). *Health Ethics Today*, 18(1), 9-11.



<u>Heidi Janz</u>

Chapters

Sobsey, D. & **Janz, H**. (in press). Violence against people with disabilities. In B. Perry (Ed.), *Diversity and Justice in Canada*. Toronto: Oxford University Press.

Non-Peer-Reviewed Journal Articles

Hansen, Nancy E., and **Janz, Heidi L.** (in press). The Ethics of Making Space for Non-Conformist Minds and Bodies in Healthcare. *Developmental Disabilities Bulletin*.

Janz, Heidi L. (in press). The Unkindest Cut of All: Portrayals of Pain and Surgery in the Tracy Latimer Case. *Developmental Disabilities Bulletin*.

Janz, Heidi L. and Hayward, Sally. (in press). Questions of Right and Left, Or Right and Wrong?: A Disability-Ethics Analysis of the Right-Wing and Left-Wing Media Portrayals of the Latimer Case. *Developmental Disabilities Bulletin*.

<u>Brendan Leier</u>

Peer-Reviewed Journal Articles

Bailey, T.M. & Leier, B. (2010). The case of Samuel Golubchuk and the right to be spared an excruciating death. *The American Journal of Bioethics*, *10*(3), 67-68.

<u>Laura Shanner</u>

Non-peer Reviewed Articles

Shanner, L. (2009). Lost in the Crowd: Individuals in Public Health and Health Policy. *Health Ethics Today*, *18*(1), 2-4.

Dick Sobsey

Chapters

Sobsey, D. & Janz, H. (in press). Violence against people with disabilities. In B. Perry (Ed.), *Diversity and Justice in Canada*. Toronto: Oxford University Press.

Razza, N. & **Sobsey, D.** (in press). Treating survivors of sexual and interpersonal abuse. In R. Fletcher (Ed.), *Psychotherapy for people with intellectual disabilities*. Kingston, NY: NADD Press.



Sobsey, D. (in press). Ethics of counseling individuals with intellectual disabilities. In R. Fletcher (Ed.), *Psychotherapy for people with intellectual disabilities*. Kingston, NY: NADD Press.

Peer-Reviewed Journal Articles

Sobsey, D. (2010). Ethics or Advocacy? American Journal of Bioethics, 10(1), 59-60.

Kelly, M.E., Darrah, J., **Sobsey, R.**, Haykowski, M., & Legg, D. (2009). Research report: Effects of a community-based aquatic exercise program for children with cerebral palsy. *The Journal of Aquatic Physical Therapy*, *17*(2), 1-10.

Published Proceedings

Sobsey, D. Medical discrimination and pandemic preparedness . In S. Watson, D. Richards, D. Griffiths, F. Owen, D. Tarulli, V. Marinos, S. Bennett, T. Gallagher, M. Feldman, B. Vyrostko (Eds,), *Proceedings of the Human Rights and Persons with Intellectual Disabilities Conference* (vol VI, pp. 6-11). Niagara Falls, ON: April 21-22, 2010.

Book & Media Reviews

Sobsey, D. (in press). A review of <u>The faces of intellectual disability: Philosophical</u> reflections by Licia Carlson. *Journal of Ethics and Mental Health*.

Sobsey, D. (in press). A review of <u>The construction of disability in our schools: Teacher</u> and parent perspectives on the experience of labeled students by Kathryn Underwood. *Exceptionality Education International.*

Non-Peer-Reviewed Journal Articles

Sobsey, D. (in press). The cutting edge: Pain and surgery in the Ashley X case. *Developmental Disabilities Bulletin.*

Calder, P., **Sobsey, D.**, & Jacobs, P. (in press). Cost of Mental Health Services in Alberta Schools. *Developmental Disabilities Bulletin*.

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*.

Sobsey, D. (2009). Perils of Protection. *Health Ethics Today*, 18(1), 7-8.



PRESENTATIONS



JOHN DOSSETOR HEALTH ETHICS CENTRE

Health Ethics Symposium, ETHICS EDUCATION: Minding the Gaps:



The John Dossetor Health Ethics Centre hosted a one-day symposium on ethics education. Ethics education should be more about the process of exploration than the content of the ethics curriculum.





Where Ethics Education Begins

CBC Newsworld: Passionate Eye Documentary, "Children Full of Life"

Educating the Educators - Laura Shanner, PhD

Ethics and the Interdisciplinary Team - Wendy Austin, RN, PhD CRC, Relational Ethics in Health Care

Minding the Gaps in Healthcare Ethics - Brendan Leier, PhD

Educating the Public - Richard Sobsey, EdD



Health Ethics Workshop, New Adult Guardianship and Trusteeship Act:

John Dossetor Health Ethics Centre		dult Guardianship Trusteeship Act
	a 1 121	day, November 16, 2009
~	Tim	ne: 8:30 am—2:30 pm
do		Location: -07 Heritage Medical
^y	Resear	ch Centre, University of Alberta
rks		Agenda
Workshop	8:30—9:45 am	Conceptual and Ethical Issues in Guardianship Dick Sobsey, Director, John Dossetor Health Ethics Centre Brendan Leier, Clinical Ethicist, John Dossetor Health Ethics Centre
	9:45—10:00 am	Break
	10:00 am—Noon	Alberta's New Adult Guardianship and Trusteeship Act Brenda Lee Doyle, Provincial Director, Office of the Public Guardian Shirley Peleshytyk, Public Guardian, Edmonton Regional Office
	Noon—12:30 pm	Lunch
Government	12:30—1:00 pm	Brief question and discussion period
of Alberta 🔳	1:00—2:30 pm	Guardianship and the Law Tracey Bailey, Executive Director, Health Law Institute

FOR MORE INFORMATION:

John Dossetor Health Ethics Centre 5-16 University Terrace University of Alberta Edmonton, Alberta T&G 2T4

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ALBERTA





The *New Adult Guardianship and Trusteeship Act Workshop* held on 16 November 2009 was extremely successful and presented to full capacity attendance. Due to wide interest, the John Dossetor Health Ethics Centre had a repeat offering of workshop on January 29, 2010 in Bernard Snell Hall, Walter Mackenzie Health Sciences Centre. Through collaboration with Alberta Health Services the workshops were teleconferenced to health care facilities across Alberta.

Health Ethics Seminars:

Each academic year, the John Dossetor Health Ethics Centre invites speakers to present as part of its Health Ethics Seminar series. The seminar series is open to scholars, students, health care practitioners, clinical ethics committee members, health care administrators, patients and their families, media and the general public. Most of these seminars are teleconferenced to health care facilities across Alberta.

18 September 2009

CIHR's Guidelines for Health Research Involving Aboriginal People: implications for funding, reviewing and training Malcolm King, PhD, Scientific Director CIHR Institute of Aboriginal Peoples' Health and Professor, Pulmonary Medicine, Faculty of Medicine and Dentistry, University of Alberta

22 January 2010

Disability, Parenting and the Rights of the Child

David McConnell, PhD Associate Professor, Department of Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta

19 March 2010 *Ethical Issues in Organ Donation: Views of Recent Immigrants & Healthcare Professionals* Erika Goble, MA, PhD Student Research Coordinator for Relational Ethics in Healthcare Research Faculty of Nursing Julija Kelecevic, MD, PhD(c) Bioethicist, Thunder Bay Regional Health Sciences Centre and Collaborative Group 11 December 2009

Use of Digital Media as a Means of Promoting Reflection on Ethical Issues in the First Year Medicine Patient Centred Care Course Pamela Brett-McLean, PhD Assistant Professor, Faculty of Medicine & Dentistry Co-Director, Arts & Humanities in Health & Medicine Program, University of Alberta

26 February, 2010 *Newborn Screening...Just because we can?* Victoria Seavilleklein, PhD Ethicist & policy Director, Provincial Health Ethics Network



Health Ethics Week 2010:

2 March 2010 Addressing Moral Distress in Caregiving at the End of Life Eric Wasylenko, MD, BSc Palliative Care Physician Executive Director, Clinical Ethics for Alberta Health Services and Co-Founder Foothills Country Hospice 5 March 2010 *Relational Ethics and Hope: Examining responsible caring when hope is challenged* Denise Larsen, PhD, R. Psych Associate Professor, Department of Educational Psychology and Director of Research, Hope Foundation of Alberta, University of Alberta

Grand Rounds:

5 October 2009 **On the Lost Virtue of Hospitality or Whose Home is this Hospital?** Brendan Leier, PhD Clinical Ethicist University of Alberta and Stollery Children's Hospital, Mazankowski Alberta Heart Institute and John Dossetor Health Ethics Centre

JDHEC FACULTY

Wendy Austin:

28 April 2009 *Nurses' Experience of Compassion Fatigue* Canadian Association of Critical Care Nurses. 29 April 2009 Supporting Relationships Between Family and the Healthcare Team in Traditional Continuing Care Settings Alberta Association of Gerontology, Edmonton, AB.

30 April 2009 *Ethics and the Interdisciplinary Team* John Dossetor Health Ethics Centre – Health Ethics Symposium, University of Alberta Edmonton, AB. 21 May 2009 *Ethical Issues in Organ Donation: The Views of Recent Immigrants and Health Professionals* 4th World Bioethics Conference, Gijon, Spain.



28 May 2009 *Relational Engagement: The Challenge of Contemporary Nursing Practice* Canadian Advanced Practice Nurses in Hematology, Oncology, and Bone Marrow, Lake Louise, AB. 1 June 2009

"The Nurse I Used To Be": Systemic Effects on the Professional Self Annual General Meeting of the Sigma Theta Tau International Honor Society of Nursing, Mu Sigma Chapter,

Edmonton, AB.

30 June 2009 *What were they thinking? How appalling acts can spring from good intentions* Congress of the International Academy of Law And Mental Health, New York City, New York.

<u>Heidi Janz:</u>

25 - 26 May 2009 *Darwin's Lethal Legacy: 21st-Century Eugenics* Canadian Disability Studies Association Conference, Ottawa, Ontario. (with Nancy Hansen and Dick Sobsey) 25 - 26 May 2009 Director's cut: Portrayals of pain and surgery in the Ashley X Case" & "The unkindest cut of all: Portrayals of pain and surgery in the Tracy Latimer Case Canadian Disability Studies Association Conference, Ottawa, Ontario. (with Dick Sobsey)

<u>Brendan Leier:</u>

30 April 2009

Minding the Gaps in Healthcare Ethics

John Dossetor Health Ethics Centre – Health Ethics Symposium, University of Alberta Edmonton, AB. 29 June – 4 July 2009 *Compassion* Congress of the International Academy of Law and Mental Health New York City, New York.



5 October 2009

On the Lost Virtue of Hospitality or Whose Home is this Hospital?

Grand Rounds - University of Alberta and Stollery Children's Hospital, Mazankowski Alberta Heart Institute Clinical Ethics Committee

18 January 2010 Understanding the New Adult Guardianship and Trusteeship Act Workshop by Provincial Health Ethics Network Rockyview Hospital, Calgary, AB. (with Dick Sobsey)

16 November 2009

Conceptual and Ethical Issues in Guardianship

Workshop by John Dossetor Health Ethics Centre New Adult Guardianship and Trusteeship Act University of Alberta Edmonton, AB. (with Dick Sobsey)

29 January 2010

Conceptual and Ethical Issues in Guardianship

Workshop – John Dossetor Health Ethics Centre New Adult Guardianship and Trusteeship Act University of Alberta Edmonton, AB. (with Dick Sobsey)

Laura Shanner:

30 April 2009 *Educating the Educators* John Dossetor Health Ethics Centre – Health Ethics Symposium, University of Alberta Edmonton, AB.

17 August 2009 *Aha! Moments and Open Moral Spaces* Public Health Summer School (APHA, UA, UC, UL) Calgary, AB.

February 2010 *Health Care Reform: Hope, Hype, and Having Enough* International Week University of Alberta

13 August 2009 *Tips, Tricks, and Insights for Teaching and Learning Bioethics* Workshop for high school science teachers

Workshop for high school science teachers. Alberta Heritage Foundation for Medical Research, Heritage Youth Research Summer Program

16 October 2009

Teaching Global Citizenship: Health Sciences and Ethics

Pedagogical Provocations Series panel discussion University of Alberta





Dick Sobsey:

30 April 2009 *Educating the Public* John Dossetor Health Ethics Centre – Health Ethics Symposium, University of Alberta Edmonton, AB. 25 - 26 May 2009 *Darwin's Lethal Legacy: 21st-Century Eugenics* Canadian Disability Studies Association Conference, Ottawa, Ontario. (with Heidi Janz and Nancy Hansen)

25 - 26 May 2009

Director's cut: Portrayals of pain and surgery in the Ashley X Case" & "The unkindest cut of all: Portrayals of pain and surgery in the

Tracy Latimer Case Canadian Disability Studies Association Conference, Ottawa, Ontario. (with Heidi Janz)

18 January 2010 Understanding the New Adult Guardianship and Trusteeship Act Workshop by Provincial Health Ethics Network Rockyview Hospital, Calgary, AB. (with Brendan Leier)

February 2010 Intimate Partner Violence Against People with Disabilities

Keynote, Workshop on Domestic Violence. Developmental Disabilities Resource Centre and Calgary Social Services Calgary, AB. 16 November 2009

Conceptual and Ethical Issues in Guardianship

Workshop by John Dossetor Health Ethics Centre New Adult Guardianship and Trusteeship Act University of Alberta Edmonton, AB. (with Brendan Leier)

29 January 2010

Conceptual and Ethical Issues in Guardianship

Workshop – John Dossetor Health Ethics Centre New Adult Guardianship and Trusteeship Act University of Alberta Edmonton, AB. (with Brendan Leier)



John Dossetor Health Ethics Centre Annual Report 2009 – 2010

TEACHING



Core members of the John Dossetor Health Ethics Centre contribute to teaching ethics across many faculties at the University of Alberta, as well as outside of the University.

Wendy Austin:

INT D 570 - Healthcare Ethics

Winter 2010

Paul Byrne:

Co-instructor for a number of academic half-days per year (12-20) which amounts to **medical sub-specialty ethics teaching**. These days are directly related to ethics content requirements for accreditation in the Faculty of Medicine and Dentistry. (with Brendan Leier)

<u>Brendan Leier:</u>

Co-instructor of all the **undergraduate ethics and law curricular requirements** for medical students in yrs 1-4. (with Tracey Bailey, Health Law Institute)

5 and 10 ethics electives per year, which are either 12 hour or two week directed education sessions for medical students

Tutor and facilitator for the Arts and Humanities in Health and Medicine Program content for the last two years.

Co-instructor for a number of academic half-days per year (12-20) which amounts to **medical sub-specialty ethics teaching**. These days are directly related to ethics content requirements for accreditation in the Faculty of Medicine. (with Paul Byrne)

Ethics Education for Alberta Health Services, Caritas and Provincial Health Ethics Network



Laura Shanner:

PHS 709 – Ethics in Health Care Organizations	Fall 2009
PHS 543 – Public Health Ethics, Law and Policy	Winter 2010
Co-instructor for Public Health 3420, Public Health Ethics, University of Lethbridge	
Curriculum Co-Chair, Public Health Summer School (APHA, UA, UC, UL), Calgary AB	
Incidental Guest Lecturer: 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 Evaluation	
Lunch and Learn: Ethics Across Cultures	
INT D 600 – Ethics in Maternal-Fetal Research	
MED 650 – Gender, Ethnicity and Vulnerability in Research	



Dick Sobsey:

Co-instructor for CMPUT 605 – Ethics in the Software Development Life-Cycle: A Case Study of Health	Winter 2010
Informatics Systems	
Incidental Guest Lecturer:	
PTHER 525 – Professional Issues II – Health Care, Ethics and Medical-Legal Issues	Summer 2009
MED 526 – Patient-Centred Care Part II	Fall 2009
DDS 520 – Patient-Centred Care	Fall 2009
PHARM 362 – Pharmacy Laws & Ethics	
EDPY 456 – Collaboration and Consultation in Education	Winter 2010
EDPY 546 – Hope and the Helping Relationship	Winter 2010



GRADUATE STUDENT and POST-DOCTORAL FELLOW SUPERVISION



Wendy Austin:

SUPERVISION, POSTDOCTORAL FELLOWS

Nina Erfani, April 2009 – April 2010

Funded by the Social Sciences and Humanities Research Council, Research Project "Compassion Fatigue" As Experienced by Canadian Health Professionals

SUPERVISION, DOCTORAL DEGREES

Supervisor (in progress):

Diane Kunyk, Nursing, 2007 - Nurses' Experience of Addictions Nicole Snow, Nursing, 2006 - Community Mental Health Ethics Cheryl Webster, Nursing, 2003 - Depictions of Psychiatric Nursing in Film Cindy Peternelj-Taylor, Nursing, 2002 - Ethics, Engagement & Forensic Nursing

Co-Supervisor (in progress):

- Jocelyn Dye-Grech, Nursing, 2003 (Co-Supervisor with Paul Byrne) The Lived Experience of IVF & Selective Reduction/ Abortion of Infertile Couples
- Julija Kelecevic, Forensic Anthropolgy, 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
- Catherine Thibeault, Nursing, (McGill University), 2005 (Supervisory Committee) The Relational Experience of Hospitalized Persons with Acute Mental Illness and their Nurses

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

Completed:

Danielle Leigh Fullerton, Educational Psychology, 2004 – 2009 (Supervisory Committee) Well-Being of Female Academics



SUPERVISION, MASTERS DEGREES

Supervisor (in progress):

Sara Calderon, Nursing, 2006 -

Dawn Kocuper, Nursing, 2005 - Ethical Decision Making

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

Co-Supervisor (in progress):

Michael van Manen, Neonatology-Perinatology Subspecialty Resident, Pediatrics, 2010 - (Co-Supervisor with Paul Byrne) - Parents' lived relational moral experience of direction-of-care decisions in the NICU
 Katherine Fisher, Nursing, 2007 -

Completed:

Robyn Sacks, Health Promotion Studies, 2009 - Processes of Participant Engagement with Edmonton Drug Treatment Court: A Grounded Theory (Examining Committee Member)

Dawn Pepper, Nursing, 2006 – 2009 (Co-Supervisor) - Ethical Decision Making for Parents in the NICU

Paul Byrne:

SUPERVISION, DOCTORAL DEGREES

Co-Supervisor (in progress):

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

Supervisory Committee Member:

Katherine Duthie, School of Public Health, 2008 - (Supervisory Committee) Organizational Influences on the capacity for Ethical Clinical Practice in the NICU

SUPERVISION, MASTERS DEGREES

Co-Supervisor (in progress):

Michael van Manen, Neonatology-Perinatology Subspecialty Resident, Pediatrics, 2010 - (Co-Supervisor with Wendy Austin) - Parents' lived relational moral experience of direction-of-care decisions in the NICU

Supervisory Committee Member:

Natalie Ford, Nursing, 2008 - (Supervisory Committee) Nurses' Conscientious Objection in the NICU



<u>Brendan Leier:</u>

SUPERVISION, DOCTORAL DEGREES

Supervisory Committee Member:

Katherine Duthie, School of Public Health, 2008 - (Supervisory Committee) Organizational Influences on the capacity for Ethical Clinical Practice in the NICU

Laura Shanner:

SUPERVISION, DOCTORAL DEGREES

Supervisor (in progress):

Katherine Duthie, School of Public Health, 2008 - Organizational Influences on the capacity for Ethical Clinical Practice in the NICU

Supervisory Committee Member:

Christopher Michell-Viret, Faculty of Medicine, 2007 - (Supervisory Committee) Spatiotemporally Enabling the Seamless Health Record

Dick Sobsey:

SUPERVISION, POSTDOCTORAL FELLOWS

Heidi Janz, September 2008 -

Funded by the Social Sciences and Humanities Research Council, Research Project "Defining Disability Ethics Project"

SUPERVISION, DOCTORAL DEGREES

Supervisor (in progress):

Robert Cey, Educational Psychology - Changes in Sexual Preferences Wanapa Intaprasert, Educational Psychology - Families of Children with Developmental Disabilities Jocelyn Wilkie, Educational Psychology - PRN Orders and Dementia Shane Lynch, Educational Psychology

Supervisory Committee Member:

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



- Kent Cameron, Educational Psychology, (Supervisory Committee) *Relaxation Carrels* for Children with Behavior Disorders
- Keith Johnston, Physical Education and Recreation, (Supervisory Committee) Dignity in Sports for individuals with disabilities
- 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
- Shin-Yi Wang, Educational Psychology, (Supervisory Committee Member) Meta-Analysis, effect size in single-case research
- Cheryl Webster, Nursing, (Supervisory Committee) Depictions of Psychiatric Nursing In Film

Completed:

- Tim Weinkauf, Educational Psychology, (Supervisor) Ambivalence Amplification Theory & People with Disabilities
- Sandra Hodgetts, Rehabilitation Medicine, (Supervisory Committee) Weighted Vests and Autism

SUPERVISION, MASTERS DEGREES

Supervisory Committee Member:

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

Completed:

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



COMMITTEES and MEMBERSHIP



Wendy 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

Paul Byrne:

Ethical Consultant - Pediatric Advisory Team, Province Wide Service, Provincial Advisory Group Bioethicist Consultant-Alberta Health Services/Covenant Health/University of Alberta Member - Canadian Bioethics Society Member - Canadian Pediatric Society

Stacy Cabral:

Committee Member - University of Alberta and Stollery Children's Hospitals' Clinical Ethics Committee

<u>Brendan Leier:</u>

Committee Member - University of Alberta Hospital, Stollery Children's Hospital and Mazankowski Alberta Heart Institute

Research Ethics Review Committee - College of Physicians and Surgeons of Alberta Member - Capital Region Health Ethics Coordinating Council

Carol Nahorniak:

Secretariat - University of Alberta Hospital, Stollery Children's Hospital and Mazankowski Alberta Heart Institute



<u>Laura Shanner:</u>

Advisory Member - Stem Cell Oversight Committee, Canadian Institutes of Health Research
Consultation, Pandemic response planning. Kevin Taft, Member of Provincial Parliament, Alberta
Member - Board and Chair of Issues and Actions Committee, Alberta Public Health Association
Executive Committee, Co-Chair Curriculum Committee - APHA/UC/UA/UL Public Health Summer School
Editorial Board Member - Philosophy, Ethics and Humanities in Medicine

Member – Global Citizenship Education Working Group

Dick Sobsey:

Steering Committee Member - Alberta Consortium on the History of Eugenics
Awards Committee Member - Canadian Disability Studies Association
Research Integrity Committee Member - Canadian Institutes of Health Research
Reviewer - American Journal of Bioethics: Primary Research
Reviewer - International Journal of Disability, Development, and Education
Reviewer - International Journal of Feminist Approaches to Bioethics
International Editorial Board Member - Journal of Adult Protection
Committee member - Edmonton Catholic Schools Parent Inclusion Committee
Training Facilitator - Alberta Association for Community Living, Advanced Family
Leadership Training

Member Task Force for Values and Ethics - Canadian Association for Community Living External Reviewer - L'Arche Association of Edmonton









Administrative support for the Clinical Ethicist and the consultation service of the University of Alberta Hospital, Stollery Children's Hospital and Mazankowski Alberta Heart Institute's Clinical 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. This 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. Through the clinical ethics service the John Dossetor Health Ethics Centre has created a partnership with Alberta Health Services for an ethical delivery of health care in the community.



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:

U
ACTA Bioethica (2000-2001)
Bioetica Informa (1999-2002)
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 (1973-2010)
Health Law Journal (1993-2008)
Health Law Review (1991-2009)
HEC Forum (1998-2005)
IRB: A Review of Human Subjects Research (1989-2010)
Journal of Clinical Ethics (1990-2010)
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)
Nursing Ethics (1997-2003)



MEDIA AND PUBLIC **INQUIRIES**



The faculty of the John Dossetor Health Ethics Centre responds to a variety of health ethics inquiries from academics, health care professionals, the general public and the media. The responses have appeared as feature articles in local (Edmonton Journal and the University of Alberta's Express News) and national (Globe and Mail, CTV and CBC Radio and TV) media on a variety of health ethics issues. Some examples:

Wendy Austin:

CBC Radio "White Coat Black Art" on the topic of Compassion Fatigue

Laura Shanner:

CTV Primetime Live "Reproductive Tourism" 25 May 2009.

- CBC <u>Ideas</u> "From Here to Maternity" 2-part program on assisted conception, interviewed by Alison Motluk and aired repeatedly; 1st air dates 15-16 June 2009.
- Edmonton Journal "Transgender Case Goes to Reconciliation" 15 October 2009 <u>http://digital.edmontonjournal.com/epaper/viewer.aspx</u> Lengthy quote in article about transgender discrimination and religious freedom case.

CBC Radio "Ethical Issues in H1N1 Response" 20 November 2009.

Dick Sobsey:

- CBC-TV "Interview on the Death of Bay Isaiah" CBC News.
- CHED-AM Radio "Interview on Ethics of withdrawing care from infants" 630 CHED AM, 19 January 2010.

CTV Edmonton News "Interview on withholding care from infants with severe disabilities" CTV Edmonton News 19 January 2010.

CJCA AM- Radio "Interview on Ethics of withdrawing care from infants" Life Talk with Wade Sorochan Show. 930 CJCA AM, 20 January 2010.

Edmonton Journal "Disabled Infant Gets Reprieve" 20 January 2010.



Globe & Mail "Legal fight has child's life in the balance" 26 January 2010.

Folio "Provincial eugenics archives awarded one of two U of A SSHRC awards" interviewed by M. Brown 12 February 2010.

CTS-TV "Discussion on Challenges of Disability" CTS-TV network, 11 March 2010. Edmonton Journal "UofA Cuts Ethics Centre Funds" 26 March 2010. Alberta Primetime Interview on "Health Ethics" 31 March 2010.

References:

http://www.google.ca/images