



ETHICS IN ACTION

CEN Town Hall Meeting

On June 10th, 2009, the Community Ethics Network (CEN) held its first town hall meeting at VHA Home Healthcare in Toronto. Representatives from member organizations were brought together for an afternoon of learning, sharing experiences and brainstorming ideas. Divided into two parts, the first half of the meeting featured speakers and presentations and the second half involved interactive discussions.

The meeting started off with the CEN Steering Committee releasing the work plan for 2009–2010. Kim Ibarra, Toronto Central CCAC, then provided a short overview and report on the progress to date of CEN's web site development. Next on the agenda was a presentation by David Gibson, Bellwoods Centres for Community Living, which detailed how organizations can embed ethics into their organization's culture. Those in attendance were provided with a checklist

of strategies on how to build an ethics infrastructure within their organization. Strategies included developing and implementing a code of ethics policy, a decision-making framework, and an evaluation tool. In addition to having an ethics infrastructure, David suggested that an ethics culture can be enhanced by embedding ethics into standard organizational activities such as orientation and performance evaluation. A number of participants used the evaluation form to rate this session as the best part of the Town Hall.

In the second half of the Town Hall, Susan Burns from COTA Health presented an update of the Apology Act and an overview of the implications of this new legislation for organizations. Susan defined the term 'apology' and emphasized that according to the Act an apology does not imply admission of fault or liability and shall not be taken into account in determining fault or liability. However, it is also important to note that an apology does not prevent legal prosecution.

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For an update on CEN activities visit our website: <http://www.jointcentreforbioethics.ca/index.shtml>

Participants then divided into two discussion groups, one focused on developing a model to train ethics trainers (termed ‘train the trainer’), and another focused on how to educate front-line staff on ethics.



Each group had a leader and a facilitator to offer guidance in exploring the topic under discussion. Participants from the ‘train the trainer’ session believed such a model would “build ethics capacity”, “maximize resources” and “promote sustainability”, as well as promote “synergy” and “inter-professional collaboration”. Participants from the ‘education of front-line staff’ session proposed that real life ethical dilemmas shared by front-line staff would be the best way to educate their peers, because it would be easier for staff to relate to the situation. They felt that sharing real life experiences would “get people to start talking” and, as a result, increase the ability of front-line staff to retain their ethics learning. During the discussion, participants showed an interest in developing a chat room on the CEN website as a resource with the potential to enhance and expand ethics support in the community.

The CEN Town Hall was successful in providing CEN members with ethics capacity building tips, an update and overview of implications of new legislation, and an opportunity to share and gather ideas on how to increase ethics capacity within the community health care sector.

Prepared by Anna Ma, Ethics Summer Student, Toronto Central CCAC

Canadian Bioethics Society's 20th Annual Conference

The Canadian Bioethics Society (CBS) held its twentieth annual conference in Hamilton, Ontario, June 11 to 14, 2009. The conference, entitled ‘Just Evidence?’, provided a forum where ethical issues around evidence-based knowledge, clinical care, health law, health policy and health-related research could be raised.

The conference showcased a number of scholars interested in the ethics of home and community care. For example, Marie Edwards, Assistant Professor in the Faculty of Nursing of the University of Manitoba, presented, on behalf of her colleagues, empirical work on long-term care nurses’ responses to moral distress. Moral distress has long been identified as an important issue in nursing, however empirical examinations of nurses’ experiences and responses have been limited. Marie Edwards and colleagues’ findings highlight the importance of the creation and availability of safe spaces to discuss ethical issues and conflicting values in long-term care institutions.

Taking a more systemic approach, Maria Bouzidi discussed “Clinical ethics and community care”, analyzing some of the issues that are put forth to ethics committees of some Centres de santé et de services sociaux (CSSS) in Quebec.

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The Centres, responsible for overseeing and allocating community care, deal with ethical issues that often arise in the context of care provided in the home of clients or in long-term care organizations. Interestingly, Maria Bouzidi discussed the lack of uniform and standardized process for decision-making by the ethics committees of the CSSS.

The Community Ethics Network was also represented during the conference. Kim Ibarra, Renaud Boulanger, and Frank Wagner traveled to Hamilton to discuss the need for homecare ethics capacity. The aim of the presentation was to share quantitative and qualitative data from the internal quality improvement project (Outreach Project) conducted in 2008, as well as to provide some insight into how to develop integrated, accountable, and sustainable community ethics networks. By providing an overview of the unique ethical dilemmas faced by community healthcare workers, the presentation also shed light on gaps and areas of priority for building ethics capacity in community care.

Upcoming Conferences

October 20–21, 2009

The Ontario Community Support Association (OCSA) will hold its Great Ideas 2009 Conference at the Sheraton Parkway Hotel, Suites and Conference Centre in Richmond Hill, Ontario. The theme is “Growing from Good to Great”.

October 28–30, 2009

The Canadian Home Care Association (CHCA) will hold its 2009 Conference at the Fairmont Banff Springs, Banff, Alberta. The theme is “Connections...Connexions”. Caroline Hunter and Kim Ibarra have had a poster presentation accepted for this Conference.

Overall, the conference was an important step in validating the approach developed by the CEN. Marie Edwards’ data, for example, confirms the need to create capacity and spaces to discuss and address front-line care providers’ ethical dilemmas. Similarly, Maria Bouzidi’s discussion of the CSSS’s ethics committees suggests that diligent processes for ethics review are crucial to the process of legitimization. Opportunities to adapt some of the tools developed by the CEN to the CSSS context might be explored in the future. Finally, inquiries from the audience suggested a high level of interest in the work of the CEN. We are looking forward to continued communication with several individuals who are committed to addressing individual, organizational and systemic causes that give rise to ethical dilemmas in the home and community care sector.

Prepared by Renaud Boulanger, June 2009

As part of **We Care Home Health Services** year-long 25th anniversary celebrations, Directors from across Canada came to Toronto recently to meet and learn from each other. Frank Wagner, Ethicist at the Toronto Central CCAC, led a concurrent session, speaking to the attendees about “Building Ethics Capacity in the Community”.

Jamie Sutherland, London Branch Director, Frank Wagner, and Julia Sommers, Manager of Quality and Education.



Case Study

Summary: A teenager with severe seizure disorder, global developmental delay and significant motor regression is being cared for in the home. Parents are the substitute decision-makers with the mother being the primary decision-maker. Community care agencies are concerned that the patient is at risk and has deteriorated both physically and functionally, as evidenced by significant weight loss and muscle wasting. The patient has minimal accessibility to recommended treatment or to any safety equipment in the home. The mother has a deep faith which influences her decisions to seek Naturopathic interventions and reject traditional medical interventions. She is refusing to seek additional medical screening to determine the exact health status of the patient and is also resistant to or refusing visits and assistance from community health care providers. Community health care providers are concerned that the mother's refusal to accept seizure medications and a G tube for the patient will lead to an increased risk for aspiration and pneumonia, and may ultimately lead to the patient's premature death.

Facts: Joy (not her real name) is in her late teens living with her family and totally dependent upon others for all her care needs. Her family is deeply involved in her care and provides a loving and caring environment in the home, although her mother takes a lead in caring for Joy as well as in decision-making as her father is often working and not present. There is a sibling in the home along with grandparents who are also involved. Joy is currently bed-bound and requires 24-hour supervision. There are several community-based service providers involved in supporting the patient and her family.

Joy has a long history of seizure disorder, as well as significant developmental delays, but at present the origin is unknown. Her physician has recommended a round of tests in order to better understand the origin of the most serious of Joy's conditions. Her mother has resisted the recommendation for tests and believes that Naturopathic approaches are what is best for Joy at this point. She has refused to agree to the placing of a G tube, to reduce the aspiration risk, and will not administer the prescribed anti-seizure medications. Her mother bases much of her understanding regarding what she feels are appropriate interventions for Joy on her strong faith-based convictions.

Care providers from the various community organizations involved in Joy's care have deep concerns regarding what they perceive as significant risks to her health and wellbeing. They are concerned that Joy has deteriorated both physically and medically within the last year to the point where she could potentially be at risk for death. Joy's mother has continued to refuse to accept the recommendations presented to her by the team regarding treatment options and other interventions. The team strongly believes their proposed recommendations would improve Joy's quality of life and reduce the level of risk to her.

The team believes that it has been quite respectful of the mother's religious convictions as well as being supportive of her desire to pursue Naturopathic interventions, as far

as possible. They also feel as though they have made every attempt to be culturally sensitive and respectful of diversity. However, they are feeling torn between wishing to respect the mother and her approach to Joy's ongoing health care issues and providing Joy with the most appropriate care possible in order to minimize risk and maximize quality of life. They believe at this point the mother's approach is harmful to Joy and will ultimately lead to continued deterioration and possibly death. The team has attempted to meet with the family and negotiate an acceptable course of action with little success. One notable exception was in getting the mother to agree to hospitalize Joy in order to have a series of diagnostic tests conducted.

In considering its options, the team tried to balance the needs of Joy with the wishes of her mother. As Joy is beyond the age of 16, the Children's Aid Society is not able to intervene. The team is not comfortable with doing nothing due to the significant risks posed to Joy by the lack of intervention. They have considered approaching the office of the Public Guardian and Trustee in order to have another substitute decision-maker appointed, but they do not wish to further alienate the family and feel that this would be an extreme measure. They have also considered engaging the larger family and have attempted to bring the father into the conversation with the hope that he would be a moderating influence on the mother. So far those attempts have failed as the father continues to

A Warm Welcome

We extend a very warm welcome to **Toronto Homemaking Service**, the newest member of the Community Ethics Network. This brings our CEN membership total to 37 organizations.

absent himself from any decision-making. There was also a discussion of trying to engage the grandparents in the process but due to time constraints this may not be possible. Another option considered was to send a detailed letter to the family describing the current problems and the potential risks to Joy if the current direction is not changed. Again, the team feels this may increase the mother's resistance to traditional medicine and cause her to further withdraw from interacting with the various community agencies involved.

For Consideration: There are a number of significant ethical issues at play in the above case. Can you identify some of them? It is often a challenge to care providers when they enter a home or family situation where their own values and sense of what is appropriate are in conflict with either the patient or family. How might you balance the tension between protecting the patient and respecting the mother's wishes? The care team spent a considerable amount of time considering various options and approaches in order to resolve the ongoing conflict over approaches to care. Can you think of additional options or approaches that might help to alleviate the conflict between the mother and the care team? What might you do in this case? How do you feel about the possibility of involving the Public Guardian and Trustee or other "official" agencies in the process?

Prepared by Karina Santiago, Client Service Manager, Mississauga/Halton CCAC. Thanks to Tom Foreman, Ethics Fellow, University of Toronto Joint Centre for Bioethics for his contribution to preparing this case study for publication.