

Whose Ethics Are They, Anyway?: Some Troubling Results From the 2009 Alberta Survey

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Background / Introduction

- In the Spring of 2009, the Defining Disability Ethics research project commissioned the Population Research Laboratory at the University of Alberta to survey Albertans regarding their opinions on various disability-related health-ethics issues.

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- Over 1,200 interviews with adults in Edmonton, Calgary, and other locations in Alberta were conducted in April and May of 2009.
- In this presentation, I will examine some of the data collected in this survey concerning Albertans' attitudes regarding beginning-of-life and end-of-life issues involving disability.

"Defining Disability Ethics"

- Two simultaneous research projects, funded by the Canadian Institutes of Health Research and the Social Sciences and Humanities Research Council were conducted between 2008 and 2010.

"Defining Disability Ethics"

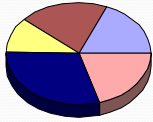
- While both of these research projects were geared towards further defining and developing Disability Ethics as a distinct field of academic inquiry, the CIHR-funded project was focused specifically on transcending the conventional social and medical models of disability in exploring Canadian values and ethics related to our understanding of disability.

"Defining Disability Ethics"

- Our research in this project was intended to contribute to the further definition of the emerging field of disability ethics by examining specific philosophical and bioethical concepts, such as autonomy, quality of life, and justice, from a disability-ethics perspective.

General Attitudes Toward Disability

Having a disability lowers quality of life



Strongly Disagree
 Somewhat Disagree
 Neither Disagree nor Agree
 Somewhat Agree
 Strongly Agree

Disability = Lower Quality of Life

- Combined Agreement = 50.3%, Combined Disagreement = 38.7%
- Roughly half of the people surveyed agreed, to some extent, that having a disability **necessarily** lowered a person's quality of life. Just under 40% disagreed, and about 10% of the people surveyed said that they did not know if having a disability necessarily lowered a person's quality of life.

Responses to Select Issue-Based Ethical Questions Involving Disability

When an infant is born with a severe disability, parents, with the guidance of a pediatrician, should have the choice to keep the infant alive or allow it to die.

- A combined total of 56.7% of respondents—over half—either strongly agreed or agreed that parents of an infant born with “a severe disability” should, with the guidance of a pediatrician, have the choice to either keep the baby alive or allow the baby to die.
- In contrast, a combined total of 30.2% of respondents either disagreed or strongly disagreed that parents should have that choice.

When an infant is born with a severe disability, parents, with the guidance of a pediatrician, should have the choice to keep the infant alive or allow it to die.

- It is interesting to note that these results, 56.7% in favour of parents having a choice whether or not to keep their disabled baby alive, versus 30.2% opposed, do appear to have some correlation with the 50.3% who agreed that having a disability necessarily lowers the quality of a persons life, versus the 38.7% who disagreed that disability lowers quality of life.

When an infant is born with a severe disability, parents, with the guidance of a pediatrician, should have the choice to keep the infant alive or allow it to die.

- At no point in the survey was the term “severe disability” specifically defined or elaborated on. Consequently, the integrally related question of exactly what constitutes a “severe disability” was left totally open to the interpretations of the respondents.

When an infant is born with a severe disability, parents, with the guidance of a pediatrician, should have the choice to keep the infant alive or allow it to die.

- Likewise, the terms “keep alive” and “allowed to die” are neither defined nor elaborated on at any point in the survey. As a result, no distinctions between active and passive euthanasia were explicitly made in the survey.

Prenatal screening for disabilities should be available and strongly encouraged for all pregnant women.

- Approximately three-quarters of respondents, 75.3%, either somewhat agreed or strongly agreed that prenatal screening for disabilities should be available and strongly encouraged for all pregnant women. In contrast, only 16.5%, less than one-quarter, of respondents either somewhat disagreed or strongly disagreed that all pregnant women should be strongly encouraged to undergo prenatal screening for disabilities.

Prenatal screening for disabilities should be available and strongly encouraged for all pregnant women.

- This question contained no type of qualifier for the term “disabilities” – e.g. “severe.”
- The potential ultimate purpose of prenatal screening—i.e, abortion of the foetus identified as having disabilities—was not alluded to in this question.

Abortion is justifiable during any stage in a pregnancy if prenatal screening identifies a severe disability.

- A combined total of 49% of respondents—just under half—either somewhat agreed or strongly agreed that abortion is justifiable during any stage in a pregnancy if prenatal screening identifies a severe disability. A slightly lower percentage, 40.9%, of respondents either somewhat disagreed or strongly disagreed that abortion is always justifiable if prenatal screening identifies a severe disability.

Abortion is justifiable during any stage in a pregnancy if prenatal screening identifies a severe disability.

- Thus, the respondents were pretty evenly divided on the question of whether abortion is always justifiable if prenatal screening identifies a severe disability. This is a notable contrast from the 75.3% agreement among respondents that prenatal screening for disabilities should be available and strongly encouraged for all pregnant women.

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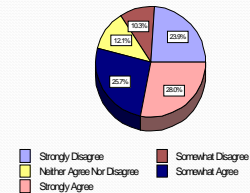
- The marked difference in the response to the question about whether prenatal screening for disabilities should be encouraged versus whether abortion is always justifiable if that prenatal screening identifies a severe disability seems to suggest a certain level of ambivalence—if not unawareness—about the actual purpose of prenatal screening for disability, which is arguably to reduce the number of infants born with disabilities by encouraging the termination of pregnancies in which the fetus is identified as having a disability.

Abortion is justifiable during any stage in a pregnancy if prenatal screening identifies a severe disability.

- In fact, research over the past four decades have consistently indicated that prenatal screening is concerned with the detection, and often the avoidance, of disability in utero (Fletcher, 1975; Kaplan, 1993) and has been found to significantly decrease the prevalence of infants born with disabilities (Bull, 1999; Forrester, Merz, & Yoon, 1998; Richards, Bentley, & Glenny, 1999).

Canada should create a compassionate homicide law, eliminating punishment for 'mercy killing' of individuals who have terminal illnesses or chronic conditions that result in a poor quality of life.

Canada should create a 'compassionate homicide' law..



- A combined total of 53.7% of respondents strongly or somewhat agreed that Canada should create a compassionate homicide law, eliminating punishment for 'mercy killing' of individuals who have terminal illnesses or chronic conditions that result in a poor quality of life. Conversely, a combined total of 34.2% of respondents strongly or somewhat disagreed with the creation of such a law.

- Worth noting, I think, is the fact that we deliberately constructed the question so as to make the definition of "compassionate homicide" very broad, including not just those who are "terminally ill" but also those who have "chronic conditions that result in a poor quality of life."

- When we were constructing this question, we had in mind public reaction to cases like that of Robert Latimer, the Saskatchewan farmer who killed his twelve-year-old daughter, Tracy, with carbon monoxide in the cab of a truck on their Saskatchewan farm.
- This deliberately broad definition of "compassionate homicide" evidently did not significantly trouble or confuse respondents, as only 3.1% said they don't know whether or not Canada should create a compassionate homicide law.

Doctor-assisted suicide should be made available to people with terminal illnesses or severe chronic disabilities

- A combined total of 62% of respondents either agreed or strongly agreed that doctor-assisted suicide should be made available to people with terminal illnesses or severe chronic disabilities; a combined total of only 26.9% of respondents either disagreed or strongly disagreed.

Doctor-assisted suicide should be made available to people with terminal illnesses or severe chronic disabilities

- As with the previous question on “mercy killing,” we deliberately combined the categories of “terminal illness” and “severe chronic disabilities.”
- More respondents were in favour of a law permitting physician-assisted suicide than were in favour of a law permitting “mercy killing.” By the same token, fewer respondents expressed opposition to legal sanction for physician-assisted suicide than expressed opposition to legal sanction for “mercy-killing.”

Voluntary sterilizations should be strongly encouraged for people with disabilities that can be genetically transmitted.

- Given Alberta’s long, controversial, and relatively recent history involving the sterilization of people with disabilities that can be, *or are thought to be*, genetically transmitted, we hypothesized that the responses to the questions dealing with this issue would be highly polarized. However, this did not turn out to be the case.

Voluntary sterilizations should be strongly encouraged for people with disabilities that can be genetically transmitted.

- Only 21.2% of respondents *strongly disagree* with the voluntary sterilization of people with genetically transmitted disabilities, while only 24.3% *strongly agree* with this practice.

Voluntary sterilizations should be strongly encouraged for people with disabilities that can be genetically transmitted.

- A combined total of 50.3% of respondents either strongly agree or somewhat agree that voluntary sterilizations should be strongly encouraged for people with disabilities that can be genetically transmitted. On the other hand, a combined total of 36.9% of respondents either strongly disagree or somewhat disagree with encouraging such voluntary sterilizations of people with genetically transmitted disabilities.

Voluntary sterilizations should be strongly encouraged for people with disabilities that can be genetically transmitted.

- 12.8% of respondents said that they neither agreed nor disagreed. This is a rate consistent with the other questions in the survey.
- In a manner similar to the design of other questions in the survey, no definition or qualifier was provided for the term disability, other than, in this case, “genetically transmitted.”

Involuntary sterilization is justifiable for people with chronic mental or intellectual disabilities who rely on government supports.

- A combined total of 35.4% of respondents either somewhat agreed or strongly agreed that involuntary sterilization is justifiable for people with chronic mental or intellectual disabilities who rely on government supports. On the other hand, a combined total of 53.8% of respondents either somewhat or strongly disagreed with the idea of such a practice.

Involuntary sterilization is justifiable for people with chronic mental or intellectual disabilities who rely on government supports.

- This results are essentially a mirror-image reversal of the response to the question about whether or not voluntary sterilizations should be strongly encouraged for people with disabilities that can be genetically transmitted. Again, my hypothesis is that this is at least partially due to the high value that we, as a society, place on the ethical principle of autonomy.

Involuntary sterilization is justifiable for people with chronic mental or intellectual disabilities who rely on government supports.

- Although the majority of respondents were opposed to involuntary sterilization for people with chronic mental or intellectual disabilities who rely on government supports, this opposition was not universal. A significant number of respondents, 35.4%, were in favour of involuntary sterilization for this broadly-defined group of people. It would be interesting to find out, what effect, if any, a more precise definition, and/or allusions to examples, of "chronic mental or intellectual disabilities" would have on this result.

Conclusion: "So What?..."

- These survey results appear to indicate that Albertans are more or less evenly divided on most ethical issues involving disability at the beginning and end of life. The tendency or temptation is to characterize results like this as typically Canadian, middle-of-the-road, "So what's the big deal?"
- According to the results of this survey, half of Albertans believe people with disabilities have a lower quality of life than people without disabilities. This "half of Albertans" includes among them healthcare professionals.

Conclusion: "So What?..."

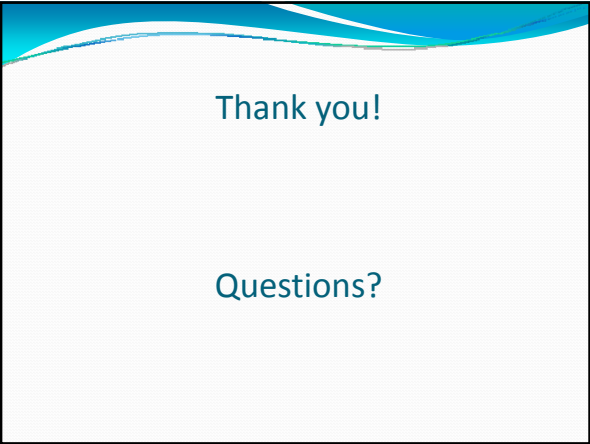
- Difficult decisions regarding the allocation of limited medical resources are having to be made every day. And surely, attitudes about the ethical meaning of disability are playing a role in how many of these decisions are being made.

Conclusion: "So What?..."

- At the other end of the spectrum, prospective parents are being routinely counselled to terminate pregnancies in which prenatal screening has identified the fetus as having disabilities. All of these scenarios raise fundamental questions about what kind of society we are creating, and what sorts of people we will accept as full members of our society.

A Disability-Ethics Perspective

- Incorporates the perspectives of people with disabilities into ethical discussions and debates
- Connects with the broader fields of disability studies and the traditional disciplines of philosophy and health ethics.
- A disability-ethics perspective is a holistic approach that moves beyond the dichotomy of the Medical and Social Models of disability.



Thank you!

Questions?