



PERSPECTIVE
Euthanasia Is Out of Control
in the Netherlands

by Stephen Drake

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The March 10 issue of the *New England Journal of Medicine* featured an article by two Dutch doctors defining a "problem" and a "solution." Drs. Verhagen and Sauer announced that a survey had found that, contrary to Dutch law, some infants with severe disabilities have been euthanized. In an effort to end "uncontrolled" euthanasia, they proposed adoption of a set of protocols, known as the "Groningen protocol," for legally euthanizing infants with disabilities and serious medical conditions.

It's hard to believe anyone could be surprised by the news of this latest effort to expand the practice of euthanasia in the Netherlands. For the sake of brevity, one might compare Dutch euthanasia practices to a highway system. In this system, drivers are responsible for monitoring their own speed. As long as they tell officials how fast they're driving, the authorities generally won't issue tickets for speeding.

Here's the hitch: the problem of speeding has become so problematic that every few years a driver is actually issued a ticket. In every reported case, the offender was given a slap on the wrist, and the speed limit was raised. Predictably, this just results in a general rise in the speed of traffic and further requests to raise the speed limits. This is, in effect, what happened in 1994 when Dr. Boudewijn Chabot was convicted of aiding the suicide of a woman in despair over the death of her two sons. It happened again in 2001 when Dr. Wilfred van Oijen was tried and convicted for "euthanizing" an elderly woman without her permission.

The main difference between the Dutch system and the American system, I'd suggest, is one of degree. We've set the speed limits at a lower level and mostly resisted requests to raise them. However, there is significant evidence that at least some medical professionals in the United States would embrace legalization of infanticide based on disability. It wasn't that long ago that passive euthanasia of infants with Downs Syndrome and spina bifida was an accepted practice here, and it's still unclear to what extent the practice persists.

The sentiment for facilitating the deaths of infants with disabilities is evident in numerous research studies. For example, in 2001, Streiner and colleagues published a study in *Pediatrics* comparing the attitudes of parents and health care professionals in "quality of life" assessments of premature infants. The study found that neonatologists and neonatal

nurses were both more pessimistic about pediatric outcomes, and also more likely to judge death to be the best outcome, than were the parents or siblings of the same children. This study, conducted in Canada, is consistent with earlier U.S. studies that have demonstrated a bias on the part of medical professionals in devaluing the lives of infants with severe disabilities. No one should mistake this bias for anything other than what it is an over-valuation of physical and mental norms, which is bigotry.

That prejudice is often mistaken for objectivity in bioethics discussions. It's one reason most public discussion of euthanasia is tainted by misinformation. For example, the Associated Press story on the Groningen protocol misinformed readers that the protocol applied to "euthanizing terminally ill newborns." This is a gross distortion: Verhagen and Sauer made no attempt to hide that they were talking about newborns with "serious medical conditions."

It's both puzzling and disturbing that this misinformation was met with total silence from the bioethics community. You would think that bioethicists, eager to claim expertise and promising to bring clarity to public debates, would have jumped all over the Associated Press report. This silence reinforces the cynical view that the righteous anger bioethicists express at outspoken disability advocates has less to do with providing clarity than protecting turf.

Bioethicists who appear in popular media often decry the simplistic way in which complex issues are addressed. On behalf of Not Dead Yet and other disability rights organizations, I have a not-so-respectful request: admit your failure to promote a complex and accurate public discussion of bioethical issues and make room for those of us who seem more willing and able to lead the effort.

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