

Preface: End of Life, Religion, Disability, and Health: Where All the Paths Converge

This publication is based on the premise that issues faced by people with disabilities and their families, friends, and supporters frequently raise stark and key issues that bridge the perspectives of religion/spirituality on the one hand and health care on the other. Or, in other words, disability often becomes the place where inherent, ever present, and universal questions about life, faith, and caregiving become starkly evident. That intersection is nowhere more obvious than where the various paths and perspectives from different disabilities and disciplines converge at the end of life.

Several issues ago, we published Russ Cooper-Dowda's moving account of her own journey and that of Terry Schiavo, just as Terry Schiavo was becoming a household name. In the last few months, newspapers have carried the issues around her story and the stories of euthanasia for certain kinds of children in hospitals in the Netherlands and other places. Email listservs have almost come to blows with debates about the Oscar awards going to *Million Dollar Baby* and *The Sea Inside*. The "usual suspects" in various political debates around issues with people with disabilities often end up on very different sides, or aligned with political bedfellows that seem very strange.

What's going on? Huge issues, for one, because that intersection highlights one of the dangers that many people with disabilities face, i.e., that of serving as the "canary birds in the mines" where dangerous and risky issues that impact everyone first get raised, or tested, around

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people whose quality of life is assumed to be different. Are we seeing, as Hans Reinders (2000) notes in his book, *The Future of the Disabled in Liberal Society*, a time when the inherent value assumptions of reason, freedom, and choice in a generally liberal society end up endangering the very people they also supposedly respect and protect? James Mostrom, a doctor, writing in a Syracuse paper, notes how the arguments had gotten framed as a right to die issue, when in fact the real issue is about the right of people with disabilities to live (Mostrom, 2005).

We also often hear that policy and practice issues could bridge the fields of disability and aging, but issues of stigma and value assumptions also get in the way, e.g., “I may be getting old, but at least I am not disabled.” But as we move towards end-of-life issues and concerns, the “differences” fade away, and the common themes and questions emerge. How do we honor life? Caregivers? Family and friends? Related, do we even do a good job of recognizing how people with intellectual disabilities think about death, how they grieve, and those around them? How do we help individuals (with or without intellectual disabilities) prepare for their own death? How do we help those around them deal with grief and loss?

We are honored to use this volume to explore some of the questions and the dialogue. We had started to plan a collection focusing on end-of-life issues, thinking we would have to go and solicit the papers and perspectives. We were mistaken. They literally came to us, perhaps a metaphor for what will happen to all of us around these issues in one way or another.

In the summer of 2004, one of us (Bill Gaventa) had the good fortune of going to the IASSID Conference in Montpelier, where there were more than ten sessions with two or three papers or presentations in each session dealing with issues of death and grieving with people with intellectual disabilities. Rud Turnbull, Co-Director of The Beach Center, then sent us a draft of a presentation he had been asked to make as a parent, lawyer, and policy expert to the National Association of Protection and Advocacy Systems. Mary Jane Iozzio then sent a paper, from her perspective as daughter and theologian, about the caregiving issues raised for her mother and family around their care for her father with Alzheimer’s. When we asked others to review their papers, their reviews, such as Stan Hauerwas’, turned out to be so interesting that we decided to revise and include them in the volume so that others could be part of this dialogue. Hans Reinders just happened to be here in New Jersey for six months at the Center for Theological Inquiry. Ginny Pugh directs Black Mountain

Center, where they support both people with multiple disabilities and people with Alzheimer's.

At The Boggs Center, we were doing some work with Leigh Ann Kingsbury in Essential Lifestyle Planning when she told us how she was working on using that process in a project for end-of-life planning for people with developmental disabilities. Then the Boggs Center invited Angela King, director of the Last Passages Project, to New Jersey for one of our Developmental Disability Lecture Series. As I said, the possibilities and resources just kept coming. David Wetherow had shared a very moving account of the final hours of life of David and Faye's daughter, Amber, on a national listserv. Then, Richard Rienstra sent me, just for my interest, Susan Harrison Wolffis' story about the funeral of his friend, Paul Novoselick. Personal experiences, conceptual theology and policy, suggested practices, responses and dialogue: the first of what may be several volumes was born.

Another volume is being compiled by guest editors from the sessions on death and dying, grief, and people with intellectual disabilities from the IASSID Conference. We believe and hope that these collections will be provocative food for both our professional and personal souls.

What else will guide our thinking and prayerful/ethical action in this area with so many issues and questions? Just as this publication goes to press, David Coulter led a presentation at a conference in Atlanta, and outlined four principles from his work as a neurologist. To summarize them:

1. All persons with I/DD (Intellectual/developmental disabilities) are valuable and deserve respect.

Individuals with developmental disabilities do not experience their disability as a loss. People who acquire a disability (such as in a car accident) do experience a loss, but that is different. Thus persons with DD are not "suffering" from their disability. We must not project our own fears of loss onto people who have never had such a loss and conclude that their life is not worthwhile just because we would not want to live like that.

2. We should try to find out what the person with I/DD wants (as much as possible) and honor that.

This relates to the principle of autonomy and self-determination, of course. In bioethics, informed consent to treatment (or withdrawal of treatment) is based on three elements:

- A. Information—having sufficient information upon which to make a decision.
- B. Capacity—having the ability to assess the information adequately.
- C. Voluntariness—being free from undue influence by others.

Thus, the challenge is to determine the authentic voice of persons with I/DD, understand the choices they have made and are making (which our field knows how to do), and place this in context.

- 3. *We should always act to promote the best interests of the person with I/DD.*

This relates to the ethical principle of beneficence. I talked about the need for a subjective perspective on quality of life (see the books on this topic edited by Bob Schalock) and seeing things from the point of view of the person with I/DD. I also mentioned the principle of double effect, which allows one to provide a well-intentioned treatment such as pain relief, knowing that it may have other effects that could be life-limiting.

From a spiritual perspective, I also mentioned that continued life is not always the highest good. For a Christian, salvation is the highest good, and reconciliation with God may be more important than continued life. The best interest of a Christian with I/DD may well be the assurance of a personal relationship with God and “saving one’s soul.”

- 4. *Physicians should not kill.*

This relates to the ethical principle of non-maleficence. The question here is what are the allowable options at the end of life. The focus should be on palliative care and hospice (true “caring at the end of life”) rather than termination of life. “Rational suicide” is probably permissible (as in the movie *MDA*), but physician-assisted suicide is not. Withdrawal of life-sustaining treatment such as nutrition and hydration may be permissible in highly selected situations (primarily true PVS) but not in other states of limited consciousness (as in Terry Schiavo’s case). Euthanasia is never permissible, particularly when decided by surrogates (such as parents asking to have their child’s life terminated).

Where do we hope this discussion goes? For one, David Coulter will be working with others to develop a policy statement for the AAMR and other organizations related to end-of-life care. See for yourself the policy recommendations from the Last Passages Project, which they have graciously allowed us to reprint in this issue, along with their resource

list. As you read this collection, let your reflections and thinking be guided by your relationships with others, as each author in this volume has labored to integrate their personal experience with their professional expertise. “How do we integrate love and public policy?”, as my boss Deborah Spitalnik at The Boggs Center provocatively asked last spring in an address for our 20th Anniversary. It is not easy work, as Hans Reinders so pointedly says in his response to Rud Turnbull, because most of us are not at all certain about what we want and think about our own end-of-life questions, much less those for the people whom we love and support.

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