

Receiving the Gift of Friendship

PROFOUND DISABILITY,
THEOLOGICAL ANTHROPOLOGY,
AND
ETHICS

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Chapter One

One of Us

It must be clearly affirmed that the disabled person is one of us, a sharer in the same humanity.

Pope John Paul II, March 4, 1981

1. Introducing Kelly

Among the factors that have caused the lives of persons with disabilities to change is the fact that the defect model has been abandoned. A new vision demands that people be supported in what they can do rather than being accommodated for their “special needs.” This change is significant. Do you see incapacity and neediness? Or do you see possibility for growth? More and more people have shifted their views to the latter perspective, and this has opened up more opportunities for people with disabilities than ever before. The key word is “empowerment.” The disabled are more in control of where they live, how they live, and with whom they live — as well as how they can participate in and contribute to society. These changes have significantly enhanced the quality of many lives. But not all persons with a disability have benefited from these changes, partly because many still live in isolated situations, but also because the new vision has limitations itself that have not been sufficiently recognized so far. This is particularly true of people with intellectual disabilities.

There can be no question that the lives of people with intellectual disabilities are not nearly as good as they could be if their potential and

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actual abilities would be more fully appreciated. Much remains to be done; but there is also no question in my mind that improving their lives should not be made dependent on their abilities. It is here that the new vision shows its limitations: it assumes that living a truly human life depends on the quality of agency. Let me explain what I have in mind by introducing Kelly.

Kelly is a young girl I encountered a number of years ago in a group home for people with intellectual disabilities. The director of this home happened to know that I was thinking about a book on people with profound intellectual disabilities. "You should pay Kelly a visit," she said. She told me that Kelly is a *micro-encephalic*, which means that a significant part of the normal human brain is missing in her. When Kelly came to the institution as a baby, there were serious doubts about whether the institution should take her.

The first time I visited the group home where she lives, I found a twelve-year-old redheaded girl who was sitting in a wheelchair, her big brown eyes "staring without seeing," as was my first reaction. I talked a bit to her as a way to make myself feel at ease more than anything else, and I asked the staff a few questions about her. I was invited to stay for the afternoon in order to get an impression of who she was and how she lived. So I stayed. I noticed that the nurses around her had a perfectly natural way of approaching her. For them Kelly was just Kelly, and she could be just as "happy" or "sad" as any other resident in the home. Nonetheless, it appeared that there had been doubts about Kelly's life. This I learned when I interviewed the director of the group home, who told me about their response to Kelly when she was brought to the home as a little baby:

When Kelly was still a baby, the only thing she seemed capable of doing was to take a deep breath now and then. In her case we did not think of this as something she did, say, as something like "sighing," as if she were lamenting her condition. Instead, we assumed her taking a deep breath was only a respiratory reflex. Until somebody noticed it seemed to depend on who spoke to her. When spoken to by particular voices the changing respiration pattern stopped. Once the voice stopped, she started again. Thank Heavens! At least she could do something, if it was only "sighing." Our Kelly turned out to be human.

Apparently, the recognition of Kelly's humanity was not beyond doubt even among those who cared for her on a daily basis. Kelly is what some people in our moral culture probably would call a "vegetable." Even if one rejects the term and the judgment that it implies, as I think we should, the director's comments answered to some of the most fundamental beliefs of our moral culture. Human being does not count as truly "human" unless it can do something. This belief raised a question mark about Kelly's humanity, and the reason is not difficult to grasp: Kelly never had, and never will have, a sense of herself as a human being. Leaving technical details aside for the moment, standard definitions would rank her as being "profoundly disabled," meaning that for all the important activities that characterize our lives — health, safety, relationships, communication, and so on — she will be entirely dependent on others. Kelly will not reach even a minimal stage of determining what she wants for herself. Words such as "I," "me," or "myself" will never mean anything to her, nor will any other word for that matter. As far as we can tell, Kelly's condition does not allow her any "interior space," by which I refer to the inner life, that part of me where I am with myself. It is concerning this interior space that the language of selfhood becomes intelligible in the first place. If we only realize how crucial this space has been for how human individuality commonly has been valued in the history of Western thought, it does not take long to see why these facts about Kelly's condition may raise questions about her being, questions that could even place her humanity in doubt.¹

However, the people in the group home where she lived, as I was soon to find out, did not seem troubled by any such questions at all. During that afternoon of my first visit, I noticed a nurse coming in for the late afternoon shift. Entering Kelly's room, she approached her with a spontaneous "you are looking cheerful today." On my subsequent visits to Kelly's group home, I noticed that such descriptions of mental states were quite frequent. One day I came for tea, and as soon as I entered the living room, I was approached by Daniel, a young boy with au-

1. Hans S. Reinders, "The Meaning of Life' in Modern Society," in *Meaningful Care: A Multidisciplinary Approach to the Meaning of Care for People with Mental Retardation*, ed. Joop Stolk, Theo A. Boer, and R. Seldenrijk (Dordrecht: Kluwer Academic Publishers, 2000), pp. 65-84.

tism; he came to me repeating that Kelly looked "very sad," and then he would go over to her wheelchair and stroke her beautiful hair. Others might say occasionally that she appeared to be happy, or that she loved to be bathed. Apparently, Kelly was included in the language that we are accustomed to speaking to and about each other. In any event, she was never approached or spoken to as though she were a "vegetable."

Once I began thinking about these matters, I realized that the use of this kind of language must appear inappropriate when it is seen from the perspective of selfhood that plays such an important role in modern concepts of what we are as human beings. The phrases spoken about her — "looking cheerful," "being sad," "being happy," "loving to be bathed" — all seemed to imply a capacity for having certain mental states, a capacity that is not very likely present in Kelly's case. I then realized a disturbing conclusion that seemed to follow from this perspective: when Kelly lacks the capacity for having mental states such as "being sad," the perspective of selfhood forces us to conclude that the things said about her were in fact said metaphorically. To use the language of mental states to refer to profoundly disabled human beings such as Kelly is to turn that language into metaphor. People speak about Kelly *as if* she were happy, or *as if* she were sad.

I then returned to the notion of doubt regarding her humanity. I realized that the director's relief was wholeheartedly meant to give Kelly's humanity every benefit of the doubt; but people outside her group home may be less inclined to do so. Usually the notion of our humanity is believed to entail more than the ability to produce a sigh every now and then. More disturbing questions arose at this point. At the very least, human agency seems to entail some sense of what one is doing, and having a sense of what one is doing entails the awareness that one's action has a point. Human beings act for a purpose. However, if the capacity for purposive action is what makes us human, where does that leave human beings like Kelly? Should we not say, then, that the language implying that Kelly is a human being must also be spoken metaphorically? People speak about someone like her *as if* she is a human being. Can one speak honestly about Kelly as a human being when one knows for a fact that in her case this predicate is a metaphor?

These thoughts made me very uneasy. Suppose that the people who work with Kelly and her friends would believe something like this. Suppose they believed that they could not speak about her as a human be-

ing without deceiving themselves. I vividly remember a scene in which the general director of another institution introduced me to the people of a group home similar to Kelly's. We watched a nurse working with what appeared to be a profoundly disabled young man. They were both laughing; the nurse told us they were playing a game and having great fun with it. When we left that scene, the general director apparently thought that he owed me an explanation. "Of course, that young man has no clue to what's going on, but I greatly admire these nurses. I could not do it." Using the language of playing games with someone with a profound disability, I was to understand, is a form of self-deception for which caregivers are to be admired. They probably could not do their job without the ability to fool themselves, or so this director implied.

Now suppose that the people actually working with Kelly and this young man would indeed believe something like this. What effect would that belief have on their practice of caring? For one thing, they certainly would stop playing games. What could possibly be the point of playing a game with someone who does not have a clue as to what's going on? Of course, I know that you start playing games with your children long before they actually understand what's going on in the game. That is how you enable them to grow into these activities. But with human beings such as Kelly, there is no "growing into" any kind of activity, so why bother? Why bother with a birthday party — or a Christmas dinner? Why have dinners at all? Why not just feed them?

The world within which Kelly is approached as a human being was gradually beginning to evaporate. Examples were multiplying. Can one in good faith say, as I did above, that one is working "with" a profoundly disabled human being like Kelly? Can she really be said to have "friends"? Can she be "happy"? I asked the staff at Kelly's group home some of these questions, to see what they made of all this. It turned out that most of them did indeed believe that a capacity for purposive agency is what gives meaning to human life. They also believed that purposive agency presupposes at least some level of self-awareness. Yet this did not seem to bother them at all when it came to explain how they related to Kelly. For them, Kelly was just someone in need of care, and caregiving was what they did. In doing so, they included Kelly in the language that shapes the meaning of what is going on in her home, which is the practice of caring for people who are dependent on it. They seemed to require no other reason for what they

were doing.² On the other hand, if the notions of selfhood and of purposive agency are indeed crucial to what it means to live a human life, then the questions I raised are difficult to avoid. What is the point of treating someone as a human being when one's belief about what it means to be human implies that she is not, in fact, a human being?

That was the problem I was stuck with after my visit to Kelly's group home. How could I account for the practice of caring for people like her when some of the most cherished beliefs in our moral culture cannot but cast doubts on their humanity? If I would be pressed to give an account of Kelly's life as a human life, what would I say? If we are inclined — as I was at the time, and still am — to accept Pope John Paul II's claim that Kelly is "one of us," how can we define ourselves in a way that makes this claim intelligible? These reflections suggested to me that there is something seriously amiss when we make selfhood and agency critical to what it means to be human. At least this must be true if we assume that the nurses in her group home are not just fooling themselves when they approach her as a human being.

2. The Hierarchy of Disability

Disability is "out of the closet." People who were invisible have become visible. The general public knows their stories, at least to some extent, and that has put an end to their hidden existence. In the old days it was not uncommon for families to hide disabled children in their homes, or to put them away in institutions out of shame, or because they were worried that their children would be a "burden" on society. These things have changed mostly because of the disability-rights movement, which emerged in the 1970s and 1980s in the United States and then spread to other parts of the globe.³ It has changed our thinking about

2. See David A. Pailin, *A Gentle Touch: A Theology of Human Being* (London: SPCK, 1992), p. 103. In Ch. 6 I will take up an extended conversation with Pailin's book.

3. On the disability-rights movement, see Joseph P. Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* (New York: Times Books, 1993); James L. Charlton, *Nothing about Us without Us: Disability, Oppression, and Empowerment* (Berkeley: University of California Press, 1998); Doris Zames Fleischer and Frieda Zames, *The Disability Rights Movement: From Charity to Confrontation* (Philadelphia: Temple University Press, 2001); Richard K. Scotch, *From Good Will to Civil Rights: Transforming Federal Dis-*

disability by insisting on people's right to tell their own story. The general mood regarding disability as a catastrophe usually produced a response of pity and compassion; but the disability-rights movement rejected that response, as well as the assumptions on which it was based. What was traditionally regarded as a matter of charity and benevolence came to be considered a matter of equal rights and social justice. In his well-known history of the disability-rights movement, Joseph P. Shapiro says that the movement testifies to an "ongoing revolution in self-perception" on the part of people with disabilities in which they reject the images of neediness and failure. "There is no pity or tragedy in disability. It is society's myths, fears, and stereotypes that make being disabled difficult."⁴

While I have no doubt that this claim about changing self-perceptions is true, it does reveal at the same time a serious limitation in the ethical framework that is guiding the disability-rights literature. To a very large extent, this literature has little to say about the lives of persons with intellectual disabilities,⁵ let alone those, such as Kelly, with profound intellectual disabilities, because the nature of their condition does not enable them to develop a sense of self. Or if it does, their sense of self often has limitations that usually are not true of other human beings. In many cases, developing "selfhood" is the problem rather than the solution for people with intellectual disabilities. But this fact goes entirely unrecognized in the disability-rights literature. I

ability Policy (Philadelphia: Temple University Press, 2001); Duane F. Stroman, *The Disabilities Rights Movement: From Deinstitutionalization to Self-Determination* (Lanham, MD: University of America Press, 2003); Jacqueline Vaughn Switzer, *Disabled Rights: American Disability Policy and the Fight for Equality* (Washington, DC: Georgetown University Press, 2003).

4. Shapiro, *No Pity*, pp. 4-5.

5. "Intellectual disabilities" is distinct from "mental disabilities" in that it refers to cognitive impairments rather than conditions of mental illness. The term refers to what, in the United Kingdom, is usually referred to as "learning disabilities." Charlton's otherwise very perceptive book has a remarkable blind spot regarding this distinction. He acknowledges that there is a hierarchy of disability, supported by comments from international disability-rights leaders, who almost without exception say that people with "mental disability" lead the most difficult lives. However, while a number of these witnesses clearly speak of "mental retardation," Charlton interprets them as speaking of mental illness, which means that, even in his hierarchy of disability, the "lowest of the low" are not adequately represented (*Nothing about Us without Us*, pp. 97-99).

am not denying, of course, that in many cases the perception of intellectual disability has resulted in living conditions that are much worse than they would have been had there been positive support. Quite a few people are designated "intellectually disabled" about whom one wonders about their having received the label in the first place. But this is not true of the profoundly disabled human beings to whom the "ongoing revolution in self-perception" fails to apply.

This observation has serious consequences for how the disability-rights movement argues the case for inclusion, because it indicates that the argument itself may well have exclusivist implications. If the important thing to liberate me from social stigma is that I reclaim the authority over my own story, then this is a serious setback for those who cannot possibly know what it is to have a story. Another way of making this point is to say that there apparently exists something like a "hierarchy of disability" that assigns persons with intellectual disabilities in general, and with profound intellectual disabilities in particular, to its lowest ranks.

Recent sociological research confirms the existence of this kind of hierarchy.⁶ Those whose intellectual functioning does not allow them to represent themselves are generally perceived as being the "worst off." In addition to pervasive negative attitudes toward people with disabilities in general, there is a hierarchical order of social acceptance of disabilities, within which "mental retardation and mental illness have consistently been identified as the least accepted disabilities in social relationships."⁷ This is characteristic of most of those so disabled in that this hierarchical order creates "greater social distance and fewer friendship opportunities." People stay away from persons with intellectual disabilities because they do not consider them to be desirable as friends.

6. For a reflection on this phenomenon from within disability studies, see Anne Louise Chappell, "Still Out in the Cold: People with Learning Difficulties and the Social Model of Disability," in *The Disability Reader: Social Science Perspectives*, ed. Tom Shakespeare (London: Cassell, 1998), pp. 209-20. Chappell's analysis, however, does not move beyond the claim that the theoretical focus on the body in the social model leaves much to be explained for experiences related to impairment of the intellect.

7. Phyllis A. Gordon, Jennifer Chiriboga Tantillo, David Feldman, and Kristin Perrone, "Attitudes Regarding Interpersonal Relationships with Persons with Mental Illness and Mental Retardation," *Journal of Rehabilitation* 70 (2004).

Underlying my argument in this book are two premises. The first is that the hierarchy of disability reflects the hierarchy of moral values in our culture. People move upward on the ladder of cultural attraction because of what they are capable of achieving. The second premise is that this hierarchy of moral values reflects a basic assumption about our human nature, namely, that selfhood and purposive agency are crucial to what makes our lives human in the first place. That is, our culture cherishes the notion that the point of my life is what I make of it; most people with intellectual disabilities are perceived as lacking in the ability to make anything out of their lives. In terms of what our culture regards as interesting, such persons do not make interesting friends. Some of the features that explain their unattractiveness are that their walking and their talking are usually slow, their behavior is often unpredictable and incomprehensible, and their actions are frequently seen as embarrassing. Given this perception, the issue of "friendship" in the lives of people with intellectual disabilities is very much to the point. The realities of their impaired cognitive and intellectual functioning diminish their opportunities for upward social mobility in significant ways. They lose out in our cultural hierarchies. Therefore, they are most likely to stay where they are currently located in these hierarchies. The paradigm of the successful achiever that dominates our careers will make sure that they stay where they are.

The above observations mark the point of departure of my argument in this book. My quarrel with the disability-rights approach is that it does not question this paradigm in any significant way; on the contrary, that approach is entirely dependent on this paradigm. While I do not belittle the importance of equal rights and social justice for any person — with or without a disability — persons with intellectual disabilities need friends more than they need anything else, or so I will argue here. But for my argument to work, I must try to remove notions that tend to make Kelly's humanity questionable. Whatever it means that I am capable of thinking about myself as well as about her while she cannot, it is not crucial to the understanding of what our common humanity entails. That is, notions of our humanity that put selfhood and purposive agency at center stage render the claim that Kelly is "one of us" unintelligible.

3. The Problem and Its Problems

Years have gone by since I first met Kelly. Since then I have only become more convinced of the importance of friendship in the lives of people like her. I also have become more convinced that the issue of friendship is tied to the question of what it means to say that Kelly is "one of us." This is a double-edged question, of course, because I cannot say how I understand Kelly's existence without considering how I understand my own: my conception of my own humanity is at stake within my concept of her humanity, and vice versa. But I have also learned in the meantime that the intellectual interest in this kind of problem is met with suspicion, particularly by parents and family advocates of intellectually disabled children. And rightly so, I should add. Why question the humanity of their children when they already have all the problems they can handle, to be able to support those children and give them a tolerable quality of life? "Intellectual curiosity" is surely not the answer that is going to satisfy the suspicious. Just think of my observations about the people working in Kelly's group home. What was the point of posing my questions to them when they managed perfectly well to treat her as a human being without those questions? Why suggest to these people that what they are doing is unintelligible without an account of what it means for Kelly to be human?⁸ So there are problems with raising the question of Kelly's humanity that I need to address before I go on to say anything else.

The first of these problems concerns the issue of what I call "appropriate writing."⁹ It is not unusual in the literature on disability to find authors who present their credentials before they start developing their thoughts.¹⁰ Apparently these authors find themselves compelled to ex-

8. See Stanley Hauerwas, "Timeful Friends: Living with the Handicapped," in *Sanctify Them in the Truth: Holiness Exemplified*, ed. Stanley Hauerwas (Nashville: Abingdon, 1998), pp. 143-56. Hauerwas poses the same question: "How do we care for the mentally handicapped in such a manner which would forestall our felt need to provide reasons why we should care for the mentally handicapped, thereby rendering their lives unintelligible?" (p. 144).

9. Hans S. Reinders, "The Virtue of Writing Appropriately. Or: Is Stanley Hauerwas Right in Thinking He Should Not Write Anymore on the Mentally Handicapped?" in *God, Truth and Witness: Engaging Stanley Hauerwas*, ed. L. Gregory Jones, Reinhard Hütter, and C. Rosalee Veloso Ewell (Grand Rapids: Brazos Press, 2005), pp. 53-70.

10. See, for example, Deborah Marks, *Disability: Controversial Debates and Psychological Perspectives* (London: Routledge, 1999), p. xi.

plain why they should be in a legitimate position to say what they want to say. Frequently the author begins by identifying herself or himself as a person with a disability: with very few exceptions, this means a physical, not an intellectual, disability.¹¹ The need for this identification answers to a moral presupposition of this literature: since persons with disabilities are the subjects of their own experiences, talk of their experiences by other people is patronizing; in fact, taking their own stories from them is showing a lack of respect.¹² Thus, by presenting their credentials as writers in this way, disabled persons can "reclaim their experiences" and "find their own history."¹³

The language of reclaiming indicates a question of intellectual ownership and, at the same time, of intellectual reappropriation.¹⁴ Peo-

11. This is true of much of both the theological and the sociological literature on disability: Harold H. Wilke, *Creating the Caring Congregation: Guidelines for Ministering with the Handicapped* (Nashville: Abingdon Press, 1980); Stewart D. Govig, *Strong at the Broken Places: Persons with Disabilities and the Church* (Louisville: Westminster/John Knox Press, 1989); Nancy L. Eiesland, *The Disabled God: Toward a Liberatory Theology of Disability* (Nashville: Abingdon Press, 1994); Deborah Creamer, "Finding God in Our Bodies: Theology from the Perspective of People with Disabilities," *Journal of Religion in Disability & Rehabilitation* 2, no. 1 (1995): 27-42 (Part 1); 2, no. 2 (1995): 67-87 (Part 2); Kathy Black, *A Healing Homiletic: Preaching and Disability* (Nashville: Abingdon Press, 1996). For the field of sociology, see, for example, Mike Oliver, "A Sociology of Disability or a Disablist Sociology?" in *Disability and Society: Emerging Issues and Insights*, ed. Len Barton (London and New York: Longman, 1996), pp. 18-42, 25; Robert F. Drake, "A Critique of the Role of the Traditional Charities," in *Disability and Society*, ed. Len Barton, pp. 145-66; Deborah Marks, *Disability: Controversial Debates and Psychological Perspectives* (London: Routledge, 1999), p. x. In explaining the "emanicipatory approach to the sociological study of disability," Barton lays out some of its key issues. The first is: "What right have I to undertake this work?" (Len Barton, "Sociology and Disability: Some Emerging Issues," in *Disability and Society*, pp. 3-17).

12. According to Jennie Weiss Block, this implies that any attempt to think theologically about disability "must be informed by an understanding of the thinking that shapes the disability rights movement" (*Copious Hosting: A Theology of Access for People with Disabilities* [New York: Continuum, 2002], p. 18).

13. J. Ryan and F. Thomas, *The Politics of Mental Handicap* (Hammondsworth: Penguin Books, 1980), p. 13; Nancy L. Eiesland, *The Disabled God: Toward a Liberatory Theory of Disability* (Nashville: Abingdon, 1994), p. 20.

14. The issue of ownership can also be taken in an economic sense. See Marks, who writes (in *Disability: Controversial Debates*): "It behooves all people working around issues of oppression to acknowledge their own structural location, even if this location is not seen as being immutable, but is rather performed to reflect upon, although not make nec-

ple with disabilities are perfectly capable of representing themselves and should be recognized for their right to do so.¹⁵ Not only should they be in control of their own lives; they should also be in control of what is said about them. What makes living with a disability difficult is not necessarily the impairment itself, but rather the adverse attitudes of prejudice and social stigma. What makes this experience oppressive is the fact that other people wish to explain to you what your life is about — usually in negative terms. In technical language, the disadvantages a disability brings into the material world are reproduced in the symbolic world. Negative images hurt just as much, if not more, than closed doors do. These negative images and the stories that produce them need to be destroyed, so the common argument runs, which is why people with disabilities must be acknowledged as the authors of their own stories. This is the logic behind the claim that they are involved in a struggle for “the power of naming difference.”¹⁶ According to this logic, the act of writing about disability issues is a political act of appropriation. Therefore, if raising the issue of Kelly’s humanity is appropriate at all, it is definitely not appropriate for just anyone to do so. It takes credentials.

Regarding my own credentials in writing about Kelly and others, it will have to suffice for the moment for me to explain what I intend to do in writing this book. First of all, my raising the question of Kelly’s humanity is not a way of introducing the lives of disabled persons as moral quandaries. Moral quandaries are the favorite subject of ethics textbooks: they supposedly teach people correct ways of moral reasoning about “hard cases.” My aim in this book is the opposite: my main burden is to eliminate the suggestion that Kelly’s humanity presents us with a moral quandary. Regarding my reflections on the metaphorical

essarily publicly available, their own personal motives. Failure to reflect on what the member of the privileged group is getting out of the encounter may serve to mystify their own position” (p. xiii). See also M. Oliver, “Changing the Social Relations of Research Production,” *Disability, Handicap and Society* 7, no. 2 (1992): 101-15.

15. Charlton, *Nothing about Us without Us*, p. 3; Diane Driedger, *The Last Civil Rights Movement: Disabled People’s International* (New York: St. Martin’s Press, 1989), p. 28, quoting Ed Roberts: “When you let others speak for you, you lose.”

16. Len Barton, “Sociology and Disability: Some Emerging Issues,” in *Disability and Society: Emerging Issues and Insights*, ed. Len Barton (London and New York: Longman, 1996), pp. 3-17, 11.

nature of approaching her as a human being, I had to find a different perspective. Since the perspective of individual selfhood was casting her humanity into doubt, it occurred to me that an appropriate move for me to make would be to question that perspective — rather than questioning her humanity. I discarded the notion that the people who approach her as “one of us” are capable of doing so only because they are fooling themselves. In a sense, my aim in this book is very simple: I am trying to understand what makes approaching Kelly as a human being an intelligible act.

In this respect, my inquiry here is radically different from those inquiries in which human beings such as Kelly are introduced to discuss the question of when it is morally permissible to end their lives. It is radically different because I want to explore understanding our humanity in a way that will sustain the effort to include profoundly disabled human beings in our lives, not question whether they should live at all. In other words, this is not the kind of ethical inquiry that is commonly known under the heading of “bioethics”; nor is it about the kinds of issues that hold sway in contemporary bioethics readers.¹⁷ Especially with respect to intellectual disability, the most prominent issues in these textbooks are whether it is morally permissible to abort a human fetus once it is known that the future child will have a severe disability (“selective abortion”), whether there is a moral obligation to prevent disabled lives as much as we can (“prenatal screening for genetic defects”), whether it is morally justifiable to withdraw life-sustaining treatments for disabled newborn infants (“infanticide”). Of course, not all bioethicists come up with the same answers when they discuss these questions. But even though many authors in the field hold that our society has an obligation to provide adequate care for children with disabilities once they are born, there is a current of thought in that field that questions whether they should come to life at all.¹⁸

The discussion in this book is different. It aims at developing an account of our humanity that eliminates the problem: not by denying dis-

17. See, for example, Helga Kuhse and Peter Singer, *Bioethics: An Anthology* (Oxford: Blackwell, 1999).

18. The notorious example is Helga Kuhse and Peter Singer, *Should the Baby Live? The Problem of Handicapped Infants* (Oxford: Oxford University Press, 1985).

ability, of course, but by denying that what constitutes it is *not* crucial to our humanity. The positive question is found in how Kelly's humanity is similar to yours and mine. My hope is that the answer will sustain supportive attitudes toward people with disabilities in general, and toward those with profound intellectual disabilities in particular. The most important thing that this kind of inquiry can do is make people think twice.

However, the aim of my analysis is not only to change readers' minds — if they need changing — but also to advocate participation in the task of sharing our lives with disabled people. Having been a regular guest in Kelly's group home for some time, I know that raising abstract questions about their existence is a futile intellectual enterprise if it is not directed at changing social practices. Thinking about Kelly's life needs embodiment, I have learned. If we are not practically involved, it is very difficult, if not impossible, to understand the practices of care and support for these human beings. I want this book to vindicate the people who have devoted their lives, or parts of their lives, to disabled persons — whether they be families, advocates, or professional caregivers. Given the current role models that dominate our contemporary culture, their practices need this kind of support. This is not only for their sake, I should add, but also for our own: we desperately need countercultural experiences that expose the myth of humans as forever youthful, ideally attractive, aggressively mobile, and physically and mentally strong.¹⁹ This myth is exemplified by, among other things, the current hype about "remakes" and "makeovers" that indicates that the desire to be in possession of our own lives is now extended to our bodies as well. The craving for bodily perfection is but the latest exemplification of that other great myth that holds sway in our culture: that "meaning" is made rather than found. The inevitable implication of this view is that the lives of the Kellys of this world must be pointless. It is no wonder that our culture is interested in the "ethical issue" of ending their lives. In view of these popular beliefs, the question is how to conceive of our lives as truly human so that we will be able to welcome persons with profound disabilities into our midst, as Oliver de Vinck's parents were capable of doing. At the root of the

19. Don S. Saliers, "Toward a Spirituality of Inclusiveness," in *Human Disability and the Service of God: Reassessing Religious Practice* (Nashville: Abingdon, 1998), pp. 19-31.

problem is the fact that our moral culture is replete with images of the good life in which such persons have no part. That fact must also be part of our investigation.

4. No Moral Taxonomy

Apart from the question of credentials, however, there are other problems with raising the problem of Kelly's humanity that we need to consider. One is the problem of appropriate method. The question is not only what to say, but also how to say it. In the bioethical literature, as I have suggested, the common approach to profoundly disabled lives is to regard them as a source of moral quandaries. Their lives are seen as confronting us with "hard cases" of medical decision-making, where medical doctors — together with nurses and families — face issues of "life and death." I will consider this approach briefly in order to show how my investigation is different.

When issues of life and death come up, the question is usually about whether we can distinguish features that make human life worthy of protection. What is it about human life that obligates us to save it? In answering this question, many ethicists have sought to establish a defensible notion of personhood, which they base on the assumption that being a person is somehow critical to the moral obligation not to end human life. If a human being is not recognized as a person, he or she appears to be without moral standing. The assumption underlying this approach is that human life *as such* is regarded as a biological entity that lacks the dignity intrinsic to the human person.

In his recent book *Making Medical Decisions for the Profoundly Mentally Disabled*, Norman Cantor, a professor of law at Rutgers University, follows this same approach to life and death issues concerning human beings like Kelly and Oliver de Vinck. He explains how the question of whether they qualify as persons may be decisive in the withdrawing of life-support systems, particularly with regard "to the interests of surrounding family and caregivers, that is, 'real persons.'"²⁰ Another question Cantor raises is whether harvesting nonvital tissue can be prohib-

20. Norman L. Cantor, *Making Medical Decisions for the Profoundly Mentally Disabled* (Cambridge, MA: MIT Press, 2005), pp. 14-15.

ited to protect profoundly disabled human beings, for example, when biological material might save the life of a "real" person, or several "real" persons.²¹

With regard to how to resolve such issues, Cantor explains, the common approach is to define the criteria for personhood in terms of psychological and/or social characteristics.²² Evidently, the most cherished of these characteristics refer to functions of the self, which are located, neurologically speaking, in the neocortex of the brain. It follows, according to some bioethicists, that the interests of human beings whose neocortex is not functioning cannot be said to have the same moral weight as the interests of persons with a functioning neocortex.²³ A well-known argument runs as follows: Without a capacity for self-consciousness, one cannot have a conception of oneself; this necessarily implies that one's life cannot be valuable to oneself.²⁴ Without self-consciousness, the argument concludes, one's life cannot possibly mean anything *to oneself*, and thus it has no "intrinsic value."

However, Cantor is not satisfied with this argument, because he believes that all human beings should be regarded as persons, even those with profound disabilities. But his support for that belief is surprisingly weak. As a "starter," he mentions that American society recognizes as persons with full moral status all living human beings. Then he shows that the American courts and legislatures have done the same. Next, he suggests that there are social benefits to adopting this position: for example, protecting the profoundly disabled can be viewed as a reminder

21. Cantor, *Making Medical Decisions*, p. 16.

22. Cantor lists about a dozen different philosophical accounts of the criteria for personhood (pp. 17-18).

23. This is the logic exhibited in Kuhse and Singer's book *Should the Baby Live?* For a few examples of similar positions, see John Arras, "The Severely Demented, Minimally Functioning Patient: An Ethical Analysis," *Journal of American Geriatrics Society* 36 (1988): 938; Allen Buchanan and Dan Brock, *Deciding for Others: The Ethics of Surrogate Decision Making* (Cambridge, UK: Cambridge University Press, 1989); Lainie Friedman Ross, *Children, Families, and Health Care Decision Making* (New York: Clarendon Press, 1998); Peter Singer, *Rethinking Life and Death: The Collapse of Our Traditional Ethics* (New York: St. Martin's Press, 1995). For a critical reappraisal of the concept of personhood in the bioethical literature, see Tom L. Beauchamp, "The Failure of Theories of Personhood," *Kennedy Institute of Ethics Journal* 9, no. 4 (1999): 309-24.

24. John Harris. *The Value of Life: An Introduction to Medical Ethics* (London: Routledge and Kegan Paul, 1985).

of the sanctity of life.²⁵ But none of his considerations can count as proving anything, of course, because they all make the ascription of personhood dependent on moral and legal convention. One cannot defend personhood for the profoundly disabled by referring to what people believe about them, because, if adherence to certain beliefs justifies the ascription of personhood, then a change in these beliefs may do the opposite.

To close this anticipated gap in his argument, Cantor then provides a theoretical reason for his position. He adduces "conative conduct" — that is, the will to achieve some goal for oneself — as both a necessary and sufficient criterion for personhood.²⁶ That is to say, profoundly disabled human beings are to be regarded as persons with the full moral status attached to this notion insofar as they are purposive agents. Of course, this implies, as Cantor admits, that there will be profoundly disabled human beings who fail to meet this criterion. To remedy this fault, Cantor relies on the fact that "any profoundly disabled person who does not meet the suggested criterion for moral status (conative conduct) would still receive full legal protection for the practical reasons cited above."²⁷ Apart from the fact that his argument here is an example of circular reasoning — the "theoretical" reason was intended to sustain actual legal practice, not the other way around — Cantor's argument fails to do anything for all the cases he started with, namely, profoundly disabled human beings who lack consciousness.²⁸

As this account of Cantor's argument about personhood indicates, debates in the bioethical literature about who is to count as a human person do not always excel in rigorous logic, even though in actual medical practice much depends on how the question is answered.²⁹ In general, there seems to be little doubt about this strategy as such. As indicated, most authors proceed by identifying a set of characteristics to

25. Cantor, *Making Medical Decisions*, pp. 20-23.

26. Cantor, *Making Medical Decisions*, pp. 25-26.

27. Cantor, *Making Medical Decisions*, p. 26.

28. To succeed in view of these cases, Cantor would have to let go of the capabilities approach, which he fails to do, as his argument implicitly acknowledges.

29. See M. B. Mahowald, "Person," in *Encyclopedia of Bioethics*, rev. ed., Warren T. Reich (New York: Macmillan, 1995); Mahowald observes that many questions about the morality of particular medical procedures are explicitly or implicitly decided on grounds of the ascription of personhood.

determine "personhood," and then continue to test the result against individual cases in order to see whether they can live with the consequences.³⁰

In view of this literature, some Christian writers in the field of bioethics have proposed a different account of personhood according to which the human person is conceived of in terms of his or her "relations." My humanity is not dependent on my capacity for self-consciousness, these authors argue, but it is constituted by the web of social relationships of which I am a part. In other words, personhood is not psychologically, but socially, constituted.³¹ What often goes unchallenged in presenting this alternative concept, however, is the strategy that produces the rejected outcome. That is, the unchallenged presupposition is that a morally significant account of my humanity is based on a moral taxonomy. In order to be morally considerable — to have "moral status" — I must qualify as a *P*, which condition is satisfied if I meet criterion *S*. Only when one accepts this as a valid kind of argument is there a point in arguing that *P* is more properly conceived of as meeting the criterion of *R*. That is, arguments of this kind only make sense on the basis of a moral taxonomy.³²

The methodology in this book for thinking about our humanity does not depend on offering a moral taxonomy: that is, I will not en-

30. There is a renowned body of literature on this matter that has become quite suspect in the disability-rights movement (some of the authors are Michael Tooley, John Harris, Helga Kuhse, Mary Anne Warren, and, most prominent of all, Peter Singer). What distinguishes these writers is not the logic of their position, however, but the fact that they are prepared to follow the argument wherever it leads. They can live with outcomes for actual cases that many "traditional" people consider abhorrent. That is, these authors don't reject "counterintuitive" results, because they believe that the intuitions that produce them are obsolete. They find arguments such as Norman Cantor's to be logically confused because these arguments attempt both to respect these intuitions and, at the same time, go beyond them.

31. R. Spaemann, *Personen: versuche über den Unterschied zwischen "etwas" und "jemand"* (Stuttgart: Klett-Cotta, 1996).

32. For a Roman Catholic critique of the liberal position on personhood in the bioethical literature that confirms the method of offering a moral taxonomy, see L. Palazzani, "The Meanings of the Philosophical Concept of Person and their Implications in the Current Debate on the Status of the Human Embryo," in *The Identity and Status of the Human Embryo: Proceedings of the Third Assembly of the Pontifical Academy for Life*, ed. J. de Dios Vial Correa and E. Sgreccia (Città del Vaticano: Libreria Editrice Vaticana, 1997), pp. 74-95.

deavor to offer a set of characteristics to convince you that profoundly disabled human beings are also in fact human beings — not only biologically speaking but also ethically speaking. This is because I believe that the procedure is wrongheaded, because taxonomies by definition constitute boundaries and, by the same token, constitute marginal cases. In this book I defend the view that there are no marginal cases of being human. The reason for my claim is theological.

5. A Theological Inquiry

Put positively, my methodology starts from a different assumption. What we are to think about a life like Kelly's I take to be a question of how we understand our own lives. The theoretical task is interpretation rather than classification. That is, rather than classifying what we believe to be the distinguishing characteristics of human beings that make them morally considerable, our task is to interpret humanity — our own as well as that of others — in the light of our existence in this world. In one of his essays on disability, Stanley Hauerwas puts it this way:

The appropriate moral context for raising the question of the "essentially" human should not be an attempt to determine if some men are or are not human, but rather what we must be if we are to preserve and enhance what humanity we have. In other words, the question of the criteria of the human should not be raised about others but only about ourselves.³³

According to this principle, the way we regard the lives of other people reflects the way we understand our own, which is no less true of our understanding of the lives of people with a profound intellectual disability.

By way of determining what we must understand about ourselves, what is the underlying assumption guiding my inquiry in this book? It is that there is absolutely nothing important about my being if it were not

33. Stanley M. Hauerwas, "The Retarded and Criteria for the Human," in *Truthfulness and Tragedy: Further Investigations into Christian Ethics* (Notre Dame: University of Notre Dame Press, 1977), pp. 156-63.

for the love of God. In the vastness of the universe, both in time and space, my existence is even less than what is contained in the blink of an eye. Only the love of the eternal God can make the difference: it is because of the love of God that our humanity retains its special quality. The traditional theological way of expressing this view has been through the doctrine of *imago dei*. Whatever else it may mean to say that I am created in the divine image, it must surely mean that I am created in God's love, since love is what defines the God in whom Christians believe. This is what makes my existence as a human being incredibly important. For exactly the same reason, it makes the existence of human beings like Kelly incredibly important. Affirming the first claim but denying the second would mean that God loves human beings like me but not human beings like her. I do not see how such a distinction could be defended from a Christian point of view.

In contrast, philosophical accounts of what makes our humanity significant must necessarily rely on some account of our human nature. For example, philosophical naturalism tells us that there is nothing incredibly important about our existence; it is a sheer accident in the history of the universe. All that is valuable to us is only valuable to the extent that it contributes to the satisfaction of what we want. Whatever goods there are, they are such because they are the objects of desire. Good does not exist beyond that. It follows that what we value about our humanity is necessarily grounded in our appetites. In this view there is no meaning that goes beyond satisfaction.

Of course, there are philosophical alternatives to my Christian account other than philosophical naturalism. But I am not sure they do much better. For example, Kantian transcendentalism grounds the significance of our humanity in transcendental reason. But this is far from consoling because transcendental reason can only survive historical criticism on the basis of absolute knowledge, which is not a very plausible notion with regard to human being (*pace* Kantian transcendentalism). What this leaves us with is a kind of historicism, which comes in many varieties in contemporary philosophy. There is no meaning that exceeds the limits of our historical understanding, and this goes for understanding our humanity as well. This position only confirms — albeit in a different way — that whatever we make of our humanity is the result of historically situated cultural constructs. Beyond those there is no meaning.

life, we can safely say that the way our moral culture values our lives, it would render hers as the lowest of the low, dominated as the paradigm is by personal achievement. In view of that valuation, if I were to have as my point of departure the lives of mildly disabled persons, I would fail to bring out the problem in full measure. Many people with a mild intellectual disability are, to a considerable degree, capable of pursuing their own goals in life. That they do not have equal opportunities to do so is nothing less than a shame; and here I agree with the disability-rights movement on the importance of the political struggle. To argue from a perspective of profound intellectual disability, therefore, is not to deny the problems faced by people with other disabilities in this society. Rather, it is to affirm that a concept of being human can be truly universal if and only if it illuminates human existence as such — profoundly disabled persons included. Many people in our moral culture fail to see this, I'm afraid, and that includes many Christians.

6. The Politics of Friendship

In order to clarify the political aspect of the approach I take in this study, however, I must return to my "quarrel" with the disability-rights approach. Admittedly, the disability-rights approach has effectively contributed to the creation of more opportunities for people with disabilities than ever before. Hence it is important to explain why my argument in this book will not follow in its path. The disability-rights approach correctly tackles the social, economic, and political dimensions of exclusion and inequality, which in our society means that the language of rights is the most effective vehicle for launching its claims. However, my support of its claims to equal rights and justice does not necessarily imply that I accept the underlying theoretical framework that produces such claims. At stake here, once again, is the ambivalent nature of rights talk as far as people with intellectual disabilities are concerned.

In order to understand this ambivalence, the reader may wish to be mindful of the sociopolitical history of exclusion. In the wake of Michel Foucault's work, social historians have established that the invention of "liberty" as the inalienable right of citizens in liberal democracies

has gone hand in hand with the dehumanization of various groups that the democratic polity believed were out of place. In the nineteenth and early twentieth centuries, the emerging democracies created special places for people who they believed needed to be isolated from the rest of society because they either did not deserve, or could not be entrusted with, the freedoms that healthy and normal citizens enjoyed.³⁷ Coercive exclusion went hand in hand with the invention of liberal citizenship, as we now know it. The moral justification for the labels of exclusion — “deviancy,” “feeble-mindedness,” “insanity,” and so forth — invariably followed the same pattern: inadequacy or irresponsibility demanded that the rights of the liberal subject be taken from those not living up to its standard.³⁸ The disability-rights movement has effectively shattered the supposedly “humanitarian” concern that turned those excluded people into targets of “rehabilitation.” In doing so, it has successfully repeated the strategy of previous struggles for civil rights, which is why it rightly deserves the name of the “last civil rights movement.”³⁹ Its main strategy has been to acknowledge the subjectivity of humans with disability in telling their own story, using their own language.⁴⁰ In this way it has exposed the awkward fit of coerced isolation with fundamental democratic values. It has done so by using liberalism’s own weapon of claiming equal rights and social justice for people who have been unjustifiably marginalized.

Thus rights language has once again proved to be the most effective language in our society to open up spaces that remained closed for “displaced” persons, such as persons with disabilities. Nonetheless, it is important to see that rights claims, while necessary, are not sufficient to counteract exclusion simply because of the kinds of spaces they can open.⁴¹ In opening up institutional roles and public spaces they are crucial to our capacity as citizens. But rights cannot open up spaces of

37. Alison Bashford and Carolyn Strange, “Isolation and Exclusion in the Modern World,” in *Isolation: Places and Practices of Exclusion*, ed. A. Bashford and C. Strange (London: Routledge, 2003), pp. 1-19.

38. Bashford and Strange, “Isolation and Exclusion,” p. 4.

39. See footnote 12 above.

40. Diane Driedger, *The Last Civil Rights Movement: Disabled People's International* (New York: St. Martin's, 1989), p. vii.

41. Hans S. Reinders, “The Good Life for Citizens with Intellectual Disabilities,” *Journal of Intellectual Disability Research* 46, Part 1 (Jan. 2002): 1-5.

intimacy, which are the kinds of spaces where humans have their need of belonging fulfilled. Put simply, disability rights are not going to make me your friend.⁴²

Given that it perceives inclusion as a political goal, the disability-rights approach derives its strength from what it can do in the public sphere, aiming at how our society shapes its institutions as well as its public spaces. In the context of liberal democracy, however, the public sphere is separate from that other space — called the “private” sphere — where citizens are free to rule over their own lives. By using democracy’s weapon of equal rights against its own creations, the disability-rights movement has bought into this division of space into public and private spheres. In doing so it has given away the possibility of addressing the issue of friendship as one of the central goods in our lives. The reason is that, within liberal democracy’s division of spheres, friendship is part of our private lives, equal to marriage and family life. Therefore, the disability-rights movement has surrendered the possibility of saying anything about what is for many disabled people one of the fundamental issues, if not *the* fundamental issue: the question of sharing our lives together, not only as citizens but as human beings. If disability rights are not going to make me your friend, neither does reclaiming your own story force me to listen to it. It will only do so when I regard myself, and the purpose of my life, in a light that makes me willing to pay attention to what your life is about. Far from denying the crucial importance of disability rights, and far from belittling the importance of the ownership of one’s own story, I do not believe that they will be sufficient to show what it means to say that Kelly is “one of us.” And that goes for other people with disabilities as well. “My boy now has all the rights the ADA could possibly assure him of,” a mother once said to me about her son with Down syndrome, “but he still has not got a friend.”

Given the centers of gravitation in our moral culture, the argument for inclusion has gone toward questioning the ways our society marginalizes particular groups of people. In my view, the processes of marginalization work through the underlying images of who we are.

42. Joseph Shapiro discusses the transition from “pity” to rights; in the course of that discussion he claims that “pity opens hearts” (*No Pity*, p. 23). Lest I be misunderstood, friendship cannot be motivated by pity without becoming corrupt.

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The most fundamental question is thus not about how disabled people regard themselves, nor is it about how "we" regard "them." Ultimately, the question is how we — readers and writers of books, if you will — regard ourselves, and our own lives. That question will decide whether or not we are the kind of people who want to share our lives with disabled persons.

No doubt there will be those who read my argument as an argument that "depoliticizes" disability. It would be a failure if it did. Just as there is no ethics that does not rely on a particular anthropology, there is also no ethics that does not have its own politics. What, then, are mine? The politics of my argument that we should go beyond the disability-rights approach is to point out that, if the opening of institutional and public spaces is to become really effective, then we are dependent on moral sources that differ from rights and justice. I do not doubt for a moment that people with intellectual disabilities ought to be treated as equal citizens, but I am equally certain that this concern is not adequately grounded in the moral values of political liberalism. Advocates of disability rights fail to see that the moral values of self-determination and choice they bring to the table in defense of equal citizenship for disabled people are exactly the same values that give other citizens the right not to be interested. Rights create the bonds of citizenship; unfortunately, they do not forge the moral bonds of friendship. Institutional space creates new opportunities that will become effective only because of the support of people. Without people who are disposed to be supportive, opportunities will turn into frustrations. Therefore, the politics of my investigation here is to argue for the inclusion of people with intellectual disabilities in our lives, which is more and greater than including them in our institutions.

7. Terminology

Despite the claim that the crucial issue is how we understand our own humanity, with or without a disability, this book is nonetheless about people with intellectual disabilities, especially profound intellectual disabilities. Of course, not all people with a profound intellectual disability live with conditions as serious as *micro-encephaly*. Difficult as it

may be for the “outsider” to imagine, there are huge differences even among people whose developmental stage does not reach beyond the level of a toddler. Who are we talking about when we say “people with profound intellectual disabilities”? To answer this question, I need to say a few things about definition and classification. Before I do, however, I want to offer a preliminary critical remark about semantics.

In this book I will frequently speak first of “people” and “persons,” and then often add the prepositional phrase “with disabilities.” They are “people first” — before they are anything else.⁴³ Many writers in the disability-rights movement are careful to use the correct language as a sign of paying respect, and if writing per se is a political act, this makes sense. There is a moral point, then, in following the language that people with disabilities use to refer to themselves. However, there is also something deceptive about the practice of changing the language every few years, as the disability-rights movement has been doing in the last decades. Consider the following passage from a novel, written by the Swedish novelist Majgull Axelsson, about a young woman with a physical disability. The woman is a quadriplegic who stays in a hospital because of her very serious convulsions. She is a bright, intelligent person who absolutely hates to be patronized, which is exactly what some of the nurses do (“Oh, you poor thing . . .”). She remembers that she once attacked a nurse — with her teeth! — because she detested the way this nurse made her subject to “the cause of goodness.” She goes on to say:

It needs to be said. There is no state of being that has worn out so many names as this one; every decade for the last century has spit out some bitter old word and found a new, sweeter one. Thus the cripple became maimed and the maimed soul lame and the lame an invalid, the invalid a handicapped person, the handicapped person disabled, and finally, the disabled became the developmentally challenged.⁴⁴

Old, bitter words are spit out and replaced by new, sweeter ones. It is a ritual that nobody manages to escape. Everybody knows the sequence. “Idiots” became “morons,” then “morons” became “feeble-minded,”

43. People First is the name of an organization of self-advocates with intellectual disabilities; visit its website at: www.peoplefirst.org.

44. Majgull Axelsson, *April Witch*, trans. Linda Schenck (New York: Villard, 2002), p. 15.

"feeble-minded" became "mentally retarded," then "mentally retarded" became the "mentally disabled," and finally we have settled on "persons with intellectual disabilities." We do not speak of "feeble-minded" or "mentally retarded" anymore, because it came to be thought, at a certain point in time, that these terms were charged with negative connotations. For that same reason we now prefer not to speak of "the disabled" but of "persons with disabilities." The deception in all this is that we cannot remove the negative connotations of words by changing the language. What induces us to look for new words again and again is not inherent in language but in the attitudes of the people who use the language. Persons with disabilities do not need different words; they need different people. Negative connotations do not reside in words, but in the mind. Negative connotations are attached to words because of how people think about disability; thus, without changing their habits of thinking, people will use new words just as they used the old ones.

Regarding the definition of the term "disability," there are a number of positions to be found in the literature. There are those who believe that it is impossible to offer a universal definition of the term, given its many different uses.⁴⁵ To some extent, this is true. The concept of disability falls into the category of what the British philosopher W. B. Gallie has described as "essentially contested concepts."⁴⁶ But it does not follow that the term "disability" has no clear meaning. It only follows that definitions of its meaning are dependent on particular semantic communities. Defining the term appears to be a form of verbal legislation, as if it is saying, "If you want to be part of our discourse you need to know that this is how we use the word." Psychologists, for example, will use the definition found in DSM-IV; lawyers in the United States use the definition found in the Americans with Disabilities Act; policy-makers and service-providers throughout the Western world use

45. In the theological literature, this position is found in Weiss Block, *Copious Hosting*, pp. 32-33; see also Pailin, *A Gentle Touch*, pp. 29-30.

46. W. B. Gallie, "Essentially Contested Concepts," in Gallie, *Philosophy and the Historical Understanding* (New York: Schocken, 1968), pp. 157-91. The central idea behind Gallie's notion of "essentially contested concepts" has been explained by John Gray as concepts whose necessary and sufficient conditions of correct application are in dispute. See John Gray, "Political Power, Social Theory, and Essential Contestability," in *The Nature of Political Theory*, ed. David Miller and Larry Siedentop (Oxford: Clarendon Press, 1983), pp. 75-101.

the standard definition of the AAMR (American Association of Mental Retardation). In each case, the definition depends on the goal it is meant to serve. This also explains why the disability-rights movement uses a definition of its own: "A disability is the condition of being stigmatized and marginalized by society."⁴⁷

A position that has gained considerable support in the field is to define "disability" as the effect of a (negative) societal response, and thus distinguish it from "impairment," which is then the physical or mental condition that elicits this response. The principle underlying this distinction is to affirm that there is a condition that causes (some) limitations in bodily functioning — physical or intellectual or mental, or any combination of these three — but to deny that these limitations in themselves justify negative evaluation. Human limitations vary in numerous ways, just as abilities vary in numerous ways. The condition of impairment thus points to human diversity and is, as such, to be considered a neutral fact. The negative evaluation attached to "disability" can then be located in the societal response to this neutral fact. This means that, while the condition of being impaired is a function of a person's body, the person's disability is a function of the way his environment responds to his body. This distinction opens up the possibility of targeting the disability as a "social construct" without targeting the impairing condition.⁴⁸

In this book I don't intend to join forces with any of the semantic communities in the field, and thus I have no stake in elaborating on either definition or classification. What definitions and classifications there are can be abused to reinforce taxonomies that exhibit the logic of exclusion.⁴⁹ Having said that, I should add that I find the above distinction between impairments and disabilities helpful, that I don't doubt

47. Quoted from Eiesland, *The Disabled God*, p. 24.

48. The philosopher Susan Wendell succinctly defines a disability as "socially constructed from a biological reality" ("Towards a Feminist Theory of Disability," *Hypathia* 4, no. 2 [1989]: 104-23). See also Creamer, "Finding God in Our Bodies" (p. 35), who claims that disability is a physical condition and a sociopolitical category. She sees "two interrelated factors: the bodily experience of disability and the societal response to these bodies." She argues that "disability can only be fully understood by looking at the interplay between the physical condition and the environment, for each has relevance to theological reflection."

49. This verdict holds across the entire spectrum of moral and political views. In many accounts of the disability-rights movement, there is no place to represent intellectual disability, let alone profound intellectual disability. I return to this claim in Ch. 5.

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that negative responses to impairments of any kind are socially constructed, but that I also think that the distinction is not equally powerful with regard to all kinds of disabilities. Here the first condition to come to mind is, of course, the condition of profound intellectual disability. I find it difficult to conceive of a social order in which a cognitive impairment in which a person cannot grasp distinctions between "me" and "you," or between "now" and "then," or "here" and "there" could be effectively regarded as neutral.⁵⁰

My phrase "intellectual disability" is what Americans used to refer to as "mental retardation," but what is now more often known as "developmental disabilities"; this is roughly the same as what the British usually mean when they speak of "learning disabilities." The impairments in question are permanent; they are not a disease or an illness, which distinguishes this term from "mental disabilities" as a reference to psychiatric conditions of mental illness. These impairing conditions may occur at birth or later in life as the permanent effect of an illness or accident. Moreover, these impairments are manifested in limited cognitive functioning, which distinguishes intellectual disability from physical disability. "Intellectual disability" indicates irreversible developmental delay.

The phrase "profoundly disabled" indicates a developmental stage of mental development that has not gone beyond a toddler's stage of development. Whatever else is true of these human beings, it is quite unlikely that one will find them advertised as "being successful" in the way persons with mild intellectual disabilities — the proverbial "happy kid with Down syndrome" — are sometimes advertised in the media. While such kids also have an intellectual disability, and their parents or siblings can inform you about the darker sides of their lives, nobody in their right mind would think of raising a question about their humanity (I do realize that this is an overstatement).⁵¹ Given cultural images of being "successful," or "being happy," things must appear as very different indeed for human beings like Kelly and Oliver de Vinck.

50. I will have more on the subject of social constructionism in the following chapter.

51. For the wonders, the darker moments, as well as the overstatement, read the story told by Martha Beck in *Expecting Adam: A True Story of Birth, Rebirth, and Everyday Magic* (New York: Berkley Books, 1999).