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Short title: Remembering Ann

Abstract: The article reflects on the significance of *Disability in the Christian Tradition* in light of the experience of a forty-three years’ relationship with someone who had multiple sclerosis and was eventually totally disabled and mentally impaired.

Keywords: disability, multiple sclerosis, theodicy, humanness

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# Remembering Ann

 My first wife, Ann, lived for forty-three years with multiple sclerosis. For her last years she was wheelchair-bound, unable to do anything for herself, and unable to speak – not because she couldn’t move her lips but because she couldn’t work out what she wanted to say. Her life made me think about disability, and the angle from which I have approached *Disability in the Christian Tradition* has been to ask what I learned that helped me think about Ann or that resonated with ways I have thought about her, and to ask how my experience with Ann raised questions in connection with the material in the reader. The title for this chapter comes from my memoir about Ann (Goldingay 2011).

In recent years, concern about disability has emphasized justice for disabled people that will enable them to play a full part in society in realms such as work, education, and sport. Ann could be involved in none of these. She could not speak for herself. She belonged to the group of human beings that John Swinton describes, whose experiences are the exact opposite of the goals and ideals of modernity and liberal democracy, people who have very limited ability to communicate, no self-care skills, and significant intellectual and cognitive difficulties. Ann required full-time care through the last decade of her life. Compared with other accounts of the connections between theology and disability, Jean Vanier’s work is particularly significant in

relation to her, because it shows only a limited interest in issues of freedom and self-determination. Whereas, for example, accounts originating from liberation theology put their emphasis on empowering people with disabilities to shape their own lives, Vanier prefers the language of strength in weakness as a way to build community. His primary aim is not to create equal opportunities for people with disabilities to help them shape their own future (pp. 479-80).

Likewise I appreciate the emphasis attributed to Søren Kierkegaard, on becoming the sort of human being God intends you to be, which has little in common with social and cultural standards and norms (p. 290). I don’t think I was ever very tempted by the question “Why” about Ann’s disability. Certainly as far back as I can remember I have been aware that the only answer the Bible gives to that kind of question concerns what God might achieve through the loss in question. Kierkegaard’s theology, too,

Is not overburdened by questions of theodicy. Determining some meaning for suffering is not his primary problem. Pain and death are for him simply tragic realities of life which all individuals must confront in one way or another. The real threat to human flourishing and Christian spirituality is the individual’s relationship with herself. Spiritual illness, or “sickness unto death,” is, for Kierkegaard, far more significant a concern than physical or mental illness…. In his view, the many physical sufferings and ailments that human beings may have operate in a different register from emotional and spiritual anxieties. Engaging with his perspective on this may help support a theology of disability that is concerned to decenter the issue of suffering in its approach to disability, and to encourage an approach that focuses on the individual’s agency and responsibility for responding to the world from his or her specific situation and condition. (pp. 291-92)

There is a link with John Swinton’s comments based on Stanley Hauerwas:

It seems “obvious” that people with intellectual disabilities suffer; therefore, it is “obvious” that preventing the existence of such lives is the most appropriate, compassionate, and right thing to do. However, the simple fact that “compassionate” acts of prevention often mean the elimination of the subject should alert us to the possibility that there might be more at issue here than immediately meets the eye. When we begin to explore precisely what is meant by the “suffering of the retarded” (i.e., when we look at the presuppositions behind such a statement), things begin to look different. (p. 515)

With regard to the questions of theodicy, however, I did appreciate the account of John Calvin’s comments on Job. God, Satan, and the Chaldeans were all involved in what happened to Job. “We do not have either to blame the subject for his or her own suffering or suggest that God is absent during times of suffering, both of which can be problematic from a disability perspective, as these beliefs function in ways that separate the person with a disability from God.” God can be present even if we are unable to understand God’s intentions or role in a situation, and God can be present even if we do not see God as having brought about the loss (p. 222).

Like Brian Brock in his introduction, I have found much of my thinking revolving around the question what it means to be human. For Ann, being fully human and contributing to the lives of others and to God’s purpose had to take a different form from the one it takes for most of humanity or that it took for her earlier in her life, when she worked as a physician and then as a psychiatrist. Ann was a human being until the day she died, and was so in the way she lived and related to people and ministered to people. How does that reframe an understanding of what it means to be human? At one stage I used to fret about whether it was possible for Ann to relate to God when she seemed unable to cogitate, and I resonate with the comment that for Augustine and Thomas Aquinas, it is one thing to have a sense of self (an inner or hidden life) and a wholly other thing to reason discursively about one’s self (p. 103).

In related fashion, insights from G. W. F. Hegel can be summarized as follows:

Mentally disabled people are… freed from being viewed as inferior beings stuck in their particularity, unable to develop. Instead, their process can be appreciated as the open, unending process that characterizes all human life…. Mentally disabled people now appear as unities of body and spirit, their spirit being engaged in the unending process of development, in common with the spirit of all humans. The form of religion in general and the content of Christianity in particular would thus appear as an invitation and an obligation to enable mentally disabled people to take part in the sphere of the absolute spirit. Christianity facilitates the development of the relational autonomy which is adequate to them. (p. 262)

On the other hand, I do not know what can be the basis for Aquinas’s conviction that the first state or degree of relational intimacy between the image of God and Godis the always-active awareness of self common to all human beings, which is the basic condition of the human creature’s capacity for relationship with God.

For Aquinas, at all stages, the dynamic inner life of the human creature is animated with desire for its creator…. Aquinas is keen to reject arguments suggesting that there are types of bodily infirmity which affect or otherwise impair the realization of the ultimate good for particular human creatures, which is the beatific vision…. According to Aquinas, persons who have even the most profound sorts of cognitive impairment are capable of receiving and responding to the movements of divine grace, operative in the sacraments of the church. It is in this way that Aquinas grounds his theological understanding of the *amens* (and the doctrinal significance of *amentia*) in the life of the Body of Christ: where damaged bodies and wounded souls are drawn toward their ultimate perfection in Christ, the Crucified One. (pp. 103, 110, 114)

Kierkegaard’s emphasis on inwardness being the one thing that really matters can also seem oppressive in relation to disabled people: “when all is said and done, what matters most is inwardness — and when everything has been forgotten, it is inwardness that still matters” (p. 301). Admittedly Aquinas is agnostic regarding what we can reasonably speculate concerning the hidden or inner life of the person with severe mental disabilityin relation to God. Nevertheless, for him, the Christian faith entails a primary certainty that God can and does objectively communicate with the human creature, including mentally disabled people*,* in the sacramental life of the church (p. 115).

I resonated with Dietrich Bonhoeffer’s emphasis on the danger or trap of benevolence or beneficence towards disabled people (p. 403).

To hear Bonhoeffer mark out benevolence as a dangerous temptation for Christians must have been as disturbing to his hearers back then as it is to readers today. After all, does this classical virtue not look like the closest thing to the Christian calling to neighborly love? And had the preacher of these same words not asked his same hearers to give freely to the Bethel institutions and thus show benevolence by practicing beneficence? Bonhoeffer obviously felt the need to elaborate more on this warning: In any attempt to mediate neighborly love by translating (and hence narrowing) it into benevolence and beneficence, he explained, “the seriousness of the problem is not [at] all recognized. Weakness to them is nothing but imperfection. With all due respect for the real sacrifices that have been made in such a benevolent attitude, it must be said frankly that this approach is wholly wrong and unchristian, for it means condescension instead of humility (pp. 363-64).

As I have implied, Ann was not merely someone with needs that deserved to be accommodated, someone broken or mentally and physically challenged and functionally deficient, but someone who made a unique contribution to the humanity of the individuals she related to and the bodies she belonged to.

Over against a moralizing perception of the other, who is either judged by the value of his or her attributes or by the absolute value of his or her origin, Luther shifts the focus of the debate from the metaphysical or physical qualities of people to their permeability to God’s working.(197)

One way in which Ann made a unique contribution to the humanity of people is closely related to benevolence. As Jean Vanier puts it, “their thirst for friendship, love, and communion leaves no one indifferent: either you harden your heart to their cry and reject them, or you open your heart and enter into a relationship built on trust, simple, tender gestures, and few words. Hidden in those who are powerless is a mysterious power: they attract and awaken the heart” (p. 479).

So beneficence, doing good, can turn out to be two way. In La Forestière Jean Vanier learned to see himself in such a way that the distinctions between “helper” and “helped” vanished. The writings of L’Arche point to the “core members” of their communities, “the poor” as their “teachers” (p. 477).

People often come to L’Arche to assist in the community because they want to help people with intellectual disabilities. Vanier does not want to question their motive to help, but he does encourage the assistants in L’Arche to question such motives themselves. While in itself commendable, the desire to be good to other people can easily become self-serving, particularly when it is fueled by the presumption that one’s role in the community is to give. People entering L’Arche with this presumption have to learn something that, according to Vanier, is essential for its community, namely, that the marginalized and the despised—“the poor”—have something to give. (p. 474)

Vanier and his friends in L’Arche would certainly maintain that they have been blessed with very special people, but they would not mean this in a moral sense. The key notion in their view is that more than anything else, people with disabilities can open the door to our hearts. (p. 471)

 Ann contributed to the humanity of others through her lacking the freedom and capacity for self-determination that we often regard as essential to true humanness. As Dietrich Bonhoeffer put it, the lives of disabled persons reveal something of the truth of human existence — a truth that healthy people typically try to ignore. It is thus not the mentally handicapped who are insane, but those who assume they can distinguish their own “healthy” existence from that of the handicapped in a way that eliminates those others who powerfully reveal the fundamental fragility of human life shared by everyone (p. 355). Ann brought home to people the truth that all humans are marked by what Mary Jo Iozzio calls “radical dependence” (p. 154). Bonhoeffer again comments:

Their experience of life must be most extraordinary, not having control over their bodies, having to be resigned to the possibility of an attack at any moment. Today in church was the first time this really struck me, as I became aware of these moments. Their situation of being truly defenseless perhaps gives these people a much clearer insight into certain realities of human existence, the fact that we are indeed basically defenseless, than can be possible for healthy persons. (p. 370)

The subtle though by no means marginal difference between neighborly love and benevolence, which Bonhoeffer pointed out, is still a decisive, if often unrecognized, underlying feature in discussion about disabled life today. Becoming alert to the differences between these two concepts will sensitize us, for example, to the problematic nature of the “inclusion” debate…. Should we “include” the disabled in the protective zone of the language of “personhood,” a moral attitude which would still be based on a condescending “us-them” rationale, or should we instead summon those who consider themselves not disabled to find themselves included in the same frail and dependent human existence as God’s creatures that the disabled exemplify? (p. 364)

As Stanley Hauerwas puts it, “we have not been created to be ‘our own authors,’ to be autonomous. We are creatures. Dependency, not autonomy, is one of the ontological characteristics of our lives. That we are creatures, moreover, is but a reminder that we are created with and for one another. We are not just accidentally communal, but we are such by necessity. We are not created to be alone. . . . That the mentally handicapped are constituted by narratives they have not chosen simply reveals the character of our lives” (p. 518).

In her discussion of Julian of Norwich, Amy Laura Hall raises another issue I recognize.

What some people with disability most fear is that someday their disability will become *too much* for their loved ones to bear. What frightens some people called to live together with a person with disability is that they will indeed come to the end of their capacity to love, that they will reach a point past which there will be nothing holding them together. It is in this crux of need and fear and pain that physical struggle can result in the irresolvable suffering of alienation, one from another. And it is in this crux that Christians are called most resolutely to a life of what Mary Jo Iozzio calls “solidarity.” She narrates this work of resilient kinship as indicative of a “God who stands in solidarity with humankind from the moment of kenosis and conception in Mary’s womb until today”…. Pulling together here Iozzio’s suggestion and Julian’s text, we may see that the blood of the Crucified One does not grant secure impermeability so much as it reveals “radical dependence” (Iozzio’s phrase). God’s work in Christ enters through our permeability to create hope, merciful wisdom, and a courage sufficient for presence at the times of rupture. Julian received a vision that may be of use even for a family struggling toward solidarity in the midst of alienation and the often-resultant rage and/or depression. For, as Julian reminds us, “He did not say, ‘You shall not be tormented, you shall not be troubled, you shall not be grieved,’ but he said, ‘You shall not be overcome.’ ” (p. 163)

Jean Vanier, again:

I can only continue when I accept that God has made a covenant between Eric and myself. Because of this covenant we are responsible to one another. If God has done this, then He will also help us to deepen our relationship. He will offer me His grace and give me patience to accept my own darkness, and He will help me to trust that someday it will disappear. (p. 478)

In light of my experience with Ann, I appreciate Brian Brock’s comment that an ecclesial view of what it means to be human focuses on what each person brings to the body and on who we are together. This ecclesial view also points to an understanding of the body of humanity outside the church. Further, describing disabled people as part of the body ofChrist (or part of the image of God) points to the vocation they have in God’s purpose and in God’s service, as indispensible as that of any other part of the body. Almut Caspary notes that both Gregories, Gregory of Nyssa and Gregory of Nazianzus, base their concern for the disabled on the fact that they are made in God’s image (pp. 31-37). I thus liked the way in which Augustine, even though speaking of the image of God as lying in our possessing reason, acknowledges that disabled people may be created with “strange vocations.” (p. 78). Even people with impairments have something to give to others. But what society had constructed as negative is now reversed and turned into a positive identity, but this is but the other side of the same coin. The basic power dynamic of the “disabled” person’s relationship to society remains in place (p. 293).

Likewise I resonate with the analogy between the complementary place of women and men in the church and in the human body and the complementary place of disabled and ordinary in these two bodies.

This social model of disability has some parallel strands in theological discourse and feminist thought. In the 1970s, some feminists began to think in terms of “cultural feminism” or “gynocentric feminism.” Ruether names and describes this kind of feminism as “romantic”…. Romantic feminism will often name women as the peacekeepers, as gentle and nurturing caregivers, and therefore as having no disability. On this account, women bring unique gifts to humanity by their very woman-ness. Mary Aquin O’Neill writes of this form of feminism: There is a male way of being and a female way, and these can be known from an examination of the bodies of the two and given a fair degree of specificity. Thus men are supposed to be, by nature, active, rational, willful, autonomous beings whose direction goes outward into the world; women are to be passive, intuitive, emotional, connected beings whose natural inclination is inward…. Humans share one nature, and men and women together demonstrate what that nature is. Men need women to fill in gaps, and vice versa: men have roles and habits that are complementary to women’s. We cannot be fully human without knowing ourselves in relation to members of the other gender, and so what it means to be fully human is to be in relationship with each other as men and women. Thus, men and women together comprise the many members of the one body of which Paul speaks. (pp. 433-34)

And I appreciate the comment from Karl Barth suggesting that *this* life of Ann’s was not futile; she was someone God loved as she was. He is responding to Heinrich Vogel, whose daughter was severely disabled. Vogel’s theological commitments resonated with his wish as a father that — in God’s new creation—his daughter would be freed from present restriction.

“She will walk!” he exclaimed. To which Barth replied, No, that makes it sound as if God has made a mistake in your daughter’s case, one which he is obliged to put right. “Is it not a much more beautiful and powerful hope,” Barth asked, “that something becomes apparent there that at present we cannot understand at all — namely that *this* life was not futile, because it is not in vain that God has said to it: ‘I have loved: 392 *you!*’?” And, he added, the final revelation of the truth and meaning of this life will involve a radical re-ordering of prevailing cultural values: “*She* will sit at the head of the table, while we—if we are admitted at all—will have to sit right down at the other end.” (p. 393)

Earlier this year I gave a paper that talked about the way Ann ministered to people, and afterwards a friend asked whether a more suspicious hermeneutic might be applied to people’s reactions to her, and to my own response to those reactions. I was struck by the questions raised about Julian.

The perception of her revelation as of *love* rather than self-delusion turns on the fulcrum of this gift. By seeking the marks of suffering and human sin, she may be read to reveal herself as a self-destructive poseur. Has she tried to substitute her own suffering for Christ’s own? By seeking to know Christ’s work *bodily,* rather than in a primarily scholastic way, has she proven herself guilty of the worst sort of masochistic works-righteousness? Has she sought suffering for her own salvation? There is no definitive answer to these questions. (p. 155)

Julian watches as not the brow but the whole body of Christ begins to bleed, “so abundantly that it seemed to me that if at that moment it had been natural blood, the whole bed would have been blood-soaked and even the floor around”…. She reflects here on the strange fittingness that God gives us “holy blood to wash away our sins,” given that “it is so plentiful and it shares our nature”…. Yet, again, what about sin? Does it remain? How does his blood conquer the sin passed down through our inheritance from Adam? She receives the words “By this is the Fiend overcome.” This — the abundant, plentiful blood of Christ’s body in distress and darkness—is the way that God “holds fast all the Devil’s power,” “scorn[s] his wickedness and set[s] him as nought”…. As she gropes toward the significance of this vision, she receives the assurance that, through this blood, “all manner of things shall be well,” and that through this blood those beloved by Christ are “filled with compassion” for others…. For, as Christ’s blood enters her, washes her, and clothes her, she is made compassionate—part of his passion and part of Christ’s love for all others. (pp. 159-60)

I have the impression that the reader had two aims. One is to show that the tradition is more enlightened than has been believed; in this it succeeds. The other is to show that it offers insight for our own reflection; I am not so sure it succeeds in this aim. Reflecting on my own reflections, I realize that it is the most recent work such as that of Jean Vanier that resonated most for me. In writing about disability (Goldingay 1997, 2010), as well as Jean Vanier I found other contemporary theologians such as Wolfhart Pannenberg, Jürgen Moltmann, and John Zizioulas gave me most help. I don’t think I learned a great deal from the writings of earlier centuries. Yet the reflection this conclusion in turn prompts is an awareness of the need for us to relativize our own questions and attitudes. In the modern and post-modern age we are inclined to take for granted that we are enlightened, that our questions and answers are the right ones. We need therefore to show that the tradition we affirm looks at things our way even where at first sight it doesn’t appear to do so. Or alternatively it will be appropriate for us to critique the tradition in light of our perspective. Either way, the center of gravity lies with us. Postcolonialism offers a good current instance of this process. Most of all, we have to project back onto Jesus the views that we hold dear. Contemporary stress on non-violence offers a good current instance of this process. It means we forfeit the possibility that in offering a different perspective from ours the tradition may be able to move us forward in our thinking, move us out of our current parameters.

Such considerations make me want simultaneously to make two affirmations that are in tension with each other, that postcolonialism or feminism or non-violence or disability studies are really important to me, but that the tradition’s not sharing my concerns doesn’t mean it’s wrong.

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