Whose Table For "The Retarded"?

A Reflection on

Stanley Hauerwas, "Community and Diversity: The Tyranny of Normality"

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In the past 30 years I have often eaten my portion of the casserole before rising to address the annual meeting of an association that supports people with intellectual disabilities. Noticing in a footnote that Stanley Hauerwas delivered this paper as a talk in a similar setting opened my way into his wise and puzzling contribution. As I imagined Hauerwas's words in the familiar setting of a celebratory meal I wondered, "That night, who shared the table with these people he calls 'the retarded' and who, to Hauerwas's way of thinking, was missing?"

The paper's wisdom needs no interpretation. We are called to the difficult work of creating good communities. Good communities include diversity and difference based on a conviction that we cannot be whole without others being different from us; in such communities people can be different without regret. In building good communities we must act from conviction deep enough to overcome our fear of difference and safeguard our temptation to either separate those who carry frightening differences away from us or attempt to discipline them into simulacra of a tame and bland normality. The prevalence of thin, impoverished, ahistorical, and misleading accounts of difference in relationship to society, community, and family makes forming the necessary conviction difficult. The language of rights and the language of equality are not sufficient to carry us as far as we need to go toward communities that enhance us all. People with mental retardation have an important, if easily ignored, role in deepening the conviction that sustains community sufficiently to keep the language of rights and the language of equality in their proper context: they call us out of too thin official explanations and theories and quietly confront us with differing gifts.

This summary is not, of course, Hauerwas's message. The message is the story he told about "the retarded" to the assembled parents and workers who "have felt the sadness, suffering, and joy of being, having, and working with retarded citizens." It is in following the shape and turning s of that story that I grow puzzled. In thinking about my puzzlement I identify three differences with this paper: 1) its account of the potential gifts of people with intellectual disabilities is too

thin; 2) consequently its call to community is too weak; and 3) it has too limited an understanding of the way modern projects, like implementing the principle of normalization, can open spaces for the Holy Spirit's work.

The quotation marks surrounding "the retarded" are not a postmodern gesture but the fruit of counsel offered by my friend, Peter Park, who has lived his whole life with the consequences of being understood and treated in terms of the label, including spending18 years in an institution for "the retarded" after his parents followed professional advice to place him there. Peter abhors the word as an enemy of the kinds of relationships that he and I believe are fundamental signs that the Spirit is at work slowly building a decent and diverse community. "'Retarded'", Peter advised, "was the excuse for putting us in institutions, for sterilizing us, for keeping us without any real work to do, for putting us in time-out cells and restraints because we didn't do what staff told us quick enough to suit them. It's even the excuse people like Doctor Singer use for saying it would be good to kill us as babies. If you have to write the word because somebody else did, at least put marks around it and remind them of the harm it has done us."

Who are "the retarded" to Hauerwas?

Hauerwas begins his talk by defining himself as "an outsider", lacking the right to be heard by those who have or work with "those born not like us that we describe with the unhappy word 'retarded'." Because this claim to outsider status survived the collection of the talk into a book, it deserves consideration as more than a rhetorical move: does it name a distance between himself and "the retarded"? Based only on this text, I think it does, and I think this distance thins his account of the gifts people with intellectual disabilities can bring to building community.

Four out of five things "the retarded" do for the rest of us arise from what Hauerwas says having them has done for their parents: "the retarded" have bound their parents into association with others who are different from themselves beyond the fact of sharing what he calls similar children; they have taught their parents that life without suffering is illusory but that suffering can be the basis for help and support(here I am uncertain but I think he is talking about the suffering of the parents and the help and support they offer one another rather than about the suffering of "the retarded" and the help and support that they offer); their presence has caused their parents to become more politically informed and active than the average citizen; and they have

freed their parents from deference to experts. What interests me about this list not its overgeneralization of the qualities parents display —e.g. many hundreds of parents would tell a story of deferring to experts in institutionalizing their children — but the passivity of "the retarded" in the process. As best I can understand him, Hauerwas thinks that simply by being "the retarded" they engender in their parents the sadness, suffering, and joy that parents, in association, turn into a kind of community that can resist at least some of the temptations of the Enlightenment. This argument seems to me to have many steps missing.

The fifth contribution of "the retarded" is to model acceptance of personal and social limitations, even to the point of suffering injustice without resentment. This gift arises from "a special grace" that frees "the retarded" from thinking of themselves as victims, though they suffer some of the worst of society's injustices. This grace allows them to understand that we all get "stuck with" certain limitations. I have been taught much by the fact that many people with significant cognitive differences do communicate a deep sense of wholeness to those with eyes to see and ears to hear. But the notion that rejection and exclusion do not wound and stunt "the retarded" is simply a nonsense that would put "the retarded" somehow above or outside the need for the same church that the rest of us sinners are called to count on.

Jean Vanier (2001; 1998), another Aristotelian, provides a more provocative account of the gifts of people with intellectual disabilities. He left his philosophy teaching job in 1964 to live in a faith-founded community based on sharing everyday life and seeking friendship among people with and without intellectual disabilities. He did so because, with the support of his spiritual accompanier Father Thomas, he heard the call to live community from Raphael and Philippe, two institutionalized men. In their life together, these four men called others and their household has seeded many small communities where disabled and non-disabled people struggle to practice the virtues in common.

Vanier expresses a clearer sense of the daily consequences of the wounds that many people with disabilities suffer because others do not relate to them as even potential friends than this paper does. Therefore he communicates a deeper sense of people's unique and ordinary gifts, given the chance to struggle with the continual imperfections of a journeying community founded on the possibility of friendship. His is not a romantic account. "Community is the place where are revealed all the darkness and anger, jealousies and rivalry hidden in our hearts," he says (Vanier,

1992, p. 29), drawing no distinction between disabled and non-disabled community members. But it is exactly in sharing weakness and need, in telling and hearing each other's stories, in forgiving and asking forgiveness over and again, in holding one another to account for living up to common agreements that Vanier(1999, p. 89) can say "people with intellectual disabilities brought me more into my body... [and]led me from a serious world into a world of celebration, presence, and laughter: the world of the heart."

Whose community?

It is hard to tell from this text who Hauerwas wants to call to consciousness as a community, largely because the pronouns keep sliding around. Most often he calls forth a "you" that binds parents or parents and staff together. Sometimes the parent-staff "you" becomes an "us" in which the speaker slips from his outsider status. He does not seem to directly address "the retarded" as listening, acting members of "us" (indeed I wonder how many people with disabilities shared the meal at which he spoke). Beyond counseling restraint in appeals to rights, and suggesting that outsiders should know how supporting "the retarded" matters to everyone, Hauerwas does not ask his listeners to imagine how to make their "you" bigger, to include more current outsiders in the direct and personal involvement in relationship with the people with intellectual disabilities who offer important benefits to their parents and staff. By the time Hauerwas talked, seven years experience with citizen advocacy–focused efforts to build relationships between intellectually disabled people and ordinary citizens– had demonstrated the practical possibility, and the difficulty of constructing a more capacious "you" (O'Brien & Lyle O'Brien, 1996).

Hauerwas does not invite his listeners to recognize and struggle to transform those habits and practices of their daily life that allow him to place himself in the outsider role. He does not ask his listeners to consider how to move beyond the separating out "the retarded" as a group that draw the limits of human community, maybe in part because he has a notion that "the retarded" are somehow a distinct human group, like Hungarians or Texans, he says. This analogy defines overcoming fear of difference as the problem and might lead to the thought that some form of tolerance will suffice to build community. This could be true for Texans in general, but I think it oversimplifies the issue for Texans with intellectual disabilities. And I think the oversimplification matters because it underestimates the role of God's grace in sustaining the hard work of building community.

In my experience, personal contact often dissolves the perception of difference that separates people on the basis of intellectual disability; unusual movements, unique ways of communicating, strange appearances ,and obvious limits in learning often fade when people meet each other in almost any ordinary setting. What does not dissolve is the reality of dependence: this person needs specific and unusual assistance or accommodation from most others every single day. The asymmetry generated by dependence continually tempts those who offer assistance and those who receive it to freeze themselves into postures of power and dependency that obscure gifts and distract from taking the next steps in a shared journey. I think that the most frightening reality that people with intellectual disabilities raise is the difficulty of living gracefully with the continuing demands and temptations of practical dependency. The illusion they confront, an illusion that is often tangible enough to keep them segregated with "their own kind", is the idol of individual self-sufficiency.

Absent the chance of being touched in the heart by someone who has seemed frighteningly different and remains dependent, it is doubtful that the community Hauerwas points toward will have much chance of becoming real. If Hauerwas wants his listeners to imagine needing a few more place settings each year to feed the slowly growing numbers of former outsiders who come to the table because they count people with disabilities as friends, he is shy to say so here. If he knows that the Holy Spirit must have room to work in order to sustain a community that makes friendship possible despite difference and dependence, he is shy to say so here.

Reconsidering normalization

Hauerwas urges caution about enthusiasm for the principle of normalization. My friends and I experienced normalization in the 1970's as a resource for groping our way along our journey toward decent relationships with people we held power over, a journey that did not end as our ability to express its guiding principles left the easily misunderstood word, normalization, to a cherished place in our history. Hauerwas apparently takes normalization to be a mix of two things. One of these things he approves of, allowing "the retarded" do what they are able in the way of dressing, dating, spending money and other typical activities. The other he and I see as deeply dangerous: attempting to make "the retarded" normal (whatever Enlightenment nightmare that may be) and thus striping them of differences important to their identity and history. This could have been what he heard and saw of normalization in South Bend, but he settled for a shal-

low take on the hard practical and conceptual work that was going on in many places in North America the 1970's.

A history of the idea of normalization up to the date of Hauerwas's talk is found in Wolfensberger (1999) in a book whose multiple contributors bring some of the story into the mid-1990's. Peter Park (1999), my friend and advisor quoted above, reflects in this volume on the way the principle of normalization has influenced his 61 years of life with a label. He develops his understanding of the relationship between honest efforts to follow the principle of normalization and having what he calls "more diverse communities where people with different abilities can learn from each other".

None of this detracts from the prudence of Hauerwas's suspicions. The principle of normalization expresses the Enlightenment project in just the same way that the association that invited him to give this talk does. Without a deeper sense of community to found it, it will lead to silliness, mischief, and sometimes outright harm justified in the language of rights and the language of equality. But such is the power of the Spirit that honest attempts to live and work even in its modern terms have sometimes set the conditions for friendships to emerge that take their participants another few steps toward that community that enhances us all.

References

- O'Brien, J. & Lyle O'Brien, C. (1996). *Members of each other: Building community in company with people with developmental disabilities*. Toronto, ON: Inclusion Press.
- Park, P. with French, B. (1999). The impact of normalization on my life. In R. Flynn & R. Le-May, eds. *A quarter-century of normalization and social role valorization*" *Evolution and impact*. Ottawa, ON: University of Ottawa Press. Pp. 475-476.
- Vanier, J. (2001). *Made for happiness: Discovering the meaning of life with Aristotle*. Toronto, ON: House of Anansi Press.
- Vanier, J. (1998). *Becoming human: The CBC Massey Lectures*. Toronto, ON: House of Anansi Press.
- Vanier, J. (1992). From brokenness to community. The Wit Lectures at Harvard Divinity School. New York: Paulist Press.

Wolfensberger, W. (1999). A contribution to the history of normalization, with primary emphasis on the establishment of normalization in North America between 1967-1975. In R. Flynn & R. LeMay, eds. *A quarter-century of normalization and social role valorization" Evolution and impact*. Ottawa, ON: University of Ottawa Press. Pp. 51-116.