

The Paradox of Disability

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*Responses to Jean Vanier and
L'Arche Communities from
Theology and the Sciences*

Edited by

Hans S. Reinders

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Acknowledgments

This book came out of a project that was initiated by the John Templeton Foundation in Philadelphia and named the Humble Approach Initiative. The foundation asked Xavier Le Pichon and me to chair a conference on the question of what there is to learn from people with disabilities. The conference eventually took place in the village of Trosly-Breuil in northern France in March 2007, where we were hosted by the community of L'Arche.

The contributors to this volume wish to express their gratitude to the John Templeton Foundation, whose support, particularly in the person of Mary Ann Meyers, the executive director of the project, made this book possible. We are also grateful to the people of L'Arche, whose presence made the event much more than just another academic gathering. We wish to express a special word of appreciation to Jean Vanier, the founder of this community, for not only hosting us but also for his participation in our proceedings, which was an enriching experience.

As we bring these fond memories to mind, it was with all the more poignant sadness that we learned of the tragic death of Dr. Christopher Newell, our Australian colleague, whom some of us have known for many years as a friend. As the reader can see from the table of contents, Christopher's essay is the final one in this volume, and it turned out to be his last finished paper. Rereading this essay, which in many ways expresses the magnitude of the problem of academic discourse in the presence of disability, one becomes painfully aware of how gifted people like Christopher must constantly battle to live the life to which they aspire with as serious an impairing condition as he had. His battle is over. *Requiescat in pace.*

PART I

Introduction

Human Vulnerability: A Conversation at L'Arche

HANS S. REINDERS

The Occasion

This volume is the result of a conversation held by its contributors in Trosly-Breuil, France, in March 2007. The village is known as the hometown of the community of L'Arche, where people with and without intellectual disabilities live and work together.¹ Since the theme of our meeting was the question of what we can learn from people with disabilities, Trosly-Breuil suggested itself as a suitable place to meet. L'Arche is a spiritual community inspired by and built on the Beatitudes, which Jesus enunciated in the Gospels of Matthew and Luke. It is intended to be a place where people who have been marginalized by society are accepted. The community of L'Arche is a celebration of difference in that it brings together not only people with various gifts but also people from various cultural and religious traditions.

The question of what there is to learn from people with disabilities can

1. L'Arche is French for "the Ark." Founded by Jean Vanier and Fr. Thomas Philippe in 1964, L'Arche is an international movement of residential communities in thirty-four countries worldwide. In L'Arche homes people with intellectual disabilities (known as core people, or "core members") live in community with their caregivers (known as "assistants"). L'Arche honors individuals as a sign of *agape* and mutual respect. In the United States, L'Arche communities often exist on a financial shoestring. Besides receiving room and board, assistants may live on a few hundred dollars per month. The earthy reality of life together is punctuated by deep spiritual commitments and experiences. L'Arche is a Christian movement that embraces other traditions.

no doubt be approached in any number of ways, but for reasons that will become apparent, it was a salutary decision to discuss it in the context of this extraordinary place. As it is expressed in the writings of Jean Vanier — and is confirmed by the charter of the Communities of L’Arche — its first and foremost goal is to build community. Due to discontent with the liberal individualism of our time, we often hear “community” spoken of in endearing terms — at least in the Western world — as a place where people positively experience the social nature of being human. As we learned from our experiences at L’Arche, the truth of the matter is quite different. More than anything else, “community” marks the experience of the brokenness of human beings. Very often L’Arche attracts people who want to share the lives of people with disabilities in order to make the world a better place. But those who have spent years of their lives in one of its communities know better. As Vanier has explained many times, there is no way of doing something *for* other people if you do not first learn how to receive whatever gift *they* have to offer, which presupposes your willingness to accept that you also are a person in need. The L’Arche community is about learning to receive other people as God’s gift.

Before introducing the various contributions of this book to its readers, let me pause to reflect on how being hosted by such a community has affected our discussions about the drafts of original papers. The people who were invited by the Templeton Foundation to contribute are academics from a variety of disciplines. Together they, too, represent a kind of community — the “scientific community.” But as we all know, the scientific community frequently turns out to be a community of division rather than a community celebrating mutual receptivity. While the university — in its original idea — was planned and designed to bring people of all disciplines together in order to reflect the universe of learning, nowadays it is much more often a place of competing departments and contesting paradigms and methodologies. There is no better way to explain the current demand for interdisciplinary study in academic circles than by pointing to the apparent lack of understanding and appreciation of what professionals in fields other than one’s own are doing. In many departments this even holds true for people in one’s own discipline.

As was to be expected, our first round of discussions in Trosly-Breuil provided ample testimony to this state of affairs. Those among us who represented the sciences seemed to wonder whether people from other disciplines — particularly theology — had any regard at all for the basic rules of science, such as, for example, the rule of building theory on sound evi-

dence. The theologians, in turn, wondered how scientists manage again and again to turn a blind eye to the metaphysical underpinnings of their scientific beliefs.

The irony of this situation is that the meeting that produced this book was organized in the context of the Templeton Foundation's Humble Approach Initiative. Whatever the qualities and qualifications that academics bring to scientific meetings, humility is rarely one of them. Despite the fact that we were hosted by a spiritual community where people learn to receive one another as a gift, the question of what we can learn from people with disabilities presented itself initially as the next opportunity for an intellectual standoff on the battlefield called "modern science."

As our meeting proceeded, however, things turned out to be slightly different. What was doomed to become a perfect example of performative contradiction turned into an exercise of performative reflection. That is to say, the way our discussions proceeded gradually tuned in to their subject matter. What they were about was reflected in how they were conducted: they changed from contest into conversation. As academics, we are often trained in thinking that our own field best explains the way things are in the world. Rarely are we encouraged to learn about the limitations of our knowledge. This is quite strange. It is only because of its limited scope that scientific method produces any knowledge at all. And it is only by recognizing the limitations of the kind of knowledge our own field produces that we can learn to appreciate difference, and thus understand what the scientific community is about.

Our meeting in Trosly-Breuil was in this respect clearly under the influence of Jean Vanier's participation. Carefully listening and responding to the papers at hand, he showed us that the task was to find each person's way of making a contribution. While reflecting on what we can learn from people with disabilities can go in many different directions, our way, guided by the spirituality of L'Arche, came to regard our very different approaches to this question as an exercise in inclusion. A truly human community is not only about unity and wholeness; it is also about learning to live with difference and limitation, which holds for the scientific community as well. Once we understand this, we can learn to see that claims to unity and wholeness are really impositions by means of which particularized perspectives usurp the world of human experience and blind us to the variety of what there is to see.

Vanier's understanding of living with people who embody brokenness as a way of building human community is a perfect illustration of this in-

sight. Of course, the brokenness and limitations of people with disabilities — particularly intellectual disabilities — is too evident to be overlooked. Much less clear, however, is that, in looking at them in this way, we may fail to see or own brokenness and limitations. To look at other people's brokenness and limitation without seeing our own is a gesture of power; to acknowledge our own brokenness and limitation in the face of theirs is a gesture of community. In this regard L'Arche is an extraordinary place of learning.

In order to show how our discussions in Trosly-Breuil have been affected by its gestures of community, I have ordered the contributions to this volume in a particular way. As I have noted above, according to Vanier, "community" is not about trying to live a shared ideal; rather, it is about learning the truth about oneself and others. Contrary to a frequent misreading of its experience, L'Arche has nothing to do with an ideal community that is shaped by morally exceptional people. Instead, it has everything to do with people learning to be with each other and be accepted as who and what they are. Thus understood, learning to live in L'Arche is not about following a pattern or a plan according to which the moral self must be shaped. Its gestures of community are about accepting brokenness and limitation in order to create the freedom of celebrating difference.

This insight immediately affects the way we answer the question of what we can learn from people with disabilities. This question has been answered frequently in terms of some kind of capacity that has been attributed to them. Very often that capacity is of a moral kind, such that the people possessing it are recommended as moral exemplars. People with physical disabilities, for example, report that they are frequently praised for their capacity of enduring suffering. People with intellectual disability — also referred to as "mental handicap," "learning disability," or "developmental disability" — are commended for their uncomplicated approach to life, which in past times earned them the pet name of "holy innocents."

In more recent times, people with disabilities have rejected all such qualifications because they do not want to be qualified in ways that make them exceptional. While many of their lives do not fit the stories of horror and disaster that are told about them, their lives are equally misrepresented by stories of praise and blessing. All these people want is to be seen as simply human — no more and no less. If we accept this demand, as I suggest we should, there will be no single answer to the question of what we can learn from people with disabilities. As a matter of fact, we may

learn many different things from them, depending on who they are and what their lives are like, and also depending on who we are and what our lives are like.

This fact of inevitable diversity is reflected in the essays brought together in this volume. However, despite the many different ways in which we approach our question, there are also overlapping issues and similar thoughts. This is particularly clear if we read these essays as responses to Jean Vanier's reflections, someone who has shared most of his life with people with disabilities. For that reason, this book takes its point of departure in his account of what he has learned from living and working in L'Arche. Therefore, his essay will appear at the very beginning of this volume as the calling initiative, so to speak. The logic of ordering the papers in this volume shows how the call to respond to Vanier's account and the issues it raises can be heard in many different ways. Each of the contributors picks up themes and thoughts that elicit a response from her or his own particular research projects.

The Essays

In considering what he believes is the *raison d'être* of L'Arche, Vanier recalls his first experience of looking at the faces of the men who lived in an institution for people with learning disabilities where his friend Father Thomas Philippe was chaplain. Written on their faces was a cry: "Do you love me? Am I important? Will you be my friend?" According to Vanier, the experiment of L'Arche began as the response to that cry.

It is to this subject of love as a fundamental "need" that Stephen Post's essay responds. His focus oscillates between the love given in the process of care and the love received as a return. Post compares the nature of the response Vanier has given with the one he has found in the work of Tom Kitwood, who is known in the United Kingdom as well as in North America for his "dementia care mapping." According to Post, what Vanier says about his work with people with disabilities resembles what Kitwood says about his work with people with Alzheimer's disease. Post finds in their views the resources to support his objection to what he calls "hyper-cognitivism," the notion that the key to our humanity resides in our cognitive faculties. Against this notion, Post argues, our humanity is constituted by "other-regarding" love. Only other-regarding love can be truly universal in that it addresses the basic need that, according to Vanier, all human be-