



# Critical Reflections on Stanley Hauerwas' Theology of Disability

*Disabling Society, Enabling Theology*

John Swinton, PhD  
*editor*

# **Critical Reflections on Stanley Hauerwas' Theology of Disability: Disabling Society, Enabling Theology**

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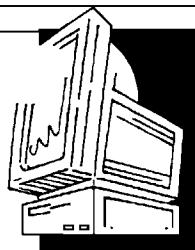
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## ABOUT THE EDITOR

**John Swinton, PhD, BD, RNM, RNMH**, is Professor in Practical Theology and Pastoral Care in the School of Divinity, History, and Philosophy at the University of Aberdeen, Scotland. He has researched and published extensively on practical theology, mental health, spirituality and human well-being, and the theology of disability. His books include *Spirituality in Mental Health Care: Rediscovering a Forgotten Dimension*; *The Spiritual Dimension of Pastoral Care: Practical Theology in a Multidisciplinary Context* (edited with David Willows); and *From Bedlam to Shalom: Towards a Practical Theology of Human Nature, Interpersonal Relationships, and Mental Health Care*. Dr. Swinton is an ordained minister in the Church of Scotland.

# Foreword:

## A Doctor's Debt to Stanley Hauerwas

**SUMMARY.** The author acknowledges his debt to Stanley Hauerwas by describing how Hauerwas' writing has influenced his work as a pediatric neurologist. Hauerwas helped him to recognize that persons with intellectual disabilities have intrinsic value and that this value is based upon a spirituality shared with all of us. This recognition led the author to develop a clinical practice that is based on trying to see the world through the eyes of the person with a disability and to celebrate the wonder and value of the person's life. Hauerwas rightly emphasizes that the so-called question of personhood is fundamentally wrongheaded because no one's existence needs to be justified. This insight has helped the author confront the continuing problem of euthanasia for persons with disabilities and is reflected in the author's belief that peace-making (based on the recognition of the value of all persons regardless of disability) is the true answer to the problem of death-making (which is based on the devaluation of the lives of persons with disability). The author concludes by hoping that readers of this book will also find applications for Hauerwas' thinking in their own life and work. *[Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2004 by The Haworth Press, Inc. All rights reserved.]*

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**KEYWORDS.** Hauerwas, disability, personhood, medicine

I did not know Stanley Hauerwas when he was teaching at the University of Notre Dame in the 1960s. At the time I was an undergraduate at Notre Dame majoring in biology, thinking more about anatomy and physiology than about theology or the education of children with intellectual disabilities (what Hauerwas calls mental retardation). When my fellow students and I went off campus to visit the bars and pizza places that catered to Notre Dame students, we would pass the Saint Joseph Center for the Retarded where Professor Hauerwas was spending so much time. I often wondered what was going on in there. I knew that some students volunteered their time to work at the Center, but none of my friends did and I never found the time or inclination to volunteer myself. Little did I know at the time that 33 years later I would be writing this preface and explaining how much Professor Hauerwas' writings have influenced my work as a physician ever since.

I began to read Hauerwas in the 1980s when I was beginning my career as a pediatric neurologist, working with children with disabilities and their families on a daily basis and trying to figure out what was the right thing to do. I was the one who was called to the Neonatal Intensive Care Unit when a child was born with significant neurological disabilities and I was the one who had to explain the diagnosis and prognosis to the family. I realized that I needed to know a lot more about ethics than I had been taught in my medical training, which was not much. Secular philosophy and bioethics provided unsatisfying answers to the questions I was confronting. Perhaps because of my Catholic education at Notre Dame, I felt that there must be something more to the debate than this, something that would address the spiritual lives of persons with disabilities and the responsibilities we all have to live with them. So it was incredibly refreshing to discover that Hauerwas was thinking about the same issues and had a wealth of insight, experience and knowledge that could help me make sense of what I was doing every day.

Reading this collection of his papers now is like visiting an old friend who had been a cherished teacher and mentor in the past. Some of the papers in this collection are familiar to me from those days, but some I never saw because they were published in places I never read. And it is particularly refreshing to read his more recent papers which bring me up to date on what he is thinking about now. Perhaps one way I can pay tribute to Professor Hauerwas, the mentor I cherished but never met or knew personally, is to draw upon my own writing and experience to comment on his work and to show how much he has influenced my work as a doctor.

Hauerwas spends a lot of time trying to show that persons with intellectual disabilities are individuals with intrinsic value equal to those without disabilities. It is as if he starts by thinking that many people perceive an inequality, so he must show that this inequality is false. But what if we could start by thinking that there is a fundamental equality among all persons regardless of disability? In my clinical work, I developed a method for doing this that I called “the three ways of looking” (Coulter, 2001). I would sit down with a patient or family and try to get some idea of who they were as human beings and to try to see things through their eyes. I soon realized that I needed to share myself with them too and give them some idea of who I was. Thus the “first look” is to see the other person as an individual human being, and the “second look” is to see the other person as an individual like myself. If I know what it means for me to be alive and what I value in my own life, I can then try to understand what it means for the other person to be alive and what he or she values in his or her own life. And if I can do this, then I can value in the other person what I value most in my own life.

I came to realize that what we were sharing was our spirituality and that this did not depend on age, race, sex, wealth, or ability. Indeed, the “third look” is to see in each other the ground of all being and existence, the transcendence or divinity that informs our spirituality. This simple method was showing me that all persons are equal in value and human dignity, regardless of these various other characteristics, because they all possess intrinsic and universal spiritual worth. When this fundamental acceptance of the equality of all persons is our starting point, we do not need to justify the value or worth of persons with intellectual disabilities. We only need to see them as spiritual beings like us, which brings us to the same point Hauerwas emphasizes in his writing.

Thus my task as a physician and neurologist is to try to see the world through the eyes of persons with disabilities and to explain what I see to others, including families, friends, teachers, and therapists. My job is to try to understand what they are thinking and why they do what they do from a human perspective. If I can explain their behavior to others, then others will be better able to accept them as fully human persons too.

I have no doubt that reading Hauerwas during my formative years helped me to develop this clinical method and I readily acknowledge my debt to him. But Hauerwas goes further to emphasize the role each of us plays in the human community and our inextricable interdependence on each other, regardless of disability. He emphasizes that our role in the community is to live our own stories and through doing so, to live out the story of the Gospel. Our “value” to the community rests in these life stories, not in any “liberal” interpretation of autonomy or self-control. But what binds each of our life stories to each other?



Hauerwas may have the answer to this question. His concern about terminology and about “speaking for” persons with intellectual disabilities leads him to reflect on the nature of relationships within such a Christian community. In Chapter 1 he reflects on the wisdom of Jean Vanier and points out that there is no need to justify living in community with persons with intellectual disabilities because “you do not need to ask such questions about your friends.” Some years ago I was listening to a professional debate about whether we should call persons with intellectual disabilities “patients” or “clients” or “consumers” or some such thing. I rose to suggest that perhaps the best term to use would be “friends.” My professional colleagues did not like this idea, but I think Vanier and Hauerwas would have approved. Perhaps I got the idea from them.

The practical application of Hauerwas’ thinking in my professional work shows up in other ways that are illustrated by the papers in this collection. In Chapter 2 he rightly emphasizes the respect parents deserve for loving and raising their children with disabilities. Twenty-five years of practice as a pediatric neurologist have taught me much the same thing. I am continually amazed by the strengths of families whose unceasing efforts are driven by their love for the child with a disability (Coulter, 2002). I tend to agree more with John O’Brien’s response to this paper, but O’Brien is writing 25 years after Hauerwas gave the talk upon which Chapter 2 is based. This discussion illustrates another practical application of Hauerwas’ thinking for us today. Normalization means many things, but today it means the right of persons with disabilities to live in the community of their choice and to experience the joys and friendships we all take for granted. Hauerwas rightly (if indirectly) emphasizes the need we all have for living together in community, which also means there can no longer be any justification for “putting someone away” in an institution.

I have spent a lot of time thinking about prevention of intellectual disability, mostly from a professional perspective (see Chapter 8 in American Association on Mental Retardation, 2002). Hauerwas addresses this topic in Chapter 5, which is reprinted from a book that I studied carefully when it was published. What he writes in the conclusion to this paper is the basis for the “third look” I described above. In the end, I have concluded that prevention should not be about reproductive choice, as Hauerwas implies. Rather, prevention should be about identifying ways that we can support individuals with disabilities and their families so that they can overcome limitations and enhance functioning to live more personally satisfying lives.

Hauerwas is vitally concerned about what it means to be a person, especially a person with an intellectual disability. To some extent this reflects the

historical debate that was prominent at the time he was writing these papers, especially those in Chapters 6 and 7. I have struggled with this concept too, particularly in trying to figure out how to respond as a neurologist to patients with severe disabilities. Hauerwas is uncomfortable with the very question of personhood, and in these chapters he provides a way out of the dilemma. He suggests that the question itself is fundamentally wrong-headed because it implies that some human beings are persons and some are not, and all we need to do is figure a way to tell them apart. He suggests a different way of phrasing the question so that we focus on the disability of presence instead of the presence of disability. He uses Michael Bérubé's comment about accepting his disabled son, Jamie, "now that he is here" to show that we are all human creatures, created by God to "be here" and to be dependent on one another, just as Jamie is dependent on those around him. The presence that we all have "now that we are here" allows us to recognize the presents we all give to each other through our dependency on each other, including our ability and disability. Hauerwas returns to this point in his concluding response to the responses. He writes that the existence of persons with disabilities does not need to be justified (as, for example, by arguments about personhood) because no one's existence needs to be justified. "I exist, you exist, Jamie exists, turtles exist, the earth exists by the grace of God. The task is to learn to rejoice in our existence without resentment."

This is an important conclusion for those of us involved in bioethics because of the very real threats of euthanasia and devaluation of the lives of persons with disabilities. Hauerwas does not address this threat directly but he provides a way for us to respond by emphasizing the intrinsic dignity and worth of all persons who are created by God and now "are here" as valued members of a Christian community that depends on and cares for each other. As a physician and neurologist, I welcome this perspective and am able to apply it in my medical practice. Thank you, Professor Hauerwas, for helping me respond to these issues and showing me how to teach others to share this perspective.

I suspect I have not done justice to the wealth and depth of Hauerwas' theological arguments. I am, after all, a physician and not a theologian. I was given the opportunity to write this preface because I am the co-editor of *Journal of Religion, Disability & Health*, in which this collection appears. The mission of our *Journal* is to bridge clinical practice and spiritual supports for persons with disabilities. I hope that these remarks demonstrate one way to do this through the application of the theology of Stanley Hauerwas in my own clinical practice. Hauerwas hopes that this book will be read by those who have

never had to think about the disabled and who will come to see that “there is nothing more significant to be done in a world of such deep injustice than to take the time to be friends with the handicapped.” I share his hope and his vision for peace embodied by this book.

*David L. Coulter, MD*

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- Coulter, D.L. (2002). The strength of families and individuals. *Journal of Religion, Disability & Health*, 6 (1), 1-5.

# Introduction: Hauerwas on Disability

John Swinton, PhD

**SUMMARY.** Swinton outlines some central aspects of Hauerwas' theology and ethics that relate to the papers in this volume. He clarifies the type of disability that Hauerwas addresses in these papers and draws out the social and political dimensions of Hauerwas' critique. The chapter explores issues of terminology, politics, and citizenship. In so doing this chapter lays down a foundation for the various papers and responses that are presented in the book. *[Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2004 by The Haworth Press, Inc. All rights reserved.]*

**KEYWORDS.** Disability, ethics, theology, liberal society, politics, empowerment

A couple of years ago I had the pleasure of meeting Stanley Hauerwas and spending an afternoon with him. He was in the United Kingdom doing the *Scottish Journal of Theology* lectures at my own university, the University of

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Aberdeen in Scotland, United Kingdom. The morning had been interesting to say the least. Stanley had provided an excellent blend of solid, challenging imaginative theology, interspersed with the odd off the cuff comment that caused some of our more conservative students to raise their eyebrows! However, despite the odd bit of controversy the lectures went very well and we were all blessed and challenged.

Midweek I was allocated the task of spending an afternoon entertaining this "strange" visiting Texan professor. Entertaining strangers is not always my greatest gift, but I was happy to oblige. Suffice it to say that any fears I might have had were instantly dismissed as I found myself wrapped up in a fascinating encounter with a man who was warm, deceptively gentle, and fully committed to many of the issues that filled my own life horizons. As we spoke, it became clear that the deep theological and ethical issues that Hauerwas has made a career out of wrestling with were not taken on at a superficial level. There was more to Hauerwas than simply rhetoric and flair. As we talked, I began to develop a picture of a man who understood what it was like to suffer; someone who had experienced the consequences of disability first hand and who knew the practical as well as the theoretical meaning of suffering and joy. As we spent time together it became clear to me that Hauerwas' voice was one which deserved to be listened to, not only by the academic community, but also by the wider community who wrestle with the meaning of being human and living humanly in an age of complexity and change. I left our encounter feeling privileged to have spent time with someone who had taken the time to reflect thoughtfully and critically on the meaning of humanness and who has offered the world some fascinating and challenging insights into what it means for us to live lives which are fully human irrespective of the perceived state of our mental and physical faculties. It is, therefore, with great pleasure that I offer readers the opportunity to share in some of Hauerwas' thinking and to give all of us the opportunity to reflect carefully and thoughtfully on his contribution to our understanding not only of disability, but also of what it means to be human and to live humanly in a complex and rapidly changing world of diversity and change.

### ***ABOUT THIS BOOK***

Hauerwas' writings on disability are disparate and diverse. They are to be found in various journal articles and book chapters which have been written over the course of the past thirty years. With one notable exception, there has been no attempt to draw together Hauerwas' thinking on disability (Hauerwas 1986); neither has there been any effort made to reflect critically on the implications of his perspective for the praxis of caring for and offering support to

people with disabilities and those who strive to offer such care and support. This volume seeks to address this gap in the continuing process of critical reflection on Hauerwas' work. The book brings together ten of Hauerwas' key essays on disability and draws them into critical dialogue with an international group of practitioners, ethicists, theologians and carers, in an attempt to tease out the significance and contemporary relevance of his contribution to the theology and ethics of developmental disabilities. It concludes with a final new essay from Professor Hauerwas within which he draws together the various threads of reflection and critique and offers some concluding pointers for the future.

The commentators were asked to reflect critically and imaginatively on Hauerwas' work and to draw out that which is relevant and challenging as well as that which is questionable or even mistaken. The result is a rich and fascinating tapestry of thoughts and ideas which clarifies, challenges, enhances, and contextualises Hauerwas' thinking within contemporary theological reflection on disability. It is hoped that the multidisciplinary dialogue presented within this book will enable readers to reflect deeply on Hauerwas' work and to draw out and put into practice that which is relevant for today.

Like all good theologians, Hauerwas' talent lies not simply in what he actually says, but equally in what he challenges others to say. Not everyone agrees with his position and some of the commentators offer some trenchant critiques of his approach and thinking. However, despite their concerns, it is clear that each participant in this book has been challenged by Hauerwas' thinking and forced to work through the issues in new ways. In so doing they have produced some valuable reflections and insights which would not have existed had they not taken the opportunity to engage thoughtfully and constructively with Hauerwas' thinking. For that and much more, I am certain that each person who has contributed to this book feels indebted to Professor Hauerwas. It is our hope that readers will be similarly challenged to move on in their exploration of the true meaning of disability.

The essays and responses presented here were gathered together and edited by Professor Swinton and reflected on by Professor Hauerwas. We hope that they will enable people to see disability differently and in seeing disability differently begin to act differently in the presence of those whom we choose to call 'disabled.'

### ***Hauerwas on Disability***

In order to understand the significance of Hauerwas' contribution to the debate about the theology and ethics of disability, it is necessary to begin by doing some basic ground work. It is not possible or necessary here to offer a

comprehensive overview of Hauerwas' theology and ethics. This has been done very effectively elsewhere (Berkman and Cartwright 2001; Wells 1998). In the following sections I will outline some of the main points of Hauerwas' general thinking as it relates specifically to the essays presented in this book. The outline is intended to orientate readers within the parameters of Hauerwas' view of the world and to provide them with some initial guidance as to how and why he views disability in the way that he does.

### ***Why Listen to Hauerwas?***

It is important to begin by noting the fact that Hauerwas has been advocating for people with disabilities and their families since the late 70s (Hauerwas 1973). To the best of my knowledge no other mainstream theologian has so consistently and trenchantly taken a stand with and for people with developmental disabilities. Whilst some ethicists continue to make the case for the eradication of people with developmental disabilities (Singer 1993), Hauerwas has consistently (if unsystematically) produced a significant critique of practices, attitudes, and philosophical positions which attempt to dehumanise and ultimately eliminate people with intellectual disabilities.

Until relatively recently mainstream theology has not taken the practical and hermeneutical challenge of disability as a serious dimension of theology and praxis. Understandings of disability have traditionally been tied in with ideas of charity, action towards disabled people coming as an end point of a process of ethical reflection on the "poor" or the "weak." Hauerwas has always understood the issues to be much deeper and more profound than simply caring for those whom society perceives as "poor" and "weak." For Hauerwas, the issue at stake is our understanding of the nature of what it means to be human and to live humanly within the coming Kingdom of God. Hauerwas turns the ethic of charity around and begins his ethical reflections with the perspective of a group of people whom society deems to be "poor" and "weak" and as such worthy only of pity and charity. In listening to and taking seriously the experience of people with profound developmental disabilities and their families, Hauerwas offers a response to their challenge which reframes and disturbs our worldviews at both a personal and a socio-political level. Charity is not enough. What is required is a radical change in our perspective. A change which leads us to participate fully in the paradigm shift that was initiated by the life, death, and resurrection of Jesus and which the church has been given responsibility for embodying and living out. It is in wrestling with this process of embodying and living out the gospel that Hauerwas finds genuine revelation in the lives of people with developmental disabilities. But how does Hauerwas come to such a conclusion?