

The background of the cover features a person in a meditative pose, possibly a yoga or Tai Chi position, with their arms raised and hands near their head. A vibrant, multi-colored aura surrounds the person, transitioning from purple at the top to green and yellow at the bottom, resembling a rainbow or a spiritual light field. The overall tone is peaceful and spiritual.

Spirituality and Intellectual Disability

International Perspectives
on the
Effect of Culture and Religion
on
Healing Body, Mind, and Soul

William C. Gaventa, Jr., MDiv
David L. Coulter, MD
Editors

**Spirituality
and Intellectual Disability:
International Perspectives
on the Effect
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Foreword

The history of the place of people with an intellectual disability in society has been characterised by a consistent denial of their “personhood” or “humaness.” Even in the enlightened times of post modernism an intact intellect or mind is still the metric by which society judges the value of a person.

In many ways science has contributed to this phenomenon. Spectacular discoveries emerging from the human genome project have emphasized society’s quest for the “perfect” child, born without imperfection of mind or body. Science is also breaking new barriers in the prevention or amelioration of disease leading to life expectancies earlier generations could only dream of.

In the field of scientific inquiry into the causes and “treatment” of intellectual disabilities we have made enormous advances in the last half of the century that have benefited people with disabilities and their families, especially in the western, industrialized world.

We have also been fortunate in having a parallel set of forces that have more philosophical foundations. Civil and human rights movements have assisted the emancipation of our brothers and sisters with a variety of disabilities.

However, there has been an uneasy relationship in this field between those who pursue a “scientific” approach and those who choose to emphasize the human rights approach. At the international level we have two organizations working to improve the quality of life of people with intellectual disabilities that symbolize the artificial divide between these two approaches. One is the International Association for the Scientific Study of Intellectual Disabilities (IASSID) and the other is the parent-based body, Inclusion International.

During my presidency of IASSID I have striven to achieve two goals. One has been a greater collaboration between scientists who approach

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the question of “what is truth” from a variety of methodological and epistemological perspectives. This alone is a daunting task! The other goal has been to draw together the scientists and the very people they study into a stronger partnership.

The hallmark of science it is claimed, is its objectivity, but we have neglected over the years the very ingredient that identifies us as human beings—that is our subjective experiences, including our spirituality.

It was therefore a great joy to me personally, and I believe to the benefit of the 2000 Congress of IASSID, that we for the first time had dedicated sessions devoted to exploring this essential dimension of quality of life. It was even more gratifying that the organisers of this stream were able to include presentations from a variety of faiths.

I am hopeful that this initiative will blossom into a more permanent component of the work of IASSID through the formation of a Special Interest Research group. The exploration of the relationships between spiritual, physical and mental health will enrich our field. Hence this collection of papers for the Congress is a veritable harbinger for the continued growth of the Association.

*Trevor R. Parmenter, PhD
President, IASSID
1996-2000*

Preface

SPIRITUAL HEALTH AND PEOPLE WITH INTELLECTUAL DISABILITIES: INTERNATIONAL PERSPECTIVES AND INVITATIONS

In this volume, (co-published as a special double issue of *Journal of Religion, Disability & Health*), we are delighted to present a collection of articles on spirituality, religion, and people with intellectual disabilities which came from presentations at the 2000 Conference of the International Association for the Scientific Study of Intellectual Disabilities. These sessions were part of a first for the IASSID, an organized strand of sessions and papers focusing on the importance of spirituality and religion in supports and services for people with intellectual disabilities. Because this was a “first” for many of the presenters at an Association whose name focuses on the word “science” rather than “spirit,” there was not a little uncertainty about how the topic and strand would be received. We should not have been worried. The welcome and hospitality was wonderful, as was the attendance at many of the sessions. Many said, “It is about time this was discussed.”

Our goal for this strand was to have a series of international voices that could represent practitioners and researchers from major faith traditions and different parts of the world. The IASSID has done major position papers on aspects of physical health and psychological health for people with intellectual disabilities. Thus our organizing principle became the concept of “spiritual health,” a framework for bridging the worlds of “science” and “faith,” and exploring the ways that a variety of faith traditions, cultural backgrounds, and professional roles might help us move towards a consensus about what “spiritual health” means within specific cultures and faiths and across disciplines.

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We wanted papers that addressed the following issues:

1. How might “spiritual health” be defined from within a particular tradition and/or religious perspective?
2. What are traditions or themes from within those traditions that particularly relate to, or focus upon, persons with intellectual disabilities?
3. What are resources from within those traditions that can be drawn upon to enhance the lives of persons with intellectual disabilities and their families?
4. Outline and/or summarize creative initiatives (including practices, policies, and research) in parts of the world that draw upon those traditions to support people with intellectual disabilities and which attempt to integrate spiritual perspectives in human services and supports.

Our open invitation led to a series of papers that organized themselves into sessions on varied cultural and religious perspectives, theoretical perspectives, research, and creative models of ministry and practice. Some had been submitted to the conference without knowing about the Spiritual Health strand. A couple are from people who wanted to be present, but could not. We are very grateful to the authors, and to many who spent their own funds to come to Seattle. Some did much more. Chaplain Anja Vogelzang from the Netherlands produced a video of their model of worship for and with people with multiple disabilities as an accompaniment to her paper. We can’t include it in this publication, but she has graciously made it available for order.

The international nature of the conference was underscored by the varied familiarity with English (the official language of the conference) expressed by the many speakers and participants. Some were quite fluent and others struggled to express themselves clearly. The universal language of spirituality and disability was heard through voices that reflected their country and culture of origin. The richness of this dialogue is preserved in the papers published here. As Editors, we have chosen to edit lightly in order to allow the reader to experience some of the atmosphere of the conference that brought together people from all over the world.

This volume of edited papers from the conference is simply a first step in addressing those questions and issues. There are so many voices that were not part of this first strand. We did not receive papers about Eastern or African religions, we would welcome those voices on this

Journal. We know there are many more models of creative research and practice around the world. The door and the dialogue are open. Here are some ways you can participate:

HELP FORM A SPECIAL INTEREST RESEARCH GROUP WITH IASSID

Become a founding member of the Special Interest Research Group of the IASSID that will become a network for dialogue and planning of future initiatives within this international association. You can represent any discipline or faith background. We need ten members of the IASSID to begin an official SIRG. The next conference is in Montpellier, France, in 2004. Membership in the IASSID is \$75.00 per year, which includes a subscription to their *Journal of Intellectual Disability Research* (\$50 without the journal.) Join by sending a check or money order made out "IASSID" to IASSID Membership Office, 31 Nottingham Way South, Clifton Park, NY 12065-1713.

If you want to be a member of the Special Interest Research Group on Spiritual Health, email that interest to Bill Gaventa, gaventwi@umdnj.edu, and indicate when you have joined the IASSID.

JOIN AN INTERNATIONAL LISTSERV ON SPIRITUALITY AND DISABILITY

Join an international listserv on Spirituality and Disability. Dr. John Swinton, at the University of Aberdeen in Scotland, is the founder of this listserv. It is a way of sharing ideas, resources and dialogue. To join the list serv, go to <http://www.jiscmail.ac.uk/lists/disability-and-spirituality.html>.

BECOME A REPRESENTATIVE FOR THIS JOURNAL WITHIN YOUR COUNTRY

As co-editors of the *Journal of Religion, Disability, & Health*, we are always looking for people who can represent our publication within their own country, and serve through our Editorial Advisory Board. Those representatives help recruit and review papers, encourage sub-

scriptions, and develop awareness about JRDH. If you are interested, contact either Dr. David Coulter or Rev. Bill Gaventa.

Finally, we welcome your contribution of writing from your own research and practice. The questions which we posed on “spiritual health” are fully in line with the Vision statement we have for this Journal. They need much more careful exploration. They need “Guest Editors” who might take on a topic or question and organize an issue of the journal.

In Seattle, we were extremely grateful for those who responded to our invitation, and gratified by hospitality we received. As writer, speaker, and educator Parker Palmer points out, in the understandings of hospitality to the stranger within the major faith traditions, the gift is not really to the stranger, but to the host. As the hosts, thank you. We are now delighted to share with others the refined editions from our feast in Seattle, something much more than the “left-overs.” We hope it whets your appetite for more.

Bill Gaventa, MDiv
David Coulter, MD

I. HEALING MIND, BODY, AND SOUL: THEORETICAL FOUNDATIONS FOR UNDERSTANDINGS OF SPIRITUAL HEALTH FOR PERSONS WITH INTELLECTUAL DISABILITIES

Recognition of Spirituality in Health Care: Personal and Universal Implications

David L. Coulter, MD

SUMMARY. Spirituality may be difficult to recognize among persons with significant intellectual and physical disabilities, yet it is present even when disability is so severe that consciousness is limited or absent. A clinical method is presented, based on the author's experience as a physician, that facilitates sharing of spirituality between caregivers and persons with disabilities. Caregivers must first accept their own spirituality and then seek to discover the spiritual essence of another person. Doing so provides insight into that which all persons have in common and leads (sometimes)

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to a religious experience of the ground of all spirituality. The method has universal implications across levels of ability and disability, across cultures and world religions, and across value systems involving science, human service and politics. *[Article copies available for a fee from The Haworth Document Delivery Service: 1-800-342-9678. E-mail address: <getinfo@haworthpressinc.com> Website: <<http://www.HaworthPress.com>> © 2001 by The Haworth Press, Inc. All rights reserved.]*

KEYWORDS. Spirituality, caregiver, significant disability, clinical method, physician

SPIRITUALITY

Spirituality is an intensely personal and individual belief system usually not discoverable through reason alone. Spirituality can be expressed through statements of faith about the nature of one's identity, the impact of one's culture (including ethnicity, religious beliefs and healing practices), one's relationships of love and one's sense of meaning and purpose in life. It is easier to describe than define. We can recognize it in many diverse ways without ever really grasping "it" as an entity. Perhaps this is because spirituality is the essence of our subjective selfhood and thus resists objectification through definition. As subjective essence, it also cannot be partitioned or measured in relative terms. Thus we cannot say that a person's spirituality is less because he cannot express a sense of identity or purpose in life, because for him spirituality may consist in giving and receiving love or being part of a caring community.

Similarly, spirituality is not lessened because conscious expression is lessened (as for example following a severe brain injury). Consciousness may be a property of the brain, but spirituality is a property of the whole person (the subjective essence of being). This suggests that consciousness may not be required for spiritual personhood and spiritual essence or being could be present in a person who is no longer conscious. Spirituality does not disappear when we are asleep for the night, and I would argue that it also does not disappear just because a person will never wake up. Perhaps spiritual consciousness can be considered a mediation between the finitude of this world and the infinite aspect of being that transcends this world (Sulmasy, 1997). The absence of consciousness might then relieve the person from having to deal with the fi-