

An abstract painting with vertical bands of color. The left side features dark, textured brushstrokes in shades of brown, orange, and green. The right side is dominated by a lighter, more textured greyish-blue area with some orange and white highlights. The overall style is expressive and textured.

Daniël Louw, Takaaki David Ito, Ulrike Elsdörfer (Eds.)

# **Encounter in Pastoral Care and Spiritual Healing**

Towards an integrative and intercultural approach

LIT

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Towards an integrative and intercultural approach

edited by

Daniël Louw  
Takaaki David Ito  
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LIT

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## **Pastoral-Spiritual Care, Counselling, & Advocacy with and for those Less Able**

John C. Carr

### **Abstract:**

Grounded in his experience of co-parenting his son who is less able; in his advocacy work on behalf of his son; in his personal and professional relationships with other persons less able; and in his broad experience as a psychiatric hospital chaplain, pastoral counsellor, parish minister, and pastoral educator—the author points to several issues in the care, counselling and advocacy needs of persons less able. The author’s intent is as follows:

1. To sensitize readers to the perspective and needs of those less able
2. To explore some of the intrapsychic, systemic, and spiritual issues facing persons less able and their families
3. To foster integration of the therapeutic and advocacy functions in pastoral/spiritual care and counselling with persons who are less able and their families

### **The Author’s Perspective**

The author’s personal spirituality and theological perspective is grounded in at least the following:

- a) A relational Christology (John Patton’s relational “humanness”) which focuses more on the way in which Jesus **embodied** divinity in his way of being with God’s people—than on **divinity itself**;
- b) An understanding of the human condition as grounded much more in original blessing (Matthew Fox) by a loving God than in “original sin;” and thus
- c) An anthropology that is hopeful about human potential for participation in the tasks of justice-making, care of persons, and care of the earth;
- d) A sense of the pervasive Presence of God in persons (the “imago dei”) whether **they** have that sense or not, and in the personal and bio-mechanical systems which operate in the Cosmos;

- e) A belief that human community/koinonia—grounded in a commitment to love and service—is an essential element in the living out of Christian spirituality;
- f) A belief that the human story expresses the Divine story and that human understanding of the meaning of the Divine story is an unfolding process (*For now we see in a mirror dimly, but then we will see face to face. Now I know only in part; then I will know fully even as I have been fully known.*—I Corinthians 13:12 NRSV); and
- g) A belief that “therapy” is a spiritual practice—not just a fixing of human problems—rather facilitation of a movement towards what is characterized as “shalom” in the Judeo-Christian tradition—shalom that is both internal and environmental.

### **The Situation of Persons Less Able**

The author has lived and/or travelled extensively in North America (his home base), Europe, Australia & New Zealand, and SE Asia. In all of those cultures, persons who are less able are regarded as non-persons—either completely or almost so.

Some nations have finally begun to enshrine the rights of less able persons in constitutions and in legislation. There are, increasingly in North America and in other cultural contexts, programs intended to improve and normalize the situation of persons less able. Sometimes those programs have been designed with input from those they are intended to serve and their families—but often that has not been the case.

Moreover, the legislation which is in place and the programs which are provided often do not really reflect core values of the government in power or of the civil service which implements government policy. That is, those policies have been put in place as a matter of political expediency—to create the appearance of care for persons when the prevailing political philosophy/ideology really does not include “care of persons” as a core value. A recent comment by a senior civil servant in the Canadian province in which the author lives illustrates this. He said: “Why should we provide educational support for persons with autism? They will never contribute anything to the economy.”

It is also important not to excuse the behaviour of religious institutions so far as their treatment of those less able is concerned. Frequently, when making a decision about what kind of religious institution to build or where to set up a counselling practice, or what kind of building a pastoral counselling centre or educational facility should be located in, scant attention is paid to the accessibility needs of those less able. Very little attention is paid to the fact that there are some



persons in our society for whom climbing stairs poses a major challenge or makes access impossible.

Here are two examples.

1. The author was part of a decision-making process about a new building which had been acquired for a counselling centre. The centre leadership had recently been sensitized to the issue of access because the author was doing therapy with a person who was paralyzed from the neck down and was unable to use arms or legs (notice that the term “quadriplegic” was avoided—labeling is another way that we convert persons into non-persons). In the existing two-storey building, fortunately, there was one room at ground level (with no internal steps to navigate) that could be used for therapy. Initially, the plan was to use the loading dock at the back of the building for wheelchair access to the ground floor because there were several steps up to the ground floor level at the front entrance. After the author pointed out the inequity of this approach, the plan was changed and the front entrance was re-designed, using a ramp, so that all could enter by the front door.
2. The small college where the author is Associate Faculty has only recently created an entrance which makes the lower of its three floors accessible to all. The building was built in the 1950s and was not accessible to persons with mobility challenges. The front entrance was at the mezzanine between the lowest level and the second level, where most of the offices were located. Social events and some classes are now held on the lower level—and the top level is mostly classrooms.

During the early 1980s through the early 1990s, when the college’s Academic Dean’s wife came to the college (she had MS), the Dean had to carry her up and down stairs on his back. The small community which supports the college raised an amazing amount of money in an attempt to make the building totally accessible, but government and foundation matching grants were just not available for an elevator system. The only option available was to redesign the lower floor and create non-elevated ground level access—including creation of a dropoff for “Disabled Adults Transportation System” vehicles. It is a compromise, and not one that anyone is happy with, but it was the best that could be done given the available financial resources.

There are many ways that we create barriers which exclude persons less able. However, perhaps this suffices by way of making the point that, when we are working therapeutically with persons less able, individually or as members of families (if they are even able to get to see us), we are working with deeply ingrained experiences of marginalization, depersonalization, and negation. Pastoral/Spiritual caregivers have a responsibility not to participate in that kind of

destruction of personhood—and, of course, a responsibility to address it in our caring and healing work.

### **Personal History**

Here is some of the author's relevant personal history.

The author's ten years younger cousin was born in the late 1940s with a chromosomal abnormality which resulted in severe developmental challenges. His parents were "working class" persons who lived in a large USA city suburb and there were absolutely no resources available for families such as theirs. Much attention had been given, and rightly so, to the pervasive institutionalized racism of that particular city in the middle and later decades of the 20<sup>th</sup> century. Very little attention had been paid to the institutionalized injustice which resulted in ignoring the plight of families such as the author's aunt and uncle and cousin.

Fortunately for the author's cousin, and for many persons like him and their families in Greater Detroit, the author's aunt was not the kind of person who would lie down and let the tanks of injustice roll over her. The author's aunt was the second female child born in a large farm family (the author's mother was older than her by a couple of years). She was used to taking charge. She organized fundraising events. She organized people to set up specialized schools and sheltered workshops and lobbied for government funding.

The author's family visited back and forth with his aunt and her family frequently. Spending time with her, and hearing her stories of what she was doing in their community, was the author's training for the birth of his son in 1968. Also, as a congregational minister at the time of his son's birth, the author had come to know and love two young girls in the congregation who were developmentally challenged, and to admire the way their families coped.

A relatively minor physiological incident during the author's son's gestation, or perhaps during his birth, caused a neurological deficit and that resulted in significant developmental challenges. During a two years' residency in New Jersey in the early 1970s, the author's son benefitted greatly from assessment, physiotherapy, and speech therapy resources—and then, for the next three years, his potential was maximized by a new preschool intervention program in Evanston, Illinois and a pioneering school for children with developmental challenges in nearby Niles Township.

When the author and his family arrived in Edmonton in 1975, they discovered that people like his aunt had been at work doing the same sorts of things which his aunt had done. However, the author and his spouse had to be assertive in seeking out resources for their son. It was and is an ongoing battle, and programs and resources are constantly being eroded.

The author and his spouse are both professional persons with more knowledge than the average couple about the way political systems work and the author has a family history of assertive advocacy. They are able to advocate strongly for their son's needs and empower themselves and encourage others. Many—perhaps most—families are not as well-prepared. For many, the result of trying to find assistance for a family member with ability challenges is helplessness, hopelessness, and despair.

### **Working with Persons Less able and their Families**

The author believes that the key issue which needs to be addressed when working with persons less able and their families is a pervasive experience of negation and powerlessness which is the result of institutionalized injustice.

However, the sense of loss and grief which also permeates the psyches of persons less able and their families also needs our attention. When, as a result of a birth anomaly, an accident, or a physiological or psychiatric disorder, someone is deprived of the ability—actual and potential—that most persons have, it is not too extreme to compare responses to that experience with the loss and consequent grief which occurs when someone dies.

During an intensive period of training in Gestalt therapy (probably one of the better ways to work with family grief), the author got in touch with the grief which had long lain buried in his soul about his son's loss of potential—and his body writhed with the pain of it for 30–40 minutes. There have also been times when the author's son has experienced the pain of his loss of potential deeply and has expressed it in his own unique ways. A few years ago the author disposed of a kitchen table which had deep gouges in it—inflicted one day by his son with a round-ended table knife when he came up against his limitations and losses and felt his deep grief and anger.

Sometimes, work with persons less able and their families may involve facilitating and accompanying them into that deep soul-wrenching pain. It will also involve addressing the powerlessness and negation referred to above.

However, the author **does not believe that we can “empower” others**. As he wrote those words, he was reminded of the text from the hand of the apostle Paul in Romans 1:16–17.

<sup>16</sup>For I am not ashamed of the gospel; it is the power of God for salvation to everyone who has faith, to the Jew first and also to the Greek. <sup>17</sup>For in it the righteousness of God is revealed through faith for faith; as it is written, “The one who is righteous will live by faith.” (New Revised Standard Version)

Empowerment has to do with one's belief system.

- Supportive pastoral/spiritual care and couple and family pastoral/spiritually informed therapy **can** assist persons to discover within themselves the spiritual resources which they need in order to begin to empower themselves. **For example:** One can learn how to pray, not as a demand placed on the Divine, but as a conversation in which one knows that God is holding our hand as we struggle with whatever it is we have to deal with.
- Such care and therapy **can** assist persons to develop the spiritual and religious practices which facilitate self-empowerment and practical coping with whatever burdens are imposed by the experience of being less able or having to care for a family member who is less able. **For Example:** One can achieve catharsis of the pain of loss and grief and the capacity to function in centered ways.
- Care & therapy **can** help persons uncover ways in which their personal and multigenerational narrative has prepared them for dealing with injustice and grief. **For example:** Genogram work can help to uncover coping strategies (both helpful and unhelpful) in the family's multigenerational narrative.
- Care and therapy **can** prepare persons with helpful information so that they know how to deal with the "principalities and powers" (Romans 8:38, King James Version) of inept or demonic bureaucracies in their struggle to make the world a just and equitable world. **For example:** Individuals/Families can be referred to specialized agencies and support groups.
- We, who purport to care, **can** walk alongside them in that struggle, sometimes exercising a prophetic role. **For example:** We can exercise a ministry of encouragement and sometimes of writing letters to key politicians and civil servants. In some instances our role as representative religious persons will mean that we are heard when others might not be.

### The Giftedness of Persons Less Able

The author has made reference to his ten-years-younger cousin and to the two girls in the congregation which he served as a parish minister. The author does not believe that God "caused" these three to be part of his life experience—although he is aware that that is the way some persons of faith might construe the situation. Neither does the author believe that God "caused" the chromosomal abnormality, the brain damage, or the Down's syndrome that rendered them less able. And the author certainly does not believe that God inflicts mental illness or accidents on anyone.

However, the author does believe that the persons whom he has known who have struggled with fallout from these and other kinds of disabling conditions have gifted him with understanding which helped to prepare him for the experience of

caring for his son and for the ministry of care, counselling, and education in which he has been involved for five decades.

Also, while they are “less able,” persons with challenges are also “very able.”

The two girls were, and the author’s son is, especially tuned into feelings at a level that is far more acute than the author was until he realized that and learned from them. And they have not hesitated to let the author know what they were and are “seeing.”

The author was experiencing considerable frustration with his son who was trying to get his attention, one day when the author was working to get something done in order to meet a deadline. Finally, the author could take no more. He stood up, threw his slipper on the floor, and let out a loud roar. His son’s response: “You’re really frustrated with me, Dad.”

Here is an example of that sensitivity to feelings from the author’s work as a chaplain in a psychiatric hospital. He was working against a deadline in his office next door to the chapel when a patient who had schizophrenia dropped in for a visit. After a couple of minutes, she said: “You really don’t want me here right now, do you?” The author acknowledged the truth of her experiencing of him, told her that he had limited time to finish what he was working on, and invited her to come back the next afternoon.

A young man with Down’s syndrome is the official greeter in one of the congregations of the author’s denomination and he is very skilful at making persons feel welcomed. Another young man with Down’s syndrome wrote a book about what it was like for him to live as a person with Down’s syndrome.

Of course, we should not be surprised about this. **Persons less able are persons first**—with gifts and limitations just like us all. Their limitations lead to their being characterized as “less able.” However, their gifts are often accentuated in part because they are less able.

### **Transformative Action and Research**

Here the author offers an example of the persuasive power of properly conducted action research in effecting transformation of societal norms. Following is the abstract for an instance of that kind of research conducted in the city of Calgary in the Canadian Province of Alberta.

The authors describe a participatory research project undertaken by a group of people with schizophrenia under the guidance of a university researcher. Participatory research involves members of the research group in meaningful participation in all stages of the research process. In this study, group members chose the topic (experiences with medical professionals) and method of data collection (in-depth interviews that they conducted with each other). They developed and performed a readers’ theater presentation of the results

and their recommendations for how they would like to be treated by medical professionals. The results indicate that good communication with medical professionals is essential to people with schizophrenia; it helps them accept the fact that they are ill and learn to live with the illness. The research offered a transformative experience to group members and is contributing to change in the practice of health care for people with severe mental illnesses. Schneider et al. (2004)

When discussing their methodology, Schneider et al. wrote the following:

This research project is embedded in a tradition of cooperative inquiry that emphasizes working with community groups as co-researchers (e.g., Fals-Borda & Rahman, 1991; Reason, 1994). This approach stands in stark contrast to the traditional scientific approach to knowledge generation, which places the academic researcher at a distance from the subjects of the research to produce “objective” knowledge. The participatory approach assumes that the experts are the people who live the experiences that are being studied, and that knowledge is something that is produced through the active engagement and interaction of all members of the research group. Participatory research thus strives to transform the social relations of research (Oliver, 1992; Zarb, 1992) by regarding participants as both co-researchers and co-subjects. In particular, participatory research involves the members of the research group in meaningful participation in all stages of the research process, including developing the research question, gathering the data, analyzing the data, and disseminating and using the results. Ideally, the research not only produces knowledge but also is transformative in some way for the participants. Schneider et al. (2004)

This is very different from the Research Methodology the author learned in the 1970s from people like Donald Campbell (1962/1966) and Lee Sechrest (Webb et al. 1971). At that time, the emphasis was on trying to emulate, in social psychological research, the objective stance of the so-called “hard sciences.” Researchers in social psychology were just beginning to come up against the fact that only so much could be learned from this “objective” stance. Especially in research on Education, Nursing Care, Human Services, and Pastoral/Spiritual Care & Counselling we have gradually developed the criteria which guide what we now call Qualitative Research. Vandecreek, Bender, & Jordan (1994/2009); Swinton & Mowat (2006); and Wilson (2008) provide a helpful entry to this way of understanding the nature of inquiry into human functioning.

### **Epilog**

Not long ago, at the monthly meeting of the DMin (Doctor of Ministry) Program Committee of the theological college where the author is Associate Faculty, one of our members shared something which is relevant here. She is the Director of Community Awareness and Development for an organization that supports and ad-

vocates for persons less able and their families. As a component of the reflection with which our meeting began, she talked about gathering together the research which has been done on the needs of persons with autism and the record of community and governmental action in response to that body of knowledge. She then described the way in which the document she had prepared was received positively and with appreciation (which appeared to be genuine) by the politicians she had persuaded (a monumental task) to give her a hearing. She concluded with a statement sometimes attributed to Goethe, although it is actually derivative. Here is what she shared.

*Until one is committed there is hesitancy, the chance to draw back, always ineffectiveness. Concerning all acts of initiative (and creation), there is one elementary truth, the ignorance of which kills countless ideas and splendid plans: At the moment one definitely commits oneself, then Providence moves too. All sorts of things occur to help one that would never have otherwise occurred. A whole stream of events issues from the decision, raising in one's favor all manner of unforeseen incidents and meetings and material assistance which no man [sic] could have dreamed would come his [sic] way. Whatever you can do, or dream you can do, begin it. Boldness has genius, power and magic in it. Begin it now.*

The original can be found at Goethe, *Faust I*, Zeilen 214–230.

The colleague's point was that we do not get to where we need to go unless we actually get started and that, in the act of beginning, we can trust that what needs to occur will occur. Overly optimistic? Perhaps. Unrealistic? Perhaps. In the long sweep of human history, understood as the Divine history, perhaps not.

Here is the last word from the author's son. The author wrote about this in an article in *The Journal of Religion and Disability* (Carr, 2009). The family was sharing in Communion one Sunday and, as the Bread was passed down the row of chairs, the author's son (then a young teen) decided that it was time for him to begin sharing in the Sacrament and took a piece of the bread. When the Wine was passed, the author helped him take a glass of grape juice. Afterwards, curious as to what might have motivated him that day, the author asked him if he knew what Communion was about. His reply: "God loves me."

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