

Searching for Dignity

Conversations on
human dignity,
theology and disability



Editors | Julie Claassens, Leslie Swartz & Len Hansen

Conference
Proceedings



CONFERENCE PROCEEDINGS

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Introduction

In 2001, article 8 of the United Nations' International Convention on the Rights of Persons with Disabilities outlined the following objectives:

- ➔ To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;
- ➔ To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;
- ➔ To promote awareness of the capabilities and contributions of persons with disabilities.

The language of human dignity that is used in this foundational document is a compelling means to challenge the way society perceives people with disabilities. Furthermore, the emphasis on human dignity is to be found in all three the religions of the Book (Judaism, Christianity and Islam) – this despite the fact that these religions quite often have had (and continue to have) an abysmal human rights track record, being complicit in many forms of discrimination, including discrimination against people with disabilities. Nevertheless, as Carol Fontaine points out, each of these three religious traditions also contains insights and theological traditions that can be utilised in support of universal human rights.¹ The conviction that human dignity belongs to all people regardless of factors such as skin colour, gender, social status, physical or mental capabilities and sexual orientation constitutes a basic element of religious belief that can be recovered and employed in order to move the conversation away from achievement or utility value in assessing human worth.²

This emphasis on human dignity provided the inspiration for a conference with the theme 'Theology, Disability and Human Dignity' that was hosted by Stellenbosch University's Faculty of Theology in conjunction with the Centre for Rehabilitation Studies in the Faculty of Health Sciences in May 2011. Within a broader context the conference on which this volume is based formed part of the Stellenbosch University's Hope project. Inspired by the millennium goals set by the United Nations, the Faculty of Theology and the Faculty of Health Sciences both chose to focus on the promotion of human dignity and health. The conference brought together members of various disabled communities, theologians (represented in this volume by the likes of Gerrit Brand, Julie Claassens, Nico Koopman and

1 Fontaine, C. 2008. "With Eyes of Flesh": Toward a Concept of Human Rights in the Bible and the Ancient Near East. In *With Eyes of Flesh: The Bible, Gender and Human Rights*. Sheffield: Sheffield Phoenix Press, 26. In both Christian and Jewish traditions, the notion of human dignity goes back to the *imago Dei*, i.e. the theological proposition in Gen 1:27 that God created both male and female in the image of God. For a helpful exposition of how this image functions in both the Jewish and Christian traditions cf. Frymer-Kensky, T. 2000. *The Image: Religious Anthropology in Judaism and Christianity*. In Frymer-Kensky, T. et al. (eds), *Christianity in Jewish Terms*. Boulder, CO: Westview Press, 321-37. Cf. also the Qur'an's emphasis on the "sacred duty" to protect life (Fontaine, "With Eyes of Flesh", 27).

2 Reinders H. S. 2006. Human Dignity in the Absence of Agency. In Kendall, S. and Woodhead, L. (eds), *God and Human Dignity*. Grand Rapids, MI: Eerdmans, 139.

Hans Reinders), medical doctors, occupational, physical and speech therapists (Martha Geiger and Gubela Mji), pastors (Pieter van Niekerk, both as pastor and as a person living with a disability), psychologists (Leslie Swartz), philosophers (Anton van Niekerk), educators (Tsitsi Chataika), social workers (Erna Möller), students (Michelle Nell and Tatjana Metzger), parents of children with disabilities (Tom Reynolds, both as theologian and parent of a child with disabilities) and other members of the public. These participants came from different parts of South Africa, but also from the Netherlands, Canada, Malawi and Zimbabwe to attend this conference, which offered a space for disabled and able-bodied persons to talk about ways in which they and the societies they form part of can confront stereotypes and prejudices, and can grow in respect for the dignity of persons with disabilities, acknowledging their unique capabilities and contributions to society. It was evident in many of the contributions that dignity remains a key issue to consider in the interaction amongst all people, able-bodied and disabled.

For a faculty not accustomed to interacting on an equal basis with people with disabilities, hosting a conference such as this was a steep learning curve in itself. For instance, when it came to the venue where we would host the first two days of the conference, members of the organising committee of the Faculty of Theology proudly showed our partners the wheelchair access ramp to the building, the elevator and the newly renovated lecture hall where most of the addresses would be delivered. However, through the eyes of our colleagues who work with disability on a daily basis, we at the Faculty of Theology had to learn that our ideas of wheelchair accessibility fell short: the ramp was too steep, the elevator too narrow, the hall only had space for wheelchairs in the front and there were no wheelchair-accessible bathrooms. Fortunately, we were able to move the conference to a nearby venue that was much more accessible. Still, this experience underlined just how often one is complicit (however unintentionally) in able-bodied privilege.

As was said, the ‘Theology, Disability and Human Dignity’ conference took place in the context of Stellenbosch University. Academics and students of different faculties contributed to this interdisciplinary exploration of issues of disability, in particular as it relates to issues of religion and faith. As such this conference served as an important start to a conversation that is far from finished and that ought to continue on the following levels.

First, it is important that the conversation regarding disability (particularly on the challenges experienced by disabled students and university staff) occur in our university at every level – in our respective faculties, as well as on administrative and management levels. Participants should be warned, though, that dealing with the reality of disability is not always an easy conversation – for one, because it has definite monetary implications (retrofitting inaccessible buildings to make them wheelchair accessible, for example, is very expensive).

Second, an honest conversation regarding disability in higher education will include difficult questions regarding what an institution such as Stellenbosch University is doing to make higher education accessible for students with disabilities. And yet this conversation also occurs with the realisation that universities in their very essence are exclusionary in nature – a notion attested to by the fact that only a very small proportion of South Africa’s population will end up obtaining a university degree. However, this fact

should not prevent the conversation from continuing and it should concern more than the issue of removing barriers at an institution like Stellenbosch University, making it a more hospitable space. It also requires the assurance that the university is able to draw on and benefit from the talents and abilities of the widest possible range of people.

This book is by no means the first such contribution from the academy in South Africa – it forms part of an on-going broader conversation (see, for example, the 2006 publication by Watermeyer, B., Swartz, L., Lorenzo, T., Schneider, M. and Priestly, M. (eds), *Disability and Social Change: A South African Agenda*. Cape Town: HSRC Press). However, as far as we are aware, it is the first contribution of this kind from a faculty of theology in South Africa. Therefore, on a third level, as is evident from the title, the ‘Theology, Disability and Human Dignity’ conference initiated an important conversation in South Africa on theology and how it pertains to disability. Internationally, this is not a new conversation at all, as is evident from the long list of publications that have appeared in Europe and the United States on this subject. (A few are listed in footnote 3 below. See also the *Journal of Religion, Disability and Health*, and the contribution to this volume by its editor, Hans Reinders, as well as the work by Tom Reynolds, who was one of the keynote speakers at the conference).³ As was noted above, religion has not always been friendly towards people who live with disabilities – one only has to be reminded of the widespread harm caused by the theological idea that human disability, disease and disasters can be attributed to human sin. On the other hand, religion is very important to many people, including many disabled people. Some of the contributions to this volume thus explicitly seek to name and rethink harmful religious expressions, as well as to reclaim those religious traditions that may serve as a source of hope for people living with disability.

It was furthermore significant that the conference on theology, disability and human dignity took place specifically at the Faculty of Theology of Stellenbosch University. In 2009, this Faculty celebrated its 150th year of existence, years that saw more than their share of exclusion. For a very long time it was the place where white male pastors were trained for the ministry in the Dutch Reformed Church. In the past twelve years, though, the face of theology at Stellenbosch University has changed considerably. Since 2000, black and coloured Uniting Reformed Church students have been studying together with white Dutch Reformed Church students – more recently being joined by Presbyterian, Anglican and students from many other Christian denominations. In terms of gender, too, the picture looks quite different today. Whereas twenty years ago there were no female lecturers and only a handful of pioneering female students (one or two per year group), there are currently six female lecturers (including a former dean who became the first female dean of a theological faculty in Africa) and almost half of the Faculty’s students are female.

3 Cf. e.g. Reynolds, T. E. 2008. *Vulnerable Communion: A Theology of Disability and Hospitality*. Wheaton, IL: Brazos; Reinders, H. S. 2008. *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology, and Ethics*. Grand Rapids, MI: Eerdmans; Eiesland, N. L. 1994. *The Disabled God*. Nashville, TN: Abingdon; Creamer, D. 2009. *Disability and Christian Theology: Embodied Limits and Constructive Possibilities*. Oxford: Oxford University Press; Avalos, H., Melcher, S. and Schipper, J. (eds). 2007. *This Able Body: Rethinking Disabilities in Biblical Studies*. Atlanta, GA: Society of Biblical Literature.

This changing face of theology at Stellenbosch University is also reflected in the goals of the 'Theology, Disability and Human Dignity' conference that sought to reframe harmful theological ideas and to find new ways to talk about God and about human beings that respect their inherent dignity as unique individuals created in the image of God. The Faculty has a long way to go, as does the University; we regard this volume as a small milestone on the way.

Before proceeding to the specific contributions and their sequence in this volume, a short note of caution on the limitations and strengths of a volume such as this. One of the core issues raised by both the conference and this resultant volume, is the question of how to change the situation regarding the everyday lives of people with disabilities, and indeed of society as a whole. In keeping with other fields of activism focusing on the undoing of oppression, such as feminism and black consciousness, disability scholarship and politics have gone through periods of separatism in which it has been argued that only people with disabilities themselves may contribute meaningfully to disability studies. There is no doubt at all that this approach has merit and needs to be taken seriously. However, the approach taken with regard to the conference and this publication has been more inclusive. None of the editors is a person with a disability, and the authors of the chapters in this volume are a mixed bag as far as their own disability status is concerned. Some critics would say, and they would have good reason to, that a volume such as this should have more extensive participation in design and authorship by people with disabilities. We agree with this criticism. We also believe, though, that a volume such as this, coming at this time in the history of theology at Stellenbosch University, has a particular importance as it begins to open up very important issues to a new but potentially very influential audience in the lives of people with disabilities in South Africa. The fact is that organised religion in South Africa (and in the case of this volume, organised Christianity of a particular kind) has a very long way to go in thinking through issues facing people with disabilities, and we hope that this book will be an important first step on a path leading to greater participation by people with disabilities at all levels of religious life and practice – and certainly not just as objects of study or as people to be cared for by the able-bodied majority.

This being said, in compiling this volume we also took some ideological decisions we regard as important, but which may not be welcomed by all. During the conference itself it was clear that some of the energy amongst participants had to do with policing the boundaries of an inner circle of those already in the know about disability issues and those new to the field. Some participants more experienced in disability politics, for example, berated those less experienced for using inappropriate terms, including using language which people with disabilities commonly find offensive. We agree that the issue of the language we use is an important one, but we believe that part of the role of the conference and of this volume is not to declare a boundary between those who know about disability issues and those who do not, but to use the opportunity of engagement to help people who have not thought enough about the politics of disability to think more deeply and more consciously about the issues at stake. A part of this rethinking does indeed involve thinking about the language we use.

But the question of how to be inclusive is more complex and goes much further than questions of the language we use. Some of the people at the conference expressed views on

disability with which we ourselves disagree and view as discriminatory, but which were interwoven with insights we believe are important to consider in debates about disability. For us, the easiest thing to do with the contributions with which we disagreed, and indeed probably the safest for us in terms of our own ever-fragile reputations as scholar-activists in the disability field, would have been simply to exclude such contributions from this volume. We have decided not to do so and to include some contributions with which we disagree, and disagree strongly. As is expected of a publication intended for a broad scholarly circle of readers, all the contributions have also been subjected to a rigorous process of double-blind peer review. This is in keeping with the best of what we believe disability politics and scholarship have to offer and shows the extent to which we value debate and contestation, and we encourage readers of this volume to engage with the contributions in the book. It will be a strength, rather than a weakness, of this volume if you as a reader like some of the chapters but dislike (and are even enraged by) others. In reviews and other writings, we hope to see reactions to different parts of this book. We are convinced that a volume that presents a homogeneity of voices is far less provocative than one that is more diverse. We look forward to a range of reactions to what we ourselves and other contributors have written in these pages. Multiple responses, multiple voices, discomfort and contestation – all these are important if scholars like ourselves and the contributors to this volume are collectively to make a useful contribution to the future of disability studies in South Africa, and beyond.

With regard to the arrangement of the contents of this volume, the following logic was at work. As mentioned above, the ‘Theology, Disability and Human Dignity’ conference wanted to contribute to the discourse on disability, and it wanted particularly to be the start of a conversation on the relationship between theology, disability and human dignity. As such, it comes as no surprise that next to the issue of change, that of the language we employ in this conversation will be of paramount importance. In fact, most contributions to this volume refer in some way or another to the issue of language and it is placed on the agenda right from the outset as Tom Reynolds, in the first essay, calls on us to “change the conversation” regarding theology and disability. In this first section, ‘Changing the Theological Discourse’, Reynolds’s essay and that of Hans Reinders are important as they serve as orientation, mapping the field of Christian theological reflection on disability that has been a growing field of interest internationally. The next essay, by Nico Koopman, serves as a further example of theological reflection on the themes of disability and human dignity, but coupled with the concepts of hope and vulnerability. Central to Juliana Claassens’s contribution is a call to find – amidst the many examples of stereotypical Old Testament views on disability, disease and suffering – elements of a counter-narrative in the Book of Job in a process of “moving towards a new kind of speech” regarding God and disability, while another theologian, Gerrit Brand, expresses his views on “language injustice” and “linguistic marginalisation”, especially of speakers of sign language.

In the second section, ‘Changing Practices’, the issue of theology, disability and human dignity are addressed by those working with people with disabilities – therapists, educators and psychologists. In fact, before one can even begin to think of the relationship between *theology*, disability and human dignity, one may indeed ask what the relevance, if any, is of *religious faith* for the topic of disability. From the perspective of his position as a lead

research partner for the Southern African Federation for the Disabled (SAFOD) Research Programme (the SRP), and as someone from outside the ranks of religious believers, Leslie Swartz reflects on this question. Without changing his own position regarding religious faith, Swartz tells of his own realisation of the importance of issues of faith and spirituality for many people despite the fact that many of them “had been excluded and vilified by aspects of religion”, and that “religion also sustained them and gave them a sense of meaning and identity”. This is something also reflected in Martha Geiger’s essay as a speech therapist on how children with severe communication disabilities “do theology”. Still related to the issue of language and conversation is the fact that the language we use in our discourse on disability is, of course, indicative of the perceptions that lie behind it. The question of perceptions is especially important in the next contribution, by Anton van Niekerk, on different views regarding bio-ethical enhancement.

Language and perceptions are two factors that, in the end, may contribute not only to the recognition or not, to the promotion or even the violation of the human dignity of people living with disabilities, but also to their inclusion in or exclusion from society. It is this exclusion and overcoming it that forms the focus of Tsitsi Chataika’s essay ‘Cultural and religious explanations of disability and promoting inclusive communities in Southern Africa’, and Erna Möller’s essay ‘The experiences of people with disabilities in faith communities and suggestions to enhance their inclusion’.

The publication ends with a section, ‘Changing Lives’, on the daily challenges (including challenges of faith) those with disabilities face, their vast (often untapped) potential and the contribution they can and do make. The four short essays are by Gubela Mji (the head of the Centre for Rehabilitation Studies (CRS) at Stellenbosch University), Pieter van Niekerk (a pastor living with a disability), and Tatjana Metzger and Michelle Nell (both students from Stellenbosch University living with disabilities).

It is our sincere hope that the above selection of contributions will reflect the fact that the conference on theology, disability and human dignity, and the ensuing conference volume, was indeed an enriching experience that forced many of us out of our respective comfort zones to cross disciplinary boundaries in a joint quest for dignity. One of the elements of this richness was the sheer diversity of viewpoints reflected here and at the conference. This diversity is also reflected in the case of the editors of this volume – two members of the Faculty of Theology (Christian and specifically Dutch Reformed) working together with a member of the Department of Psychology who is a self-professed Jewish atheist. This diversity of viewpoints, which may even include ideological differences, attests to the fact that the issue underlying this volume is important enough to us to come together and learn from one another. Of course, this publication would not have been possible without the financial assistance of the Stellenbosch University Hope Project (via the Faculty of Theology and the CRS), without SUN MeDIA Stellenbosch and the key role they played in the publication process and, last but not least, without all those who contributed by presenting papers at the conference and by submitting them for publication. You truly represented multiple responses, multiple voices. At times you did cause us some discomfort and at times your views were contested, but most of all you enriched our perceptions and understanding of disability and its relationship to theology and human dignity with your own experiences and expertise. For this, we thank you all.

A final word regarding the title of this volume. “Searching for Dignity” is a reference to Bob Dylan’s powerful song ‘Dignity’. Reflecting a context of slavery in the American South, as well as ongoing human rights violations in the USA where people are killed for no reason and others are facing hunger in the land of plenty, the singer is searching high and low and everywhere he can, asking people: “Have you seen dignity?”

This search for dignity is equally relevant in our own context. We can think of numerous instances both past and present in which people’s basic human rights have been disrespected. In terms of the title of this volume, it is thus very relevant to contemplate this search for dignity also in terms of the indignity that people with disabilities experience. The collection of essays contained in this volume seeks to recover dignity by changing the discourse regarding disability through changing the conversation, changing practices and changing lives.

Julie Claassens, Leslie Swartz and Len Hansen
Stellenbosch, June 2012

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Part ONE

Theology and disability

Changing the conversation

1

Thomas E. Reynolds¹

Disability unsettles easy assurances. It exemplifies how people can be represented in terms that exclude. Disability often signifies the way that some people are recognised as lacking something basic to what is understood as human, being abnormal, a body gone wrong. The implications of such “recognition” – which is more adequately a ‘mis-recognition’ – extend far beyond disability, and in fact touch on the cultural, social and religious systems by which human beings gain orientation in the world and traffic with each other.

I discovered this personally in the process of raising my son, Chris (now 20 years old), who is diagnosed with Asperger Syndrome (on the autism spectrum) and Tourette Syndrome, OCD, Bipolar disorder and ADHD. Chris’s own uniqueness presents itself in ways that challenge, indeed, upset and turn upside-down the taken-for-granted conventions and ideals that commonly are held up as ‘normal’ in the process of caring for and loving a child. Attending to him has meant “letting go” of my own preconceived expectations about what human flourishing means, and instead learning to listen – and listen deeply – to the ways his own humanity requires affirmation, attending and empowerment. The process has been disconcerting and painful, and has demanded patient and persistent practice. But Chris’s particular way of being in the world, his own neuro-diversity and beauty, radiates outward and serves something other than satisfying the norms of a world set up in neuro-typical terms. It is its own good, precious in its own right.

I recall one particularly powerful way that Chris’s presence in my life compelled me to adjust my orientation in the world. It happened in a theology class I was teaching. We were engaged with various perspectives on the question of evil, in particular, asking why a supposedly all-powerful and all-good God would allow suffering to exist in this world. This kind of question is usually asked under the banner of a theological-philosophical term, “theodicy”. As I was talking with the class, it suddenly occurred to me that, seen through the lens of my experience with Chris, the whole setup of the question was bogus. I had assumed disability is an example of something gone wrong, a deficiency, a site of abnormality and suffering. Consequently, I realised the answers – grand and totalising in their sweep – ended up trivialising the complexity of the life I knew in Chris, presuming that his condition was less than ordinary and therefore characterised by “suffering”. I had simply presumed he suffered, as an individual, because of his impaired condition. Suddenly, as if shocked awake by a splash of cold water, I was dis-oriented and as a result had to

¹ Thomas E. Reynolds is Associate Professor of Theology at Emmanuel College, of Victoria University in the University of Toronto and the Toronto School of Theology.

begin reconsidering my whole theological framework. For I found myself saying things that did not square with my love for Chris and how I experienced his way of being in the world.

It does not take much to recognise that serious problems accompany religious language about God and God's love when applied to disability. After all, encountering disability challenges the assumptions by which non-disabled people find order and meaning in the world. In order to uphold these assumptions, people of faith almost automatically defer to notions that imply that God somehow "causes" disability – for example, as a curse or punishment, a "cross to bear", an opportunity for God to "heal", a way for non-disabled people to demonstrate charity, a kind of moral lesson for non-disabled people ("there but for the grace of God go I"), or a spiritual lesson ("those people are so childlike and open to God").² Even though these kinds of responses can be found in biblical texts, I suggest that they trade upon a faulty way of representing disability. Namely, that disability is not "normal" (abnormal), that it displays something different than the "standard" human body should, a stigma marking a deviance considered a deprivation. But what is normal? And what constitutes a disability?

Today, then, I would like to propose that faith communities shift the way disability is thought about, and this means, as the title of my talk suggests, changing the conversation. If we think of 'conversation' as an exchange, a conversing, between people through which ideas, visions, mechanisms of power, strategies of caring, and so on are conveyed and shared, then changing the conversation involves modifying practices as well. After all, our language is a performance with certain effects. It enacts viewpoints and reflects orientation with others. It is no accident that questions of accessibility for people with disabilities are so tightly connected with attitudes and perspectives toward disability. And further, as my story above illustrates, it is often our relationships with people that challenge us to reconsider our attitudes, to rethink, for example, what 'accessible' means.

Of all places, religious communities should be models of "accessible communities", a point of entry into God's love radiating through the lives of its participants. For, in the words of Jennie Weiss Block, a Christian writer, "the Body of Christ presumes a place for everyone".³ However, "place" is difficult for persons with disabilities. Too often thresholds are encountered in our churches that signal "access denied" – whether physical, behavioural or attitudinal. This is tragic both for those with and those without disabilities. For specific kinds of people are rendered "helpless" or "deficient" or "special" in some way(s) by others. On this basis they are excluded from participation or relegated to secondary status, which diminishes their genuine humanity. Also diminished are faith communities themselves, as disabling principalities and powers come to obscure how people with disabilities can and do make real contributions to their communities. Not only is this unjust; it also restricts, I believe, the redemptive pulse of God's presence in our midst. So it becomes important to reflect theologically about how persons of faith might engage the issue of disability with a more critical and compassionate edge.

2 For an excellent survey and critique of such responses, see Kathy Black. 1996. *A Healing Homiletic: Preaching and Disability*. Nashville, TN: Abingdon Press. See Reynolds, T. E. 2008. *Vulnerable Communion: A Theology of Disability and Hospitality*. Grand Rapids, MI: Brazos Press, chapter 1, IV.

3 Weiss Block, J. 2002. *Copious Hosting: A Theology of Access for People with Disabilities*. New York, NY and London: Continuum, 131.

In my talk today I want to propose changing the conversation in three ways, moving beyond disability as

- (1) a “problem” to be erased or done away with;
- (2) something otherwise than “us”, which then must subsequently be included according to an ideal of normalcy that is established by non-disabled people (often through ablest ideologies); and finally
- (3) something merely to be accommodated and “tolerated” and instead toward genuine being with, not ‘doing for’ but receiving gifts from people with disabilities, who are valued as contributing parts of a shared communal life. There are, of course, many other issues and proposals that could be raised, and many theological implications that could be discussed. My aim is simply to suggest possibilities for interrogation and communal transformation.

I

First, as many of the papers from this conference have already indicated, it is crucial to shift away from seeing disability as a tragic flaw, the product of circumstances and bodies “gone wrong”. This entails moving away from referencing an individual’s impairment in terms of reduced ability and reduced personal fulfilment. For this not only individualises disability, when it is often the social order that makes an impairment disabling, it also makes accommodation a personal caring matter for the individual or family rather than the cultural system or society. It ends up focusing on a deficiency through curative or remediating medical practices (even prayers for “healing”) and as a result depersonalises people with disabilities and overlooks the disabling powers and principalities in the system itself. Disability scholars often highlight such a contrast in term of the “medical model” and the “social model”. The latter complicates the very notion of disability.

I adopt a view that signifies disability as the consequence of impairment, that is, an inability to perform some task or activity considered necessary within a social environment.⁴ This makes disability, to a large degree, a social construct. Disability represents a diminishment relative to a context of valuation and its conventions, a lack of ability to function in ways considered valuable to a group. In this way, as disability theorist Lennard Davis describes, disability and normalcy are part of the same system.⁵ Impairment does not necessarily mean disability. For example, visual impairment in today’s world is not considered a disabling condition, but needing a wheelchair or medication for bipolar disorder is. And sometimes impairments are caused by social systems. Why the difference between disability and impairment? Because certain conventions have become part of the status quo, constructing what is “normal” and thereby creating the difference between bodies that are “able” and those that are “disabled”. There is more at stake, then, in the matter of disability than an impairment that someone happens to have. For society disables people by representing

4 Eiesland, N. L. 1994. *The Disabled God: Toward a Liberation Theology of Disability*. Nashville, TN: Abingdon Press, 27. Eiesland refers to S. Z. Nagi’s 1979 definition, from *The Concept and Measurement of Disability in Disability Policies and Government Programs*. In Berkowitz, E. D. (ed.), *Disability Policies and Government Programs*. New York, NY: Praeger, 3.

5 Davis, L. J. 1995. *Enforcing Normalcy: Disability, Deafness, and the Body*. London and New York: Verso, 2. See also 48-9.

impairment as a flaw or deficit. Often medical communities fuel this problem by cultivating curative practices to remedy such flaw or deficiency. As Arthur Frank notes: “Society prefers medical diagnoses that admit treatment, not social diagnoses that require massive change in the premises of what that social body includes as part of itself.”⁶ In fact, even impairment itself can be seen as a social construct of sorts, its representation trading upon certain definitions of the body that include and exclude particular features governed by conceptions of normality. Disability then invokes questions of accessibility as a matter of justice and human dignity. Personhood should not be defined by disability. But this is not the end of the story.

II

A second change becomes necessary in the conversation. There is a need to move away from representing disability merely as a problem to be included, an anomaly that is somehow “other” and outside, which, according to the good graces of a community, “needs” to be brought “inside” and given access and power to be involved. For this often becomes a way temporarily non-disabled people claim nobly to give something those others – “they” – do not have, perpetuating an “us-them” or “inside-outside” dualism that retains a paternalistic ethos of exclusion. It may be true that without accommodation an impairment (physiological difference, bodily condition) becomes a disability (social and environmental experience of restriction that results from limited access, from being considered to have an impairment). However, outside preconceived programmes and expectations fuelled by dominant visions of what is “normal”, people with disabilities convey a powerful sense of personhood and dignity, which rises in multiple ways to make contributions and offer gifts to communities. So it now becomes a matter of deproblematizing the “problem” of disability and instead problematizing the way communities represent disability vis-à-vis normalising assumptions that either exclude or assimilate-normalise people with disabilities on this basis. I want, therefore, to move beyond binaries of “us-them”, especially as couched in terms of “normal” versus “abnormal”, in order to disrupt the usual “ability-disability” binary.

If we grant that the “normal” is a standard that is socially constructed, we are brought to recognise that it can also be critiqued and de-constructed. The basis for this, I believe, lies in something all human beings share, which helps undercut the “us-them” binary: vulnerability. It is an inescapable fact that we are born, live our lives, and then die as vulnerable creatures exposed to and needing each other. Not just to survive as helpless infants, but also to grow and come to flourish as people loved by others, eventually dying in the care of others helpless before our mortality. Such vulnerability binds us together with those who accompany us. As Kristine Culp recently noted, it does not simply mean susceptibility to injury or harm, as something negative, but also susceptibility to good, to joy and fulfilment through others.⁷ Highlighting this theme is essential because it provides a way into more vigorously acknowledging and experiencing our deep connecting points with one another, points that indicate a basic web of mutual dependence, but which all too

6 Frank, A. W. 1995. *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago, IL: University of Chicago Press, 113.

7 Culp, K. C. 2010. *Vulnerability and Glory: A Theological Account*. Louisville, KY: Westminster John Knox, 2-4.

often become cloaked by the exchange values that animate human communities under the sway of what I have called the “cult of normalcy”.⁸

The cult of normalcy routinises and naturalises – through systems of power and their rituals – ways of being human that are taken to be “normal” and thus the status quo. It takes what are in fact social constructions and ascribes “commonality” to them as particular standards that become prototypical for all. In this way, ableist discourses that construct disability as “other” or deviant come to mobilise representations that uphold communal identities based in binary systems of exclusion – able/disabled, “us” versus “them”. Michel Foucault famously speaks of binary divisions (mad/sane; normal/abnormal; in/out) and the “power of normalisation”, whereby exclusion is not so much ejection from community as it is productive of community.⁹ Exclusion has formative power. The excluded supplemental defines the “identity”, making language itself a vehicle for inscribing “the normal” into our everyday sense of who we are within a social identity (for example, think about how terms like “cripple”, “blind” and “deaf” are used pejoratively). The point is that there is no “natural” able-bodied person. And because of this, there is the possibility of deconstructing ableism and opening up multiple ways of being human together.

This is why, rather than to focus on what counts for “ability” – for example, the capacity to think rationally, act autonomously, look healthy, or produce and purchase things as self-interested consumers – we might explore human vulnerability as a starting point for discovering what we *share* in our differences, a source bearing the precious and fragile grace of solidarity with one another. Jean Vanier, founder of L’Arche, a network of communities for intellectually disabled people, sums it up eloquently: “We do not discover who we are, we do not reach true humanness, in a solitary state; we discover it through mutual dependency, in weakness, in learning through belonging.”¹⁰

Viewed through the lens of basic vulnerability, “neediness” or “lack of ability” is not a flaw detracting from an otherwise pure and complete human nature. Rather, it is testimony to the fact that we – all human beings – receive our existence from each other. And recognising this is a source of relational openness to others, who are in turn similarly constituted. Genuine wholeness is found not through bodily completeness or ability, but through an acknowledgment of vulnerability that is made concrete in relations of mutual giving to and receiving from others.¹¹ Human beings are exposed to one another, subject to each other even before any clear sense of self emerges. We need each other. I am not arguing that vulnerable interdependence is itself a moral virtue, but rather that it is a fact of human existence (much as Alasdair MacIntyre argues in *Dependent Rational Animals*). What is crucial here, in order to move beyond the descriptive element of ‘fact’ toward a moral posture of sorts, is the *acknowledgement* of vulnerable interdependency.

This notion is difficult and painful to process under the sway of dominant social conventions; it runs counter to the common assumption that value is based upon power and ability. We

8 See my *Vulnerable Communion*, chapter 3.

9 Foucault, M. 1979. *Discipline and Punish: The Birth of the Prison*. (Trans. Alan Sheridan). New York, NY: Vintage Books, see 29 and 199.

10 Vanier, J. 1998. *Becoming Human*. Mahwah, NJ: Paulist Press, 41.

11 See *Vulnerable Communion*, chapter 4.

suppose that our identity, our worth, derives from the power of completeness, a capacity to be independent and self-initiating, able to control our bodies in the face of others and thus be recognised as contributing to the group. The irony is, in the words of Stanley Hauerwas, “our neediness is also the source of our greatest strength, for our need requires the cooperation and love of others from which derives our ability not only to live but to flourish.”¹² Living out of this reality is a source of genuine good, for it entails helping others – in their so-called “disability” – as essential not only to our own flourishing, but also to the common good of the community in which we flourish.

Yet neediness is a difficult reality to accept. For it means recognising that we are at the core exposed to imperilment and suffering, contingent and incomplete beings who need to belong to become ourselves.¹³ Indeed, we do suffer. Vanier observes: “Weakness is at the heart of the need to belong; weakness that we may fear, because we have been hurt.”¹⁴ Fearful of being wounded, we often attempt to cover our vulnerability, protecting it by denying our dependence upon others. The irony in this, however, is that belonging is inescapable. We become who we are through community. Yet in the modality of fear, even community can become a false means to assure ourselves of strength and completeness, in effect denying our vulnerability. We buy into the cult of normalcy. We presume that security entails conforming to the projected strength of others, bolstered by the conventions of society and its power mechanisms. It is as though acquiescing to the status quo offers protection by rendering us immune to contingency and its perils.

Such pretence is what fuels efforts to build protective walls around the “normal” and classify certain anomalies as “abnormal”. We thereby come to judge the different and the strange – that which does fit into the ordered scheme of things – according to our fears. In a state of insecurity we hunt for a scapegoat for our fear, someone or something to turn into the object of fear and then our contempt.¹⁵ The different is frightening, because it mirrors our own weakness and vulnerability. It ruptures conventions of normalcy and forces us to acknowledge that which we shun and seek immunity against: inability, incompleteness and neediness. Hence disability is considered a weakness, because it concretely reveals to us what we shun in ourselves: weakness.¹⁶ Often the cement that binds a group together is cast over the sense of vulnerability that preoccupies its constituents. And this is a moral failure. Not only does it lead to representing vulnerability as a flaw, but it also seeks to objectify such flaw as an attribute of the other who is different. By projecting our own fear of vulnerability onto another, we become cut off from the wellspring of our own flourishing: mutual dependence. We deny the other, and so ourselves.

Our efforts to suppress it notwithstanding, mutual dependence is primary. It is the fulcrum from which we emerge as persons. It elicits a fundamental sense of wholeness that, even as we conceal it, rises here and there like grass through asphalt, captivating our attention. Vanier explains why: “Weakness carries within it a secret power. The cry and the trust that

12 Hauerwas, S. 2004. *Suffering the Retarded*. In Swinton, J. (ed.), *Critical Reflections on Stanley Hauerwas' Theology of Disability: Disabling Society, Enabling Theology*. Binghamton, NY: The Haworth Pastoral Press, 97.

13 Hauerwas, *Suffering the Retarded*, 100-4.

14 Vanier, *Becoming Human*, 46.

15 Vanier, *Becoming Human*, 73.

16 See Vanier, *Becoming Human*, 74-81.

flow from weakness can open up hearts.”¹⁷ The vulnerability of another is a window into our own vulnerability, evoking a sympathetic relation that eludes the tyranny of the normal, sweeping under the radar of conventional economies of value exchange. In this way Vanier suggests that those who embody weakness and are considered “nobodies” in a society – i.e. people who exhibit disabilities – “have profound lessons to teach us”.¹⁸ They invite us to move out from behind closed walls of false security and exclusion to acknowledge and accept our vulnerability. Theologian Jürgen Moltmann confirms the point in stating, “A person with disabilities gives others the precious insight into the woundedness and weakness of human life.”¹⁹ Disability is a profound symbol of human brokenness, not as a flaw but a pervasive condition.²⁰ Of course we can suppress or deny our weakness, fleeing from it by pushing away those others whose difference overtly exhibits it as something we deem ugly or dirty or deficient. But by doing this we shun what is perhaps most human about us – the need to belong and be recognised as of value.

However, this is not to say that people with disabilities are “the” vulnerable, with intrinsic transformative capabilities for “us” non-disabled people. Rather, that vulnerability is something shared differently by all humans. And it is distributed differently among humans, some being made more vulnerable than others in specific ways – such as by race, gender, class, etc. – and in specific locations and contexts – such as in Canada, South Africa or China, and in different religious contexts, and in rural or urban situations, and in various climates, etc. When seen in this light, we quickly see that disability is not the property of “them” versus an “us” – a flaw or aberration – but a pervasive condition affecting everyone in varying degrees as they are subject to imperilment, suffering and/or violence that diminish human flourishing. There is, in the end, no hard and fast line between ability and disability, but rather a nexus of reciprocity that is based in our vulnerable humanity. All of life comes to us as a gift, an endowment that is received in countless ways from others throughout our lifetime. When we acknowledge this, the line between giving and receiving, ability and disability, begins to blur. The binary “us” versus “them” language begins to unravel. Moltmann goes so far as to state: “There is no differentiation between the healthy and those with disabilities. For every human life has its limitations, vulnerabilities, and weaknesses. We are born needy, and we die helpless. It is only the ideals of health of a society of the strong which condemn a part of humanity to being ‘disabled’.”²¹ Conversely, having a disability is not equivalent to being ill or sick, needing a cure. Disability does not define a person.

Full personhood is neither diminished by disability nor confirmed by ability. Instead, it is a factor of the interdependent relationships we share with one another as creatures loved into being by God and in the image of God. There is a wider horizon in which all persons in their uniqueness and vulnerability coexist within the enfolding presence of a gracious

17 Vanier, *Becoming Human*, 40.

18 Vanier, *Becoming Human*, 45.

19 Moltmann, J. 1998. *Liberate Yourselves by Accepting One Another*. In Eiesland, N. L. and Saliers D. E. (eds), *Human Disability and the Service of God*. Nashville, TN: Abingdon, 105-22 (121).

20 See Govig, S. 1989. *Strong at the Broken Places: Persons with Disabilities and the Church*. Louisville, KY: Westminster/John Knox.

21 Moltmann, *Liberate Yourselves*, 110.

God. Again, Moltmann notes, a “person with disabilities gives others the precious insight into the woundedness and weakness of human life. But a person with disabilities also gives insight into the humanity of his own world. Through persons with disabilities, other people can come to know the real, suffering, living God, who also loves them infinitely.”²² Put in terms that avoid setting up binary tensions between people with disability (“them”) and non-disabled people (“us”), it could be said that the *issue of disability*, manifest variously in different bodies, calls us (all of us) into acknowledging our common human weaknesses and thus opens us (all of us) more radically to God’s grace.²³

To exist as a finite creature is to be vulnerable. And, speaking theologically as a Christian, it is precisely such vulnerability that God embraces in Christ, entering fully into the frailty of the human condition, even unto a tragic death. Jesus is Emmanuel, God with us. God’s sharing of the divine self in this way sends a distinct message: God is in solidarity with humanity at its most fundamental level, in weakness and brokenness. Here God reveals the divine nature as compassion not only by “undergoing” or “suffering with” human vulnerability, but also by raising it up into God’s own being. Redemption, then, is a welcoming, a divine act of hospitality. It is not a condescending move of pity. Neither does it negate vulnerable finitude by making humans inviolable and perfectly whole. Nancy Eiesland notes this by calling our attention to the fact that Jesus’ body remains scarred after his resurrection.²⁴ So instead of doing away with the capacity to suffer, redemption transforms vulnerability into a communion with God, prefiguring the final eschatological horizon to come when all things will become so transformed.

Thus I contend that disability is both anthropologically and redemptively fundamental. It signifies vulnerability as a condition of the gift of sharing life with one another. Yet there is a need for healing, not because disability signifies “bodies gone wrong”, but because it entails real suffering, sometimes bodily but in many cases communal and social in the form of alienation, exclusion and assimilation. Disability, then, is redemptively fundamental because it opens up our human vulnerability and dependence upon each other and God. This gets to Paul’s proclamation in II Corinthians 12 that God’s power is made “complete” and perfected in weakness. And it has dramatic implications for living together. Wholeness is not self-sufficiency. Rather, it is the genuinely inclusive communion that results from sharing our vulnerable humanity with one another in the light of the grace of God. Would it not be appropriate, then, to open *koinonia* communion to all God’s children, sharing the radically inclusive love of God without representing some people as “abled” and others as “disabled”? Of course, this would mean taking a hard look at our own humanity, the humanity we all share. And doing so could be transformative for ourselves, our religious communities and our society as a whole.

III

On this basis, there is need for another change in the conversation. And I would like to conclude with this (not that I have exhausted all options for change in the

²² Moltmann, *Liberate Yourselves*, 121.

²³ Vanier, *Becoming Human*, 39–41.

²⁴ Eiesland, *The Disabled God*, 98–105.

conversation), using Catholic ethicist Margaret Farley's term, "compassionate respect".²⁵ I see compassionate respect as a way of attending to human dignity. Here the ethical implications of vulnerability come to the fore. Compassionate respect honours persons by paying attention to both equality and difference. That is, it treats someone as equal without therefore being made over and assimilated into the image of what is taken by dominant visions as "normal" – which effectively erases difference – and as *different* without therefore being marginalised as "deviant" and "abnormal" – effectively denying equality.

My concluding proposal is that alterity in the shape of disability is a gift that teaches and empowers communities. As Carolyn Thompson writes: "Disability is about difference; it is one of the characteristics that contribute to the diversity, the plurality of life."²⁶ This is important to stress, first of all because such difference is often stigmatised and excluded by ableist ideologies. Second, it is important because disability itself is not singular, but diverse. The lives of people with disabilities are as varied and different as the lives of those without disabilities. Indeed, it is such difference that God creates as blessed and good, that through encountering it we meet traces of the divine.²⁷ The roots of the injunction to hospitality lie here. The full participation of people with disabilities is not an option for the church, but rather a defining feature, opening up relationships of interdependence and respect and friendship far beyond what is often taken for "inclusion".²⁸

However, is it really inclusion when temporarily able-bodied people practise care as "mainstreaming", "normalising", or "rehabilitating"? Disability scholar Patty Douglas notes in her work on autism and education that inclusion often amounts to a process by which people with disabilities "are not only brought into 'view' as a population subject to 'inclusion', then, but also as a population potentially in need of 'improvement'."²⁹ Based upon what has just been said about equality and difference, I would like to propose an alternative to this. To be *included* entails one's difference being welcomed and made a part of a community, given access to intended participation in that community, treated as an equal belonging among others, like everyone else. To be *inclusive*, then, means intentionally making room for difference, the different treated as difference, not as pathology or a deficit to be cured or fixed before being fully accepted. The link between these two, I believe, is *access*, in that disability is included through accommodation, so that a person with disabilities can participate with others as a contributing part of a community's life. This means recognising difference and diversity, bodily and neurologically, and welcoming it as part of "us" – not something "other" and abnormal, to be remade in the image of the "same" as "normal". It is not so much a matter of accommodating so "you" can be a part of "us" on "our" terms, but rather so you can be with and augment "us" differently, accessing on your

25 Farley, M. 2002. *Compassionate Respect: A Feminist Approach to Medical Ethics and Other Questions*. New York, NY: Paulist Press.

26 Thompson, C. 2009. Ableism: The Face of Oppression as Experienced by People with Disabilities. In Kugawa-Holbrook, S. A. and Montagno, K. B. (eds), *Injustice and the Care of Souls: Taking Difference Seriously in Pastoral Care*. Minneapolis, MN: Fortress, 211-26 (219).

27 See Sacks, J. 2002. *The Dignity of Difference: How to Avoid the Clash of Civilizations*. New York, NY: Continuum, 59.

28 Thompson, Ableism, 221.

29 See Douglas, P. 2010. Problematizing Inclusion: Education and the Question of Autism. *Pedagogy, Culture and Society* 18:105-21 (111).

terms and being a formative part of who “we” are. Rather than communal conformity and homogeneity, a communal heterogeneity and diversity is introduced.

However, does this train of thinking not still subject certain kinds of people to inclusion and care as somehow “special” in “their” difference precisely because of what I have just said above is common to us all (vulnerability)? Is an “us-them” dualism implied despite my efforts to recognise disability as not simply about “those others” but about vulnerability? As if there is a group of people more vulnerable and fragile, an exception to the norm, who need remunerative care and compassion? Here we must acknowledge the dangers of being inclusive, of opening up access through accommodation.

Inclusion as accommodation is potentially insidious in two ways. First, it trades upon misrecognising difference as other, and in fact names kinds of difference as “outside” and thus anomalous, something to be brought into an “inside” that functions normatively as “us”, an identity. As Miroslav Volf bluntly puts it, inclusion “implicitly portrays ‘them’ as the kind of people ‘we’ are not.”³⁰ Inclusion functions by maintaining binary divisions that play out subtle mechanisms of exclusion – to be “us” we need “them” to be different and not equal, and more, to be an inclusive “us” we need to engage “them” insofar as they can become “us”, incorporated into the same. Second, because of this, inclusion can be uncritical and lack self-awareness, assuming the rightness of its own position as an “inside”, all the while masking the fact that the inside itself is a construction based upon “othering” an outside. For people with disabilities, then, inclusion is often experienced via logic that is exclusionary at first (based in a binary figuration), and subsequently assimilative (normalising), all in the name of care and doing good.

In her provocative essay “Violence, Mourning, Politics” Judith Butler uses the term “vulnerability” to suggest that we find another way of imagining community. She contends that we admit “we are alike only in having this condition [of vulnerability] separately and so having in common a condition that cannot be thought without difference.”³¹ This holds together both equality and difference, common sharing and distinctiveness, and opens out into a relationality of vulnerable interdependence. Building from Butler, what is needed, I believe, is a transformative sense of inclusion that connects members of the community, healing by empowering creative agency, not simply by including the helpless or by restoring bodily intactness, but by opening a physical/social space of non-domination and mutuality. Here the genuine recognition of differences can help destabilise normative assumptions about what constitutes an “us”; differences become a teacher opening up communities beyond inclusion toward acknowledging diversity as productive of life together, not a deficiency, differences being equal and not incorporated insofar as they might become the same.

And yet, often practised in religious communities are forms of inclusive accommodation tantamount to tolerance, normalising assimilation, or restricted hospitality. First, with tolerance, different bodies are given minimal access and “put up with” in ways that guarantee the safety of the status quo by keeping the dominant system intact. Tolerance

30 Volf, M. 1996. *Exclusion and Embrace: A Theological Exploration of Identity, Otherness, and Reconciliation*. Nashville, TN: Abingdon Press, 58.

31 Butler, J. 2006. Violence, Mourning, Politics. In *Prekarious Life: The Powers of Mourning and Violence*. London: Verso, 27.

allows deviation, but seeks to manage by distancing it as something that remains “outside” and unable to fully participate (e.g. tolerating noises by disabled people in church, but considering them disruptive instead of communicative). Second, with normalising or assimilative gestures of inclusion, different bodies are remade and fixed/cured to reflect the “inside” as they gain access to participation (e.g. healing ceremonies). Here, romanticised notions of disability as “special” or “gifted” can become ways that people without disabilities project their own need to remake disability into a palatable and meaningful event, an ironic display of normalising powers. Lastly, hospitality itself can be a false pretence, the “host” retaining mastery of the home and the “guest” rendered dependent by receiving gifts of welcome, the home remaining fully under control by the host. All three of these manifest what Iris Marion Young, following Theodore Adorno, calls the “logic of identity”, which in an effort to provide unity and coherence either reduces differences to the same via management and control, or rejects differences as utterly other.³²

These dangers are especially real to me as a parent of a child with autism. How have I accommodated myself to ‘neuro-diversity’ in the shape of autism? Indeed, parenting has been a different life than I imagined, and it’s been hard. No ‘Hallmark Card’ glossing is possible. In relation to Chris’s predicament, I too often suppose that my identity and worth derive from the powers of my ability as a “good parent” to love Chris by helping him get along in the world, coupled with a capacity to be independent and self-initiating, to achieve and be able to control my body in the face of others and thus be recognised as contributing to others around me (children, work, church, etc.) in some way. The irony that Chris raises for me, however, is that this whole setup is bogus. Being in relationship with Chris has taught me that caring for others as different is not a matter of “helping”, of giving from a position of strength, but of recognising my vulnerability and becoming open to the ways I receive from others. Others – in ways that include their “disabilities” – become essential not only to my own flourishing, but also to the common good of the communities in which I flourish together with Chris. This opens up the power of giving through first receiving, receiving from Chris.

Receiving others in such a manner is, as Letty Russell would say, the practice of hospitality at its best.³³ There is no inside/outside binary, but rather a roundtable gathering into which each guest is invited as hosts to one another, joined in relationships of mutual partnership, and giving and receiving rather than dependency relationships of unilateral caring giving. An attentive practice listens and receives, letting-be the speaking voice of another and hearing how she or he perceives. In this way, the margins and the centre, the guest and host, each circulates and shifts among the other, distinctions blurred. The listener comes to confront the biases, false assumptions, and unequal power quotients that obscure encountering the difference of another. Furthermore, the listener responds, adjusting to the way of another by entering into their story. And the speaking voice grows into itself and gains dignity by being heard and accommodated. The dynamic shifts, then, as each trades roles and becomes an other for and with the other in an ongoing exchange of mutual welcome. Communities of genuine partnership are built upon this transformational

32 Young, I. M. 1990. *Justice and the Politics of Difference*. Princeton, NJ: Princeton University Press, 98-9.

33 See Russell, L. M. 2009. *Just Hospitality: God Welcome in a World of Difference*. Shannon, J. and Ott, K. M. (eds). Louisville, KY: Westminster/John Knox Press.

process. And these partnerships also entail a commitment to justice work – confronting enduring systems of power on micro and communal levels, because vulnerability is often not parcelled out equally within such “ongoing exchanges of mutual welcome”.

So I have proposed changing the conversation in three ways: (1) beyond disability as a bodily deprivation or problem to be cured or done away with; (2) beyond the able-disabled binary that pits “inside” versus “outside”; and (3) beyond mere inclusive “accommodation” of disability, but a receiving of its difference as a gift, one that disrupts and pre-empts easy closures, and in the end opens up new transformative possibilities for being in mutual relation. This is what my son, Chris, has taught me. Chris does not need rescuing; he is neither a moral lesson nor an object for my compassion and charity. His is a life radiating with its own preciousness, an excess that constantly disrupts the pretence of normalcy, and accordingly becomes a gift of grace that I could have never planned for on my own terms.

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Theology and disability

What is the question?

2

*Hans S. Reinders*¹

INTRODUCTION

Over the last decades there has been a growing interest in the relation between theology and disability in the academic literature that suggests we are witnessing the birth of a new field. Inspired by a series of remarkable publications, among which *The Disabled God* by the late Nancy Eiesland in 1994 surely was a landmark,² people interested in this emerging field have come together to organise conferences and form new academic platforms for the exchange of ideas and thoughts. Examples are the establishment of the *European Society for the Study of Theology and Disability*³ and the formation of a study group on theology and disability in the *American Academy of Religion*.⁴ Quite recently, people like Amos Young and Debbie Creamer have published important new books, and among these one of my own favourites is *Vulnerable Communion* by Tom Reynolds, published in 2008.⁵

Looking a bit closer at this literature, the main question we find addressed over and over again is the question of inclusion. In many ways people with disabilities and their families do not feel they are included in their communities, nor do they feel welcome to participate. Starting from this experience, the authors then raise the question of what can be done to change this. How can people with disabilities and their families become full members of their communities? Insofar as these communities are shaped by *religious* traditions, theologians try to answer this question from the perspective of the particular tradition they represent. Facing this task, it turns out there are two different ways of approaching it. The one I will identify as the approach of pastoral care. It is very practical, attuned to issues of access, enabling people with disabilities and their families to participate in their community's activities. The main point of this approach is summed up, quite adequately, in the admonition to "practise what you preach". Many people with disabilities have been told they are welcome, but this message is often not followed by appropriate action.

1 Hans S. Reinders is Professor of Ethics, VU University Amsterdam, the Netherlands.

2 Eiesland, N. L. 1994. *The Disabled God: Toward a Liberatory Theology of Disability*. Nashville, TN: Abingdon Press.

3 Online at: <http://esstd.org>

4 Online at: <http://www.aarweb.org>

5 Young, A. 2007. *Theology and Down Syndrome: Reimagining Disability in Late Modernity*. Waco, TX: Baylor University Press; Reynolds, T. E. 2008. *Vulnerable Communion. A Theology of Disability and Hospitality*. Grand Rapids, MI: Brazos; Creamer, D. B. 2009. *Disability and Christian Theology. Embodied Limits and Constructive Possibilities*. Oxford: Oxford University Press. See also Reinders, H. S. *Receiving the Gift of Friendship. Profound Disability, Theological Anthropology and Ethics*. Grand Rapids, MI: Eerdmans.

The other approach is one of critical reflection. It is the approach of systematic theology that focuses upon the belief structure underlying religious practices. Also this approach is certainly interested in changing practices for religious communities to become more inclusive, but it insists upon the primary task of deconstructing the controlling cognitive framework that underscores the existing practices of exclusion, often without people being aware of it. To paraphrase the rule “Practise what you preach”, one could read the second approach as a comment: “Before you start practising, you had better make sure you preach the right thing.”

In this paper I propose to stand back and look at the differences between these two approaches, because they will tell us something important for any theological discourse on disability and human dignity. So I will start with mapping the field to identify what I see as the important question in thinking about disability and human dignity. Particular for readers who are practitioners in medicine, education, or social work, and therefore not necessarily familiar with theological reasoning, starting with a meta-analysis may appear as a bit of a detour. But I hope to show that this procedure, even though it requires some patience, is worthwhile to get our feet back on the ground by knowing where we stand.

Before turning to this task, however, let us look at the beginning. In virtually all the literature on theology and disability that I am aware of, experience comes first. This means that we are introduced to the issue by listening to the all too often disappointing experience of people with disabilities and their families. Usually there are stories to begin with, sometimes first personal,⁶ sometimes collective,⁷ to present testimony of this experience, the experience of being excluded. So let me follow this first step by providing an extensive quotation from the late Nancy Eiesland, where she tells of her less than salutary experience as a child with a congenital disability in the congregation of her family.

As a person with a disability, I could not accept the traditional answers given to my own query of “What is disability?”. Since I have a congenital disability, I have had opportunities to hear and experience many of these so-called answers through the years. They included “You are special in God’s eyes, that’s why you were given this painful disability.” Imagine, it didn’t seem logical. Or “Don’t worry about your pain and suffering now, in heaven you will be made whole.” Again, having been disabled from birth, I came to believe that in heaven I would be absolutely unknown to myself and perhaps to God. My disability has taught me who I am and who God is. What would it mean to be without this knowledge? I was told that God gave me a disability to develop my character. But by age six or seven, I was convinced that I had enough character to last a lifetime. My family frequented faith healers with me in tow. I was never healed. People asked about my hidden sins, but they must have been so well hidden that even I misplaced them. The theology that I heard was inadequate to all of my experience.⁸

6 See Eiesland, *The Disabled God*, 19-20, 116-17; Reynolds, *Vulnerable Communion*, 11-13.

7 Webb-Mitchell, B. 1994. *Unexpected Guests at God’s Banquet. Welcoming People with Disabilities into the Church*. New York, NY: Crossroads.

8 Eiesland, N. 2002. Liberation, Inclusion, and Justice: A Faith Response to Persons with Disabilities. In Gaylord, V., Gaventa, B., Simon, S. R., Norman-McNaney, R. and Amado, A. N. (eds), *Impact: Feature Issue on Faith Communities and Persons with Developmental Disabilities* 14, 143. Online at: <http://ici.umn.edu/products/impact/143> [Accessed: 30 April 2009].

Particularly in the 1980s and 1990s a number of Christian authors testified to similar experiences.⁹ Some recall having been confronted in their local church by the belief that there must be something wrong with disabled people, because if God punishes you with a disability, there must be a reason. Others have been confronted with the opposite belief that God must love you dearly to be given such a special task to fulfil. Both beliefs have confronted many others.

“WHAT CAN WE DO TO HELP THEM?”

To reflect upon the testimony of exclusion, let us look at the first kind of theological response, the response from the point of view of pastoral care. Roughly the strategy followed in this approach goes something like this. Having listened to the experience of being excluded by people with disabilities, the author raises the question of how such people are viewed in the sources of his or her particular tradition. When the author is arguing from the perspective of the Christian tradition, this usually means proceeding from biblical stories, often taken from the New Testament, from which the picture of Jesus’ teaching emerges showing that including marginalised people was the very point of his message.¹⁰ Having established this reading of primary sources, the author then proceeds to describe the implications for a stance toward ‘disability’ as part of the human experience. This part of the analysis usually aims to show that, according to the sources, people with disability are to be recognised as full members of their communities without any justification of discrimination or marginalisation. After the key references have been put in place, the conclusion usually follows that the problem is not what the primary sources of the tradition tell about disabled human beings; the problem is in the practices of everyday life in the religious communities that supposedly live from these sources. In other words: religious traditions are okay, but religious communities and their practices are not okay.

By way of illustration, here are a few examples. Since the strategy that I am describing here is by no means typical of authors committed to the Christian tradition, I have taken them from both Jewish and Islamic sources. The first comes from an essay by Wallace Green, called *Jewish Theological Approaches to the Human Experience of Disability*. Green introduces his argument as follows:

My search of the sources [of Judaism] will reveal a very modern attitude towards disabilities and people with disabilities. Unfortunately, society as a whole, and

⁹ See, for example, Wilke, H. H. 1980. *Creating the Caring Congregation: Guidelines for Ministering with the Handicapped*. Nashville, TN: Abingdon Press; Govig, S. D. 1989. *Strong at the Broken Places: Persons with Disabilities and the Church*. Louisville, KY: Westminster/John Knox; Eiesland, *The Disabled God*.; Creamer, D., 1995. Finding God in Our Bodies: Theology from the Perspective of People with Disabilities. *Journal of Religion in Disability & Rehabilitation* 2(1):27-42; Black, K. 1996. *A Healing Homiletic. Preaching and Disability*. Nashville, TN: Abingdon Press.

¹⁰ There is also a line of argument against this move, however, because of what is seen as the exclusivist view on disability that speaks from the so-called ‘healing narratives’ in which Jesus relates disability to sin. See for example: John M. Hull. 2004. How I discovered my blind brother. In *The Bible in Transmission: A Forum for Change in Church and Culture*. London: Bible Society, 9-11. Online at: <http://www.johnmhull.biz>; see also Black, *A Healing Homiletic*.

to some extent the Jewish community as well, has acknowledged disability but did not always put forth a cogent means to address disability [...]. The power of what is socially acceptable has for too long determined the place of people with disabilities in Jewish society.¹¹

The key distinction here is between “the sources”, on the one hand, and “the Jewish community”, on the other. While the sources show “a very modern attitude towards disability”, the Jewish community apparently does not. Proof for the latter claim is found when Green continues to say that in Jewish communities some conditions were deemed to be acceptable (e.g. wearing eye glasses, using a hearing aid, or walking with a cane), without any stigma attached, but other conditions were not: “Individuals who had learning or physical disabilities, stuttered, or were otherwise labeled as ‘different’ from a societal norm were marginalised.”¹²

Another example stems from an essay by Melinda Jones in the *Journal of Religion, Disability & Health*.¹³ She argues that it is not Jewish Law that is culpable of the unjust treatment of people with disabilities, but

Rather it is Jewish practice and the social action of Jews and Jewish communities that are at fault in the exclusion or abuse of the rights of Jewish people with disabilities. It is not Jewish law that is in need of updating or change, but rather Jews need to take Jewish Law more seriously, if there is to be an inclusive Jewish community.¹⁴

Again the same pattern: the sources of Judaism are not the problem, the conduct of Jewish people and Jewish communities is.¹⁵ This pattern also occurs in an essay called *Disability in the Qur’an* by Maassa Bazna and Tarik Hatab.¹⁶ The authors introduce their approach by making a point about their methodology in the following way:

We were born Muslim and were raised in Arabic-speaking countries where we received education that included only basic and elementary knowledge about Islam. As we grew up, we found it difficult to accept many of the religious notions and practices espoused by the majority of Muslims [with regard to disability]. After several years of reflection and research, we arrived at a renewed understanding that the common Muslim has a duty and a responsibility to examine the original sources [...]. Accordingly, we base our exploration of the attitude and position of Islam towards disability on the Qur’an, in its original Arabic form, and the Hadith.¹⁷

11 Green, W. 2006. Jewish Theological Approaches to the Human Experience of Disability. *Journal of Religion, Disability & Health* 10(3-4):9-26.

12 Green, Jewish Theological Approaches.

13 Jones, M. B. 2007. Judaism, Theology and the Human Rights of People with Disabilities. *Journal of Religion, Disability & Health* 10(3-4), 101-45, (105).

14 Jones, M. B. 2007. Judaism, Theology and the Human Rights, 105.

15 I should mention that Jones argues here against her colleague rabbi Judith Z. Abrams, who in her study *Judaism and Disability. Portrayals in Ancient Texts from the Tanach through the Bavli* (Washington, DC: Gallaudet University Press, 1998) makes the case against the sources of Jewish law.

16 Bazna, M. S. and Hatab, T. A. 2005. Disability in the Qur’an: the Islamic alternative to defining, viewing and relating to disability. *Journal of Religion, Disability & Health* 9(1):5-27.

17 Bazna and Hatab, *Disability in the Qur’an*, 9.

The implication here is the same as in the examples from the Jewish literature. If one listens to how religious people habitually explain their behaviour towards people with disabilities, one is confronted by a view that is unwarranted in the primary sources of their particular tradition.

According to this view, there appears to be a gap between how religious people behave, on the one hand, and how their religion tells them to behave, on the other. The disability scholar M. Miles nicely sums up the point in a review article on the literature in this area. He writes:

Of course, it is true that the practice and behavior of Muslims (as also of Christians, Buddhists, Jews, or adherents of any other religion or philosophy), at particular times and places, has often fallen short of the highest standards taught by each faith or belief; and both belief and practice are usually mixed up with some secular practices that are less than ideal.¹⁸

Miles confirms the claim made above: when it comes to the relation between theology and disability, the problem does not seem to be what a given religious tradition teaches, but whether its followers practise what it teaches. Put differently, the problem is ethics, not theology.

In what follows I will take issue with this view by following the second approach to the task of theological reflection on disability within the Christian tradition. Christian theology has everything to do with the exclusion of marginalised people, and this concerns some of its more profound doctrines. All too often one finds that, if ethics is the problem, an idealist reference to human rights is presented as the solution. Exclusivist religious practices are pushed aside by positing human rights claims for people with disabilities, without inquiring into the underlying religious beliefs that sustain these practices in the first place. Raising human rights awareness in religious communities has a long way to go, however, if we leave the underlying theological framework of exclusion untouched. The same holds for moral appeals to human dignity. Human dignity is only a useful notion when it is developed in a critical encounter with the theological tradition. Put in another way, the approach described above as a theology of access fails to do the hard work, the kind of work that makes inclusion a painful experience for those who are currently occupying communal space, meaning – roughly – me and you. A theology of access frequently trades on the question “What can we do for them?” without recognising that the question unconsciously betrays a vantage point from centre stage. My preferred way of making the point is to say that most people with disabilities do not suffer from their disability, nor do they necessarily suffer from what ‘we’ think about ‘them’. What they suffer from, if anything, is what we think about ourselves, or – even better – our lack of thinking critically about our own position.¹⁹ The issue of thinking about inclusion is thinking theologically about ourselves in ways that eliminate the distinction between people *with* and *without* disabilities. The question to ask is, quite frankly, a very simple one: what in the eyes of God

18 Miles, M. 2007. Islam, Disability and Deafness: A Modern and Historical Bibliography, with Introduction and Annotation. Online at: <http://www.abdn.ac.uk/cshad/documents/ISLAM-DISAB-BibAbdn-070723.pdf> [Accessed: 10 May 2011].

19 Reinders, Receiving the Gift of Friendship, 43-44.

is the difference between human beings who are marked as ‘disabled’ and human beings that are not so marked. To raise the question is to answer it. Theologically speaking, there is no difference. To identify a disabling condition and distinguish it from other conditions is relevant for all sorts of practical purposes. From a religious point of view, however, the distinction between people with and without disabilities is irrelevant.

THE MEANING OF DISABILITY²⁰

To provide the argument for this claim, I propose to look in more detail at the religious meaning ascribed to disability. In the literature on theology and disability you find authors from various religious traditions emphatically denying that people with disabilities are defective human beings in the eyes of God. But of course, one has reason to deny only what other people affirm. As a matter of fact, many religious people *do* believe that disabled people *are* defective human beings and that their disability can be taken as proof. “Rabbi, tell us, who sinned so that this man was born blind?” Even the Gospel implies the belief that connects disability with divine judgment.²¹ This view, which I will call the view of popular religion, holds that there must be something wrong with disabled persons, because if not, why are they disabled? One way to respond to this view is to dismiss it absolutely out of hand as religious bigotry, but I think that would be a mistake. It warrants critical reflection, because it may tell us something important about Christian beliefs.

So let us look in more detail at the religious meanings ascribed to disability, for which I will concentrate exclusively on the Christian tradition. As the earlier quote from Nancy Eiesland already indicated, there are both negative and positive meanings. On the negative side, disability has been named a curse, a punishment for sins committed, either by the disabled person herself or by others, a lack of faith, a sign of imperfection, or a blemish that renders this person unfit to approach God in worship. In view of these negative responses, people tell us that they have caused them to consider withdrawing from the Christian Church altogether. Wounded people come to a community looking for consolation, only to find judgment, which is about the opposite of what they had hoped to find.²² The same is experienced by students in institutions for higher education in theology who are refused because they are deemed unfit, either for Church ministry or for theological research.²³ Among the positive responses are those that call disability a blessing, or a special token of God’s love, or an opportunity for spiritual growth. Disabled children have been called “holy innocents”, God’s “little ones”; they have also been referred to as “the poor” – as in the Beatitudes.²⁴

20 This section and the following contains materials from Reinders, H. S. 2011. Is There Meaning and Disability? Or Is It the Wrong Question? *Journal of Religion, Disability & Health* 15(1):62-69.

21 In the present case I am referring, of course, to the Gospel of John, chapter 9.

22 Reynolds, *Vulnerable Communion*, 11-13.

23 Anderson, R. C. (ed.). 2003. *Graduate Theological Education and the Human Experience of Disability*. Binghamton, NY: Haworth.

24 Reynolds, *Vulnerable Communion*, 16.

While such positively intended comments seem to forestall explanations of divine judgment as an affront, they are nonetheless to be rejected. Whether a curse or a blessing, the underlying assumption in both types of responses is that disability is a *special* condition of being human. But in my view the language of “special” is suspect. One finds it in standard phrases such as “special needs” and “special education”, or “Special Olympics”, all of which share the same implication: “special” refers to people excluded from mainstream society. The language of “special” predicates a culturally mediated dichotomy: there is “special” as distinct from “general”, there is “abnormal” as distinct from “normal”, each of which reflects the basic opposition: there is “disabled” as distinct from “non-disabled”.²⁵ One way or another, positive or negative responses to disability as a special condition are to be criticised for being indebted to patterns of exclusion. Whether God has blessed you or punished you, in both cases you are set aside from his other creatures about whom such verdicts are usually not communicated. That is what is wrong with them.

Looking at the issue in this way, it seems that the very act of ascribing religious meaning to disability must be inevitably suspect. Each and every attempt to do so depends on the assumption that disability is a special problem that needs a special answer. In view of this consideration, the theological question begins to take a more definite shape. Does what we want to say about disability, theologically speaking, have anything to do with ‘meaning’? It cannot be denied that religion has reinforced social stigma, even when this may not be the only thing it has done. God has too often been perceived as being on the side of ‘normal’ people, represented by ‘us’, leaving anybody perceived as ‘abnormal’ out, meaning ‘them’. Whatever religious responses have contributed to the experience of people with disabilities, therefore, empowering them in living their daily lives has very rarely been part of it. So the question before us is what theological reflection has to say to people with disabilities that does not set them apart from the rest of humanity?

RETHINKING PROVIDENCE

As indicated above, I suggest that the answer starts with reflecting critically upon the controlling theological framework underlying religious beliefs. Here I will focus on the implicit reference to *providence* in the responses listed above. Whether it is termed a ‘curse’ or a ‘blessing’, in both cases the occurrence of disability is obviously attributed to the divine will. Because it implies that nothing happens in the world that people do not somehow deserve, this attribution introduces the notion of a divinely governed universe. The pattern is apparent in the disciples’ question in the Gospel of John already referred to: “Rabbi, tell us, who sinned that this man was born blind?” The question in itself presupposes a moral geometry that regards the occurrence of disability in terms of culpability or merit. According to this presupposition, the universe is governed in such a way that for every bad result there must be a bad cause, and, conversely, for every good result there must be a good

25 Criticising this dichotomy, disability studies scholars have coined the phrase of “temporarily able bodied” to indicate that “disability”, in some form or other, is part of the human condition. It does not contradict the human condition, as the dichotomising distinctions suggest.

cause. When a disability occurs – presumably a bad result – there must be a bad cause, like disobedience to God for which you are punished with a disability.

It can be shown that this theology is in fact highly implausible, however. In fact, it can only be maintained by people who forget to ask about their own location in the scheme of universal retribution. To believe that God may send disabling conditions upon people to punish them for their wrongdoings is implausible, because it is hard to see that their wrongdoings exceed mine, or yours, for that matter. Since we have not been punished similarly, the conclusion should follow that divine justice is in fact a mockery. If it were true that God sends disabling conditions upon some but not on others, this would mean that in distributing good and evil, his will works about as randomly as chance and fortune do. In fact, this implication would render the very notion of a *divine* will meaningless. A divine will that as such is indistinguishable from chance or fortune cannot be a divine will in any meaningful sense of the term. Of course, it can be argued that this consideration is a persuasive reason to abandon the belief in a divine will, which it might well be. But it can hardly be a reason for those who implicate their belief in a divine will by attributing the occurrence of disability to it.

There is a second argument, however, why attributing disability to divine judgment is implausible. This argument appears when we bring to light another presupposition. The belief that good things happen to good people and that therefore – on the assumption that disability is not a good thing – people with disabilities cannot be good, presupposes in fact that there is no contingency in our lives. If whatever happens to people happens because of a divinely controlled moral geometry, there is no logical space left for contingency. It could never be true that some things just happen for no reason at all. Without contingency, however, religious believers could never be uncertain about God's will, for then would be nothing occurring in their lives that would not be his will. Consequently, they could never be in the dark about why God commands that bad things happen to good people. As a matter of fact, it would be hard to explain how bad things can be bad if God wills them, nor would it be easy to explain how good people can be good if God judges them to deserve such things.

The understanding of providence that eliminates contingency from its picture of the universe is implausible, because it has been experienced by all people of all times that their moral equations do not add up. Too often people who deserve to be punished walk away freely. And too often people have been hit undeservingly by life's contingencies. The cry for a providential God is most intensely felt precisely at those moments when life seems to turn against us. So it is rather *because of* the overwhelming force of life's contingencies that questions about divine justice arise. The Dutch anthropologist Van Baal writes accordingly:

Man experiences his universe as a universe full of intentions, a universe which holds a claim on him, addressing him with something undefined, urging him to act or to be in some way or another. The experience is strongest in moments of crisis, when events turn up with such an overwhelming force that it is as if they address their victim, delivering a message to him.²⁶

²⁶ Van Baal, J. n.d. Providence. In *Encyclopædia Britannica*. Online at: <http://www.britannica.com/EBchecked/topic/47249/J-van-Baal> [Accessed: 6 August 2008].

If it were not for this experience – the experience of existential crisis – the Book of Psalms would not exist. Crying out for God’s help in the feeling of abandonment at one moment, the Psalmist exalts in God’s praise in the next, reassuring himself that he will not be forsaken. Providence is what you need in the face of being swept off your feet by life’s contingencies. Put differently, it is the benumbing experience of moral *perplexity*, trying to find God in his absence, rather than the supposition of a moral *geometry* that invokes the ‘why?’ question.

When we bring both these arguments together, we see that they both point in the same direction. Attributing the things people have to face in their lives to the divine will is only plausible as long as one leaves oneself out the picture. One will refrain from such attribution as soon as one ponders the things happening in one’s own life, for it will be very hard to ‘read’ these things consistently in terms of punishments and rewards. These considerations are sufficient to conclude that the connection between disability and divine judgment cannot stand the test of critical reflection. We will resist making this connection as soon as we bring our own location in the scheme of divine justice into the equation.

At this point we see why thinking theologically about disability is first of all a question of proper self-knowledge. The claim that when people with disability suffer, they usually suffer from what ‘we’ – to the extent that we distinguish ourselves from ‘them’ – think about ourselves, can now be reformulated theologically. When people with disabilities suffer, they usually suffer from the fact that others fail to see that they are in exactly the same place in the eyes of God. *Coram Deo* there is no difference between human beings. His judgment as well as his grace rests equally upon each and every one of us. The question of whether disability has to do with divine judgment becomes implausible as soon as I realise that my own position before him is not different from yours, regardless of the state or condition of either one of us.

The same argument holds against the view that puts people with disabilities in a privileged position, as occurs in the positively intended religious responses that I mentioned before. Surely people with disabilities are special in the eyes of God, but not in the sense that they are more special than you or me, or anybody else for that matter. There is no justification for setting people apart, therefore – at least not in Judaism, Islam or Christianity. In the end the argument against ascribing a religious meaning to the occurrence of disability in terms of either culpability or merit rests on a simple mistake. The mistake is namely that of seeing the existence of people with disabilities as the exception to a divine rule – the rule that as his creatures we stand in equal relationship to him – that is what is wrong with this view.

HUMAN DIGNITY

If this is true, then the foregoing arguments have important implications for thinking theologically about human dignity as well. If we ponder the question of what human dignity is and on what grounds the respect demanded for it can be justified, we soon come across the idea that human dignity is based on our distinct human capacities. But this view cannot be true, for it is precisely the distinct human capacities that render us unequal. There is a huge difference in human individuals when it comes to their potential

for developing human capacities, even to the point where these capacities almost are completely absent, as in some persons with profound intellectual disability. But also in other cases, such as elderly persons with dementia, or persons with chronic mental disease, the view that grounds their dignity in their capacities in fact undermines the moral claim to respect. What reason do we have to respect people because of particular capacities, if it happens to be the case that they do not possess these capacities?²⁷

A theological reflection along the lines I laid out in the foregoing sections, however, immediately clarifies at least this one point. Human dignity is conferred upon each and every one of us because of our equal relationship with God. It is not the relationship we have with him by virtue of our distinctive capacities, as the theological tradition in Christianity has often maintained,²⁸ but the relationship he has with us as his creatures that grounds our dignity. In other words, human dignity is *dignitas aliena*, as Martin Luther had it. If it is true – as I have argued – that people stand equal before God because there is no difference between them as his creatures, then human dignity is a creaturely notion. It is conferred upon human being by the grace of God in which all share equally.

Finally, I would like to suggest that this theological account of human dignity has a very important ethical implication as well. It is best explained by comparing secular arguments referring to human dignity in the public domain. In the public domain we find human dignity claimed as commanding the respect for our fellow human beings that guarantees them equal moral standing as equal citizens. Important as this is for public morality, the theological account of human dignity pulls in a different direction. If the theological basis for human dignity lies in the fact that God bestows on all his creatures – *with* or *without* disabilities – his loving kindness, then it is hard to deny that he expects his creatures to do the same.

People with disabilities face some hardships in life. To the extent that these hardships are caused or reinforced by how other people treat them, it is incumbent upon Christians to support them, so that they regain trust in their lives. That is what their stories tell us. There can be any number of ways to regain trust, of course, but from a Christian point of view there is no way to regain trust in life that does not proceed from God, and the same holds true for Judaism and Islam as well. Not because in turning to God one finds all the answers. As human beings we do not always understand the divine will. Many things happen in our lives that we do not understand. Life hits us at times with its contingencies, and we do not have answers as to why that is. But instead of being a reason for despair, it does not matter, ultimately. According to the Christian tradition, Christ promised that his Spirit will be with those who find faith and hope in his life. If they turn to God, it is not because of the answers, but because of the promise that he will be with them in their times of despair. The Spirit of divine love – the Paraclete, as the Gospel of John says – will help people to regain trust in the midst of experiencing hardships because it will unite them with others. That is what the Spirit does; it forges the bonds of friendship by inspiring people to embody loving kindness toward one another. The gift of the Spirit is to open our eyes to the possibility of friendship.

27 On this question, see Hans S. Reinders, 2006. *Human Dignity in the Absence of Agency*. In Soulen, K. and Woodhead, L. (eds), *God and Human Dignity*. Grand Rapids, MI: Eerdmans, 121-39.

28 See Reinders, *Receiving the Gift of Friendship*, 229-31.

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Hope, vulnerability and disability?

A theological perspective

3

Nico Koopman¹

INTRODUCTION

This chapter attempts to offer a cursory, but hopefully nuanced, description of vulnerability. Vulnerability is firstly described in terms of the threat of unfulfilled needs. Humans are always under the threat that our physical, social and spiritual or teleological needs might not be met. The second dimension of vulnerability is that of suffering. Where our needs are not met, we experience various forms of suffering, namely physical, social and teleological. Disability is discussed as a specific expression of vulnerability. Two major responses to vulnerability will be discussed, namely anxiety and hope. Over against anxiety as a way of dealing with vulnerability, the Christological hope of the heavenly solidarity of the cross of Christ, and the expectation of renewal of the resurrection of Christ, are suggested as a faithful response to vulnerability. This hope is described as realistic hope, responsible hope and resilient hope. Throughout the paper a distinction is made between the general vulnerability to which all human beings are exposed, and the specific vulnerabilities that specific humans (people with disabilities) live with.

ON VULNERABILITY

The notion of vulnerability is used in a variety of ways. Vulnerability firstly means that we are at risk and face the threat to suffer. We are predisposed to various forms of suffering. We are frail and fragile and can easily be wronged and hurt. Theologian Thomas Reynolds² refers to the root meaning of vulnerability to illustrate this point. Vulnerability derives from the Latin word *vulnerare*, to injure and harm, and to be open to be wounded, or in my words, to be under the threat of, and be predisposed to, being hurt and wounded. Secondly, vulnerability refers to our actual and concrete suffering in a variety of forms.

1 Nico Koopman is Professor of Systematic Theology, Dean of the Faculty of Theology and Director of the Beyers Naudé Centre for Public Theology at Stellenbosch University. The ideas and arguments in this article build upon, advance and appropriate previous work of the author on related themes. See, for instance, Koopman, N. 2009. Endgültige Heilung? Vorläufige Heilung? Fürsorge? Christliche Hoffnung und Krankheit. In Thomas, G. and Karle, I. (eds), *Krankheitsdeutung in der postsäkularen Gesellschaft. Theologische Ansätze im interdisziplinären Gespräch*. Stuttgart: W. Kohlhammer, 393-407; Koopman, N. 2003. The dis(ot)herly)-abled and public morality. *Scriptura* 1(82):72-81.

2 Reynolds, T. E. 2008. *Vulnerable Communion. A Theology of Disability and Hospitality*. Grand Rapids, MI: Brazos, 108.

Vulnerable beings are always at risk and under the threat that our basic needs for dignified living might not be met. Three types of needs need to be addressed in order to avoid severe suffering and to experience a life of dignity.

Psychologist Abraham Maslow and, in line with his thinking, Dutch social scientist Rob Buitenweg, identify three sets of basic human needs to be addressed in order for humans to flourish. The first set of needs pertains to our physical needs, namely the need for goods such as housing, food, water, clothing, medical care and education. Our vulnerability with regard to the fulfilment of these needs might be called physical vulnerability.

The second set of needs refers to our need for safety and security, and also the need to participate in different spheres of life, including the political and economical domains. Living in communion with others and not being alienated and excluded are central aspects of the fulfilment of this second set of needs. The predisposition to the non-fulfilment of these needs might be called social vulnerability

The third set of needs refers to our quest for the freedom to actualise our potentialities and to render meaningful service to others. The fragility that we experience with regard to the fulfilment of these needs can be termed teleological vulnerability, since it has to do with the meaning-giving *telos*, purpose and aim of our lives.

When these sets of needs are not met, we experience suffering in a variety of forms. Dutch theologian Bram van de Beek³ discusses the various faces of human suffering, i.e. physical, psychological, social, political and economic. Suffering takes on the form of homelessness, hunger and famine, dehydration, nakedness, illness, death, assault, violence, alienation, exclusion, political oppression, poverty. Suffering is intensified by the powerlessness to overcome forms of suffering such as severe poverty, illness and death. Van de Beek states that all forms of suffering, also the suffering of animals and perhaps also plants, constitute the violation of wholeness and *shalom*.

DISABILITY AS EXPRESSION OF VULNERABILITY

Our vulnerability comes to expression in multiple ways. The various disabilities with which human beings live may be one concrete expression of our vulnerability.⁴ Indeed, Alasdair MacIntyre⁵ explains that all humans face forms of disability and dependency throughout their lifespan. “This dependence on particular others for protection and sustenance is most obvious in early childhood and in old age. But between these first and last stages our lives are characteristically marked by longer or shorter periods of injury, illness or other disablement and some among us are disabled for their entire lives.”

3 Van de Beek, A. 1984. *Waarom? Over Lijden, Schuld en God*. (Why? On Suffering, Guilt and God) Baarn: Nijkerk: G.F. Callenbach BV, 24-6.

4 Not all people with disabilities would regard themselves as more vulnerable than other people, nor would they be regarded as such.

5 MacIntyre, A. 1999. *Dependent Rational Animals. Why Human Beings Need the Virtues*. London: Duckworth, 1.

MacIntyre⁶ is convinced that Western societies, and I would add African and other societies of the world, attend inadequately to the depth of the challenge of vulnerability, dependency and disability.

From Plato to Moore and since, there are usually, with some rare exceptions, only passing references to human vulnerability and affliction and to the connections between them and our dependence on others [...]. Dependence on others is of course often recognised in a general way, usually as something that we need in order to achieve our positive goals. But an acknowledgement of anything like the full extent of that dependence and of the ways it stems from our vulnerability and our afflictions is generally absent.

This illuminating description of the general vulnerability and general disability, and consequent dependency, of all human beings does not relativise or minimise the variety of specific vulnerabilities and specific disabilities, and the consequent unique challenges, that human beings have to live with.

People with disabilities experience vulnerability in ways which are different from those experienced by the general population. If we listen to their experiences, we will hear the various narratives of risk, predisposition, fragility, vulnerability and actual suffering and wrongs.

People with disabilities experience physical vulnerability, as described above, in a specific way. Many, for instance, experience viscerally how buildings are constructed in unfriendly manner. Most of our buildings in South Africa do not cater for the variety of needs of people with disabilities. The conference where this paper was originally to be read had to be moved to another venue because the buildings of the Faculty of Theology were not adequately accessible for people with mobility impairments.

People with disabilities also experience social vulnerability in a specific way. At a recent conference I was saddened to see how people started to avoid those conference participants who were disabled. People with disabilities were excluded to some extent from some of the very important informal social interaction between sessions during conferences. This social exclusion is an issue across the board for people with disabilities, but may be especially acute for people with sensory and communication impairments.

People with disabilities also experience teleological vulnerability. They are to some extent excluded from opportunities to make unique, indispensable contributions. In a culture of economisation, commodification and the estimating of someone's worth in terms of economic value, people with disabilities experience that their contributions are valued less, because they are presumed to have less economic value. In a culture of economisation these people often experience that they are not making a meaningful contribution. It is

⁶ MacIntyre, *Rational Animals*, 1-3. MacIntyre's post-liberal anthropology of dependent living constitutes a criticism of liberal anthropologies that are dominated by the idea of rationality, autonomy and independence. His work is, however, increasingly attended to in modern-postmodern societies. I appreciate the fact that more attention is given to the notion of vulnerability and dependence in contemporary anthropological discourses, as well as in the work of philosophers such as Eva Kittay (see, for example, Kittay E. 2009. The personal is philosophical is political: a philosopher and a mother of a cognitively disabled person sends notes from the battlefield. *Metaphilosophy* 40(3-4):606-7 (607e27), and social theorists such as Judith Butler (see, for example, Butler J. 2006. *Precarious Life: The Powers of Mourning and Violence*. New York, NY: Verso).

more difficult for them to receive messages from society that they are making unique and indispensable contributions to the common good.⁷ It is consequently more difficult for them to live with the knowledge that their lives have meaning, purpose, *telos*.

ANXIETY AS RESPONSE TO VULNERABILITY

The very influential North American theologian, Reinhold Niebuhr,⁸ argued decades ago that individual human beings, and even groups and nations, respond to vulnerability with anxiety. We struggle to accept our vulnerabilities and to live constructively with them. He even argues that we hide our anxieties in various forms of pride, namely the pride of power, intellect, morality and religiosity. This pride is often the cause of personal and public expressions of aggression and violence.

Another influential American theologian, Paul Tillich,⁹ identified three forms of anxiety that we as vulnerable human beings live with. His typology exercises great influence to this day, and in fact receives renewed attention in modern-postmodern societies with high levels of anxiety. These anxieties are the anxiety about fate and death, emptiness and meaninglessness, guilt and condemnation. We are sinners, and we have the status of being guilty, and we therefore face the risk of condemnation and rejection. We are finite beings who are exposed to the threat of fate, tragedy, contingency and death. The most severe form of anxiety is the anxiety about emptiness and meaninglessness.

Tillich argues that we simultaneously experience all these anxieties, which are inter-related.¹⁰ Sometimes one of them is prominent, whilst the others are also present. These types of anxiety manifest in the personal biographies of individuals, but also in the histories of broader societies and civilisations. Up to the Middle Ages fate and death were the prominent causes of anxiety. During the late Middle Ages and Reformation period guilt and condemnation had to be addressed, and in the modern period since the Enlightenment the anxiety about meaninglessness and purposelessness has had to be dealt with.

Many people respond to vulnerability and disability to offer judgemental and condemning explanations of the causes of disability. These explanations often evoke the type of anxieties that Tillich refers to. People with disabilities in both the general and specific senses often have to face these anxieties. Often well-meaning, self-appointed people who attempt to make sense of their lives with disability evoke these anxieties. They explain

7 There are two issues at stake here. First, it is true that some people with disabilities will not make the same economic contribution as other people, and it is an indictment that their humanness is therefore seen as less valuable than that of others. Second, despite some good evidence that people with disabilities are often more productive employees than other employees, social values and organisational cultures may create barriers to economic participation by people with disabilities who have a substantial economic contribution to make (see, for example, Schur, L., Kruse, D. and Blanck, P. 2005. *Corporate Culture and the Employment of Persons with Disabilities*. *Behavioral Sciences and the Law* 23:3-20.

8 Niebuhr, R. 1949. *The Nature and Destiny of Man. A Christian Interpretation*. Vol.2. New York, NY: Scribner, 161-213.

9 Tillich, P. 1952 (1961 repr.). *The Courage to Be*. Digswell Place: James Nisbet, 1961 repr., 37-51.

10 Tillich, *The Courage to Be*, 53-9.

that their disability or the disability of a family member is a matter of fate. This is simply how the dice have fallen for them, and they must make peace with that. Their disability might also be attributed to their sin and guilt, or the sin and guilt of a forebear, and an expression of their condemnation. These explanations of the causes of especially specific disabilities, as well as inadequate confirmation by society of the unique contribution to the common good made by people with disabilities, may contribute to a sense of emptiness and meaninglessness among some of them.

Anxieties experienced by both vulnerable people in general, and people with disabilities, might lead to despair, which can only be overcome by courage and fortitude that flow from hope.

HOPE AS RESPONSE TO VULNERABILITY

Over against anxiety as a response to vulnerability and disability, the Christological hope of the heavenly solidarity of the cross and the expectation of renewal of the open grave are suggested as a faithful response to vulnerability. This hope is described as realistic hope, responsible hope and resilient hope. This threefold hope perspective might have meaning for all of us in all our vulnerability, as described above, and especially for people with disabilities.

► Realistic hope

German theologian Gerhard Sauter describes hope in terms of a so-called realistic eschatology. Sauter bases hope in the promises and actions of the triune God.¹¹ Hope means trust in the good that God has promised and provided. Hope is rooted in God's promises and through it in the confidence in God's providence.¹² Hope, according to Sauter, is not only based in the historical act of the resurrection of Christ, but more so in the communion with the resurrected Christ who is present through his Spirit. This communion with the resurrected Christ who, as One seated at the right hand of the Father, enjoys inner-Trinitarian communion, says Sauter, is the basis of our hope.¹³ This inner-Trinitarian communion between Father, Son and Spirit is why Christ is present with us, why we enjoy communion with Him, and why we have reason to hope. Sauter also writes about God's hope.¹⁴ God waits patiently and tirelessly for us to put our confidence in his promises and acting, and for us to leave room for his redeeming activity. On this hope of God for us, our hope rests!¹⁵ Sauter bases our hope in communion with the resurrected and ascended and reigning Christ.

11 Sauter, G. 2000. Our Reasons for Hope. In Polkinghorne, J. and Welker, M. (eds), *The End of the World and the Ends of God. Science and Theology on Eschatology*. Harrisburg, PA: Trinity Press, 211-16.

12 Sauter, Our reasons for Hope, 211.

13 Sauter, Our Reasons for Hope, 212.

14 Sauter, Our Reasons for Hope, 214.

15 For a more extensive account of Sauter's views on eschatology and the Trinitarian roots of hope, see his 1999 publication, *What dare we hope? Reconsidering eschatology*. Harrisburg, PA: Trinity.

Realistic hope also rests in and grows from the reality of our communion with the living Christ who is also the crucified Lord. On his cross we witness God's ultimate identification and solidarity with vulnerable and suffering people, with people having to live with disabilities. In the cross of Jesus Christ God reveals Himself as the God of "com-passion". Some theologians would even go further and state that in Jesus Christ we meet God as the vulnerable God, even the disabled God.

Realistic hope does not call us to a withdrawal from the world with all its challenges. Realistic hope sees the reality of this world, but also imagines and envisages new possibilities. Famous Brazilian theologian Rubem Alves also describes hope as realistic hope.

What is hope? It is the presentiment that imagination is more real and reality less real than it looks. It is the hunch that the overwhelming brutality of facts that oppress and repress is not the last word. It is the suspicion that Reality is much more complex than realism wants us to believe; that the frontiers of the possible are not determined by the limits of the actual, and that in a miraculous and unexpected way life is preparing the creative event which will open the way to freedom and resurrection.¹⁶

Decades ago, the German theologian Eberhard Jüngel¹⁷ argued that hope enables us to imagine what is possible in the midst of the old broken reality. Realistic hope enables us to consistently distinguish between current reality and envisaged possibility. Applied to the theme of this paper, we can argue that realistic hope enables us to acknowledge the struggles and suffering of especially people with disabilities, as well as the prejudices, wrongs and injustices against them. Simultaneously realistic hope enables us to imagine, envision and work for the actualisation of new possibilities where all people, especially people with disabilities, experience justice, peace and joy.

One also needs to emphasise that this realistic hopes resides in the reality of the presence of the resurrected Lord who is also the crucified Lord. Exactly the central Christian conviction that Jesus Christ had experienced specific vulnerability, suffering and even the ultimate specific disability of god-forsakenness, communicates the hopeful reality of heavenly solidarity with people with disabilities.

► Responsible hope

Responsible hope means that we give account of the hope living in us. And we give account of this hope by responding faithfully to God's call to seek a life of wellbeing and wholeness for his people and all of creation, a life of dignity, justice and freedom. Responsible hope is responsive to, answers to, this vision of dignity. Responsible hope is also responsive to betrayals of this dignity, especially with regard to the most vulnerable in society.

Responsible hope comes to expression in the quest for justice for all people. Famous American theologian Nicholas Wolterstorff explains how exposure to suffering and wronged people made him change his mind.¹⁸ He no longer emphasised responsibility as a

16 Alves, R. 1972. *Tomorrow's Child. Imagination, Creativity, and the Rebirth of Culture*. New York NY, Evanston, IL, San Francisco, CA, London: Harper & Row, 194.

17 Jüngel, E. 1969. Die Welt als Möglichkeit und Wirklichkeit. *Evangelische Theologie* 29:417-42.

18 Wolterstorff, N. 2011. *Hearing the Call. Liturgy, Justice, Church, and World*. Gornik, M. R. and Thompson, G. (eds). Grand Rapids, MI/Cambridge: William B. Eerdmans, 13-14.

faithful response to the gospel, but justice for all, especially the most vulnerable. He makes justice to the most vulnerable – and for the purpose of this article, justice to people with disabilities – the acid test for a just society.

A society is just when all the little ones, all the defenceless ones, all the unprotected ones have been brought back into community, to enjoy a fair share in the community's goods, and a standing and voice in the affairs of the community.¹⁹

Wolterstorff even reminds us of John Calvin's statement that to wreak injustice on one's fellow human beings is to wound and injure God.²⁰

Responsible hope is concrete hope, active hope. Stellenbosch theologian and University Vice-Chancellor, Russel Botman, describes this responsible hope as hope in action. Botman writes remarkably about this hope in action.

When the scientist works with conscience to find a cure for cancer, we see God's mission as hope in action. When people call for the forgiveness of the debt of "the third world countries", we see God's mission as hope in action. When an investor in North America conducts business as if the children in Africa are his or her own, we see God's mission as hope in action. When a Cuban doctor goes to the poor villages of South Africa to reduce the infant mortality rate, we see God's mission as hope in action. When a person in sub-Saharan Africa is trained to care for people living with HIV-AIDS, we see God's mission as hope in action. When a church opens its heart to the homeless, we see God's mission as hope in action. When subjugated cultures find their way back into the church, we see God's mission as hope in action. When communities opt for reconciliation instead of civil war, we see God's mission as hope in action [...]. I know you want to stop me here, saying, "But these things are already happening." I answer, "Precisely, my argument as well".²¹

This hope in action compels all of us to work for the realisation of dignity and compassionate justice to all people, in a special way to people with disabilities. This quest for dignity and compassionate justice implies care for those with disabilities. It also challenges us to work for the fulfilment of human dignity and human rights for all, including people with disabilities. The three generations or dimensions of human rights, namely political and civil rights, socio-economic rights, and the right to develop environmental sustainability, all address the three sets of needs of humans.

Responsible hope addresses the plea of people like feminist theologian Christine Smith, who argues that the plight of people with disabilities be addressed with a focus on particular individuals with their particular narratives in the context of human dignity and human rights. Smith pleads that the variety of disabilities be recognised and that disabilities and people with disabilities not be generalised and stereotyped, but that the particularity of not only a specific disability but also of the life of a specific person with a disability be heard, read and known.²² This plea for particularity is affirmed by a woman with a disability, who is quoted by Smith:

19 Wolterstorff, *Hearing the Call*, 14.

20 Wolterstorff, *Hearing the Call*, 15.

21 Botman, H. 2001. Hope as the coming reign of God. In Brueggemann, W. (ed.), *Hope for the World. Mission in a Global Context*. Louisville, KY/London: Westminster John Knox, 80.

22 Smith, C. 1992. *Preaching as Weeping, Confession, and Resistance: Radical Response to Radical Evil*. Louisville, KY. Westminster/John Knox, 21-30.

So many factors influence how we experience our disabilities. Money. Degrees of mobility. Relationships. Community structures. Cultural/ethnic/racial backgrounds. Whether our disabilities are progressive or stable; whether they're visible or hidden; whether they're life-threatening; whether they're clearly diagnosed or mysteries to Western medicine; whether they cause us pain; whether they break up regular sleeping and eating patterns; whether we grew up with them or they were caused by disease or accident later in life.²³

Responsible hope helps us to view the plight of people with disabilities as a common good plight. Alasdair MacIntyre pleads that the plight of people with disabilities be addressed as a common good challenge. He articulates this inclusive understanding of dependence as follows:

[...] consequently our interest in how the need of the disabled are adequately voiced and met is not a special interest, the interest of one particular group rather than of others, but rather the interest of the whole political society, an interest that is integral to their conception of their common good.²⁴

Responsible hope enables us to relate the notion of care to the idea of responsibility and justice. Sharon Welch argues that an ethic of caring as responsiveness to others,²⁵ as preventing harm and maintaining relationships, as Carol Gilligan describes it, is not a sufficient response to brokenness in the form of social injustices. She rather pleads for an understanding of care in terms of an ethics of risk. She describes the aims of an ethic of responsibility and risk as follows:

The aims of an ethic of risk may be modest, yet it offers the potential of sustained resistance against overwhelming odds. The aim is simple – given that we cannot guarantee an end to racism or the prevention of nuclear war, we can prevent our own capitulation to structural evil. We can participate in a long heritage of resistance, standing with those who have worked for change in the past. We can also take risks, trying to create the conditions that will evoke and sustain further resistance. We can help create the conditions necessary for peace and justice, realising the choices of others can be influenced and responded to, never controlled. Even if we prevent nuclear war in our lifetime, the challenge of preventing such destruction will also be faced by another generation. We cannot make their choices; we can only provide a heritage of persistence, imagination, and solidarity.²⁶

An ethic of risk, according to Welch,²⁷ entails that those who benefit from an unjust system are called upon not to be oblivious to the nature of their exploitation of oppressed people, to acknowledge this exploitation, to repent and converse, to be aware of the fact that our ancestors who were well educated, well-mannered, loving and kind people, participated in a mechanism of oppression, to overcome the inability to hear and tolerate the rage of oppressed people, to let go of the upper-class certainty of the right to control others and of the arrogant assumption of the universal validity of upper-class morality, to acknowledge the equality in dignity of oppressed people and to be open to developing a new identity in the light of the legacy of oppression without being afraid that this change implies loss

23 Smith, *Preaching as Weeping*, 21-2.

24 MacIntyre, *Dependent Rational Animals*, 130.

25 Welch, S. 1990. *A Feminine Ethic of Risk*. Minneapolis, MN: Fortress.

26 Welch, *A Feminine Ethic*, 22.

27 Welch, *A Feminine Ethic*, 55-64.

and self-destruction, to share in the ‘dangerous memory’ of oppressed people that it had been a people of dignity and self-respect who had been oppressed, to be freed from despair in the discovering of injustices by participating in the heritage of courage and wisdom of oppressed people.

Responsible hope is embodied through an ethic of risk, an ethic that proposes epistemologies, policies and practices that seek the actualisation of dignity, justice and freedom for all struggling people, including people with disabilities. Welch’s analysis provides illuminating parameters for discussing the pursuit of justice for people with disabilities.

The needs of people with disabilities, therefore, need to be addressed in the context of a broader quest for justice. The plight of people with disabilities is specifically to be discussed and addressed in the framework of human rights discourse. It needs to be addressed in the framework of first-, second- and third-dimension human rights. This implies that their first-dimension political and citizenship rights are to be advanced, as well as their second-dimension socio-economic rights, and also their third-dimension developmental rights in the context of the sustainability and ecological rights of the natural environment.

This brief discussion makes it clear that responsible hope entails that our ethos, our epistemologies, our individual choices and communal policies, as well as our individual conduct and collective practices should facilitate the expression of dignity, compassionate justice and freedom to all, and particularly to people with disabilities.

► Resilient hope

Resilient hope enables us to live with patience amidst vulnerability, fragility and disability; with courage amidst suffering; with fortitude amidst injustice and dehumanisation. Paul Tillich’s notion of courage and fortitude might be viewed as a manifestation of resilient hope. He pleads for a courage that is both ethical and ontological.

Courage as a human act, as a matter of valuation, is an ethical concept. Courage as the universal and essential self-affirmation of one’s being is an ontological concept. The courage to be is the ethical act in which man [sic] affirms his own being in spite of those elements of his existence which conflict with his essential self-affirmation.²⁸

The courage that is an expression of resilient hope is the courage to be, the courage to act morally and to accept your being amidst many threats to that being.

This courage to be is manifested in the realisation that I am part of a whole, that I can also be alone, and that I receive my courage from a transcendent being, in the case of Christianity from the triune God. And where I live with this courage to be I overcome despair which is especially the outcome of the anxiety of meaninglessness and purposelessness.

Stanley Hauerwas and Charles Pinches argue that the virtue of patience is the most neglected and most needed virtue in contemporary societies.²⁹ They claim that patience is the most neglected virtue in modern societies where the levels of addiction to hyperactivity are very high. Where people are aware of the presence and involvement of God in the

²⁸ Tillich, *The Courage to Be*, 3.

²⁹ Hauerwas, S. and Pinches, C. 1997. *Christians Among the Virtues. Theological Conversations with Ancient and Modern Ethics*. Notre Dame, IN: University of Notre Dame Press, 175, 176.

world, they oppose the impatience of Eve and Adam, which made them break God's commandment, and the impatience of Cain, which made him become the killer instead of the shepherd of his brother, and the impatience which makes us desert our suffering brothers and sisters, because we impatiently think that if we cannot cure immediately, we can also not care patiently.

Joel Shuman identifies various virtues of care.³⁰ The virtues of dependency and constancy are virtues of the receivers of care. Hospitality and presence are the virtues of caregivers.

According to Shuman, dependence means to let one be cared for by the members of the body of Christ.³¹ He uses the phrase 'letting the body be the body' to express the fact that this care is not contractual, but that the body, according to I Corinthians 12, is constituted in such a way that its members live in relationships of dependence and interdependence. The essential nature of the body of Christ implies that its members give care and receive care.

Constancy, according to Shuman, is the virtue which means that Christians live, in the face of illness, suffering and death, in congruence (consistency) with the good life that we led before.³² It is the skill which enables suffering and dying people to look back on their lives and to be able to make sense of it, to be able to say it was worth it and we would not have it otherwise. In the exposure to these virtuous people others acquire these skills as well.

The virtues of the caregivers, which are the more active corollaries of the two patient virtues discussed above, are hospitality and presence:

Hospitality and presence are in fact not readily separable. Formally, at least, it can be said that hospitality is the name given to the virtue that enables us to welcome others into our lives, whereas presence is an expression of our willingness to enter into and share the lives of others. In this sense these virtues represent our willingness to share our bodies and our sustenance with one another.³³

Although these virtues have a long history in the church, in modern times with their emphasis on efficiency, these virtues which take time and are in terms of modern managerial science ineffective, according to Shuman, have to be acquired through training.³⁴ They are after all no longer integral parts of our lives. In acquiring these virtues we must be aware of the challenge to resist what Shuman calls the gods of the modern world, namely efficiency, hard work, success and the accumulation of private property, private wealth, private space and private time.³⁵ Hospitality for Christians implies sacrifice. It means taking time and sharing space.

Shuman's thoughts provide liberating perspectives for the nurturing of resilient hope. Resilient hope is expressed in the quest of so-called abled people who practise an ethic of hospitality and presence, to seek caring justice with and for people with disabilities. Resilient hope is also expressed in the ethic of dependency and constancy of people with disabilities as they bear and resist wrongs.

30 Shuman, J. 1999. *The body of Compassion. Ethics, medicine and the church*. Boulder, CO: Westview, 130-50.

31 Shuman, *The Body of Compassion*, 131-4.

32 Shuman, *The Body of Compassion*, 134-5.

33 Shuman, *The Body of Compassion*, 143.

34 Shuman, *The Body of Compassion*, 152-3.

35 Shuman, *The Body of Compassion*, 145.

Resilient hope, with its building-blocks of patience and perseverance, fortitude and courage, dependency and constancy, hospitality and presence, enables us to care even though we cannot always cure. It enables us to survive in the most despairing situations. And this resilience paves the way for caring, penultimate forms of curing as expressed in our quest for dignity, justice and freedom, whilst we realistically, actively and courageously wait upon the dawn of the reign of perfect caring and curing – for people living with vulnerability in general (that is, all people), and for people with specific vulnerabilities and disabilities.

CONCLUSION

As human beings we are all vulnerable. We are under threat. We are fragile. We suffer. In general we live with various vulnerabilities. Millions of human beings live with specific vulnerabilities and some have disabilities. These disabilities are expressions of the vulnerability of humans, and confront all of us with our own vulnerabilities. We are called to respond to our vulnerability, disabilities and dependency not with anxiety, camouflaging and violent pride, and pacifying despair. We respond with hope that is based in Christological faith and that comes to expression as realistic hope that stems from the reality of the crucified and resurrected Christ, responsible hope that actively seeks the fulfilment of dignity, justice and freedom, and resilient hope that is illustrated in a life of patience and perseverance, fortitude and courage, dependency and constancy, hospitality and presence amidst threats and practices of dehumanisation, injustice, oppression and despair.

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Job, theology and disability

Moving towards a new kind of speech

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L. Juliana M. Claassens¹

Probably one of the most daunting challenges facing people living with disabilities is the stereotypes and misguided perceptions regarding disability that pervade society today. One sees this clearly illustrated in the “Ag Shame”/“Siestog, foei tog”² attitude that is epitomised in the image of the plastic girl with her blue dress and harness on her leg that one often sees in stores collecting money for children with cerebral palsy (most recently I have seen her standing at the SPAR across from the Paul Roos Gymnasium),³ as well as in the image of the superhero who, according to Leslie Swartz, is portrayed as “overcoming enormous obstacles to triumph over adversity in spectacular ways” (cf. the following real life examples cited in Swartz’s book *Able-Bodied*: “Men Climb Kilimanjaro in Wheelchairs”; ‘Touch the Top of the World: A Blind Man’s Journey to Climb Farther than the Eye Can See’; ‘Beating the Odds: Beauty Queen with Cerebral Palsy’⁴).

But perhaps one of the most harmful stereotypes is the numerous examples that portray disability in terms of monsters, evil or punishment. Swartz writes: “This is where club-footed ghouls come in, and their surrogates, such as the monster created through human arrogance in Mary Shelley’s *Frankenstein*.”⁵ The message sent is, as in the case of the Hunchback of Notre Dame, that people living with disabilities are misfits in society, not fully human.

The Bible is not helpful in this regard. Religion has done more than its share in instilling and reinforcing negative stereotypes regarding disability. For instance, in Leviticus 21:16-23,

1 Juliana Claassens is Associate Professor of Old Testament in the Department of Old and New Testament, Faculty of Theology, Stellenbosch University.

2 Colloquial expressions of pity in South African English and Afrikaans.

3 The reference to “the plastic girl with her blue dress and harness on her leg that one often sees in stores collecting money for children with cerebral palsy” refers to a fundraising initiative that for many years was often found in shopping centers and that would be widely recognised in a South African context as a symbol of disability intended to garner sympathy. SPAR is a reference to a local grocery store in South Africa and Paul Roos Gymnasium is a boy’s school in my home town of Stellenbosch, South Africa.

4 Swartz, L. 2010. *Able-Bodied: Scenes from a Curious Life*. Cape Town: Zebra Press, 112-13. Swartz also writes: “A number of comic book superheroes are also disabled, such as Dare-devil, who is blind but able to use a special ‘sixth sense’,” 113. Cf. also the essay by Kathleen McDougall. 2006 “Ag Shame” and Superheroes: Stereotype and the Signification of Disability. In Watermeyer, B., Swartz, L., Lorenzo, T., Schneider, M. & Priestly, M. (eds), *Disability and Social Change: A South African Agenda*. Cape Town: HSRC Press. McDougall notes that the reason that these two stereotypes are so problematic is that the “Ag Shame” image contributes to the notion that people living with disabilities are helpless and in need of support, whereas the superhero narrative “implies that those who do not fit the ‘superhero’ success mould are failures” (390, 392).

5 Swartz, *Able-Bodied*, 112-13.

several of the conditions that today may be classified as “disabled” are described in terms of the Hebrew word *mûm* (“blemish”) that aligns with the idea that those who suffer from some sort of ailment or disability have restrictions placed on their ability to participate in cultic events.⁶ Moreover, the Hebrew Bible often uses language and imagery related to disability to denote some kind of negative quality. For instance, Isaiah 56:10 uses words like “blind” and “mute” as metaphors to denote the lack of leadership in Israel.⁷ But probably most disturbing is the way in which disability is used as a curse in the biblical traditions. In Deuteronomy 28:28-9 it is said that God will punish the transgressor with madness and confusion of mind so that he/she will be like a blind person in the dark. This text is representative of the numerous texts in the Hebrew Bible that draw a link between disability and sin, viewing disability as a punishment of God. Rachel Magdalene outlines this problem as follows:

The theological idea that human disability, disease, and disaster stem from human sin is very ancient and continues to hold sway in some theological circles. This concept has contributed to the terrible abuse or total neglect of persons with disabilities and chronic illness in religious settings. Such theology remains highly problematic to those who experience disability, illness, or any kind of trauma, whether or not the subject defines himself or herself as a religious person, because of the predominance of such a theology.⁸

What is needed is a radical change in how we think, talk and act when it comes to disability, and specifically when it comes to a religious framework for disability. Closely aligned with the conference objectives that took human dignity as an important focal point in our discussion on disability, this essay will contemplate ways in which we can challenge stereotypes and learn a new kind of speech that values the capabilities and contributions of persons with disabilities.⁹

To assist us in this endeavour, we will turn to the same biblical traditions that have been responsible for instilling harmful stereotypes. The reason for this is that it is vital to develop a different way of reading Scripture. In what Thomas Reynolds calls a “hermeneutics

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- 6 Creamer, D. B. 2009. *Disability and Christian Theology: Embodied Limits and Constructive Possibilities*. Oxford: Oxford University Press, 43. Cf. also Schipper, J. 2011. *Disability and Isaiah's Suffering Servant*. Oxford: Oxford University Press, 63, who argues that “the list of physical blemishes that disqualify a priest from certain activities (Lev. 21:16-23)” may have influenced texts like 1QIsa^a that focus on physical requirements in terms of cultic participation. Cf. also 1QSa 2:11-22: those members of the community who have some kind of ailment, who are paralysed, blind, deaf, or have some skin disease, are excluded from the great banquet (Bailey, K. E. 1980. *The Great Banquet*. In *Through Peasant Eyes: More Lukan Parables*. Grand Rapids, MI: Eerdmans, 90-1).
- 7 Jeremy Schipper argues that the “Hebrew Bible separates its language of disability from the context of people with disabilities and applies it rhetorically to able-bodied people” (Schipper, J. 2006. *Disability Studies and the Hebrew Bible: Figuring Mephibosheth in the David Story*. New York, NY: T&T Clark, 68). These texts, though, tell us very little regarding the way people with disabilities really lived, but mainly that disability was regarded in a negative light and that people living with disability were victims of social stigma.
- 8 Magdalene, R. 2007. The ANE Legal Origins of Impairment as Theological Disability and the Book of Job. *Perspectives in Religious Studies* 34:23-60 (23).
- 9 In this regard, there are some exciting developments in the field of biblical studies that investigate disability in the various temporal and social locations reflected in the biblical text and employ the experience of people living with disability as hermeneutical lens to read biblical texts. Cf. e.g. the work by Schipper, *Disability Studies and Disability and Isaiah's Suffering Servant*, and Avalos, H., Melcher, S. J. and Schipper, J. (eds). 2007. *Thisabled Body: Rethinking Disabilities in Biblical Studies*. Atlanta, GA: Society of Biblical Literature.

of disability”, this essay will seek to resist particularly harmful parts of biblical text by identifying counter-voices that elevate and amplify a different kind of speech.¹⁰

In particular, this essay will focus on selected examples from the Book of Job that represent something of this movement of learning a different kind of speech when it comes to people living with disabilities.¹¹ In the Book of Job one encounters some of the religious stereotypes regarding suffering, disease and disability common to the Hebrew Bible, which relate to the many stereotypes and misguided perspectives that people living with disability in today’s society have to face. In the Book of Job, though, one also sees glimpses of a counter-narrative that moves toward a new kind of speech regarding disability and theology, particularly with regard to what it means to be human. These glimpses of an alternative way of speaking about theology and disability serve as encouragement in our own journey to find a different kind of (theological) speech regarding disability rooted in values such as human dignity, inclusion and hospitality.

THE BOOK OF JOB AND DISABILITY

The Book of Job offers a classic example of a person moving from able-bodied privilege to disability through a series of losses (children and possessions), including a debilitating disease.¹² In Job 2:7-8 it appears that Job is suffering from an unidentified skin disease that has a dramatic effect on his daily life – the stigma associated with this disease leading him

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- 10 Thomas Reynolds proposes that such a hermeneutical approach allows us to read the Bible against itself, according to which “texts which are themselves polyphonic or even contradictory” are carefully juxtaposed (Reynolds, T. 2008. *Vulnerable Communion: A Theology of Disability and Hospitality*. Wheaton, IL: Brazos, 34-5). A good example of such an approach is found in the work of John W. Rogerson, who reads the image of the suffering servant in Isaiah 53 in terms of disability saying that Isaiah 53 read in this way becomes “good news for handicapped people, especially if they have been told by no doubt well-meaning but misinformed Christians that their handicap is in some way an outworking of divine disfavor”. He argues as follows: “The Old Testament speaks with many voices and is invariably at its most interesting when it appears to contradict itself and to undermine commonly held views. Part of the question ‘what does it mean to be human?’ is that from God’s perspective it does not entail outstanding physical appearance or perfection. God looks on the heart and, in the case of the servant, uses someone who has a physical handicap” (Rogerson, J. W. 2010. *A Theology of the Old Testament: Cultural Memory, Communication and Being Human*. Minneapolis, MN: Fortress, 184).
- 11 This essay does not intend to offer an exhaustive analysis of the Book of Job but will rather draw on selected examples that are suggestive of this movement toward a new kind of speech regarding disability.
- 12 And yet most of the major commentaries on Job do not read Job in terms of disability. See e.g. Balentine, S. E. 2006. *Job*. Smyth & Helwys Bible Commentary 10. Macon, GA: Smyth & Helwys; Habel, N. 1985. *The Book of Job*. OTL. Philadelphia, PA: Westminster; Newsom, C. A. 2003. *The Book of Job: A Contest of Moral Imagination*. Oxford: Oxford University Press; Clines, D. J. A. 1989. *Job 1-20*. WBC. Nashville, TN: Thomas Nelson; Clines, D. J. A. 2006. *Job 21-37*. WBC. Nashville, TN: Thomas Nelson. This failure of major commentators to address or even acknowledge the reality of disability with reference to the Book of Job is indicative of the silence and continuing marginalisation of people who live with disability today. In addition to the essays by Magdalene (ANE Legal Origins) and Raphael (Raphael, R. 2004. Things Too Wonderful: A Disabled Reading of Job. *Perspectives in Religious Studies* 31(4):399-424) cited in this essay, one exception would be the essay by Hector Avalos in *This Able Body* (Avalos, H. 2007. Introducing Sensory Criticism in Biblical Studies: Audiocentricity and Visiocentricity. In Avalos, H., Melcher, S. J. and Schipper, J. (eds), *This Able Body: Rethinking Disabilities in Biblical Studies*. Atlanta, GA: Society of Biblical Literature, 47-60.)

to be ostracised from his community, alienated from his family and friends, and relegated to the outskirts of society.¹³

Even though it is true that disability is not necessarily connected to disease,¹⁴ and the writer probably would not have thought of his main character as facing the challenges of disability, in the case of Job, there are quite a few parallels with the experience of disability that warrant a “disabled” reading of Job.¹⁵

What makes the Book of Job particularly interesting is that it offers us a first-hand perspective of the challenges facing a person who lives with disability. In the Book of Job we see how Job emerges as a subject who insists on telling his own story. This act of sharing his own experiences serves as a means of challenging his able-bodied friends’ attempts to define Job and his experience of disability. We see, for instance, harrowing self-descriptions of his diseased and disabled body (30:16-19), as well as the social and physical isolation Job is experiencing due to his disability (30:1-15). One text is representative of Job’s anguish:

He [God] has put my family far from me, and my acquaintances are wholly estranged from me. My relatives and my close friends have failed me; the guests in my house have forgotten me; my serving girls count me as a stranger; I have become an alien in their eyes. I call to my servant, but he gives me no answer; I must myself plead with him. My breath is repulsive to my wife; I am loathsome to my own family. Even young children despise me; when I rise, they talk against me. All my intimate friends abhor me, and those whom I loved have turned against me. My bones cling to my skin and to my flesh, and I have escaped by the skin of my teeth. (Job 19:13-20 NRSV)

In this description, something of the dehumanisation and rejection that people living with disability may experience is evident. The effect of prolonged suffering and the accompanying social stigma is devastating, so much so that Job even wishes that he had not been born (cf. also Job 3:3-16).¹⁶ We read, for instance, in Job 10:18-20 how Job rebukes God for acting as midwife at his birth:

Why did you bring me forth from the womb? Would that I had died before any eye had seen me, and were as though I had not been, carried from the womb to the grave (Job 10:18-20 NRSV).

13 Clines, *Job 1-20*, 47-8; Habel, *The Book of Job*, 95 This text furthermore points to the systemic nature of disability that is often linked to factors such as poverty and psychological and social exclusion. Cf. Emmett, T. 2006. Disability, Poverty, Gender and Race. In Watermeyer, B., Swartz, L., Lorenzo, T., Schneider, M. and Priestly, M. (eds), *Disability and Social Change: A South African Agenda*. Cape Town: HSRC, 219-20. Emmett not only outlines the relationship between poverty and disability but also considers the impact of factors such as race and gender.

14 One should note that there exists a complex relationship between disease and disability. Not all disability can be traced back to disease and not all disease inevitably leads to disability. For instance, a person may lose the use of his/her legs due to polio, which then can be termed an impairment. However, if this person then cannot function in a social and/or working environment due to inadequate access ramps, this becomes a disability. This distinction relates also to the medical model versus the social model regarding disability. The medical model tends to reduce disability to a problem that needs to be fixed; an obstacle that needs to be overcome. In contrast, the social model rather focuses on the capabilities rather than the disabilities of a person, striving to remove those barriers that prevent full social participation (Raphael, *Things Too Wonderful*, 400-1; Reynolds, *Vulnerable Communion*, 25-7).

15 Raphael, *Things Too Wonderful*, 401.

16 Carol Newsom (*The Book of Job*, 96) writes that “the intentionality of human existence, which expresses itself in projects and relationships and gives to life a sense of coherency, has been shattered for Job. All that remains is turmoil – incessant and emotionally charged events without coherent meaning – from which misery only death can provide relief.”

The Book of Job moreover offers an excellent example of the stereotypes regarding disability that were highlighted before. So one repeatedly finds the notion that disability or disease is the direct consequence of sin. Particularly in the friends' speeches, one hears the refrain that Job must have done something wrong to warrant the predicament he is in (e.g. Job 22:5-11). Job resists this idea; again and again pleading that he is innocent and does not deserve the debilitating disease that he considers as an unfair punishment. Related to this, one encounters in Job's response to his situation a harrowing description of divine violence (Job 16:8-17) – God is depicted as a hostile presence whose arrows, according to Job, have pierced his diseased body (Job 6:4).¹⁷ Within this theological construct, it is God who is held responsible for disability.

These stereotypes that occur in both the friends as well as in Job's contemplation serve as a way to make sense of disability and suffering.¹⁸ However, such a theological framework is limited as well as limiting, and most certainly harmful to people who live with disability.¹⁹ The Book of Job is interesting, though, as it already offers signs of deconstructing the stereotypical ideas that assume a narrow connection between sin and suffering. In her essay that offers a disabled reading of the Book of Job, Raphael argues that the friends' convictions are so thoroughly undermined by Job, by God's speeches and by the ending of the book that the reader is urged to query the traditional view represented by the friends. As Raphael argues: "to explain the suffering by finding fault with Job is to cling to the tidy worldview that the book seems bent on demolishing."²⁰

In the rest of the essay I will focus on two instances with reference to the Book of Job in which we see signs of the development of a different kind of speech regarding disability. I propose that these examples offer us the impetus to develop a new theological framework when it comes to disability as well as people who are living with disability.

AM I A MONSTER?

The first example from Job that denotes the development of a different kind of speech has to do with the way monsters function in this intriguing book. I mentioned in the introduction that, in the cultural mindset, a connection is often assumed between monsters and disability. It is interesting that in the case of Job the main character expresses his

17 Newsom, *The Book of Job*, 138-9.

18 Newsom describes the friends' moral explanation in terms of the therapeutic, i.e. attempts to remedy and fix whatever they perceive as upsetting the cosmic order – as Newsom puts it: "Wickedness disorders. Prayer reorders." Thus because Job must be guilty of something, he needs to turn to God in prayer, and all will be well again (*The Book of Job*, 127-8).

19 Reynolds formulates this concern as follow: "Whatever the intellectual merits of the theodicy question, it leads down a path with troubling consequences for thinking about human disability. Indeed, it trades upon the medical model and fosters a theological reductionism that equates disability with personal tragedy" (*Vulnerable Communion*, 32).

20 In this regard, Raphael points out that Job's innocence forms a central theme in the book, repeatedly maintained by Job himself (9:15, 20) and reiterated by God in the beginning and the end of the book (1:8; 2:3; 42:7-8) (Things Too Wonderful, 402-3). Cf. also David Clines (*Job 1-20*, xlvi) who argues that God's viewpoint in the divine speeches does neither affirm nor deny the doctrine of retribution but marginalises it.

experience of disability in terms of the mythical monsters, such as Rahab, Yam (sea), Tannin (dragon), Tehom (chaos) and the Leviathan, which in the *Chaoskampf* alternatively constitutes the object of God's attacks.²¹ Job's experience of his disease, and particularly his description of physical dismemberment, leads him in 7:12 to make a comparison between himself and the primordial monsters. He asks: "Am I the Sea, or the Dragon, that you set a guard over me?"²²

Job's experience of his disease is that he, like the monsters, is attacked by God. Moreover, as in the stereotypes that have followed people living with disabilities throughout the ages, Job feels like a monster that is vilified and pushed out of society. As Raphael argues:

Just as the monsters exist on the margins, before creation or in the still-chaotic sea, so also the chaotic (crippled) human body is ostracised to the margins of the social world (19:13-20). His defeated body and isolation from human society make him a monster of sorts, on a small scale.²³

The answer to Job's rhetorical question in 7:12, "Am I a monster?" is, of course, "No!" Job maintains that he is *not* a dangerous monster that God should attack and dismember, so resisting society's stereotypical characterisation of his condition (even though leaving intact the idea that disability is deemed subject to an attack by God).

God's speech from the whirlwind though changes the picture. The speeches offer a radically different picture of the way in which the primordial monsters and by implication also Job's disability is understood. The divine speeches in some way alter the core presuppositions regarding both the monsters as well as Job's disability.

One thus finds in Job 40 and 41 an expansive exposition regarding the Behemoth and Leviathan. Forming a central part of God's speech, both these monsters are portrayed as powerful and majestic. It is significant that instead of destroying and dismembering the chaos monsters, God lauds these monsters as majestic – an integral part of God's creation inspiring awe. For the greater part of these two chapters, the monsters take up the central place while the humans take a back seat.²⁴ This focus on the monsters is employed to help Job as well as the rest of the community think differently about the situation in which Job finds himself. Raphael says it well:

The descriptions of the monsters take up and transform the vocabulary of Job's experience. By the choice of monsters, the speeches draw Job farther along the path on which he has set out, rather than forcing him back into the neat categorizations of the friends.²⁵

By presenting himself in terms of a monster, Job is voicing his own feelings of anguish as well as the stereotypes that prevail in the community. However, it also changes the discourse by giving Job's experience a new meaning, moving "the monsters", and by implication the

21 Raphael, *Things Too Wonderful*, 404. Habel, *The Book of Job*, 162. In Job 26:12-14, God's power is denoted in terms of the slaying of the mythical sea monster Rahab. Cf. also Isa 51:9 (Rahab); Ps 89:9-10 (Yam); Ps 74:13 (Tannin); Isa 27:1 (Leviathan).

22 Cf. Habel's translation of "muzzle", which enriches the traditional translation of "watch" or "guard" for *mišmār*. The notion of "muzzle" relates well to the idea of Job who feels that he has no voice (cf. 9:2-3, 14-30, 32-5), (*The Book of Job*, 153).

23 Raphael, *Things Too Wonderful*, 402-3.

24 Raphael, *Things Too Wonderful*, 413.

25 Raphael, *Things Too Wonderful*, 423.

disabled Job, to the centre of the cosmos, so celebrating their strengths rather than their weaknesses; valuing their capabilities instead of their disabilities.

This transformation regarding Job and the primordial monsters' relationship to God does not change the fact that the Book of Job remains a complex book. Even though one sees signs of resistance, the book leaves intact the conviction that God, in quite a sadistic fashion, is responsible for Job's suffering. Moreover, Job also does not take his protest far enough; ultimately he just wants to be restored to his prior position of able-bodied privilege.²⁶

And yet one sees in this movement of finding a different kind of speech in the Book of Job "glimpses" of an alternative vision of the world. This book offers us a means to start a conversation on the stereotypes and negative religious perceptions of disability, God and suffering that still prevail, challenging us to change the way we speak.

AFFIRMING HUMAN DIGNITY

A second instance in the Book of Job in which we find the possibility of a different kind of speech regarding disability pertains to the profound expression of vulnerability experienced by the main character. It is exactly Job's experience of a debilitating disease and the accompanying physical, emotional and social effects of this disease that raise important questions regarding what it means to be human. In particular, I propose that reflection on the notion of human dignity might be valuable for the conversation regarding theology and disability.

The Book of Job bravely takes on what in today's terms can be called "the cult of normalcy". In the world of the biblical text the ideal of the good life was equated to health, wealth and progeny – all blessings that were directly linked to living an upright life. The fact that the main character, fairly early on in the book, loses all three of these blessings for no reason at all challenges the preconceptions about what constitutes "normal" or a desired life.

The cult of normalcy is everywhere to be found in our society today. Thanks to the media, Hollywood celebrities as well as sporting heroes, people have developed a fascination with physical beauty and perfection. As Reynolds writes:

Normalcy is made desirable and enforced in public venues as the standard. We see this illustrated on network television and in advertisements, novels and popular magazines. The ideal is held up as normal: the perfectly sculpted and athletic body presented as commonplace, even though it actually represents only a slim margin of thin people.²⁷

26 As Carol Newsome argues: in Job's mind there is no doubt that God as the Sustainer of the moral world would in the end "declare Job to be righteous and so confirm his honor" (*The Book of Job*, 196). At first glance it seems as if this indeed is the case in the conclusion of the book (42:7-17), when Job is said to receive twice as much as before: riches; a long life and many children. However, it is significant that the epilogue does not mention that Job's disease was ever healed. Thus, while Job returns to a position of social privilege, it is not necessarily able-bodied privilege. In this regard see Jeremy Schipper's article, *Healing and Silence in the Epilogue of Job* (Schipper, J. 2010. *Healing and Silence in the Epilogue of Job*. In *Word and World* 30(1):16-22 (21-2)).

27 Reynolds, *Vulnerable Communion*, 33. Reynolds reminds us that many of us "participate in the cult of normalcy and require ongoing transformation by God's love in the context of human frailty. Most of us do", 33. Cf. also Rogerson, *A Theology of the Old Testament*, 181.

The consequence of this cult of normalcy is not only that people spend a lot of money on beauty products, health clubs and even cosmetic surgery to reach the impossible ideal of physical perfection and beauty, but even more serious is the pervasive message that they receive, i.e. that there is no room in society for anyone who does not fit the idealised vision of health, wealth and beauty.

In his book *Eccentric Existence*, David Kelsey pleads for another understanding of the human that is not based on people's characteristics such as physical appearance, intellectual or sporting aptitude, or in the case of Job, wealth, health and progeny, but that rather holds on to the inherent dignity of a person that demands unconditional respect.²⁸ Kelsey grounds this view of being human in the person's "eccentric existence", i.e. personhood is not rooted in one's intellectual or physical capacities, but in the individual's relationship with the Creator God, who enters into a special relationship with each and every unique person regardless of his/her ability, thus relating "to different kinds of creatures on their own terms".²⁹

This unique relationship is no more evident than in one's own story of being created. Kelsey writes that "being born is a gift by the Triune God who is immediately and intimately involved in the process."³⁰ In the Book of Job we see this illustrated in Job 10:8-12, where Job invokes reference to his birth story when he addresses God in the following manner:

Your hands fashioned and made me; and now you turn and destroy me. Remember that you fashioned me like clay; and will you turn me to dust again? Did you not pour me out like milk and curdle me like cheese? You clothed me with skin and flesh, and knit me together with bones and sinews. You have granted me life and steadfast love, and your care has preserved my spirit (Job 10:8-12 NRSV).

In this creation narrative reminiscent of Ps. 139:13-16 and Gen. 2:7, one sees an image of God that is intimately involved with Job – like a potter, fashioning him like clay; like a seamstress covering his frame with skin and flesh and knitting together his bones and sinews. The image in v 10 of God pouring Job out like milk and curdling him like cheese may have to do with an ancient understanding of the role of conception and gestation. Robert Gordis (1978) suggests that these metaphors denote the specific stages of the gestation process: "the embryo is fashioned out of clay, the semen being poured out like milk, solidifying like cheese, being clothed in skin and flesh and finally knitted together with bones and sinews."³¹

From the depths of his despair, and as a person facing disability, Job invokes these images of his birth in order to remind God of their close personal relationship. This relationship

28 Kelsey, D. 2009. *Eccentric Existence: A Theological Anthropology*. Louisville, KY: Westminster John Knox, 289-90. Kelsey warns that is dangerous indeed to judge people on their utilitarian value as history has taught us that people or whole groups of people can at any moment loses their status as persons, e.g., the Jews, Gypsies and homosexuals in Nazi Germany – not even to talk about our own history in apartheid South Africa.

29 Kelsey, *Eccentric Existence*, 256. He proposes a "theocentric concept of 'person'", according to which "human creatures are constituted as personal beings by God relating to them, rather than by certain types of creaturely capacities – emotional, moral, or intellectual" (291).

30 Kelsey, *Eccentric Existence*, 250.

31 Gordis, R. 1978. *The Book of Job: Commentary, New Translation and Special Studies*. New York, NY: JTS, n. 12, 522. This vivid description of a craftsman shaping and forming the embryo with care and skill on the one hand highlights God's involvement in the prenatal process, but on the other sets up the "tension between God's tender concern in the past and his ruthless destructiveness in the present" (Clines, *Job 1-20*, 247. Cf. also Habel, *The Book of Job*, 199).

that affirms Job's dignity as one of God's creatures deserving of unconditional respect is not dependent on Job's state of health nor his socio-economic status. Their relationship endures the loss of all these elements that traditionally were thought to be responsible for a person's honour – including also by Job who views himself as cast out from his former situation of honour to the outskirts of society.

Within this relationship there is room for passionate disagreement. In vv 8-9, Job expresses his bewilderment that God would destroy the work of his own hands, turning his prize work of art into dust. Within these words of resistance, one observes Job's desire to be treated once more as a human worthy of respect – also by God, whom Job considers to be responsible for the situation in which Job finds himself.

In the divine speeches it is significant that God affirms Job's experience by employing birth imagery as well. However, God extends Job's argument of the special relationship between creator and created being to include other entities as well. So God applies birth language to the formation of the greater universe when God is said to be participating in the birth of the ocean. We read in Job 38:8-11 how God, instead of acting as the ocean's opponent in battle as in the traditional understanding of the *Chaoskampf*, rather acts as a midwife who assists at the birth of the baby monster called Sea and wraps it "in the swaddling bands of darkness and cloud". Newsom describes the significance of this image as follows:

Wrapping a baby in swaddling bands serves to restrain its arms and legs from moving about and so to calm the child. Through this imagery both the traditional aggressiveness of the sea and the restraints placed upon it are taken up. But the image of a baby in place of a battle foe transforms the emotional register and introduces novel implications. The metaphorical filter diminishes the sense of the sea as a hostile, alien power and associates it rather with the vigor of new life. Moreover, the restraints placed upon it are cast in terms of nurturance and protection.³²

As in the previous section regarding the monsters, we see in this text how the traditional understanding of the ocean as symbol of chaos is taken up and transformed in terms of an image of divine care.

In the divine speeches God is furthermore said to be intimately involved in the birth stories of the animals, acting as midwife to the mountain goats and the deer (39:1-3).³³ Even the ostrich, which is not known for its wisdom and leaves its offspring in plain sight to be trampled by wild animals (39:13-17), is portrayed as created in a unique and special way by God.³⁴ Habel writes how "the ostrich is a comic anomaly" that demonstrates the belief that all creatures have some sort of natural wisdom (ability). He writes: "She has no wisdom,

32 Newsom, *The Book of Job*, 244. Habel says that "the image is deliberately absurd; the violent chaos monster is but an infant, born from a womb, wrapped in baby clothes, placed in a playpen, and told to stay in its place" (*The Book of Job*, 538).

33 Newsom notes that almost all the animals are chosen for belonging to the realm of the desert wilderness that is beyond human control, particularly the mountain goats and wild deer are contrasted to the domesticated sheep and goats, (*The Book of Job*, 245).

34 Marvin Pope suggests that "the judgment on the ostrich's intelligence is understandable even if not entirely fair in comparison with other creatures." He argues that the "peculiarities of this amazing bird are elaborated in order to suggest that, in spite of his stupidity, God looks after it and gives it speed greater than that of a horse" (Pope, M. H. 1973. *Job*. AB; New York, NY: Doubleday, 310).

but she laughs at the awesome horse; she has not discernment but her young find food just as the eagle's do; she cannot soar like the hawk but her stubby wings rejoice (39:13-18)."³⁵

By using birth imagery in the divine speeches, it seems as if God is saying that God relates to different entities in a unique way: wild animals with different strengths and weaknesses; the sea as the quintessential symbol of chaos, and by implication humans on different levels of health, ability and socio-economic standing. This varied response that is rooted not in the individual's intellectual or physical ability but in an intimate relationship with the Creator God has profound implications for how we think about disability.³⁶ Kelsey rightly argues that "there is a great variety in the range of human creatures' capacities for intentional responses to neighbors and to God" – including many individuals "whose relevant capacities were significantly limited at birth as well as others whose capacities have been damaged in the course of their lives". However, as Kelsey points out:

The theologically important point remains: human living bodies are unique and unsubstitutable one for another in the accountability each has for whatever response each is capable of making into God relating creatively.³⁷

CONCLUSION

The Book of Job and its portrayal of the main character who is suddenly faced with the challenges of disability confront all of us with our own vulnerability and limitations. Reynolds puts it well: "For all humans are only partially and temporarily able-bodied. We are subject to limitations, suffering, and finally death – and at any moment."³⁸

We are indeed all temporarily able-bodied, "living", as Kelsey (2009) so poetically expresses it, "on borrowed breath".³⁹ We are all faced with aging, and many of us have already learnt that our bodies are fragile and limited in a number of ways. Moreover, accidents happen. One moment a person can be healthy and on the go, and the next one has to learn to live with the challenges that disability bring. Jürgen Moltmann says it well:

There is no differentiation between the healthy and those with disabilities. For every human life has its limitations, vulnerabilities, and weaknesses. We are born needy, and we die helpless. It is only the ideals of health of a society of the strong which condemn a part of humanity to being "disabled".⁴⁰

Realising our own vulnerability and accepting disability as part of human life will have the effect that we grant space to those who are equally vulnerable to also live their lives. It is significant that, by drawing attention to the wild animals and the sea that are all forces

35 Habel, *The Book of Job*, 534.

36 McDougall ("Ag Shame", 396) notes that one of the biggest problems with how people view disability is that disability is commonly understood (and portrayed) as homogenous. For instance, the whole spectrum of disability is often signified by the wheelchair user.

37 Kelsey, *Eccentric Existence*, 274.

38 Reynolds, *Vulnerable Communion*, 29.

39 Kelsey, *Eccentric Existence*, 157ff.

40 Moltmann, J. 1998. Liberate Yourselves by Accepting One Another. In Eiesland, N. L. and Saliers, D. E. (eds), *Human Disability and the Service of God: Reassessing Religious Practice*. Nashville, TN: Abingdon, 105-22 (110).

and entities beyond human control, the divine speeches serve the function of extending both Job's sense of self as well as transforming his understanding of just who are worthy of God's attention.

Such a broader vision of one's own self as well as one's fellow creatures is vital when it comes to changing the way we think and speak and act towards people living with disability.⁴¹ What is essential is that we learn, as Job had to do with the awe-inspiring display in the divine speeches, to value the "eccentric existence" of each individual by, as Kelsey (2009) puts it, "practicing delight in fellow creatures". This entails "learning patience to give fellow creatures their own space and time in which to be themselves".⁴²

We said that one of the goals of our conference is to change the way we think, speak and ultimately act regarding people who are living with disability. As in the case of Job, this entails a long and often difficult process of learning a new kind of speech, taking up old metaphors and casting them in a new framework. Ultimately this process is neither peripheral nor optional. We are changed in the process. In the end, John Rogerson (2010) is right when he says that "we become more truly human the more that we accept others as being truly human".⁴³

41 Gubela Mji envisions "a community where people with disabilities were not reduced to and defined by their disability" (Mji, G. 2006. *Disability and Homelessness: A Personal Journey from the Margins to the Centre and Back*. In Watermeyer, B., Swartz, L., Lorenzo, T., Schneider, M. and Priestly, M. (eds), *Disability and Social Change: A South African Agenda*. Cape Town: HSRC, 350-60 (359).

42 Kelsey, *Eccentric Existence*, 349. Cf. Reynolds' autobiographical excursus on love and what it means to grant space and time for his son, Chris, who lives with Asperger Syndrome (*Vulnerable Communion*, 112-17).

43 Rogerson, *A Theology of the Old Testament*, 193.

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Theology, language and human dignity

5

Hearing and seeing connections

Gerrit Brand¹

HEARING THE DEAF AS A LANGUAGE COMMUNITY

The case I wish to make in this paper stems from my involvement with the Multilingualism Action Group (i-MAG) during the first few years after its establishment in 2003.² I-MAG was established as an alliance of individuals and organisations seeking, through advocacy and community projects, and in the spirit of the language clauses in the South African Bill of Rights,³ to promote multilingualism, which can be defined as “more people using more languages in more registers and in more domains”.⁴ Central areas of concern for the organisation were the languages of instruction and communication in primary, secondary and tertiary educational institutions; the fair distribution of airtime on the television and radio stations of the public broadcaster; equitable language use in state organs such as parliament, government departments and the courts; and the interaction between different language communities in the country. The membership of i-MAG included speakers of most of South Africa’s official languages,⁵ but also advocates for other languages such as Esperanto, Nama and South African Sign Language.

Before my involvement with i-MAG I had thought of deaf people primarily as disabled – people who lack the ability to hear and who, because of that, cannot speak “normally” like

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- 1 The late Dr Gerrit Brand was Senior Lecturer in the Discipline Group of Systematic Theology and Ecclesiology, Faculty of Theology, Stellenbosch University, South Africa.
 - 2 On the launch of i-MAG, see Multilingualism Action Group 2003. Media Statement by the Multilingualism Action Group (i-MAG). Online at: <http://www.oulitnet.co.za/taaldebat/mediamag.asp> [Accessed: 26 July 2011]; Multilingualism Action Group 2003. Constitution. Online at: <http://www.oulitnet.co.za/taaldebat/multi.asp> [Accessed: 17 January 2012]. On the broader historical context in which the founding of i-MAG can be understood, see also Brand, G. 2009. The Role of “Europe” in the South African Language Debate, with Special Reference to Political Traditions. In Mar-Molinero, C. and Stephenson, P. (eds), *Language Ideologies, Policies and Practices. Language and the Future of Europe*. Hampshire: Palgrave Macmillan, 58-75, esp. 75.
 - 3 Constitution of the Republic of South Africa No. 108 of 1996, chapter 2, section 6, pages 7-39 (8). Online at: <http://www.info.gov.za/documents/constitution/1996/a108-96.pdf> [Accessed: 26 July 2011]. The constitution gives the status of “official language” to eleven South African languages and demands, among other things, that “all official languages must enjoy parity of esteem and must be treated equitably”.
 - 4 On this definition of multilingualism, see Brand, G. 2003. Imagining a Multilingual Academy. Rethinking Language in Higher Education. *South African Journal of Higher Education* 17(3):26-35 (27).
 - 5 Afrikaans, English, Ndebele, Northern Sotho, Southern Sotho, Tsonga, Tswana, Swati, Venda, Xhosa and Zulu.

the rest of us. I was also handicapped by several misconceptions about sign languages.⁶ Like many hearing people, I thought that the signs in these languages were transcriptions of words from other languages such as Afrikaans, Xhosa or English. I had not realised that sign languages are languages in their own right, each with a distinctive vocabulary and grammar.⁷ Nor had I understood the implication that, for deaf people, learning to read coincides with learning a new language the sounds of which are, to them, inaudible and cannot, therefore, be easily associated with letters on a page.⁸ I had also assumed that sign languages were artificially designed, like mathematics or computer languages – not realising that sign languages are as much natural languages as any of South Africa's official languages,⁹ and that therefore the differences between sign languages from various parts of the world¹⁰ had not resulted from a “lack of planning”, but from the very same factors that account for the differences between (say) French, Tswana and Papiamentu, namely, spontaneous linguistic evolution.¹¹

Most importantly, I learned to view sign language users (some of whom are not deaf)¹² as primarily a language community, rather than a community of disabled people.¹³ There is nothing inherently inferior about languages based on signs rather than sounds, and like all languages, sign languages are celebrated for their special beauty.¹⁴ I learned that sign language speakers, like speakers of other languages, love their language, enjoy using it and want it to be respected¹⁵ – also to the point of advocating its recognition as South Africa's twelfth official language and as an “indigenous” language.¹⁶ Since what they demand for

6 On some of the misconceptions that follow, see Emmorey, K. 2002. *Language, Cognition, and the Brain. Insights from Sign Language Research*. Mahwah, NJ: Lawrence Erlbaum Associates, Inc., 1-2.

7 Reagan, T. 2006. Language Policy and Sign Languages. In Ricento, T. (ed.), *An Introduction to Language Policy*. Oxford: Blackwell Publishing, 329-45 (330). Cf. Enabling Education Network (EENET) 1997. *Services for Deaf People in a Rural Setting. Issues and Recommendations for Sign Language*. Manchester: Initiative for Deaf Education in the Third World. Online at: <http://www.eenet.org.uk/resources/docs/signlang.php> [Accessed: 17 January 2012]; Perlmutter, D. L. (date unknown) *What is Sign Language?* Washington: Linguistic Society of America. http://www.lsadc.org/info/pdf_files/Sign_Language.pdf [Accessed: 17 January 2012].

8 See Marschark M. and Hauser P. C. 2012. *How Deaf Children Learn. What Parents and Teachers Need to Know*. Oxford: Oxford University Press, 102-5.

9 Baynton, B. C. 1996. *Forbidden Signs. American Culture and the Campaign against Sign Language*. Chicago: University of Chicago Press, 108-31.

10 See Baynton, *Forbidden Signs*, 108.

11 On linguistic evolution, see Emmorey, *Language*.

12 E.g. (hearing) “children of deaf parents” (CODA); see Padden, C. 2000. The Deaf Community and the Culture of Deaf People. In Adams, M. et al. (eds), *Readings for Diversity and Social Justice. An Anthology on Racism, Antisemitism, Sexism, Heterosexism, Ableism, and Classism*. New York, NY: Routledge, 350-1.

13 See Mirus, G. R. 2008. *The Linguistic Reportoire of Deaf Cuers. An Ethnographic Query of Practice*. Ann Arbor, MI: UMI, 14-15.

14 Cf. Baynton, *Forbidden Signs*, 88-9. The celebration of the beauty of sign languages was central in the so-called “manualist” struggle for the use of sign language in the classroom against “oralism”, which insisted on the exclusive use of lip-reading and speech for teaching. See Baynton, *Forbidden Signs*, 4.

15 See Jokinen, M. 2000. The Linguistic Human Rights of Sign Language Users. In Phillipson, R. (ed.), *Rights to Language. Equity, Power, and Education*. Mahwah, NJ: Lawrence Erlbaum Associates, Inc., 203-13; Valentine, G. and Skelton, T. 2007. The Right to be Heard. *Citizenship and Language. Political Geography* 26(2):121-40.

16 Recognition of South African Sign Language as Official Language. Briefing of Deaf Federation of South Africa. Online at: <http://www.pmg.org.za/minutes/20070215-recognition-south-african-sign-language-official-language-briefing-deaf-federation> [Accessed: 26 July 2011]. See also Reagan, *Language Policy*, 331-3, esp. 333: “The

their language is not essentially different from what other i-MAG members demanded for theirs, there were very few obstacles to our working together for the common goal of a multilingual society. Deaf members participated in meetings like everyone else, and since informal interpretation was used in such meetings to allow everyone to speak in the language of his or her preference, the presence of a sign language interpreter hardly stood out. Together we attended summits, participated in debates, published press statements and met with people in the government and public institutions in order to state our collective demands.

SEEING OTHER MARGINALISED LANGUAGE COMMUNITIES AS DISABLED

At the very same time as I was learning, in that context, to view sign language users as a language community like any other, I was also learning, paradoxically, to view speakers of other marginalised languages as in some sense disabled – a wonderful instance of what the theorist of hermeneutics Hans Georg Gadamer would have called a “fusion of horizons”.¹⁷ Whereas the politics of language, with its associated concepts such as language equality¹⁸ and linguistic human rights,¹⁹ provided a lens through which sign language users could be viewed differently, the concept and phenomenon of disability provided a means by which marginalised language communities in general could also be seen in a new light.

Against this background it started to dawn on me, furthermore, that the concept of disability²⁰ becomes virtually meaningless when applied to certain individual inabilities in isolation from their social context. Human existence is essentially characterised by inabilities, yet most of those *in*-abilities are not classified as *dis*-abilities.²¹ My regrettable inability to fly, for example, does not count as a disability. It is no more helpful to define the disabled as a minority, as if the rareness of a particular inability – like the inability to see or hear – is what makes it into a disability. After all, many inabilities that are relatively rare are not (or no longer) viewed as disabilities. Think of left-handedness – the inability to use one’s right hand as effectively as right-handed people can;²² or homosexuality –

only instance in which ‘official’ status has been considered for a natural sign language is in the case of South Africa.” (I place the word “indigenous” in parenthesis when applied to certain languages, cultures or peoples in contradistinction to others, because of its scientific vagueness and problematic ideological implications. Cf. Boyarin, D. & Boyarin, J. 1993. *Diaspora. Generation and the Ground of Jewish Identity*. *Critical Inquiry* 19(4):699 and 715.)

17 See Gadamer, H. 2004. *Truth and Method*. London: Continuum, xxxi, 217, 305-6, 337, 341, 367, 390, 533, 578.

18 On “language equality”, see Barua, J. 2001. *Social Mobilisation and Modern Society*. New Delhi: Mittal, 150-3.

19 On “linguistic human rights”, see Skutnabb-Kangas *et al.* (eds). 1995. *Linguistic Human Rights. Overcoming Linguistic Discrimination*. The Hague: Mouton de Gruyter; and more recently Skutnabb-Kangas, T. 2009. *Linguistic Rights*. In Mey, J. L. (ed.), *Concise Encyclopedia of Pragmatics*. Oxford: Elsevier, 537-9; cf. Jokinen, *Linguistic Human Rights*.

20 On different models for analysing the concept of disability, see Barnes, C. and Mercer, G. 2003. *Disability*. Oxford: Blackwell.

21 On “Impairment, Disability and the Body”, see Barnes and Mercer, *Disability*, 65-87.

22 Brym, R. J. and Lie, J. 2010. *Sociology. Your Compass for a New World*. Belmont, CA: Wadsworth, 411-12.

the (outdated) idea that “gays and lesbians lack the ability to be sexually attracted to the opposite sex”²³ (not to mention philosophy – the inability to see the obvious without having to overstate it)!²⁴

Therefore, to understand disability one has to realise that it is socially constructed²⁵ – not merely in a linguistic or discursive sense,²⁶ but also, and primarily, in the concrete political sense that the severe restrictions to full participation in society associated with certain inabilities are to a large extent a function of how society is structured.²⁷ Many examples illustrate this. In a society in which it is strictly required of everyone to write with their right hand, left-handedness is regarded, and actually functions, as a disability, since it restricts many left-handed people’s access to full literacy. Similarly, if sign language speakers could use their language in virtually all domains of life, as (say) Swahili speakers in Tanzania can, their inability to hear would be much less socially restrictive than it currently is. (Imagine how “disabled” hearing speakers of Swahili or English would be in a society where sign languages were dominant.)

But does this not apply to every language that is socially marginalised? Are not speakers of such languages, in so far as they struggle to communicate effectively in the dominant language of their society,²⁸ in some sense disabled? In this connection i-MAG has spoken of “the fact that language can be used either to limit or to extend access, participation and opportunities for the majority of South Africans who are poor and marginalised and do not understand English”.²⁹ Perhaps one might argue against this comparison on the grounds that, since hearing people can learn to use the dominant language effectively, they are not condemned to the exclusive use of their mother tongue. Yet this does not distinguish them from deaf people. Many deaf people learn how to communicate through writing in the languages of the hearing.³⁰ Some even acquire the ability to speak it audibly, although, to be sure, their pronunciation will always be markedly different from that of the hearing community.³¹ A small minority can effectively follow the speech of hearing people by closely observing the movements of their mouths.³² It remains the case, however, that such skills

23 Singer, P. 2006. Foreword. Shopping at the Genetic Supermarket. In Rasko, J. E. J. et al. (eds), *The Ethics of Inheritable Genetic Modification. A dividing line?* Cambridge: Cambridge University Press, xiii-xxxii (xxi).

24 For a light-heartedly suggestive yet insightful linkage between philosophy and autism, see Martin, A. 21 November 2010. Beyond Understanding. *The New York Times*. Online at: <http://opinionator.blogs.nytimes.com/2010/11/21/beyond-understanding/> [Accessed: 18 January 2012].

25 “Constructed” in this sense does not mean less real, just as the “constructed” nature of a building or a road is no indication of its ethereal nature. See Brand, B. 2011. Gender, Ubuntu en Geweld. (Gender, Ubuntu and Violence) *Maandblad Zuid-Afrika*. Online at: <http://www.zuidafrikahuis.nl/node/237> [Accessed: 18 January 2012].

26 See Barnes and Mercer, *Disability*, 88-109.

27 See Barnes and Mercer, *Disability*, 19-41, 134-41.

28 See Brand, G. 2011. Culture, Power and Religion. *Nederlands Theologisch Tijdschrift* 65(2):117-36 (126-7).

29 Multilingualism Action Group 2003. Media Statement. National Parliament Should not Regress on Language. Online at: <http://www.oulitnet.co.za/taaldebat/magE.asp> [Accessed: 18 January 2012].

30 Marschark and Hauser, *Deaf Children*, 108-10.

31 See Meadow, K. P. 1980. *Deafness and Child Development*. Berkeley and Los Angeles, CA: University of California Press, 164.

32 On the principles and limitations of so-called speech-reading (or “lip-reading”), see Kaplan, H., Bally, S. J. and Garretson, C. 1995. *Speechreading. A Way to Improve Understanding*. Washington, DC: Clerc, 1-14.

are only acquired with great difficulty, and that the exceptional natural talents required for some of these remarkable feats are by no means possessed by everyone.

The same applies to the predicament of linguistically marginalised hearing people. It is not the case that all, or even most, of them are in a situation where learning to use the dominant language is a realistic demand.³³ In a society such as South Africa, for example, where English, the dominant language, is spoken as a mother tongue by a very small percentage of the population, the possibility of learning English through immersion in a context where it is used naturally is necessarily available only to a minority.³⁴ A pool cannot be immersed in a drop of water. This means that the vast majority of South Africans try to learn English from other non-English speakers – very often a case of the blind leading the blind, to use an objectionable disability metaphor. Many, especially the poorest of the poor, who live in rural areas and informal settlements, acquire virtually no English at all, and where it is acquired, it is often at such a low level that hardly any doors to social mobility are opened by it. This is exacerbated by the use of English as the language of instruction in schools, which is extremely detrimental to academic development.³⁵ Yes, a few will succeed admirably in acquiring the dominant language, and they will benefit greatly from it. But the vast majority will remain second-class citizens systematically excluded from meaningful political and economic participation.³⁶ In the words of Neville Alexander: “An English-only, or even an English-mainly, policy necessarily condemns most people, and thus the country as a whole, to a permanent state of mediocrity, since people are unable to be spontaneous, creative and self-confident if they cannot use their first language.”³⁷

LANGUAGE DISABILITY AND HUMAN DIGNITY

At stake here is a question of human dignity. In the ancient world the word *dignitas* (dignity) referred to a person's place and role in society. One's worth as a human being was determined by the status of one's *dignitas* or social position.³⁸ When the word *dignitas* was taken up by early Christian thinkers, its meaning changed radically. Dignity was now

33 See Webb, V. 2002. *Language in South Africa. The Role of Language in National Transformation, Reconstruction and Development*. Amsterdam: John Benjamins, 187-91. Cf. Park, H. 2008. *Linguistic Minority Children's Heritage, Language Learning and Identity Struggle*. Ann Arbor, MI: UMI, 6-8.

34 Park, *Linguistic Minority Children*, 6. On immersion programmes in general, see Johnson, R. K. and Swain, M. 1997. Immersion Education. A Category within Bilingual Education. In Johnson, R. K. and Swain, M. (eds), *Immersion Education. International Perspectives*. Cambridge: Cambridge University Press, 1-16 (2-3).

35 On the importance of mother tongue education, see Djité, P. G. 2008. *The Sociolinguistics of Development in Africa*. Frankfurt Lodge: Multilingualism Matter Ltd., 65-9.

36 See Brand, Culture, 128-9.

37 Alexander, N. 2001. Where English Can Serve but not Empower. *Guardian.co.za*, 11 January. Online at: <http://www.guardian.co.uk/education/2001/jan/11/tefl.guardianweekly> [Accessed: 11 January 2012].

38 Soulen, K. and Woodhead, L. 2006. Introduction. Contextualizing Human Dignity. In Soulen, K. and Woodhead, L. (eds), *God and Human Dignity*. Grand Rapids, MI: Wm. B. Eerdmans Co., 1-25 (3).

regarded as something that belongs equally to all, since it is not based on someone's social standing, but on the fact that he or she is an object of God's love and concern.³⁹

Douglas Lawrie has argued that humans should not always strive to be dignified, but rather undignified – human, earthly, bodily, dependent, small and vulnerable:

Always maintain your freedom and rationality? Never submit to or be the servant of another? Never obey any laws but your own? Avoid the monkish (slavish) virtues of meekness, pity and self-sacrifice? Never scream for help because you can no longer manage on your own? Never make a fool of yourself? C'mon, 'ave a 'eart, mate! Such doctrines are cruel, unnecessary – and inhuman. If we leave no room for human *indignity*, we deprive ourselves of the solace and succour of others, the joys of serving, rest from overwhelming responsibility, many forms of love, particularly sexual love – and practically all fun.⁴⁰

I believe that Lawrie's aim, which implicitly takes the cross of Christ more seriously than many appeals to human dignity, can be served without giving up the term "human dignity" – as long as that term is deliberately turned on its head, just as the use of words like "King" and "Lord" are used of the crucified One in ways that subvert their conventional meaning.⁴¹ Precisely by speaking of human dignity in a way that runs directly contrary to the sense of autonomy, power and self-importance often associated with it, can those inhuman ideals be undermined.

Part of what is normally regarded as undignified is the kinds of dependence and vulnerability typically associated with disability, but also of other forms of social exclusion, like the linguistic exclusion that I have spoken of.

The idea of dependence on others seems almost un-American. Depending on others is foreign to our notion of human dignity. Human dignity means independence, much as national dignity is anchored in the Declaration of Independence. [...] For too many people dignity is *totally* incompatible with dependence.⁴²

By contrast, several theologians⁴³ have argued that dependence and vulnerability as such are not to be viewed as undignified, and can even be seen as profound expressions of human dignity. Friedrich Schleiermacher is famous for his analysis of religion as the awareness of "absolute dependence",⁴⁴ and of Christ as the perfect embodiment of such awareness.⁴⁵ Guus Labooy, a psychiatrist and theologian who has reflected deeply on psychiatric illness, maintains that, given God's incarnation in Christ, dependence and vulnerability can be

39 On interpretations of human dignity in early Christian thought, see Soulen and Woodhead, Introduction, 3-8.

40 Lawrie, D. 2010. The Dialectic of Human Dignity and Human Finitude in the Psalms and the Wisdom Literature. *Scriptura* 105:608-20 (618). See also Lawrie, D. 2011. On Human Indignity and the Limits of Ethics. *Scriptura* 106:81-92.

41 See Brand, G. 2002. *Speaking of a Fabulous Ghost. In Search of Theological Criteria, with Special Reference to the Debate on Salvation in African Christian Theology*. Frankfurt: Peter Lang, 124-9, on the subversive use of a Christological title such as "Ancestor", and its comparability with biblical titles such as "Lord" and "King".

42 McCormick, R. A. 1994. *Corrective Vision. Explorations in Modern Theology*. Plymouth: Rowman and Littlefield, 171. See also pages 171-2. For a legal perspective on dignity as autonomy, see Jordaan, D. W. 2009. Autonomy as an Element of Human Dignity in South African Case Law. *The Journal of Philosophy, Science and Law* 9, 1-15.

43 Among them, the just quoted Richard McCormick; see McCormick, *Corrective Vision*, 171-2.

44 Schleiermacher, F. 1830. *Der christliche Glaube nach den Grundsätzen der evangelischen Kirche im Zusammenhang dargestellt*, 2nd edn. Berlin, I:I, §4 (see Schleiermacher, F. 1999. *Christian Faith*. London: T&T Clark, 12-18).

45 Schleiermacher, *Christian Faith*, 374-424.

seen as dimensions of the *imago Dei*, the image of God, in humanity.⁴⁶ However, Labooy also emphasises that this should not be understood in such a way that the suffering of the mentally ill – and we might add: of the disabled and others who are excluded – is romanticised, welcomed or, God forbid, encouraged.⁴⁷

I believe that, in order to understand dependence and vulnerability rightly, we should not value it for its own sake, but for its function within a broader, dynamic context of relationality.⁴⁸ The community of believers does not *bestow* dignity on its members and on every child of God, but is called merely to recognise, celebrate, proclaim and act according to it:

Our value as persons is bestowed on us by God. We have a sacredness and dignity that must be respected and can never be taken away. [...] We are *given* dignity by God. We do not earn or merit it any more than we determine its presence in ourselves or in another. Our role is not to say which person or group has dignity. Our responsibility is to recognize and respect the dignity that is already and always there.⁴⁹

Indeed, the One who bestows dignity is God,⁵⁰ and it is precisely because Christians regard friendship with God, *amicitia Dei*,⁵¹ as the only source of true happiness and joy,⁵² the primary determinant of meaning,⁵³ that they also express their love for God by loving every object of God's love.⁵⁴

God's love for us, our returning of that love (in so far as it occurs), and the love of neighbour that flows from it necessarily imply dependence and vulnerability.⁵⁵ In this relational context dependence is the flipside of independence. It is precisely because your neighbour cannot be forced to love and befriend you – because he or she possesses the freedom and autonomy to embrace or refuse your love – that you are vulnerable in reaching out to him or her in love. This is not only an anthropological insight, but more fundamentally a theological one, because the God whom Christians worship is a God who, in unlimited freedom and power, chooses to reach out in love, thereby freely embracing the dependence

46 Labooy, G. 2002. *Freedom and Dispositions. Two Main Concepts in Theology and Biological Psychiatry, a Systematic Analysis*. Frankfurt: Peter Lang, 303-5.

47 Labooy, *Freedom*, 305.

48 See Schwobel, C. 2006. Recovering Human Dignity. In Soulen and Woodhead, *God and Human Dignity*. Grand Rapids, MI: Eerdmans, 46-56; Koopman, N. 2010. Human Dignity in the Context of Globalisation. In Boesak, A. and Hansen, L. (eds), *Globalisation II. Global Crisis, Global Challenge, Global Faith. An Ongoing Response to the Accra Confession*. Stellenbosch: Sun Press, 231-242 (231-3).

49 See Wadell, P. J. 2008. *Happiness and the Christian Moral Life. An Introduction to Christian Ethics*. Plymouth: Rowman and Littlefield, 77.

50 Schwobel, *Recovering*, 49.

51 On this classical concept, see Van Asselt, W. J. 2001. *The Federal Theology of Johannes Cocceius (1603-1669)*. Leiden: Koninklijke Brill NV, 310-19; Geert W. 2007. *Ruusbroeg. Literature and Mysticism in the Fourteenth Century*. Leiden: Koninklijke Brill NV, 133-45, esp. 138.

52 See Brümmer, V. 2005. *Atonement, Christology and the Trinity. Making Sense of Christian Doctrine*. Aldershot: Ashgate, 23-37.

53 On "primary determinants of meaning" or "basic convictions", see Brümmer, V. 1981. *Theology and Philosophical Inquiry. An Introduction*. London: Macmillan, 133-6.

54 On the relation between love of God and love of neighbour, see Brümmer, V. 1993. *The Model of Love. A Study in Philosophical Theology*. Cambridge: Cambridge University Press, 206-14.

55 On what follows, cf. Brümmer, *Love*, 159-63, 166, 223-32.

and vulnerability of friendship – even if that implies the cross.⁵⁶ It is not the cross, the suffering, that God seeks, but the abundant love of fellowship with human beings,⁵⁷ of which dependence and vulnerability – the *possibility* of suffering – is an entailment.⁵⁸

How does viewing dependence and vulnerability as forms of the *imago Dei* guide us in dealing with the suffering of our neighbour? The very same love that entails dependence and vulnerability will drive us to “carry each other’s burdens” (Gal. 6:2). We are dependent on one another for love, and it is that love that seeks to bring relief and healing to the afflicted. In the *eschaton* (last days), the new creation prefigured in the life of God’s people, dependence and vulnerability will not be the occasion for senseless suffering, exclusion and violations of human dignity – i.e. of disability – but rather an interdependence in which true friendship can flourish. It will be a society, a theocratic polity,⁵⁹ that is not structured to exclude and disable, but to include and enable, so that even the most humble members can have their glory recognised in the body of Christ.⁶⁰

CONCLUSION: IMPLICATIONS

I return to disability and linguistic injustice. The church – thus declares the Accra Declaration of the World Alliance of Reformed Churches (now taken up into the World Communion of Reformed Churches)⁶¹ – may never accept existing injustices and denials of human dignity as unavoidable, for to maintain that there is no alternative amounts

56 On God as “the One who loves in freedom”, see Barth, K. *Church Dogmatics, Volume II. The Doctrine of God, Part 1*. Edinburgh: T&T Clark, §28, 257-321. (Original German edition: Barth K. *Die Kirchliche Dogmatic, II. Die Lehre von Gott, I. Zollikon*: Evangelischer Verlag, §28.)

57 In contrast to Anselm of Canterbury’s answer (11th century) to the question *Cur Deus homo* (why God became human) – which focused on the need for *satisfactio* (satisfaction), i.e. for suffering and death on the part of humanity as compensation for having dishonoured God – Duns Scotus (13th century) saw the incarnation as flowing from God’s love, which by its very nature aims at reciprocation – with Christ, being truly divine and truly human, as the perfect realisation of the relational love intended by God; see Weiler, P. G. 2001, “Turn des Glaubens. Johannes Duns Scotus.” (Tower of Faith. John Duns Scotus) Cologne: Minoritenkloster (page numbers not indicated).

58 On the relation between the possibility of love between humanity and God and the possibility of evil (suffering) as it relates to the theodicy question, see Brümmer, V. 2006. Are Theodicy Arguments Convincing? In Brümmer, V. (ed.), *Brümmer on Meaning and the Christian Faith. Collected Writings of Vincent Brümmer*. Aldershot: Ashgate, 229-34.

59 See Wolin, S. S. 2004. *Politics and Vision. Continuity and Innovation in Western Political Thought*, 95-102, specifically 96, where it is shown how Origen, as representative of an early Christian way of thinking, considers the church not so much as part of, or contributor to the polity, but rather as itself an *alternative*, and supposedly (in Origen’s words) more “quiet and steadfast”, polity – somewhat akin to what some contemporary theologians, deliberately taking leave of “Constantinianism”, like to call “a ‘contrast society’ to the state, a social body in its own right” (Gascoigne, R. 2009. *The Church and Secularity. Two Stories of Liberal Society*. Washington, DC: Georgetown University Press, 47).

60 On empowering rather than dominating power, specifically with reference to divine omnipotence, see Van den Brink, G. 1999. Capable of Anything? In Van den Brink, G. and Sarot, S. (eds), *Understanding the Attributes of God*. Frankfurt: Peter Lang, 139-59.

61 See the WCRC’s website at <http://www.wcrc.ch/> [Accessed: 20 January 2012].

to idolatry.⁶² Therefore the church – expecting the “life in fullness” promised by Jesus (Jn. 10:10),⁶³ and taken up anew in Irenaeus’ statement that “The glory of God is a living man and the life of man is the vision of God”⁶⁴ – cannot acquiesce in policies, practices and structures that create disability, as in the case of the deaf and other speakers of marginalised languages. It is, to quote the title of Cornelius Plantinga’s *Breviary of Sin* (the subtitle), *Not the Way It’s Supposed to Be*.⁶⁵ To see this is to be driven to activism and advocacy in society at large, but even more important is that the culture, practices and structures of the church itself as a community should reflect the conviction that there is, and must be, alternatives, and that they will include greater practical recognition of what is God’s own cause of human dignity.

I close with a quotation from St. Methodius (also known as St. Constantine), a 9th-century bishop who, together with his brother St. Cyril, initiated the Christianisation of the Slavs, but also developed the Cyrillic alphabet.⁶⁶ When the two brothers visited Rome in the year 868 to request authorisation of their Slavic liturgy from Pope Hadrian II, the question of whether the Mass could be celebrated in the Slavic tongue caused much controversy – even to the extent that Methodius was, at one point, deposed as bishop and the Slavic liturgy banned. Only in the year 878 was he restored as bishop and the Slavic liturgy officially recognised by Pope John VIII. In his defence of the legitimacy of the Slavic liturgy, Methodius wrote (and with these words I close my case):

Does not the sun shine equally for the whole world? Do we not all equally breathe the air? Do you not feel shame at authorising only three languages and condemning other people to blindness and deafness? Tell me, do you think that God is helpless and cannot bestow equality, or that he is envious and will not give it?⁶⁷

62 World Alliance of Reformed Churches (WARC). 2004. *Covenanting for Justice in the Economy and the Earth*. Online at: http://warc.jalb.de/warcajsp/news_file/doc-181-1.pdf [Accessed: 25 November 2011].

63 See WARC, *Covenanting*, 3.

64 Quoted in Osborn, E. F. 2004. *Irenaeus of Lyons*. Cambridge: Cambridge University Press, 263.

65 Plantinga, C. 1995. *Not the Way It’s Supposed to Be. A Breviary of Sin*. Grand Rapids, MI: Wm. B. Eerdmans.

66 On this, and what follows, see Van der Linden, S. 1999. *De heiligen*. (The Saints) Amsterdam: Contact, 212.

67 Fishman, J. A. 1968. *Readings in the Sociology of Language*. The Hague: Mouton, 589; see Das, A. K. 2004. Minority Language Laws in the EU, Paper: II Mercator International Symposium, Europe 27-28 February 2004, A New Framework for all Languages? Tarragona, I. Online at: <http://www.ciemen.cat/mercator/pdf/simp-alok.pdf> [Accessed: 16 January 2012]. My thanks go to Flip Buys for bringing the Methodius quotation to my attention.

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Part TWO

Between faith and doubt

Training members of disabled people's organisations in Southern Africa in basic research skills

6

Leslie Swartz¹

Part of the historical marginalisation of disabled people and, indeed, part of the wider pattern of the violation of their dignity has been their exclusion from various forms of agency in their lives. Disabled people are spoken about, their bodies acted on, their lives the subject of a socially sanctioned expertise which they themselves do have. At the heart of the rise of what has come to be known as the 'social model' of disability studies was the assertion that authority and, indeed, authorship of stories about disability needed to be wrested away from outsider authority (chiefly medical authority) and returned to disabled people themselves. It is a core ideal of the disability movement internationally that the world moves to a situation in which disabled people themselves are those setting the agenda in terms of what we know about disability and what we do to improve the lives of disabled people. Indeed, fundamental to any project to improve the lives of disabled people should be the core involvement of disabled people in producing knowledge about disability and creating an inclusive and enabling environment.

It is no coincidence that the language of self-representation in the disability movement echoes strongly the language of other movements which have also gained social influence in policy discourse since the 1960s. Disabled people are similar to women and black people, for example, in demanding to write their own story in their own voice, and it is hardly surprising that one of the founder figures of the disability movement in the United Kingdom, the late Vic Finkelstein, who had to leave apartheid South Africa because of his anti-apartheid activities, brought to the struggle for disability rights some of the language and style of operation of anti-apartheid work. More recently, queer theory and postcolonial theory have become of interest to scholars working within disability studies and vice versa, not least because all of these disciplines are concerned with issues of voice and ownership of knowledge on the part of groups that continue to struggle to achieve equal rights and equal dignity worldwide.

Given the enormous power of historically valued outsider authority to shape thinking and practices about excluded groups, all of the movements associated with these groups have at different times and in different ways rejected or attempted to contain and control the influence of these outside voices. For example, some black liberation theorists have argued

1 Leslie Swartz is a clinical psychologist and Professor of Psychology at Stellenbosch University, South Africa.

that black people alone should have the authority to write about the experiences of black people. Separatist feminism has claimed not only that women must write and speak for themselves, but also that it is inevitable that even in relations between women and men sympathetic to feminist ideals, old established patterns of male dominance will emerge even when they are consciously resisted by both men and women. This re-emergence of male dominance will occur not necessarily because of evil or retrogressive intent, but because of habits of centuries of exclusion and also because of patterns of socialisation that have historically rendered men more comfortable with articulating their views in public, with taking up leadership roles, with setting agendas, while women more used to following others and working towards consensus. So much has changed in feminist politics and scholarships since the height of separatism in the 1970s that women's authority and leadership is far less a contested and difficult issue than it once was. The same cannot be said for disability politics, where it is still common for discussions about disability to exclude the participation of disabled people, for planning about the world and its habitability to be conducted without thought for the engagement of disabled people. Disability issues are still seen by many as an add-on, a marginal matter or a luxury when we think about the kinds of environments – both social and physical – that improve life for all people. Despite the fact that disability is far more common than many people assume (and this assumption of disability as very rare is in part of product of the very social exclusion, isolation and hiding of disability that the disability movement seeks to end), disabled people continue to struggle to have their voices heard about issues that affect them.²

For the purposes of this essay, it is important to highlight three important strategies that disabled people have adopted in the context of broader development politics in low- and middle-income countries to increase the possibilities that their views and needs will be considered adequately in development processes. The first strategy is that of mainstreaming. Disability scholars and activists argue that any social development activity should have a disability component. Campaigns for better access to services and opportunities, ranging from access to clean water, to microfinance, to improved health care and education, to name but a few, should as a matter of course consider how disabled people can contribute to and benefit from any planned programme. It is partly because of this mainstreaming agenda that there has been considerable interest by disabled people and disabled people's organisations in mainstreaming disability into the Millennium Development Goals, for example.

A second important strategy used by the disability movement (to the extent that a unified movement can be said to exist) relates to how able-bodied people should be deployed (if at all) as part of the disability and development agenda. The ideal in this regard would be for disabled people themselves to produce all knowledge about their own situation and to work on an equal footing with all others creating knowledge and contributing to change in the development context. Because of the reality of exclusion of disabled people, especially in low- and middle-income countries, from access to equal education and training opportunities, the fact is that there are forms of expertise that very few disabled people have. It is important to stress that this is not on the basis of any lesser ability, but on the basis of social exclusion – it is the case, for example, that many secondary schools catering for disabled children simply do not offer the same range of training in fields such

2 World Health Organisation and World Bank. 2011. *World Report on Disability*. Geneva: WHO.

as mathematics and the physical sciences as do mainstream schools. For this reason, with access to mainstream schooling an important long-term goal, disabled activists in low- and middle-income countries need the skills some able-bodied experts have. The strategy used here is that of working alongside able-bodied people with these skills, but confining (or attempting to confine) their influence in terms of setting the agenda. Drawing on Winston Churchill's dictum about scientists that they should be "on tap and not on top", disability scholars and activists make a similar strategic argument about able-bodied professionals. Essentially, their skills are to be used, but they are not to set an agenda which only disabled people themselves may set. In this regard, it is useful here to quote in full the guiding principles for disability research set at a meeting of the Disability Knowledge and Action Research (DKaR) in Malawi, and used as a set of guiding principles in research work on disability and development issues.

► **Guiding principles for thematic research established at the Disability KaR Roundtable in Malawi**

- Include democratic and accountable voices of disabled people
- Reflect diversity of disabled people
- Resource voices of disabled people
- Facilitate equality of power relationships
- Conduct emancipatory research/policy development – be empowering
- Have active and equal partners
- Professionals should be “on tap” not “on top”
- Disabled people should be seen as experts in own lives/situation
- Have equal value of expertise – recognise power relations within expertise
- Benefit disabled people
- Include knowledgeable and skilled disabled people relevant to the topic
- Be inclusive of all disabilities within the range of research topics
- Be gender sensitive.³

These principles lead to the third strategy for disability and development work – clearly, if professionals (and able-bodied professionals in particular) should be “on tap and not on top”, and if disabled people have been excluded historically from a range of opportunities, it is important that the skills of disabled people be developed to maximise their capacity for leading disability and development research initiatives, and for becoming equal players in mainstream initiatives. In this regard, an important way to use the skills of able-bodied professionals is to deploy them to develop the capacity of disabled people towards achieving their more equal participation.

It is against this background that I, as an able-bodied professional, came to work as what was termed a ‘lead research partner’ (this is terminology used by the funder) for the Southern African Federation for the Disabled (SAFOD) Research Programme (the

3 Online at: http://www.disabilitykar.net/roundtables/malawi_rt.html [Accessed: 28 May 2011].

SRP).⁴ In the rest of this chapter I will provide an introduction to the SRP, describe my work in the programme, and consider the ways in which issues of faith, doubt and religion challenged me in my attempts to fulfil a role appropriate to my designation as an able-bodied researcher building capacity amongst disabled people in Southern Africa.

THE SAFOD RESEARCH PROGRAMME (SRP) TRAINING

The Southern African Federation of the Disabled is an umbrella organisation for Disabled People's Organisations in ten Southern African countries, namely Angola, Botswana, Lesotho, Malawi, Mozambique, Namibia, South Africa, Swaziland, Zambia and Zimbabwe. Headquartered in Bulawayo, Zimbabwe, its vision and mission are as follows:

- ➔ **Vision:** "A society new society [sic] where all people, including disabled people, women and workers, men and children, are treated with dignity, respect and on the basis of equality."
- ➔ **Mission:** "To strengthen Disabled People's Organisations in SAFOD member countries through training, research, coordination, information sharing, promotion of human rights and adoption of appropriate strategies for stimulating people with disabilities to enhance their economic, political and social development."⁵

The core values of SAFOD are given on the SAFOD website as: "Participatory, Transparency, Accountability, Commitment, Gender Sensitivity, Empowerment" [sic].

The largest project undertaken by SAFOD recently, with the financial support of DFID (UK), was the SAFOD Research Programme (SRP).⁶ Conducted over a period of three years, the programme had two main aims. First, the SRP sought to produce policy-relevant information on disability for use in the region, largely through commissioned research. Second, the SRP provided a platform for basic research skills training for two representatives (one man and one woman) from each of the country organisations making up SAFOD. I was appointed Lead Research Partner to the SRP and I ran the training.

The training comprised four face-to-face training sessions a year of three days each, plus assignments and homework in between. The training was registered as a short course at Stellenbosch University and trainees who completed the requirements for the course were given certificates at the end of training. I have discussed the content of the course and some of the issues raised in some detail elsewhere.⁷ In the rest of this chapter I consider how issues of faith, doubt and religion played their part in the training.

4 I am grateful to my colleagues, friends and trainees in SAFOD for working constructively with me over a long period, to the funders of the SRP, Department for International Development (DFID), UK, and to the National Research Foundation. Melanie Basson, Margie Schneider and Richard Vergunst assisted with training. The views expressed in this chapter are my own, and not those of any other person or organisation.

5 <http://www.safod.org/>

6 Full information on the programme can be found at <http://www.safod.org/SRP%20Web%20site/index.htm>

7 Cf. Swartz, L. 2009. Building disability research capacity in low-income contexts: Possibilities and challenges. In MacLachlan, M. and Swartz, L. (eds), *Disability and International Development: Towards Inclusive Global Health*. New York, NY: Springer, 91-103. Swartz, L. 2010. *Able-bodied: Scenes from a Curious Life*. Cape Town: Zebra.

FAITH, DOUBT AND THE SRP STORY

My entry into the SRP as Lead Research Partner was not smooth for a range of reasons, one of which is germane to the present argument. Very shortly after I undertook the work, the Secretary General of SAFOD (the late Alexander Phiri, a man I admired a great deal) informed me that a well-placed person, influential in the disability movement in the region, objected to my appointment on the grounds of my being a white academic working at an historically racist institution. Clearly, there was more at stake in terms of identity politics than questions of disabled versus non-disabled identity. Race, gender and the undoubtedly problematic racial and political history of my own institution clearly played a part. I entered the work, therefore, feeling tremendously privileged to be doing it, but also worried about how I might be perceived, how I should deal with the issue of my own authority as a trainer, while at the same time respecting the sentiment of my being required to be “on tap” rather than “on top”. As I have discussed elsewhere (*Able-bodied*, 2010), I was aware of the limits of an over-emphasis on participation and empowerment as the only criteria for disability-related research, and I agreed with Tom Shakespeare’s (2006) concerns about disability research in the UK:

While I value the achievements that have been won through the close alliance of disability politics and disability research, I believe that the weaknesses of the British approach now outweigh the benefits. Translation of ideas and ideologies from activism to academia have not been accompanied by a sufficient process of self-criticism, testing and empirical verification.⁸

In short, though I wanted to be “on tap” rather than “on top”, I believed, with Shakespeare, that ideology masquerading as empirical research was not a good thing for realising the rights of disabled people. I believed (and believe) that scepticism, doubt and openness to changing opinions on the basis of new evidence were at the heart of good research, and I worried how I would reconcile this view with my positioning as a trainer in what was essentially an activist enterprise – developing capacity in order to strengthen SAFOD’s broader agenda.

As far as my engagement with SAFOD and the SAFOD trainees was concerned, many of my early worries proved unfounded. Overall, I was welcomed by the organisation and treated with great kindness and respect. Some of this hospitality, though, had another side to it, a side I had not anticipated. I had prepared myself for mistrust and enmity on the basis of my able-bodied white South African privilege, but I had underestimated the extent to which my position as a professor at a prestigious institution would lead to my being greatly respected by colleagues. There is nothing wrong with people respecting learning and academic achievement. Respect for academic authority, though, does not lie in unquestioning acceptance of what academic seniors say. On the contrary, for me, as is the case for many empirically-minded colleagues, respect in an academic context means taking the trouble to interrogate the views and conclusions of others, to put their ideas to the test, to treat their views with the same scepticism with which one treats one’s own. This is an approach to knowledge I struggle to impart to my university students, many

⁸ Shakespeare, T. 2006. *Disability rights and wrongs*. London: Routledge, 11.

of whom seem to have succeeded at school by being obedient to authority. Given the rhetoric of the disability movement, the oft-mentioned mistrust of able-bodied people, the scepticism of a professional knowledge which for centuries has excluded and marginalised able-bodied people, and given the more immediate politics of my own positioning in this project, I anticipated a high degree of scepticism about me from the trainees. In fact, I was looking forward to this scepticism, because I believe that much of the best and deepest learning takes place at the interface between differing points of view – we learn, I believe, from being discomfited.

It is important for the purposes of this discussion to recognise two aspects about the way in which I was welcomed into the SRP as an expert. At one level, I was treated with what I believe to be hospitality. As Derrida's scholarship has pointed out, to be in a position to offer hospitality, one must be, or feel oneself to be, the master of one's house.⁹ At all the training sessions (with the exception of the very few trainees with whom I had difficult relationships), I was welcomed, but, as was entirely appropriate, I was welcomed into a space that was defined as belonging to SAFOD and the trainees, and not to me – they were benign masters of the house, but masters nevertheless. When it came to what I had to offer as a trainer, however, it took some time for me to convince trainees that I do not know everything, that I make mistakes as a researcher, and that I am not an expert on the lives of disabled people. The process of negotiating this issue of my authority, though, took some time. I had to acknowledge that I did see myself as an authority on issues of method and epistemology as they pertain to research (and I have no doubt of my superior knowledge and expertise over these issues as compared to the knowledge and expertise held by trainees themselves). But I did not regard myself as an authority on the content we were discussing – issues that affect the lives of disabled people and those around them. To a novice researcher, I came to see, it was very hard to see the distinction between expertise in method (which I comfortably claimed I had) and expertise on content issues (in which I did not and do not believe myself to be the expert). Looking back on the training, I can see how I would confuse and bewilder participants early in the process by apparently in the same breath claiming that I did not have special knowledge about many things, and asserting my superiority to the trainees in engaging with issues of method.

I began to see that our training was operating at the interface between different systems of faith, scepticism and doubt. As a researcher, I believe very strongly that all knowledge is, and should be, open to question and doubt, and indeed when one of the trainees said that the most important thing she had learned from the training as a whole was that we should take nothing at face value, I felt very gratified. I believe in the power of logical and systematic argument, and in the essentially democratic idea that it does not matter who is professing knowledge – what matters is the extent to which that knowledge is robust and stands up to contestation. I also believe that knowledge is provisional – when new ways of thinking, and new evidence come to light, we should change our views. My faith in science or in the methods of research more broadly understood is a faith not in the content of what we come to know or of who makes claim to knowledge. It is instead, a faith in the power of contestation. To me, empirically trained as I am, research methodology is less a set of

9 Derrida, J. 2005. The principle of hospitality. *Parallax* 11(1):6-9.

steps about how to do things, but more a systematic way in which we can scrutinise truth claims about the world.

The people I was training had a wide range of educational backgrounds. Some were studying for Master's degrees and some had not completed high school. But I think it is fair to say that early on in the training with me, all had different ideas about faith and doubt than I did. All of them were disabled people living in highly stigmatising societies, and yet all of them had achieved the success that joint activism can bring – they had reached positions of power within their national DPOs and had been selected by their DPOs to undergo further training. They knew from the inside the benefits of activism and solidarity, and they understood the achievements that people and organisations can make on the basis of standing together on the basis of a shared identity and ideology. They had faith, in a word, in solidarity, whereas my faith lay in the scepticism which is at the heart of the scientific method – the belief that knowledge is open to change. But where my scepticism was about how we come to know things about the world, theirs was a scepticism based on visceral experiences of social exclusion. They had learned not to trust all sorts of people – especially able-bodied people and researchers from the outside who promised much but delivered little, they told me, in terms of changing their lives. There were some important exceptions in this regard, but their activist positioning enabled them to return frequently to discussions about the duplicity and unreliability of many able-bodied people and researchers.

The trainees and I were, in short, entering the world of research training from very different worlds of faith. I believed in some ways that the less sure disabled people became about what was told to them or about what they see in the world, the better researchers they would be; whereas they expected (understandably, and in common with many other people who enter research training) that the more skilled they became, the more they would know, and the more sure they would be about their own knowledge. It may appear from this formulation that my commitment as a Lead Research Partner was to a somewhat acontextual and even naïve view of what “research” is and does in a context like that within which the SRP was functioning. Was it not the case that the trainees were indeed looking for more expertise, more certainty, more heft in the struggles they would have with a disablist and unfriendly world? I am the first to agree that the simple performance of trainees' having gone through a training certificated by a reputable university may be of help to them. The fact that they have been seen to have attended workshops and passed some tests of technical skill would be likely to increase the degree to which they could lay claim to authority about knowledge and the world in which disabled people live. Indeed, it has been gratifying to me to learn of trainees' using their certificates as bargaining chips to improve their credibility as researchers and activists in a range of contexts. A number of trainees are now working on other research projects. But I believed (and continue to believe) that though it would have been quite possible for me to train the trainees simply in a suite of technical procedures about research (for example, interviewing skills, basic numeracy skills, dissemination skills, all of which we did cover in the training), the opportunity for genuine empowerment would be lost were we not to have tackled fundamental questions about knowledge. Too often have I seen in the Southern African context, but by no means only here (as the work of Shakespeare (2006) has shown), ideological statements masquerading as empirical fact.

There are many studies that set out to show, for example, how excluded and oppressed disabled people are, but that do not allow for any data to be collected which may question that view. I have seen many questionnaires with leading questions, many reports that start out assuming that things are bad for disabled people, which collect data, and then return inevitably to the point at which they started – to conclude that things are bad for disabled people. Research, as Shakespeare (2006) says, has to be organised in such a way that we can have the capacity, however idealistic, to be surprised or even shocked by our findings. Repeated statements of the same ideological positions in the absence of carefully collected and reporting of data, including findings we did not expect and do not like, have a very limited shelf-life. In the admittedly highly problematic discursive world of evidence-based policy, volumes of research based on poor methods no longer have the influence they once might have had. It was not, therefore, in my view, a trivial or luxury matter to engage with trainees on issues of falsifiability, of doubt, of scepticism – not on the basis of identity, but on the basis of research methods.

I believe that most of the trainees came to see the value of rigorously sceptical thinking over superficially easy solidarity in the way they engaged with research, and I regard this as an important (though somewhat intangible) outcome of the training. But much as I have spoken here about the value of discomfiting trainees about their own assumptive ideological worlds, I do not believe this could have happened without an equal discomfort¹⁰ on my part, and it is to this issue which I now turn.

ON BE(COM)ING JEWISH IN UNJEWISH PLACES

I am a secular Jew and I am an atheist.¹¹ Much of my engagement with the world, despite my not believing in God, is strongly informed by Jewish traditions. Though there is much to criticise about organised Judaism (and I am critical of many of its practices and ideologies), I believe that two of the core commitments I have come from my Jewish roots. First, there is a strong strain of Jewish teaching and thought which requires a commitment to social justice, and it is no coincidence that Jews have been strongly represented in liberation movements in many countries, including South Africa. Second, Jewish scholarship relies heavily on ideas of contestation and debate with struggles with authority – a founding myth for Jewish people is that of Jacob struggling with the angel (the name Jacob was given subsequent to this struggle was Israel – he who struggles with God). The influence of Jewish traditions is strong in many scientific disciplines, and certainly in my own field, which is psychology.

Early on in the SRP training, when discussing emotive or difficult issues, trainees would say things like: “We are all Christians here”, or: “As Christians, we all know ...”. At first

10 Boler, M. and M. Zembylas. 2003. Discomforting truths: The emotional terrain of understanding difference. In Trifonas, P. (ed.), *Pedagogies of difference: Rethinking education for social change*. New York, NY: RoutledgeFalmer, 110-36.

11 Reviewers of this chapter and others with whom I interact have expressed some incredulity at my use of this self-ascription. I use the term “atheist” in the sense used in the Merriman-Webster dictionary – “a disbelief in the existence of deity”. I do not regard this disbelief as incompatible with a respect for and interest in spirituality.

I was reluctant to engage with these statements of solidarity in part because I would be drawing attention to myself. But it seemed to me as this bubble of shared identity was constructed around all of us (including me) that it would be simply dishonest to allow this issue to pass. So I told the trainees I was not Christian but Jewish, and when they (predictably enough) said that that was all right because I believed in God and was one of God's chosen people, I told them that I did not believe in God.

This revelation on my part was greeted with a mixture of humour and disbelief, and I did not wish to dwell too much on the issue as it seemed to me tangential to the main business of the research training work. I was wrong about this. Some trainees let the matter go more or less immediately, but some (including many who I believed had engaged most seriously with the training) could not, or would not, let the matter go. We had long discussions over meals about issues of religion and why this was important. Some trainees were worried about my soul; others simply could not believe that a person who had chosen this kind of engagement with disabled people could not be religious. As much as in the back of my head I found the idea offensive that the only basis for engagement in human rights work must be charity or religious commitment, I felt I was missing something important about what my interlocutors were saying.

As we discussed these matters further over a period of months and years, and as I began to search out for the trainees texts on Christianity and disability, my views began to change. I did not become more Christian, more Jewish, or more religious, but I was forced to concede that questions of Christian spirituality, and of experiences of inclusion and exclusion from the church (some exclusionary practices seemed to me extremely inhumane), were central to the lives of the people with whom I was working. Not only that – the liveliness of debate which trainees engaged in about religion (but all within the shared world of them as committed Christians, and every one of them claimed to be a committed Christian) – seemed to me to embody much of what I valued in terms of debate in research contexts. They could disagree passionately on difficult theological issues, some of which have particular relevance to disabled people – for example, on issues of selective abortion, genetic screening, separate ministries for disabled people, and so on. They drew links between debates about homosexuality to the exclusion they had often felt as disabled people from the world of sexuality. Somewhat to my surprise, given what I thought to be high levels of homophobia in the group, some of the trainees argued that their own experiences of having their own sexual desire being seen as disgusting by some religious leaders led them to have empathy for gay men and lesbians.

As a person comfortable in the largely secular environment of the university, I had had no difficulty anticipating the importance of activist ideology and identity politics for the trainees and for how they thought about knowledge and the world. What I had completely missed prior to my engagement with these trainees, despite my academic knowledge that Christianity and religion are so important in our part of the world, was that religion was equally as important for them as activist ideology and identity politics. They had been excluded and vilified by aspects of religion, and they spoke movingly about the pain they felt at being seen as punishments from God, but religion also sustained them and gave them a sense of meaning and identity.

Thinking about these debates (and these debates about religion and spirituality are amongst what I remember most fondly about the training), I realised that on the ideological battlefields of faith and doubt, it was not only I who was doing the discomfiting. The trainees paid me the compliment of helping me to be discomfited about my own notions of what it means to be a researcher/activist. I have no doubt that contestation is at the heart of research. But I have also come to believe that faith (and this was not a faith consumed in an authoritarian way, but a faith struggled with by people who had experienced religious exclusion) may be part of what sustains people, and provides a safe and nurturing environment for people whose lives are far more precarious than mine, to use Judith Butler's phrase. Within that environment, the discomfort of what it means to be a researcher, the uncertainty and the temporality of knowledge, may be easier to bear.

It astonishes me now how silent much development work and scholarship on disability is on issues of faith and religion, apart from the rather easy rejection of religion (along with medicine) as a form of oppression of disabled people. I have also learned from the trainees with whom I worked that despite my secularity, despite my atheism, I have some way to go in understanding the heretofore unacknowledged influence of religion on my own life and practices. It is easy (and often glib) to claim that empowerment processes should be mutually empowering and challenging. It is another matter to sit as I now do at the end of what was a transformative training process for me, left with many personal challenges posed by the trainees, one of which is the question of where I stand on matters of religion and faith. The short answer is that I do not know – but given my deep commitment to not knowing, that may be the best answer – better than the answer I would have given years ago. I cannot believe any longer that issues of faith and spirituality are irrelevant to the training of disabled researchers – they are relevant and challenging for the trainees, but also, in this case at least, to the trainer.

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Through the eyes of children

Children living with severe communication disabilities doing theology¹

7

Martha Geiger²

INTRODUCTION

In my work with children with severe disabilities and little or no speech, I am repeatedly amazed at how fervently many of these children *communicate*, even though they cannot *speak*. And what profound truths can be communicated by gestures, eye gaze or eye blink responses or grunts and squeals! There have been wonderful developments, including diverse sign languages, written or pictorial communication systems and the whole arena of computerised communication systems. These have revolutionised the participation and contribution of people with extreme disabilities, such as the world-renowned scientist and writer, Professor Stephen Hawking, among others.³ The focus here, however, is on those who cannot benefit from formal communication systems or assistive devices, either because of the severity and complexity of their disability, and/or because of poverty and lack of access to appropriate services.

Cerebral palsy is the most common cause of the conditions of the children with whom I work. Gestures, body language, facial expressions, eye pointing, a wide range of laughs and cries, and moreover the *timing* of laughs and giggles are only a few of the forms of expression which these children use to communicate with others. Most of them have a considerably higher level of understanding than their expressive communication would indicate. The challenge is to find ways of connecting with the child, understanding what is important to the child, how she expresses this and building on her form of communication to create opportunities for her to convey her thoughts, desires, fears, joys and insights – and so to get to know the child as a unique person.

The purpose of this paper is twofold. On an academic level, it aims to add to discussions about the spiritual and theological realities of children with severe disabilities. On a practical level, it aims to encourage those who have not had opportunities with such children and who lack confidence or are even fearful of where and how to begin with interactions with

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 - 2 Martha Geiger is Senior Lecturer at the Centre for Rehabilitation Studies, Faculty of Health Sciences, Stellenbosch University, and a speech therapist, engaged in community-based training of caregivers of children with severe disabilities.
 - 3 Hawking, S. 2011. Foreword. In WHO. 2011. *World Report on Disability*. Geneva: World Health Organisation and World Bank, ix.

them. The hope is to raise a positive expectancy and an enjoyment of the communication potential, the spiritual wealth and the theological realities of these children.

REFLECTIONS FROM THEORY AND PRACTICE

Interacting and communicating with others is part of the essence of being human. The practice of speech therapy – or rather *communication* therapy, considering that I work with children who cannot speak – opens opportunities to learn about personalities, personhood and human relationships in many ways. In the tradition of reflective practice⁴ I have collected, reflected upon and learnt from observations and experiences with the children and have included some of these here, to illustrate and expand upon the documented developments in the areas of *disability* in general and *communication disabilities* in particular, as well as in the *culture and attitudes* to persons with diverse communication disabilities, and *children and theology*.

► Disability

Disability constitutes an extremely complex issue. Early understandings of disability were rooted in supernatural explanations of otherwise inexplicable phenomena.⁵ The development of popular knowledge about disability mirrors the accessibility of scientific knowledge and the acceptance of medical discoveries regarding the nature and causes of disabilities. Resultant concepts and definitions have evolved from diverse histories, through to the comprehensive World Health Organisation classification of 2001, which is helpful in explaining disabilities in terms of their interrelating impairments, activity limitations and participation restrictions.⁶

According to this definitive classification, *impairment* refers to the underlying problem of physical structure or function. Examples may include the neurological damage to the lower brainstem acquired during the prolonged labour and birth of a child with cerebral palsy, or the hereditary auditory nerve damage causing deafness⁷ in another (deaf or deafness with a lower case relates to audiological, severe to profound hearing loss, as opposed to capitalised Deaf, referring to Deaf culture and the Deaf community). These two impairments could cause very different *activity* limitations in the affected children's daily lives; the child with cerebral palsy may not walk, talk or eat independently, but may understand everything as her intelligence is unaffected, while the deaf child learns physical independence quickly but cannot understand spoken language and does not learn to speak. The third level addressed by the WHO classification is that of *participation*.⁸ This concerns environmental and social

4 Schön, D. A. 1995. *The Reflective Practitioner: How Professionals Think in Action*. Aldershot: Ashgate.

5 Ross, E. and Deverell, A. 2004. *Psychosocial Approaches to Health, Illness and Disability: A Reader for Health Care Professionals*. Pretoria: Van Schaik.

6 WHO. 2001. *International Classification of Impairments, Disabilities, and Handicaps (ICF)*. Geneva: World Health Organisation; WHO 2011. *World Report on Disability*. Geneva: World Health Organisation and World Bank.

7 WHO, ICF, 18. WHO, *World Report*.

8 WHO, ICF, 18. WHO, *World Report*.

factors which either help or hinder the person's involvement in family, peer and general community life. Environmental factors enabling participation include a school which embraces diversity and has made structural alterations (e.g. ramps and wider doorways) to include the child with cerebral palsy. Barriers may include the family of the deaf child, who feel strongly that she must learn to speak and discourage the use of gestures and signs as a way of communicating, at the cost of her developing functional communication for participation at all.

Viewing disability as a medical issue affecting the individual is characteristic of the earlier 'medical model' school of thought.⁹ As a result of this, many children with severe disabilities were (and still are) institutionalised and cared for as 'sick' children; being fed, cleaned and medicated in high-sided hospital cots – albeit with much love and dedication, but with little or no stimulation. Among disability theorists and policy makers, the proverbial pendulum then swung to the other extreme and the 'social model' emerged in which people were seen as being disabled by society rather than by their bodies. Terminology has evolved intertwined with such views.¹⁰ At the risk of over-simplification, the term *person with a disability* is generally accepted in international policy contexts and is intended to reflect a respectful person-centred or people-first approach.¹¹ This is critiqued, however, as being impairment-orientated by disability activists preferring the human rights-based term *disabled person*, which needs to be understood against the view that the environment or society is considered the disabling factor and not the person's body or impairment.

As with all theoretical models, both the medical and the social models have their limitations. Disability is most certainly not merely a medical issue as there are countless environmental and social factors that can increase or decrease the impact of the disability.¹² However, even if all the best possible environmental and social supports are in place to facilitate participation in their communities à la social model, persons with disabilities often still experience *disabling* problems directly related to their health condition – for example, chronic pain. A helpful compromise then is the bio-psycho-social model.¹³ The interrelationship of biological (or physical) factors, psychological (or emotional) factors and social (or environmental) factors is particularly clear in communication disabilities, the essence of communication being interaction and relating to others.

► Communication disabilities

Arguably, disabilities which limit a person's ability to communicate and to interact with others present additional challenges, beyond those of other disabilities. The quote attributed to the American statesman and orator, Daniel Webster, sums it up: "If all my possessions were taken from me with one exception, I would choose to keep the power of communication, for by it I would soon regain all the rest."¹⁴ Among those with severe

9 WHO, *World Report*.

10 WHO, *World Report*.

11 United Nations. 2008. *Convention on the Rights of Persons with Disabilities*. Online at: <http://www.un.org/disabilities/default.asp?id=259> [Accessed: 6 May 2011].

12 WHO, *World Report*.

13 Ross and Deverell, *Psychosocial Approaches*.

14 *Daniel Webster Quotes*. Online at: <http://www.goodreads.com/author/quotes/31180> [Accessed: 24 June 2011].

or multiple disabilities, it is indeed evident that those who can communicate (even if they cannot speak) are less 'disabled' in terms of participation in interactive relationships and in their environments than those who cannot (or are not given the opportunity to communicate).

The distinction between *speech*, *language* and *communication* is critical in understanding a child's abilities and disabilities. *Speech* constitutes only one way – next to writing, etc. – of transmitting a formal *language* system such as English, isiXhosa or Afrikaans. Examples of non-verbal languages or systems developed to facilitate communication where speech is not possible include South African Sign Language and, for people who cannot speak nor form complex hand signs, picture communication systems such as PCS¹⁵ and Minspeak.¹⁶ *Communication* is the actual interaction, the sending and receiving of messages between two or more people, whether it is by means of a universally understood facial expression such as a smile; a more specific gesture such as a head shake for 'no' or by a formal *language* system such as South African Sign Language or a picture communication system or a spoken language such as English.

As mentioned earlier, augmentative and alternative communication, or more usually just the abbreviation AAC, refers to "an area of clinical practice that attempts to compensate either temporarily or permanently for [...] people with severe speech, language and/or writing impairments".¹⁷ AAC includes strategies using a range of communication aids (from home-made cardboard picture boards to high-tech speech synthesisers) as well as the whole range of 'unaided' systems including gestures and signs. International and local developments in the specialised field of AAC have delivered revolutionary possibilities for people with severe communication disabilities¹⁸ – if they live in environments where they can access them.

Referring back to the opening sentence, most children with severe disabilities and little or no speech have surprising potentials to *communicate* – even without speech. Examples include facial expressions, body language, learned eye-blink or eye-pointing responses to spoken questions (one blink or look upwards for 'yes' and two blinks or look aside for 'no' etc.), voicing (though not able to articulate words, the voice can express much through differently intoned sounds!) – to name but a few. Eye pointing in particular is a very powerful and often used expression, picked up and developed most effectively by observant and 'listening' caregivers and communication partners! In pointing out these possibilities, I do not wish to diminish or play down the impact and the frustration of communication disabilities, or the affliction of not being able to speak or communicate easily.

Any potential forms of expression such as those mentioned above depend upon the people in the child's environment responding and/or providing opportunities to *use* them. In one of the residential special care centres where I regularly work, visitors and volunteers

15 Mayer-Johnson, R. 1990. *The Picture Communication Symbols. Volumes I, II and III*. Solana Beach, CA: Mayer-Johnson.

16 Baker, B. 2001. *Semantic Compaction Systems*. Online at: <http://www.minspeak.com> [Accessed: 23 June 2011].

17 Beukelman, D. R. and Mirenda, P. 1998. *Augmentative and Alternative Communication*. London: Baltimore, MD: Paul H. Brookes, 3

18 Alant, E. 2005. Cultural and socio-economic influences on communication. In Alant, E. and Lloyd, L. L. (eds), *Augmentative and Alternative Communication and Severe Disabilities: Beyond Poverty*. London: Whurr, 95-107.

were often seen trying to make contact with the children, most of whom spend the day in a wheelchair or buggy, with a lap tray in front for activities. Seeing the frustration on both sides, we wrote a short individualised introduction for each child and stuck these laminated, brightly coloured introductions on the children's lap trays so that any visitor can know where to begin.

Examples include: "Hello, my name is Nikiwe. I can look up for 'yes' and I blink for 'no'. Please ask me *short* questions and *give me time to respond!*" or: "Hello, my name is Emmy. I am sleepy because of my medication. I smile when I like something and I close my eyes if I don't. Hint: rub my hands gently and see!" It has been wonderful to see how empowered visitors are in beginning a conversation, and how much easier it is for them to get to know individual children in this way. Caregivers', visitors' and other communication partners' responses to the child depend upon their attitudes to, and expectations of, the child. Some will experiment and encourage the child to do more and more and the lap tray introductions have only been the trigger to wonderful friendships. Others cannot get over the idea that it is a very sick child, and while love and care are not lacking, the child is not expected to do or learn anything.

► Culture and attitudes

Over time, changes in the understanding of and attitude to disability have mirrored the evolution of the medical, social and bio-psycho-social models, described earlier. In addition, attitudes and responses to people with diverse disabilities vary widely across and even within cultures.¹⁹ Most attitudes and responses are rooted in beliefs about the causes of disabilities – which in Southern African indigenous cultures are predominantly attributed to spiritual or supernatural sources.²⁰ Reports have been published of both negative responses to disability including ostracism, abuse and even killings, as well as positive stories of non-discriminatory community values and caring inclusion of people with disabilities.²¹ A discussion of the range of cultural attitudes in southern Africa alone is beyond the scope of this paper, but a first-hand observation in Botswana may suffice to illustrate the extreme variations in attitudes and responses from within a single community. It also underlines the danger of making any generalisations.

While working at a children's rehabilitation centre in Botswana, my therapist colleagues and I did follow-up home visits to children who spent school terms at the centre and returned to their home villages for vacations. During one vacation two boys with similar forms of cerebral palsy, the same level of physical and intellectual impairment and benefiting from similar stimulation programmes at the centre during term time were visited at their respective homes in a single village, representing a single language, tribal and cultural

19 Helman, C. G. 2002. *Culture, Health and Illness*. 4th ed. London: Arnold.

20 Chataika, T. 2011 Cultural and Religious Explanations of Disability: A Call for a Rights-based Approach and Fostering of Inclusive Communities. Paper presented at the *Theology, Disability and Human Dignity Conference*, Faculty of Theology, Stellenbosch University, 18-20 May 2011; Merriweather, A. M. 1992. *Puisanyo ya Bongaka ka Sekgoa le Setswana: Medical Phrasebook and Dictionary*. Gaborone: Botswana Book Centre.

21 Geiger, M. 2010. Using cultural resources to build an inclusive environment for children with severe communication disabilities: A Case Study from Botswana. *Children's Geographies* 8(1):51-63; Ingstad, B. 1997. *Community-based Rehabilitation in Botswana: the Myth of the Hidden Disabled*. New York, NY: Edwin Mellin; Ross and Deverell, *Psychosocial Approaches*.

community. At the first home the son with the disability was happily included in the family circle and participated, albeit passively, in social activities such as receiving visitors – while in the other home, the disabled son was found tied to a tree behind the family hut. Thankfully changes in attitudes over time are predominantly positive – as is the end of this particular story: the village chief became a passionate advocate for the human dignity, appropriate treatment and inclusion of the second boy and supported his family further.

Among the many different culturally determined responses to specific *communication disabilities*,²² one is of particular relevance here. It is the perception that someone who cannot speak, can also not hear or understand. In spite of many positive developments, this belief is particularly persistent over time and seems to occur widely across several cultures, as illustrated by the following two experiences, among many. The first one occurred in a day-care centre for children with severe mixed (physical and intellectual) disabilities. During one of my sessions there, a caregiver and I were encouraging a young partially paralysed boy, who cannot speak, to choose and point to one of several pictures as a means of answering our questions. As we were asking the questions, the young boy was slowly but accurately indicating the answers by pointing to the correct picture. A visitor from the community, who knows the children well, joined us and exclaimed: “Why are you talking to him – he can’t talk!” The second experience happened with a young Xhosa boy with a sharp mind and a wonderful sense of humour – but locked in a body profoundly impaired by cerebral palsy. Lack of resources and no early interventions meant that his body had become fixed in a pattern of contractions, and his only voluntary movements were eye blinks, ‘pointing’ with his eyes and a smile. His mother and caregivers had learnt to communicate with him by reading his ‘yes’ and ‘no’ eye-blink responses to their normal speech communication. He had been hospitalised for pneumonia and his mother and I sat by his hospital bedside, each massaging one of his hands, talking to him and also singing Sunday school songs and praying with him. Several nurses came in at different times to check on him and without exception each one either asked why we were talking to him or commented that it is useless talking to him as he “cannot answer”. Each time his mother patiently explained that he could indeed understand everything and that his eye blink responses were amazingly accurate – if one knew what to look for.

It was sobering to consider that even some health care workers were under the widespread impression that no speech means no understanding.

■ Children and theology

A regular children’s Bible class in the rehabilitation centre in Botswana (mentioned earlier) was profoundly changed when one young boy, who *was* able to speak albeit with great difficulty, one day announced very authoritatively that “*bana ba ba sa bueng, ga ba na mowa*” (= the children who cannot speak do not have a spirit). This caused an outcry of anger and distress from those unable to speak – there were screams of protest and extremely panicked physical, facial and other responses. Needless to say the rest of the session was spent comforting and assuring the children that this is not so – and also comforting the young boy who had made the statement as he was merely passing on a very commonly held

22 Battle, D. E. 1998. *Communication Disorders in Multicultural Populations*. Boston, MA: Butterworth-Heinemann; Merriweather, *Puisanyo*.

perception, a kind of theology which is sadly prevalent in traditional contexts in Africa and elsewhere. This prompted a journey of enquiry into making the children's Bible class more relevant to this particular group of children.

Biblical and especially New Testament themes of children and childhood can be understood in three groupings.²³ Firstly, there is the theology of childhood, including child-parent analogies, references to child innocence and 'spiritual naivety'. Secondly, there is child theology, following the directive of Jesus to put the child in the centre and what this does to our beliefs and the way we conduct church and mission. Thirdly, there is the issue of children *doing theology*.²⁴ This refers to children's awareness and articulation of their *relationship with God*, which is more than *children's spirituality*, which has been described as children's awareness of God's existence.²⁵ While all three are of relevance here, it is the third, children *doing theology*, that is to be highlighted through some of the severely disabled children's own expressions.

Swinton *et al.* have described what it means to know God even when, intellectually, one might not know anything about God.²⁶ A repeated observation in working with children with disabilities is that they fit quite easily into a "knowing without understanding" faith, which calls into question the earlier schools of teaching children biblical truths as if they were Renaissance-type mini-adults.²⁷ Relationship is central and a further example from conversations with children illustrates how communication barriers are overcome and why the young boy's proclamation that "children who cannot speak do not have a spirit" caused such an outcry. Connie, a 13-year-old girl with cerebral palsy which paralysed one side of her body, a severe 'drooling' problem and no speech, was a particularly active participant in the Bible class mentioned earlier, although in society she was an outcast. One day, she overheard me speaking German to someone and with her very expressive frown, and signing with her one functional hand, she asked how many languages I speak. I responded: "Four: Setswana with you, English with some people, Afrikaans with others and German mostly with my family." She pondered this and then broke into a wide and mischievous smile, signing that she too uses four languages! She indicated her one-handed signing as language number one, her pointing to pictures on her communication board as number two and her unarticulated but expressive voice for crying, grunting, squealing, laughing and a whole range of other emotive expressions as her third language. Then she paused, and with a triumphant smile she pointed to her head (for 'thoughts') and then upward and a 'Number One' sign (for God). Her silent communion with God was her fourth language – particularly poignant in the African culture, where prayer is a part of the oratory tradition and silent prayer is seldom known. Yet Connie needed no speech to express her clear theology! With such profound lessons to be learnt from the Connies out there, much is

23 Hay, D. and Nye, R. 2006. *The Spirit of the Child*. (Revised Edition). London: Jessica Kingsley; Privett, P. 2009. Prologue: The Thirtieth Anniversary of the Year of the Child. In Richards, A. and Privett, P. (eds), *Through the Eyes of a Child: New Insights in Theology from a Child's Perspective*. London: Church House.

24 Privett, Prologue, xix; Hay and Nye, *The Spirit of the Child*.

25 Hay and Nye, *The Spirit of the Child*.

26 Swinton, J., Mowat, H. and Baines, S. 2011. Whose Story am I? Redescribing Profound Intellectual Disability in the Kingdom of God. *Journal of Religion, Disability & Health* 15(1):5-19.

27 Csinos, D. M. 2011. *Children's Ministry that Fits: Beyond the One-size-fits all Approaches to Nurturing Children's Spirituality*. Eugene, OR: Wipf & Stock.

missed when we are fearful of engagement because we do not know how to, or worse, if our attitudes preclude the recognition of our fellow travellers with severe disabilities.

Another place of such learning for me is a special care centre where I regularly spend time encouraging communication and training the care workers who lovingly and sacrificially care for nearly 100 children and young people with the most severe disabilities and who have been abandoned by society. Most of these children and young people have multiple disabilities: the severest forms of cerebral palsy, epilepsy, intellectual disabilities, blindness, deafness and several mental illnesses such as schizophrenia and severe depression are all represented here, often in some combination in a single person. The biggest frustration is the lack of time, human and other resources to implement any really effective programme. Much of my time as the only speech therapist involved there is to visit, greet and briefly interact with each child, giving the caregivers ideas on how to encourage more communication with each child or young person.

As I go around amid squeals and grunts and smiles and cries, it strikes me repeatedly how, in this community, the values are not about who can do what, or who owns what, or who has achieved what, or who is attractive and who is not; all that counts is the *person* imprisoned inside that body. This stripping away of all else, has triggered many thoughts about what Heaven must be like. Others – notably Henri Nouwen – have written about this awareness and experience of the theological life lessons received with and from people with severe disabilities.²⁸ I can only imagine how much is lost because I cannot understand, or in my impatience do not make the time to understand, these fellow travellers and their attempts to share glimpses of their spiritual wealth.

► Church community – the hermeneutic of the Gospel?!

Newbigin describes the church community as “the hermeneutic of the Gospel [...] that place where the gospel is lived out and interpreted to the world through the actions and character of its participants”.²⁹ For sure, our community responses are the only interpretation of the Gospel that others may ever see; even more so for children with severe disabilities to whom the ‘normal’ channels of hearing and reading the Bible message are not accessible. Gaventa and Coulter³⁰ also describe the need for ‘hermeneutical competence’. The ability to engage and commune with children (and adults) with severe disabilities and little or no speech does indeed require more than learned skills: an attitude of acceptance and a desire to know the other are fundamental.

In contrast to the imperatives for inclusion and participation based on human rights mandates such as the United Nations Convention on the Rights of Persons with Disabilities,³¹ the voices from the field of theology are calling for and committing to real relationships of

28 Nouwen, H. 1997 *Adam, God's beloved*. New York, NY: Orbis.

29 Newbigin, L. cited by Swinton, J. (ed.). 1990. *Critical Reflections on Stanley Hauerwas' Theology of Disability*. Binghamton, NY: Haworth Pastoral, 6.

30 Gaventa, C. and Coulter, D. 2001. *Spirituality and Intellectual Disability: International Perspectives on the Effect of Culture and Religion on Healing Body, Mind and Soul*. Binghamton, NY: Haworth Pastoral.

31 United Nations, *CRPD*.

mutuality³² and encourage us towards a thinking and a terminology grounded in values such as human dignity.³³ Our theology of a God of love and the essence of the Christian Gospel lights the way in welcoming the Connies out there to our fellowships as valued participants and as contributors. But how?

The terms we use to describe our efforts can be quite counter-productive and should be re-thought: for example, having a plan or strategy to learn to work *with* (not *for*) individual children regardless of ability, rather than a programme for children with disabilities.³⁴ A growing conversation³⁵ is probably the best – and only – way to proceed, and Möller³⁶ sums it up well as “a reciprocal learning process of inclusion and enhancing the role of people with disabilities in the faith community”. Learning from one another presupposes an expectation that the other has something to teach, to contribute. As pointed out several times during the conference, being allowed to contribute is something that many disabled people rarely get the opportunity to do. It can only be assumed how much benefit is missed where the richness to be given cannot be given – as was illustrated by some of the examples of children who have limited ways of expressing their theological insights.

CONCLUSION

The dual purpose of this paper was to add to discussions about the spiritual and theological realities of children with severe disabilities, and to encourage a positive expectancy of the relational, spiritual and theological contributions that these children can make. Testimonies of some of these children’s insights add to earlier academic and theological discussions about children doing theology and hopefully illustrate the richness of communication and the enjoyment of participation that is possible, even when speech and formal alternative language systems are lacking. This underscores the role that such children can play in challenging stereotypes and affirming the contributions they make to society, and thus put to rest the fears that people sometimes have when coming into contact with persons with severe communication disabilities.

Children, and by implication adults with severe disabilities and little or no speech, pose a particular challenge for inclusion and participation, because the very essence of interaction – that is communication – is affected. Health and other care workers engaged with these children – and in fact *all* potential communication partners – can be equipped and prepared with practical skills and a *hermeneutical competence* beginning with a positive expectancy, to

32 Reynolds, T. 2011. Theology and Disability – Changing the conversation. Keynote address presented at the *Theology, Disability and Human Dignity Conference*, Faculty of Theology, Stellenbosch University, 18-20 May 2011.

33 Claassens, J. L. 2011. Job, Theology and Disability: Moving Towards a New Kind of Speech. Paper presented at the *Theology, Disability and Human Dignity Conference*, Faculty of Theology, Stellenbosch University, 18-20 May 2011.

34 Pierson, J. 2010. Inclusion: Easy and Natural. In *Journal of Religion, Disability & Health* 14:182-5.

35 Claassens, Job, Theology and Disability.

36 Möller, E. 2011 The Experiences of People with Disabilities in Faith Communities: A Social Work Perspective. Paper presented at the *Theology, Disability and Human Dignity Conference*, Faculty of Theology, Stellenbosch University, 18-20 May 2011.

include and embrace them not only as recipients but as partners and as contributors in faith communities, and in society at large.

There remains a need for further exploration – whether as formal research or documented life stories in the tradition of Henri Nouwen’s *Adam*.³⁷ In addition to the attitudinal issues discussed here, practical strategies need to be explored for care workers across the disciplinary spectrum to be empowered to discover, know and then build upon the communicative abilities and the theological realities of children with severe disabilities.

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³⁷ Nouwen, *Adam*.

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Disability and biomedical enhancement

8

Conflict or co-existence?

Anton van Niekerk¹

MUST DISABILITY AND ENHANCEMENT BE SEEN AS INCOMPATIBLE?

What are generally regarded as developments – some would prefer the term “advances” – in the field of new biomedical enhancement technologies, including those operative at the genetic level, are often not welcomed or applauded by people with disabilities, or by bioethicists who concern themselves with the situation of physically and mentally disabled people.² The reasons for this are obvious. Not only disabled people, but all sensible human beings are to this very day haunted by the memory of the dehumanisation that vulnerable, particularly disabled, people suffered at the hands of the Nazi perpetrators of so-called “biomedical experiments” in the death camps during the Holocaust. Much can be said of these crimes that available space will not now allow me to embark upon.³ What cannot be denied, however, is that these atrocious acts sent a clear message to the disabled communities of Western and Eastern Europe at the time. That message was that disabled people were regarded by the Nazi authorities and their supporters as inferior, unwanted human beings that it would be preferable to rid the world of, and that the best use that could be made of them is to exploit their vulnerability in order to experimentally test the limits of human endurance, and to try and establish how a superlative, physically perfect super-race can be created – a race from which they, in principle, would be banned.

The negative reaction to the very idea of human enhancement is therefore perfectly understandable. I would, however, argue that, as a general moral response to the possibility of human enhancement, also by means of new biotechnologies, it is unwarranted and unsustainable. As a general moral reaction, it commits the fallacy of conferring guilt by association, since it uncritically and therefore unjustifiably assumes that every effort to enhance people, including researching ways and means of limiting or preventing disability, is motivated by negative attitudes towards disability and disabled people. It also assumes that research of this nature will, of necessity, be characterised by a lack of informed consent, as was overwhelmingly the case with the Nazi experiments. But that is not necessarily the case.

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- 1 Chair, Philosophy Department and Director, Centre for Applied Ethics, Stellenbosch University, South Africa.
 - 2 See, for example, Bradshaw, H. G. and Ter Meulen, R. 2010. A Transhumanist Fault Line around Disability: Morphological Freedom and the Obligation to Enhance, *Journal of Medicine and Philosophy* 35:671.
 - 3 See in this regard Miklos, N. 1962. *Auschwitz: A Doctor's Eye-witness Account* (Trans. Kremer, T. and Seaver, R.). London: Panther, and Posner, G. L. and Ware, J. 1987. *Mengele: The Complete Story*. London: Futura.

In the paper that follows I shall try to make an argument in support of the proposal that enhancement, which is not a new phenomenon and has been around as long as we can remember,⁴ and disability are not irreconcilable concepts. In fact, I would like to argue that much of what happens on the front of the development of new enhancement technologies, also of a biomedical (including genetic) nature, confers significant possibilities for the situation of some disabled people.⁵ This argument is informed throughout by the strong conviction that the search for a cure for, or a relief from, conditions or dispositions that are universally experienced as restrictive, painful or discomfiting, does not imply negative attitudes towards the individual people who live with these conditions.

I wish to make it clear that by constructing such an argument, I am in no way expressing any negative attitude towards, nor am I in any sense questioning the humanity of, disabled people or their right to life and to care. In, for example, Eva Kittay's dispute with bioethicists such as Jeff McMahan⁶ and Peter Singer⁷, I accept Kittay's arguments about the fundamental difference between a disabled human being and a chimpanzee. Although I do think that many animals, particularly the higher primates, have significant moral status, that status is lower than that of a severely mentally disabled child.⁸ When I will deal, later in the article, with an issue regarding d/Deaf⁹ people, their humanity and rights are accepted unconditionally.

I believe that enhancement technologies can (and ought to) spring from motives and the application of principles that are both morally and theologically grounded. Morally speaking, the principles of beneficence and non-maleficence are obviously applicable: the idea to better people is motivated by the commitment to do good and to prevent harm. Theologically speaking, enhancement technologies are quite compatible with the hope of the renewal of creation that is promised on the basis of faith in God's redemptive work in Christ, a redemption that transcends the idea of a mere spiritual reconciliation of God and humankind, and includes the promise of cosmic renewal, to the point of the eventual termination of all kinds of suffering in the world.

4 Cf. Buchanan, A. 2011. *Beyond Humanity: The Ethics of Biomedical Enhancement*. Oxford: Oxford University Press, 1-33.

5 Cf. Okarma, T. B. 2001. Human Embryonic Stem Cells: A Primer on the Technology and its Medical Applications. In Holland, S., Lebacqz, K. & Zoloth, L. (eds), *The Human Embryonic Stem Cell Debate*. Cambridge, MA: MIT, 3-26.

6 See McMahan, J. 2003. *The Ethics of Killing: Problems at the Margins of Life*. Oxford: Oxford University Press.

7 See Singer, P. 1996. *Rethinking Life and Death: The Collapse of our Traditional Ethics*. New York, NY: Macmillan.

8 See Kittay, E. F. 2009. The personal is philosophical is political: a philosopher and mother of a cognitively disabled person sends notes from the battlefield. *Metaphilosophy* 40(3-4):606-27. See, in particular, her recorded interchanges with McMahan and Singer on pages 621-2 of her article.

9 I will respect the custom of using "deaf" (with a lower case d) for people who do not associate with other members of the deaf community, strive to identify themselves with hearing people, and regard their hearing loss solely in medical terms. I will use "Deaf" (with a capital D) for people who identify themselves as culturally deaf and have a strong deaf identity. Deaf (capital) will therefore be used for all aspects of deaf culture, and a lower case deaf will be used when speaking solely about the hearing loss. When I'm unsure, I'll use d/Deaf. See in this regard McLellan, F. 2002. Controversy over deliberate conception of deaf child. *The Lancet* 359:1315.

THREE MEANINGS OF DISABILITY

What do I mean by “disability”? It is very difficult to agree on a single, all-encompassing definition of this problematic term. It seems to me as if the literature offers, broadly speaking, three kinds of definition, viz. a medical, social and (what I, for lack of a better term) would like to call a “philosophical” definition. In terms of the *medical* definition, disability might be looked upon as a condition resulting from the malfunction of a part or parts of the human body or mind. This might have been caused by genetic inheritance, illness or accident. It is the kind of condition in which, as Glover formulates it, “some physiological or chemical system might be missing or atrophied [...]”. The absence or malfunction of such a system results in the person having impaired abilities to cope with life”.¹⁰

The second kind of definition of disability is *social*. Here disability is understood as a social construct, i.e. an alleged adverse condition, but one that exists relative to the way in which society, by its interpretations and provisions, creates the condition. Take the inability to walk. This could be seen as a “disability” in a society where there is minimal provision for wheelchairs and wheelchair access to buildings, elevators, trains, buses and the like. In a society well provided for in this respect, the “disability” of not being able to walk becomes much less of an issue.

In the literature the situation of an 18th-century community in the USA known as Martha’s Vineyard is often used to illustrate this point.¹¹ Shapiro writes in this regard:

For 250 years deafness was commonplace on Martha’s Vineyard. The first deaf resident, a fisherman named Jonathan Lambert, settled there in 1694. He carried a recessive gene for deafness and, as a result of intermarriage among the isolated islanders, this trait spread through generations of Lambert’s descendants [...]. By the middle of the 19th century, one in 25 residents of Chilmark was deaf, and in one neighbourhood the ratio was one in four [...]. The result was [...] the entire community learned to use sign language [...]. Hearing fishermen would use it to communicate from one distant boat to another. By mid-1800s, greater mobility slowed the pace of intermarriage, and the genetic anomaly that created the deaf community disappeared.¹²

Here, clearly, what would be regarded unequivocally as a “disability” in other communities was regarded as an entirely non-significant attribute (like blue eyes) because of the kind of compensatory social interaction that was fostered within this community. Deafness as a “social construct” was, in fact, “deconstructed”.

This example, interesting as it is, nevertheless remains quite exceptional. Disability cannot always be looked upon as a mere social construct that can be radically adjusted simply if enough effort is made by society. Not all disabilities can be overcome, even though it must be admitted that science and technology, as well as sensitivity and will power in society, can achieve a lot to improve the quality of life of disabled people. The fact remains,

10 Glover, J. 2006. *Choosing Children: Genes, Disability and Design*. Oxford: Clarendon, 6.

11 See Groce, N. 1985. *Everyone Here Spoke Sign Language: Heredity Deafness on Martha’s Vineyard*. London: Harvard University Press.

12 Shapiro, as quoted in Marks, D. 1999. *Disability: Controversial Debates and Psychosocial Perspectives*. London and New York, NY: Routledge, 78-9.

however, that irrespective of social context and irrespective of practices of social inclusion or exclusion, impairments affect people's lives. No amount of social inclusion will enable a blind reader to browse the hard-copy texts in an archive in the same way that sighted people can, for example, and even if we accept the argument that it is the existence of stairs rather than ramps or lifts in the built environment that excludes people with mobility impairments, there is a reality to not being able to use one's legs to walk unaided.

That brings us to, in the third instance, the *philosophical* conception of disability.¹³ Disability must always be understood in terms of real limitations that are experienced in bodily and/or mental functioning. In this sense disability is significantly different from allegedly socially constructed disadvantages like ethnicity or skin colour. A hermit who is unable to walk is disabled, irrespective of the fact that he lives entirely on his own and not in a society. A limitation or failure of functioning, however, is only a disability if it amounts to the impairment of human flourishing.

Aristotle identified flourishing (*eudaimonia*) as our *telos* as human beings.¹⁴ This refers to our capacity to make choices, set goals and exert ourselves physically and mentally to our full potential. It could, of course, be argued that disabled people can, in this sense, also flourish. Blind people may not be able to see, but that does not mean that they cannot set goals for themselves as well as exercise and fulfil potential.

What must be added for a complete understanding of the notion of "disability" is some understanding of what for convenience may be termed "normal functioning", since we regard functional limitations as disabilities only when there is a contrast with the usual range of human functioning. The distinction between "normality" (in itself a very elastic term) and disability is notoriously difficult to adumbrate unequivocally. Glover rightly remarks that "the normality that is contrasted with disability is a hybrid of the numerical and the normative".¹⁵ By this he means that normality is first of all *numerically* determined; "its possession by a reasonable sized group is needed if something is to count as normal functioning [...]. The central idea seems to be that of a benchmark of human potentiality, demonstrated by some sizable past or present population".¹⁶

What the norm for "normality" is, is much more difficult to establish uncontroversially. Glover in this respect refers to the view of John Harris: "disability is a condition that someone has a strong rational preference not to be in".¹⁷ This is not satisfactory, since I, for example, have a strong rational preference not to be bankrupt, and yet bankruptcy does not constitute disability. Harris's formulation has to be adapted to include reference to some bodily or mental condition. My suggestion would be: *disability is a physical or mental condition, characterised by significant functional impairment, that most people have a strong rational preference not to be in*. Of course, some disabled people (members of the Deaf community particularly come to mind) do not look upon their impairment as a "disability"; they regard their Deafness

13 For this discussion, I draw strongly on Glover, *Choosing Children*, 8-16.

14 Aristotle, 1955. *The Ethics of Aristotle – The Nicomachean Ethics*. Harmondsworth: Penguin, 66-89.

15 Glover, *Choosing Children*, 12.

16 Glover, *Choosing Children*, 12.

17 Harris as quoted by Glover, *Choosing Children*, 13.

as what is “normal” for them. But I do argue that that position is the exception, and that we encounter almost insurmountable problems if we want to reach an acceptable notion of “disability” without any reference to some sense of “normality” that most people hold.

ENHANCEMENT

This brings us to the second central concept that, for the purpose of my argument in this paper, requires clarification, viz. *enhancement*. There is a tendency, the moment this notion is introduced, to conjure up alarmist ideas that allege that enhancement is morally abhorrent since it refers to the possibility of biomedically induced eugenics, i.e. the creation of some super-race that has mental and physical abilities which far supersede what we are accustomed to, and that might well represent entities that are no longer human but must rather be regarded as “post-human”. This kind of alarmist grandstanding is very unhelpful in this whole debate. What we must first of all understand is that enhancement is an inherent characteristic of our species and a natural outcome of our evolution. One of the most significant ways in which we differ from other species is the fact that we have, since our earliest origins, always impinged on our so-called “natural abilities” in order to improve ourselves. Two of the earliest and most influential mechanisms of enhancement that were created by our species are literacy and institutions. *Literacy* is our capacity to write and read, i.e. to externalise our thoughts, critically reflect on them and thereby to achieve considerable cognitive enhancement – a capacity that is unique to our species on this planet.¹⁸ *Institutions* represent our capacity to act, not only as individuals, but collectively (e.g. through the state), thereby enhancing our capacity to ascertain resources, ensure security, develop moral intuitions and live in peace – things that were impossible in our original “state of nature”.¹⁹ The point is: we have been “improving ourselves” since time immemorial. Enhancement is what has come out of our process of evolution. Enhancement need therefore not be looked upon as the quest for perfection; it is very often no more than the outcome of the process of change that is inherent to our species.

The enhancements that are the topic of this paper, however, are not of this general and societal nature, but specifically biomedical enhancements. By “biomedical enhancements” I mean, following a definition of Allen Buchanan, “deliberative interventions, applying biomedical science, which aim to improve existing capacities that most or all normal human beings typically have, or to create a new capacity, by acting directly on the body or the brain”.²⁰ Buchanan also points out that five types of enhancement are widely discussed in the literature on biomedical enhancement:

18 For this point, see Macdonald, G. and Pettit, P. 1981. *Semantics and Social Science*. London: Routledge & Kegan Paul, 14-105. On the significance of writing for human development, see Ricoeur, P. 1981. *Hermeneutics and the Human Sciences*. Cambridge: Cambridge University Press, 145-9.

19 See Hobbes, T. 1946. *Leviathan, or, The Matter, Forme and Power of a commonwealth, ecclesiastical and civil*. (Introduction by Michael Oakeshott). Oxford: Blackwell.

20 Buchanan, A. 2011. *Beyond humanity?*, 23.

(1) improvements in physical characteristics such as speed, strength and endurance; (2) improvements in cognitive capacities, such as various aspects of memory, information processing and reasoning [it is in this respect that the debate about performance-enhancement drugs such as Ritalin is pertinent]; (3) improvements in affect, emotion, motivation or temperament [anti-depressants, and, more particularly, the question as to the extent to which they ought to be made available to the general population, is very relevant in this respect]; (4) improvements in immunity or resistance to diseases; and (5) increased longevity.²¹

Buchanan's notion of biomedical enhancement and the examples just quoted suggest that the notion of "enhancement" only applies to those technologies that take us beyond what is species-typical. In other words, Buchanan's notion of enhancement seems to apply only to interventions that transcend what would be regarded as "normal" functioning in human beings without any obvious disabilities. The implication would be that technologies that enhance the ability of disabled people to manage in their environments would not be regarded as "enhancements", but only as technologies that are therapeutic or restorative. To my mind, this is too restrictive a notion of enhancement. I would like to argue that our notion of biomedical enhancement should also include the interventions that transform the "normal functioning" of people that are generally regarded as disabled. I therefore look upon a wheelchair as an enhancement of the normal mobility of a person with paraplegia, and upon cochlear implants as an enhancement of a person whose normal hearing capability is zero or very close to zero. The examples are instances of enhancements in the sense that they improve the sensory, physical and mental abilities of people whose sensory, physical and mental abilities are impaired relative to what is regarded as "normal function" in society. In that sense, the notion of "enhancement" can and does apply to disabled people.²²

CASE STUDY: DEAF PARENTS REQUESTING DEAF CHILDREN

I would now like to illustrate the relevance of emerging enhancement technologies for disabled people by developing a case study based on the widely discussed phenomenon of Deaf parents requesting a Deaf child. There are two available technologies for achieving this. The first is prenatal diagnosis (PND) with pregnancy termination (i.e. induced abortion) if the foetus has not inherited the genetic mutations(s) that will result in deafness.²³ Since induced abortion is part and parcel of this technology, and abortion is morally quite controversial, I will not consider this technology any further in this paper. The second

21 Buchanan, *Beyond humanity?*, 25. For a riveting (and controversial) discussion of the possibilities of increasing longevity, see also Harris, J. 2007. *Enhancing Evolution: The Ethical Case for Making People Better*. Princeton, NJ and Oxford: Princeton University Press, 59-71.

22 My thanks to an anonymous referee for impressing upon me the need to make this point clearer.

23 Mand, C. *et al.* 2009. Genetic Selection for Deafness: The Views of Hearing Children of Deaf Adults. *Journal of Medical Ethics* (35):722-8.

applicable technology is pre-implantation genetic diagnosis (PGD) to have a Deaf child.²⁴ First, something more about this technology.

► Pre-implantation genetic diagnosis

PGD is a recently developed technique to determine genetic defects in embryos created by in vitro fertilisation (IVF) prior to the implantation of an embryo into a uterus for gestation. The diagnosis occurs at the 6-10 cell stage of embryonic development. One to two cells are then removed from the embryo and its cellular DNA is then tested for any chromosomal “abnormalities or mutations”.²⁵ This kind of test can determine whether the embryo would be d/Deaf if allowed to develop to term. Embryos carrying disease are generally discarded or frozen indefinitely, whereas those free from disease are generally implanted. PGD can nowadays be used as an alternative to traditional techniques for prenatal disease, such as amniocentesis or CVS. As a technique it enables prospective parents to “prevent abortion”, since conditions that, when discovered in the foetus later in pregnancy and would constitute grounds for abortion, are by this technique diagnosed before implantation. The risk of abortion is thus significantly reduced.

The technique, however, also has its limitations. It is perfect for establishing the sex of the embryo, but cannot as yet identify certain other conditions such as *spina bifida* and anencephaly. It cannot therefore abolish the occurrence of abortion when these other conditions are diagnosed later in pregnancy. PGD also of necessity requires IVF, which is a burdensome, risky and expensive technique, requiring the co-operation of an entire medical team and without any guarantee of success.

► The “disability challenge”: Selective abortion

What is often called the “disability challenge” is often regarded to be the main moral problem with PGD. The fact is that this technique is not primarily used in order to *prepare* parents for the fate of having a disabled child. Its much more common use is to *prevent* the birth of a disabled child. It is, so it is argued by an author like Adrienne Asch,²⁶ on a par with the moral objection, not to abortion in general, but to *selective abortion*, i.e. abortion of a foetus purely on the basis of its impairment. Only, in the case of PGD, what would later on in pregnancy establish the basis for a selective abortion²⁷ is undercut or prevented by the fact that the impaired embryo is *ab initio* not implanted and therefore not given the opportunity to develop to a point where it can either be born or aborted. That factuality amounts to inherent and morally unacceptable discrimination against disabled people; it

24 As pointed out by Mand, C. *et al.* 2009. Genetic Selection for Deafness, these requests are not very prevalent, but do occur from time to time. A prominent case was the request in 2001 by two Deaf lesbians from Bethesda, USA, Sharon Duchesneau and Candace McCullough. For their case, see McLellan, Controversy.

25 I greatly rely for my discussion of the PGD on Steinbock, B. 2002. Preimplantation Genetic Diagnosis and Embryo Selection. In Burly, J. and Harris, J. 2002. *A Companion to Genethics*. Oxford: Blackwell, 175-90.

26 Cf. Asch, A. 1988. Reproductive Technology and Disability. In Cohen, S. and Taub, N. (eds), *Reproductive Laws for the 1990s*. Clifton, NJ: Humana Press, 69-124.

27 For an excellent discussion of the moral problematic related to selective abortion, see Hall, S. 2008. Difference, Disability and Discrimination: A Philosophical Critique of Selective Abortion. Unpublished MA thesis, Stellenbosch University.

shows a hardly deniable lack of tolerance against disabled people in society and a deliberate effort to reduce their numbers significantly.

► PGD and elective deafness

The more interesting scenario made possible by PGD, however, is that to which I alluded in terms of the case study that I want to discuss. This is the situation where Deaf parents express the wish that PGD be used, *not to prevent* the birth of a disabled child, but *particularly to ensure the birth of a Deaf child*. The argument developed in this regard is based on the claim to the reality of what is increasingly called Deaf culture.²⁸ By this is meant the fact that congenitally Deaf people do not necessarily think of their impairment as a disability at all. Since they have never been part of the hearing world, they are not aware of an alternative reality and prefer to live in the world as they know it – a world without sound. They experience much more trouble communicating with hearing people than with fellow Deaf people. What is more, when Deaf people marry or enter into stable relationships and wish to procreate, their express desire sometimes is to have a child that will also be Deaf. Thus it is ensured that the child will share their life experience and will most easily become part of their own culture. That deafness is regarded as a serious impediment by hearing people is of no consequence to these Deaf people, since they cannot form any realistic notion of the world of the hearing. All they want is a child that forms part of their everyday living environment and experience.

What, if any, is the moral problem with this seemingly problematic (and for some hearing people even shocking) wish of Deaf people? The significant moral concern in this regard seems to me to be the issue of harm.²⁹ Would compliance with the prospective Deaf parents' wish not confer an undeserved and easily preventable harm on the child born from the union of his/her Deaf parents? The prevention of harm is a fundamental principle in biomedical ethics that could and should not easily be overruled by sympathy with the preferences of parents, even if they are disabled.

► Is harm done to a deaf child selected by PGD?

If we are dealing with a situation where a normal embryo would be deliberately impaired in the sense that its hearing function would be deliberately removed in order to meet the prospective parents' desire, I do think that there would be a serious moral problem. That problem first and foremost stems from two questions: (1) What would be in the best interest of the child? (2) What would have been the preference, not of its prospective parents, but indeed of the child himself or herself – the person who will have to live with the auditive handicap? We can of course not ascertain the wishes or obtain the informed consent of an embryo or foetus, but that very eventuality ought to caution us against lightly embarking on any action that could be construed as harmful to the prospective child.

28 For this notion see Dolnick, E. 1993. Deafness as Culture. *The Atlantic Monthly*, September 1993:37-53, and Tucker, B. P. 1998. Deaf Culture, Cochlear Implants and Elective Disability. *Hastings Center Report*, 28(4):6-14.

29 For a profound and highly influential analysis of the notion of harm, see Feinberg, J. 1984. *Harm to Others*. Oxford: Oxford University Press. See also Steinbock, B. and McClamrock, R. 1994. When is Birth Unfair to the Child? *Hastings Center Report* 24(6):15-21.

However, if the selection of the embryo is done by PGD – the best currently available technique in this regard – it is not correct to claim that harm is deliberately done to the embryo *if an embryo that will develop into a deaf child is selected*. The simple reason for this is that nothing is done to that embryo to impair its potential hearing ability. All else being equal, the choice will be between an embryo that will one day be able to hear, and one that will never be able to hear. The parents could well argue that the choice is similar to a choice often made by non-disabled parents who select embryos thorough PGD: the choice namely between a boy or a girl. Sex can conclusively be established by PGD, and parents therefore have such a choice if their reproduction is administered through PGD. The issue is therefore not whether the embryo is harmed; the issue is whether or not the deaf embryo is selected. If it is selected, it will grow into a d/Deaf child, and nothing can at that stage of development stop that occurrence. The baby is therefore not harmed by what the parents chose or did, unless it could be argued that the d/Deaf child is harmed by being brought into existence at all, since deafness is allegedly such a “terrible condition”. I would nevertheless want to argue that “wrongful life” in the case of a child thus born would clearly be an absurd claim or accusation. It is surely unfounded to argue that the life of a d/Deaf person is intolerable. The d/Deaf child is not harmed by being selected and by being born; if it is selected, also if it happens on the basis of adhering to the parents’ wishes, that child will be d/Deaf; it has not and cannot be harmed by incurring d/Deafness on a child that would otherwise have been hearing. The reproach that such a birth would have been “unfair on the child” therefore also is not valid.

Note that this claim is disputed by John Harris. According to him, “a harmed condition obtains whenever someone is in a disabling or hurtful condition, even if that condition is only marginally disabling and even though it is not possible for that particular individual to avoid the condition in question”.³⁰ Note also Glover’s claim that Harris and Rebecca Bennett, who took issue with Harris on this point, use two different notions of harm. Bennett’s position seems closer to the conventional understanding of harm, i.e. the deliberate withholding of legitimate opportunities or the deliberate infliction of bodily or psychological distress, discomfort or malfunction. This is the notion of harm that I espouse. For Harris, on the other hand, “anyone in any disadvantageous position is harmed by whoever caused him or her to be in that condition. Because all of us have some disadvantages, we have all been harmed by the parents who caused our birth”.³¹ I find this an unacceptable argument. To illustrate:³² a starving person on the point of death who is fed may nonetheless be a poor person. The one who fed the starving person is the cause of that person being alive, and so is the cause of a living person who is poor, even though he is fed. Surely the person who fed the poor person did not harm that person. Being poor and alive is better in general than either being starving or being dead.³³

30 Quoted by Harris, J. 1998. *Clones, Genes and Immortality*. Oxford: Oxford University Press, 109.

31 Glover, *Choosing children*, 25.

32 I thank an anonymous referee for the example that I use here.

33 For an argument that to bring any person into the world is necessarily to harm that person, see Benatar, D. 2006. *Better Never To Have Been: The harm of coming into existence*. Oxford: Oxford University Press. I cannot respond critically to that article here and have done so elsewhere.

What must nevertheless be emphasised is that the Deaf parents who make this decision do it in spite of the fact that, had they chosen to have a “normal” child, the possibility for that “normal” child to become part of both their world and the world of the hearing emphatically exists; the normally hearing child has the option of learning sign language and associating as much as possible with the culture of the Deaf. That possibility, i.e. of being part of both worlds, does, however, not exist for the child selected for birth on the basis of his or her d/Deafness. I am not disputing the right of the Deaf parents to make the choice for the impaired child on the basis of the concerns expressed earlier; I only caution that this consideration ought to be part of the set of reasons that they consider for their eventual decision. This concern, however, does not alter my claim that I do not think that the d/Deaf child has been harmed purely on the basis of having been selected.

► **Complication: Cochlear implants**

This *prima facie* positive evaluation of the moral status of requests to select for d/Deaf children is, however, complicated by the possibility of cochlear implants.³⁴ A cochlear implant is

a surgically implanted device that is capable of restoring hearing and speech understanding to many individuals who are severely or profoundly deaf. Numerous studies show both the ability of profoundly deaf individuals to hear speech with cochlear implants and the ability of implanted deaf children to develop age-appropriate spoken and receptive language skills.³⁵

It is claimed that cochlear implants are sometimes not entirely successful, although there is growing evidence that they are yielding excellent results. Tucker quotes a report of the Advisory Council of the National Institute on Deafness and Other Communication Disorders in the USA as claiming: “It has now been demonstrated that the long-term benefits of cochlear implants in children are not limited to speech recognition but extend into dramatically improved language learning and language skills”. She also refers to a recent survey in which

parents of 176 implanted children perceived that: (1) 44% of the children had greater than 70% open speech discrimination (using sound alone with no visual clues), (2) 61% of the children had greater than 50% of open speech discrimination and (3) 84% of the children had greater than 40% open speech discrimination.³⁶

In a situation where there are serious misgivings about the success of cochlear implants, a decision of Deaf parents not to seek such a procedure for their child may be understandable. But the figures I have just quoted indicate that the success of the procedure is growing significantly. What is the moral thing for Deaf parents to do in a situation where the doubts about the success of cochlear implants are irreversibly receding? Can a decision to withhold one’s child from such a procedure in those circumstances be morally defended? That hardly seems to be the case, because in such a situation the only concern for the parents cannot be their wish to include the child in their Deaf culture. The moral concern

³⁴ This complication is also pointed out by Glover, see his *Choosing Children*, 25-6.

³⁵ Tucker, *Deaf Culture*, 6-14. See also Verhoef, S. 2001. *Tegnologie en gestremdheid – filosofies-etiese perspektiewe*. Unpublished MPhil. thesis, Stellenbosch University. [English: Technology and disability: philosophical and ethical perspectives]

³⁶ Tucker, *Deaf Culture*, 6.

must also and always be what is in the best interests of the child, particularly when the child is still incompetent to participate in the decision.³⁷ Can it cogently be argued that to remain d/Deaf while the real possibility of attaining hearing exists is in the best interest of the child? Is there not, at least *prima facie*, a very strong case to be made that to be able to participate in both the cultures of the Deaf and the hearing is more in the interest of the child than to exclusively contain the child in the culture of the Deaf? Glover rightfully remarks in this respect: “The view that deafness is a disability supports the view that parents who can give their child hearing should do so. If that is accepted, the choice of a deaf child becomes self-defeating.”³⁸

It may seem that I am contradicting my earlier support for Deaf parents’ right to choose deafness for their child. What I am arguing is that the possibility of cochlear implants complicates the moral right to elective deafness for a child considerably. Cochlear implants, as was pointed out, are not always successful. They are also not always available to all deaf parents and their children, particularly if these families are poor and find themselves in developing countries. Sometimes the decision about cochlear implants can only be taken at a time when the child is old enough to also grant assent. The child may turn out to be dead against such an intervention, in which case it would certainly be morally problematic to coerce the child into such a procedure.

Two important insights arise from this discussion. The first is that, in spite of Deaf parents’ right to elect deafness for their child, the possibility of cochlear implants complicates that right. If such implants are available to Deaf parents, the implication of elective deafness might well be that the parents initially select a deaf embryo via PGD, and yet at some future point find it necessary to reverse their choice of complete deafness for their child by opting for a cochlear implant in order to optimise the child’s choices and to enable the child to manage in both the hearing and Deaf cultures. That would be a problematic situation since, if the child’s ability to manage optimally in both worlds is a prime moral concern in our understanding of the child’s best interests, the considerably easier option for the parents would have been to elect a hearing embryo from the start.

The second important insight emerging from this discussion is the fact that a cochlear implant is an instance of enhancement, in line with the extended meaning of enhancement that I discussed earlier, i.e. the sense in which something like a cochlear implant can indeed be regarded as a biomedical enhancement of a deaf person. In addition, it should be noted that we, in this case, have to do with an enhancement that in no way reeks of eugenics or similarly morally dubious practices, or in any way substantiates the suspicion of negative attitudes towards disability or disabled people. Here we are clearly dealing with an enhancement with beneficial intent, aimed at the improvement of auditive function.

37 For a comprehensive discussion and grounding of this moral principle, see Buchanan, A. E. and Brock, D. W. 1990. *Deciding for Others: The Ethics of Surrogate Decision-making*. New York, NY: Cambridge University Press, 122-33. The authors write in this regard: “The best interest principle is clearly patient-centred because it focuses primarily on the current and future interests of the incompetent individual. As such it must take into account *quality-of-life* judgments. Whether a particular treatment is in a patient’s interest depends upon how it affects that patient’s life” (123, their emphasis).

38 Glover, *Choosing children*, 26.

CONCLUSION

It is therefore my contention and conclusion that the conventional suspicion amongst disabled people and some disability advocates toward enhancement technologies is not always justified. There need not be conflict between the culture and experience of the disabled and the unstoppable drive towards enhancement, which is not so much the outcome of a cogent modern or postmodern and morally dubious cultural project, but is much rather the outcome of our natural evolution and a fundamental disposition of our species. Efforts to avoid disability in the world or to improve the quality of human life are not expressive of negativity towards the existence or rights of disabled people. Disability and enhancement can find a cogent co-existence, to the undoubted benefit of the disabled community.³⁹

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Cultural and religious explanations of disability and promoting inclusive communities in Southern Africa

9

Tsitsi Chataika¹

MAKING SENSE OF CULTURE AND RELIGION

One's cultural and religious beliefs, rituals, customs and practices that direct thinking, decision-making and actions in a patterned way are the sum total of cultural and religious beliefs.² Hensley and Schott define culture as: "A shared set of values, assumptions, perceptions and conventions, based on a shared history and language, which enable members of a group or community to function together."³

Consequently, culture is a social practice that is a *mirror* through which we view the world and make sense of it, and eventually it influences our actions and relationships.⁴ Religion also shapes one's belief systems and practices.⁵ Thus, cultural and religious beliefs are capable of explaining why some people are disabled, how they should be treated, and what rights and responsibilities they are either entitled to or deprived of.⁶ However, within every culture and religion there are diverse sub-cultures and sub-religions, with many beliefs, values, attitudes and behaviours.⁷

Despite the emergence of the social model and the rights-based approach to disability, culture and religion still influence the understanding of disability in many societies.⁸ Therefore, the inability to understand these concepts in relation to disability is to disregard crucial reference points for fostering inclusive communities. For example, words used in the Zimbabwean Shona and Ndebele languages for a disabled person, such as *chirema* and *isilima* respectively, have been used to mean inability to function and stupidity. In

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- 1 Tsitsi Chataika is a Postdoctoral Research Fellow in the Centre for Rehabilitation Studies, Stellenbosch University, South Africa and a Research Fellow in the Centre for Global Health, Trinity College, Dublin, Ireland and the Research Institute for Health and Social Change, Manchester Metropolitan University, UK.
 - 2 Kisanji, J. 1995. Growing up Disabled. In Zinkin, P. and McConachie, H. (eds), *Disabled Children and Developing Countries*. London: MacKeith, 183-99.
 - 3 Hensley, A. and Schott, J. 1999. *Culture, Religion and Patient Care in a Multi-ethnic Society: A Handbook for Professionals* London: Age Concern England.
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 - 6 Multicultural Disability Advocacy Association: Culture, religion & disability: An introduction. (MMDA) Online at: <http://www.mdaa.org.au/publications/ethnicity/information.html> [Accessed: 8 May 2011].
 - 7 MMDA.
 - 8 Reinders, H. 2011. Is There Meaning in Disability? Or Is It the Wrong Question? *Journal of Religion, Disability & Health* 15(1):57-71.

Shona the object or animal referent “*chi*” prefixes the word *rema*. Therefore, the traditional conceptualisation of disability seems to suggest that a disabled person is on the borderline of being a human and an animal, lacking in clear social role functions; the same perception has been reported in other African countries.⁹ Divlieger describes this phenomenon as “role marginalisation” and Murphy conceptualises it as “social liminality”.¹⁰

CULTURAL AND RELIGIOUS EXPLANATIONS OF DISABILITY

There has been a gradual global paradigm shift on the aetiology of disability to medically related causes and accidents. However, in many communities, with specific reference to Southern Africa, most attitudes and responses are rooted in beliefs about the causes of disabilities, which in indigenous cultures are predominantly attributed to spiritual or supernatural sources.¹¹ Reports have been published of negative responses to disability including ostracism, abuse and even killings, as well as positive stories of non-discriminatory community values and inclusion of disabled people.¹² Geiger’s observations in Botswana illustrate the extreme variations in attitudes and responses within a single community.¹³ Consequently, there is a danger of writing a single story, or making generalisations about attitudes to disability. However, some of the following cultural and religious explanations for the occurrence of a disability have been documented.

► Disability and spirituality

Some people still look at disability as a form of punishment by some ancestral spirits who are unhappy with the family or a particular individual, or as a result of witchcraft where scores have to be settled.¹⁴ In either case, the target of the punishment is the family and the person who becomes disabled “suffers” on behalf of the family to appease the spirits. In Southern Africa, for instance, some people still believe that witchcraft is a contributory factor to the occurrence of a disability. For example, in a study conducted in South Africa most mothers strongly felt that their disabled children had been bewitched, as indicated by one of them:¹⁵

Because my husband chose to marry me instead of their daughter, they decided to make me barren. I have only this one child who they also bewitched. He cannot

9 Divlieger, P. J. 1998. Physical Disability in Bantu Languages: Understanding the Relativity of Classification and Meaning. *International Journal of Rehabilitation Research* 21:51-62.

10 Divlieger, Physical Disability.

11 Divlieger, Physical disability.

12 Geiger, M. 2010. Using Cultural Resources to Build an Inclusive Environment for Children with Severe Communication Disabilities: A Case Study from Botswana. *Children's Geographies* 8(1):51-63.

13 Geiger, M. 2012. Through the Eyes of Children: Theological Lessons with and from Children with Severe Communication Disabilities. *Journal of Religion, Disability & Health* 16(1):102-113.

14 Kisanji, Growing up disabled; Addison, J. 1986. A Historical Survey of Facilities for Handicapped People in Zimbabwe. *National Association of Societies for the Care of the Handicapped* Jan:1-38.

15 Masasa, T. Irwin-Carruthers, S. and M. Faure. 2005. Knowledge of, Beliefs about and Attitudes to Disability: Implications for Health Professionals. *South African Family Practice* 47(7):40-4.

talk or walk. They put the medicine in me when I was pregnant. My body was full of that medicine and it passed on to my child.

Similar experiences have been reported elsewhere in Africa. In 2009 the *Uganda Pulse* (newspaper) reported on a disabled girl who believed that she had been bewitched by her stepmother.¹⁶ It was reported that the girl broke into tears when *Uganda Pulse* asked her about the cause of her disability as the question brought back memories of her “evil” stepmother. The disabled child informed the reporter that her mother told her that her stepmother had bewitched her because she hated her. In addition, the girl narrated how the stepmother would brag to neighbours about causing her disability. This was despite the attempt by the Public Relations Officer of the Uganda National Action on Physical Disability to explain to the family that accidents and other health-related factors, and not witchcraft, cause disability.¹⁷ This and many other stories are common in most African communities. As such, certain cultural beliefs may be so intense in people’s minds such that no amount of explanation can make them change their minds.

Rituals and spiritual ceremonies are usually held to cleanse the “disabled person” and to dispel the evil spirits from the family; hence relatives attend such functions in an attempt to solve a *family problem*.¹⁸ Below is an example of how a disabled person underwent a “cleansing ceremony” in Zimbabwe:

I was taken up a mountain and I was left overnight on the mountain on my own. They were to collect me the following morning, traditional rituals were performed. It was expected that was the way of really helping me out. It was terrible.¹⁹

Consequently, the birth of a disabled child is viewed as a punishment or a taboo, capable of bringing bad luck to the family, if rituals are not carried out.²⁰ Therefore, some family members come to support a family with a disabled child only if there are rituals to cleanse the disability in order to remove the bad omen.²¹ This suggests that family members are not supportive of the disabled child; but rather are more interested in the desire to eliminate the bad omen (disability).

When people have congenital impairments and the cause cannot be explained, this is usually seen as God’s plan, or as God’s reaction towards people’s unbecoming behaviours.²² Miles conducted a comparative analysis of Hindu, Buddhist and Islamic historical contexts and established that responses to impairment are similar to those in Christianity.²³ For

16 Nyanzi, W. 2009. *Uganda Pulse*. *Uganda People News*: Ugandans believe disability is a result of witchcraft. Online at: <http://www.ugpulse.com/articles/daily/news.asp?about=Ugandans+believe+disability+is+a+result+of+witchcraft&ID=11666> [Accessed: 15 April 2009].

17 Nyanzi, *Uganda Pulse*.

18 Chimedza, R. 2001. Context of Deaf Education in Zimbabwe: Teaching and Learning. In Chimedza, R. and Peters, S. (eds), *Disability and Special Educational Needs in an African Context*. Harare: College, 134-59.

19 Chimedza, Context of Deaf Education, 157.

20 United Nations Children’s Fund [UNICEF]. 2001. *A Study on Children and Adolescents with Disabilities in Zimbabwe*. Harare: UNICEF.

21 UNICEF, *A Study on Children*, 76.

22 Monk J. and Wee, J. 2008. Factors Shaping Attitudes Towards Physical Disability in and Availability of Rehabilitative Support Systems for Disabled People in Rural Kenya. *Asia Pacific Disability Rehabilitation Journal* 19(1):93-113.

23 Miles, M. 1995. Disability in an Eastern Religious Context: Historical Perspectives. *Disability & Society* 10(1):49-69.

instance, the Hindu and Buddhism concept of *bad karma* (consequences of what one does in a previous life) promotes the belief that disability is caused by an individual's past transgressions.²⁴ Therefore, some religions suggest that disability is a punishment. However, John 9:2-3 suggests that blindness has nothing to do with sin, as when Jesus was asked by his disciples:

“Rabbi, who sinned, this man or his parents, that he was born blind?” Jesus answered: “It was not that this man sinned, or his parents, but that the works of God might be displayed in him.”

A common belief in the Jewish tradition was that “calamity or suffering was a result of some great sin”.²⁵ However, in this case, Jesus used the man's ‘suffering’ to teach about faith and to glorify God. The contradictory messages make it difficult for people to have a common understanding of the biblical causes of disability. For instance, when Jesus healed a man with paraplegia in Mark 2:1-12, he ended by saying: “Son, your sins are forgiven”. Literally, the text might make some readers assume that this man was more sinful than others, despite Jesus acknowledging that we are all sinful. Another example is the Shariah law, which is an Islamic code of conduct. The practice has been that if someone stole something, his/her hand would be cut off as retribution for the crime committed. Similarly, in the Bible, Mark 9:45 indicates that if one foot causes one to sin, it is better to cut it off in order to enter heaven. In such circumstances, if people see a person with an amputated arm or foot, for instance, they might conclude that he/she deserves to be disabled because of the ‘sin committed’. Yet he/she might have had the limb amputated for medical reasons.

► Disability as contagious

The idea that a disability is contagious and can therefore be caught is fairly common in many countries. This results, mostly, in actions to protect pregnant women from seeing or touching disabled people, including their assistive devices.²⁶ This belief implies that pregnant women should avoid exposing themselves to disabled people, lest, they might give birth to one:

Then sometime last year in the afternoon, my pregnant secretary was brave enough to ask me a straightforward question. “Mr X, what chances do I have in giving birth to a disabled child since I am working with disabled people?” She was simply trying to crosscheck the truth in the belief that when a pregnant woman comes across a disabled person, she must spit at her tummy so as not to give birth to a disabled child. My secretary could not imagine spitting at herself every time disabled people visited the office. She was also aware that our association regularly held workshops and seminars with disabled members. Therefore, could she always spit at herself at every workshop? Such dangerous beliefs in our culture are a thorn in the flesh for our modern society. It is good that some of our colleagues are slowly becoming free.²⁷

Thus beliefs can be transmitted from one generation to another, but can slowly change with new ways of understanding disability. Ndebele, however, argued that the first

24 MDAA.

25 Life Application Bible (New International Version). 1992. Eastbourne: Kingsway, 1887.

26 MDAA.

27 National Association of Societies for the Care of the Handicapped [NASCOH]. 2002. Disability and Exclusion, *NASCOH News* 48 (Jun), 2. Online at: <http://www.nascoh.org.zw> [Accessed: 3 May 2011].

challenge that a parent of a disabled child faces is that of accepting the child's disability.²⁸ She noted that *n'angas* (traditional healers) and 'prophets' are often consulted to reverse the condition. This was also confirmed by a disabled student in Chataika's study:

The family tried to get a cure for the deafness. We went to some faith healers, doctors, and even *n'angas* [traditional doctors]. Eventually, my parents stopped when they had exhausted all the avenues.²⁹

By implication, from early childhood young disabled children may get the message that they are unclean, inferior and unworthy, and therefore require 'cleansing'.

Mythical beliefs are hard to eradicate, as they easily become the crystallised opinions and attitudes of society.³⁰ In Zimbabwe and other Southern African countries, for example, there is a general belief that one should not laugh at a person with a disability lest the curse is transferred to the scornful individual.³¹ In a way this has resulted in society being more tolerant of disabled people, because of the fear that the disability might be shifted onto them, hence the proverb *Seka urema wafa* [Laugh at a disabled person only when you are dead].

► Blaming

Families have been torn apart by the birth of a disabled child, as reported below:

I grew up in a family, but it was not a smooth sailing journey. I lost my sight because of measles. Family siblings always found themselves in a dilemma having me as their brother and my disability. They did not want to be associated with a blind brother, but at the same time, they wanted a blood relative, who in their eyes was a "normal" person – separating the two became difficult.³²

Seventy-five per cent of the disabled children I was teaching in 1995, for instance, came from single mothers who had been divorced because they were being blamed for causing the disability, especially if no such thing had ever happened before in the family lineage. Divorce is common amongst families of disabled children in most African countries. In Zimbabwe, for example, it is a common practice for the man's relatives to blame a woman who has given birth to a disabled child.

If the wife is lucky not to be divorced, the family might decide to hide the disabled child as a way of coping with the affliction and retaining social equilibrium:

Often these children are excluded from society. They might be hidden away at home if they look different because of fear and superstition [...]. Often their needs are not recognised and they are thought to have little to contribute to their community. But this exclusion reduces children's opportunities to learn, grow and develop.³³

28 Ndebele, A. 2003. The Challenges of Being a Parent of a Child with a Disability. *NASCOH Advocacy Bulletin* 6 (Sept). Online at: <http://www.nascoh.org.zw/> [Accessed: 19 April 2011].

29 Chataika, T. 2007. Inclusion of Disabled Students in Higher Education in Zimbabwe: From Idealism to Realism – A Social Ecosystem Perspective. Unpublished PhD dissertation. University of Sheffield, UK, 167.

30 Tilstone, C. and Rose, R. (eds). 2003. *Strategies to Promote Inclusive Practice*. London: RoutledgeFalmer.

31 Mpofu, E. 2000. Rehabilitation in International Perspective: A Zimbabwean Experience. *Disability and Rehabilitation* 23:481-9.

32 Chataika, Inclusion of Disabled Students, 153.

33 UNESCO, *Overcoming Exclusion*, 10.

This was also evident during my teaching career, when I was part of the outreach team responsible for identifying school-aged children with visual impairment in rural communities. In some cases the family would deny that they had a disabled child. In an effort to establish the truth, we would go through the local chiefs and schools. In other situations we would find the children hidden in granaries. Stigmatisation does not end with family members or at community level; it can also extend to professionals, who might be quick to make an HIV diagnosis and yet might be another medical condition:

The constant visits to the hospital also made the medical staff to think that he was indeed HIV positive, so test after test of HIV as well as TB [Tuberculosis] were carried out on both me and my child. Finally, my child was labelled an FTT, which means 'failure to thrive' as he was not responding to medication.³⁴

Not all mothers lose hope when faced with such challenging situations. Instead, the experience can turn them into strong and bold "super-mums" who defy all negativity:

All this process made me bolder and eventually asking myself the question: "Why not me?" – as this was God's gift, and He could have given it to anyone else. Anyway, my child to me was just a child and the fact the he had Down Syndrome and a congenital heart defect would not change that.³⁵

Thus, Ndebele's religious conviction enabled her to draw strength to accept her disabled child.

► Disability as a test/learning

Most of the religious teachings seem to suggest that disability exists so that a learning process can occur, either for the person who has the disability or the family. For example, a Mexican mother commented about her disabled child: "It's a test. I think that by giving you a little more than you can handle, [God is] testing you, to see how you're going to face it."³⁶

Hence, a child is viewed as a litmus test that God sends to parent to measure their religious conviction. If parents pass the test, the disabled child would have enabled them to become better Christians. In trying to solicit public opinion on the religious explanations of disability, I posted a question on a social network on 24 May 2011. Some of the responses are listed below:

- (a) A test from God of one's faith, I guess.
- (b) I think God is all mercy, ever loving; but some things do occur such as disability. He never intends to inflict pain on any of His flock. But that said, it tests our faith; our relationship with the Lord; and our resolve to stay steadfast on our path; to seek all Godly things without wavering in our deep belief. God never wants us to suffer.

The above quotations illustrate how, even today, some Christians still believe that disability occurs so that God can ascertain their faith. One of the basic principles of Islam is to believe in the wisdom of the Allah, who does not create anything in vain. Also, Allah does not decree anything in which there is not some benefit.³⁷ By His wisdom, Allah tests

34 Ndebele, *The Challenges*, 3.

35 Ndebele, *The Challenges*, 3.

36 Skinner, D., Rodriguez, P., and D. B. Bailey (Jr). 1999. Qualitative Analysis of Latino Parents' Religious Interpretations of their Child's Disability. *Journal of Early Intervention Fall 22*:271-85.

37 MMDA.

parents through having a disabled child. Hence, society should recognise the blessing bestowed upon disabled children, and give thanks for Allah's blessing and pray for good health.³⁸ The following biblical text is not specifically referring to disability, but it does describe the concept of suffering to become a better person:

More than that, we rejoice in our sufferings, knowing that suffering produces endurance, and endurance produces character, and character produces hope, and hope does not put us to shame, because God's love has been poured into our hearts through the Holy Spirit who has been given to us.³⁹

The idea here is that the more we endure, the more we become better people.

► Disability as a gift/blessing

Some religious texts and practices seem to suggest that a disability is a gift or a blessing. Thus God would have recognised the parents as special individuals capable of raising such a "gift":

God gives you this type of the child because He loves you and trusts you. He presented us with this precious angel to show His love to us [...]. [She] is a blessing to our family [...] without her, we feel empty.⁴⁰

Reinders also established that some Christians believe that God must love some people so much that He finds it befitting to give them a "special task to fulfil".⁴¹ Disabled people are then signified as reflecting the 'suffering Christ' and are often perceived to be of angelic or beyond-human status to be a blessing for others. For example, in 2005 there was a media frenzy around a story of a baby girl born in India with four arms and four legs. The baby was joined to a headless parasitic twin who had stopped developing in her mother's womb. She became an object of worship as villagers believed that she was the reincarnation of the Hindu goddess of wealth and fertility, Lakshmi, which later became her name.

Both cultural and religious explanations of disability, embracing notions of sin, impurity, test, blame, holiness, gift, learning and witchcraft, have formed the dominant bases of conceptualisations of, and responses to, disabled people. Most of these beliefs systems have the potential to create the binary distinctions of them/us, normal/abnormal, cursed/not-cursed, sinner/non-sinner – thus increasingly excluding disabled people in community and national development activities. However, there are other aspects that impinge on the lives of disabled people. Here I am thinking, for example, of issues of authority, the role of women and men in society and the wider political/decision-making systems within cultural and religious settings.⁴² Africa has strongly patriarchal beliefs, which in many ways disadvantage women, and in particular, women with disabilities who experience *double marginalisation* – being a women and having a disability. Of importance now is to bridge the gap between these binaries and cultivate inclusive communities.

38 MMDA.

39 Romans 5:3-5.

40 Masasa, T. Irwin-Carruthers, S. and M. Faure. 2005. Knowledge of, Beliefs about and Attitudes to Disability: Implications for Health Professionals. *South African Family Practice* 47(7):40-4.

41 Masasa *et al.*, Knowledge of, Beliefs about, 59.

42 Lopi, B. *et al.* 1999. *Reporting Gender in Southern Africa: A Media Guide*. Harare, Bellville, Lusaka: Women in Development and SARDC.

► Promoting inclusive communities

When we work with narrow definitions of culture and religion, we are bound to exclude a large percentage of people. In relation to disability, society will barely understand the cultural and religious understanding of disability of certain communities. The implication is minimal or total lack of acceptance of disabled people. Yet, the world cannot afford to turn a blind eye to an estimated population of one billion disabled people across the world, the majority of whom live in low-income countries.⁴³ Hence the need to understand the diverse religious and cultural groups in order to establish a base line from which to engage in a meaningful advocacy role of re-educating communities on the actual causes of disabilities.

Negative cultural views of disability militate against inclusive practices. An effect of such beliefs is avoidance of direct contact with disabled people.⁴⁴ An analysis of some indigenous terms (e.g. “*chirema*”, meaning lacking competence) used for disabled people suggests that they are subhuman. The indigenous-traditionalist views about the origin of disability that equates it to a type of misfortune from the spiritual world, and the use of terms that deny the essential *ubuntu* or beingness of disabled children, would add to attitudinal barriers to their inclusion in family and community settings.⁴⁵

How an individual or society defines disability impacts on the intervention strategies employed. Earlier on I explained how a grandmother believed that her granddaughter had been bewitched. Therefore the family sought a cure for the deafness from faith healers and traditional doctors, thus perpetuating the medical model that sees a defective body as needing corrective measures to bring it back to “normal”. This may imply that to be disabled means to be imperfect, hence the need to find ways of reversing the “imperfection”:

From what I have heard, there was a problem and they [parents] thought, ‘Let’s try and sort it out’ So, I went through long operations.⁴⁶

The dynamics of families are not always transparent and traditional stereotypic attitudes that regard disabled children as a misfortune may overshadow individual families. A 2001 UNICEF Report points out that some family members saw the birth of a disabled child as an act that indicated a bad omen to the family.⁴⁷ As a result they sought supernatural powers to eject the bad spirits from the disabled child. For instance, a cleansing ceremony was described above.⁴⁸ The urgency to “sort out the problem”, as in the cases reported in this article, illustrates how disabled children are pushed into the deficit model, where they have to be constantly reminded that they are not “normal”. On the other hand, not all communities still view the birth of a disabled child as a bad omen. For instance, a study conducted in Zimbabwe among one of the most deprived ethnic groups – the *Tonga* people – reported no indications of purposely hiding or neglecting children with disabilities,

43 United Nations and the World Bank. 2011. *The World Disability Report*. Geneva: WHO.

44 Mpofu, *Psychology in Africa*, 179-86.

45 Kisanji, *Growing up Disabled*.

46 Chataika, *Inclusion of Disabled Students*, 163.

47 UNICEF, *A Study on Children*, 76.

48 Chimedza, *Context of Deaf Education*, 157.

as their attitudes towards disability had changed to become more positive.⁴⁹ The study indicated that parents did their best and displayed much love for their disabled children. Rather, when expecting a child, most *Tonga* people were more worried about whether or not the child would survive rather than whether it would have an impairment. Disability was seen as secondary as illustrated in the proverb, *Kocilema kunywigwa maanzi* (It is better to be disabled than dead). With the high mortality of children among the *Tonga*, the sentiment among mothers was that they should be grateful to have a living child. Similar findings have been documented among the Tswana.⁵⁰

Some communities attribute religious significance to disabled people; that is, they are a gift from the Supreme Being. It becomes necessary to examine what “special” or “gift” means and to understand that “special” rarely means equal.⁵¹ For example, a common response to dealing with the educational needs of disabled children continues to be to segregation through a *special school system*. They question now is: *How special is special? Does it mean that disabled children have to be segregated in order to preserve the “specialness”? Does this kind of arrangement promote inclusive communities?* Certainly not; instead, it denies disabled people their right to participate in mainstream activities.

The socio-cultural beliefs and attitudes of families and communities in which disabled people live may inevitably contribute to converting impairments into disabilities. Families and communities are very strong cultural institutions, particularly in most global countries of the South. In Zimbabwe, for instance, the concepts of “*kubatsirana*” (help each other/sharing of burdens) and “*ukama*” (relationships) are more or less representative of the cultural version of inclusion. These concepts tally well with the concept of interdependence.⁵² In Chataika’s study one of the disabled students used a quotation from Luciano De Crescenzo to sum up the concept of interdependence and its benefits: “We are each an angel with one wing and we can only fly by embracing each other.”⁵³

The Bible is clear that we are all made in the image of God, as noted by Bob Brooke, a chaplain for people with learning disabilities.⁵⁴ This says something very important about the high degree of worth that God attributes to each human being, regardless of their race, religion, gender or ability. It therefore implies that disabled people are not a distortion or an inferior image of God. Their impairments are part of their human identity. Hence, none of us is a surprise, accident or a mistake, and certainly not an embarrassment to God.

Similarly, Ortberg argues against the illusion of normalcy,⁵⁵ which entails that we endlessly attempt to fix and control disabled people. Rather, Ortberg stresses that when dealing with human beings, it is like going to the “‘as-is’ corner of the universe”, where everyone

49 Muderedzi, J. and Ingstad, B. 2011. Disability and Social Suffering in Zimbabwe. In Eide, A. E. and Ingstad, B. (eds), *Disability and Poverty: A Global Challenge*. Bristol: Policy.

50 Muderedzi and Ingstad, *Disability and Social Suffering*.

51 MMDA.

52 Nyamukapa, C. and Gregson, S. 2005. *Social Science & Medicine* 60:2155-67.

53 Chataika, *Inclusion of Disabled Students*, 190.

54 Brooke, B. 2009. *The Theology of Disability – A Starter*. Online at: http://www.communitymission.org.uk/resources/disability_resources/the_theology_ofdisability_a_starter.aspx [Accessed: 7 May 2011].

55 Ortberg, J. 2003. *Everybody's Normal Till You Get to Know Them*. Grand Rapids, MI: Zondervan.

is slightly irregular. This understanding is in line with biblical Scripture: “All have sinned and fallen short of the glory of God.”⁵⁶ Thus, suggesting that having an impairment signals misfortune, punishment or a gift is what Reinders prefers to call “cheap theology”.⁵⁷ Reinders suggests that cheap theology is based on the assumption that the universe is governed by a moral geometry such that for every bad outcome, there must be a bad cause; and every good outcome is a result of a good cause.

Reynolds reflects theologically on the kind of place the church should be in the light of the kind of human vulnerability which is manifested in disability. He claims that “disability is an often overlooked and contested ‘site’.”⁵⁸ Reynolds also argues that disability has the *theological power* to raise issues of difference, normalcy, embodiment, community and redemption. Hence, changing the paradigm upon which disability is understood effects a transformation where disability ceases to be seen as a tragedy. The most important issue here is to promote cultural and religious aspects that encourage inclusive communities, and discard aspects that undermine inclusivity. In that way disabled people will be able to enjoy the rights enshrined in the UNCRPD, and the doors of cultural and religious activities will become more open to disabled people, enabling them to nurture their cultural and religious needs without discrimination.

It is important, however, to acknowledge the positive contribution made by early missionaries to the individual lives of disabled people through services such as education, health and social support.⁵⁹ Although there has been criticism of institutionalisation, the introduction of special schools, for instance, has enabled disabled people to access some form of education, an aspect that cannot be underestimated. What is important is to draw lessons from the system and find ways of promoting inclusive education. Thus, failure to identify the actions that could be taken to replace mistaken beliefs and the potential drivers that will lead to cultural changes will be an injustice to disabled people. Therefore, actions around advocacy and empowerment of disabled people and their families within religious communities, awareness raising and education among religious communities become essential if we are to change the attitudes of communities towards this marginalised group. At the same time, it is crucial to acknowledge best practices that promote inclusive communities, as reported in the study of the Tonga people of Zimbabwe, lest we run the risk of not capitalising on the gains already achieved. Thus any advocacy and lobbying activities should aim at eliminating negative cultural and religious beliefs, and promote the positive cultural and religious aspects that promote inclusive communities.

56 Ortberg, *Everybody's Normal*, 13; Romans 3:23.

57 Reinders, *Is there Meaning*, 59.

58 Reynolds, *Vulnerable Communion*, 13.

59 Peresuh, M. and Burcham, B. 1998. Special Education Provision in Zimbabwe. *The Journal of Special Education* 25(2):75-80.

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The experiences of people with disabilities in faith communities and suggestions to enhance their inclusion

10

*Erna Möller*¹

INTRODUCTION

A group of people with disabilities in Pietermaritzburg, called disAbility ConneXion, were looking for contextually appropriate guidelines to help South African churches include people with disabilities. The researcher agreed to undertake a research project from which such guidelines could be developed. This research project was undertaken during 2009 and 2010.

A qualitative research approach was followed (based on the description by Creswell²), including characteristics such as conducting research in the natural setting of participants, and using multiple interactive methods. Individual interviews and focus group interviews were conducted with 43 people with disabilities regarding their experiences of exclusion/inclusion and with 32 church leaders regarding their views on the inclusion of people with disabilities. Three of these church leaders themselves had disabilities.

Criteria for inclusion in the sample were people with different types of disability, males and females equally represented as far as possible, people from Afrikaans, English and isiZulu language groups, and different church groups, namely, mainline, charismatic and African independent churches. Data collection took place in the Pietermaritzburg/Msunduzi municipal area where disAbility ConneXion is based. A core group of disAbility ConneXion members were involved in identifying possible participants.

The data analyses followed the steps suggested by Tesch,³ whereby the transcriptions of interviews are read several times in order to identify themes and sub-themes in the responses of participants. Responses belonging to each theme, with its identified subsections, were categorised and thus presented in the research report.

The experiences of people with disabilities in faith communities are set out in the following section.

1 Erna Möller is a social worker at the Leprosy Mission in Johannesburg. This article is based on her research for a MA degree in Social Work and an earlier version was published in 2012 as Experiences of People with Disabilities in Faith Communities: A Journey. *Journal of Religion, Disability and Health* 16:154-71.

2 Creswell, J. W. 2003. *Research Design, Qualitative, Quantitative and Mixed Approaches*. Second Edition. London: Sage, 181.

3 Tesch, R. 1990. *Qualitative Research: Analysis Types and Software Tools*. New York, NY: The Falmer, 142.

EXPERIENCES OF EXCLUSION OF PEOPLE WITH DISABILITIES IN FAITH COMMUNITIES

Two themes emerged during the research:

- ➔ The inaccessibility of the physical structure of the church;
- ➔ Experiences of people with disabilities of others' ideas of disability and healing.

Theme one: Experiences of (in)accessibility

■ Physical barriers

Various barriers present challenges for people with disabilities who want to participate in the faith community.

Accessible transport is almost non-existent, especially in less developed communities, where participants said: *"We wish transport could be arranged at least once a month, so that we can attend services."*

Entrances to church buildings seldom have ramps and are too narrow for people who use wheelchairs. *"Not many churches are accessible. I often have to be carried in my wheelchair into a church building"*, said a man who is eager to be part of a faith community. A young woman agreed: *"Whenever I find stairs and narrow entrances, they are telling me, the people don't want me here [in my wheelchair]. They have not thought about me."*

Inaccessible toilets are a source of inconvenience for wheelchair users or other people with disabilities. An elderly person with a mobility impairment, stated: *"I have to use a catheter when I go to church. I can't get into the toilets."*

Seating arrangements in the worship service are often not conducive to participation. Wheelchair users may have no choice but to sit in the aisle, where they are conspicuous and regarded as "different". When other worshippers stand in front of them while singing, wheelchair users cannot see the words of hymns on electronic boards. Other challenges are sloping auditorium floors and insufficient space to turn wheelchairs.

People with hearing loss who are dependent on lip-reading find lighting inadequate and are unable to lip-read when preachers move around.

People who use hearing aids find it hard to participate in singing: *"In some churches the music is too loud. I can't cope with it."*

Times of services and meetings are sometimes inconvenient for people with disabilities. *"The 8 o'clock service is so early, my body is so stiff, it is hard for me to get there by 8 o'clock"*; *"People with poor eyesight can't see well in the evening, so if the Bible study is at 18:30, it is not helpful for them"*, were some of the comments of participants.

People with disability say that the church is unaware of their needs. Participants gave examples of lack of awareness. Decision makers do not prioritise accessibility. *"They are slow on the uptake, they may make plans, but by Friday they have forgotten all about it"*; *"It takes a paradigm shift, otherwise nothing changes."*

People with disabilities are not consulted when structural changes are made, resulting in inappropriate alterations being done. Some church leaders argue that they do not have people with disabilities amongst their members and therefore they do not see the need to make structural changes. They are unaware of the needs of people who may visit the church for special occasions. “*But what should we do when visiting there, finding that we can’t get in?*” was the comment of a wheelchair user who is a keen church-goer.

It appears that church leaders are not aware of the National Building Regulations,⁴ which describe the requirements for people with disabilities. Consequently, church buildings do not meet these accessibility requirements.

Theme two: Experiences of others’ perceptions of disability and healing

Church members’ perceptions of disability affect the extent to which people with disabilities feel included. The following are examples of exclusionary perceptions, related to biblical interpretations and practices.

► Biblical interpretations that have an oppressing influence on people with disabilities

This theme includes ideas about ‘normalisation’, prayer and sin in relation to disability.

When other people view them as abnormal, people with disabilities feel that they have to be ‘normalised’ and that their disability should be healed. They become victims of prayer practices, for which they do not ask, and feel compelled to be healed. The following comments attest to these experiences:

“They always want to ‘fix’ you, it seems [as if] my disability is not acceptable.”

“I like to visit different churches, but when prayer time comes, everybody is on top of me, assuming that I want to be prayed for healing of my disability, which may not be the case.”

“They prayed for me, without asking my permission, took off the footrests of my wheelchair and started pushing and shouting at me, WALK!”

These practices have a detrimental effect on people with disabilities. A woman expressed it like this: “*Out of respect I say yes [when they ask to pray for me] but nothing happens, and you begin to hate yourself.*”

Treolar⁵ states that the confusion about prayer for healing of disability has its roots in interpretations of biblical texts. These interpretations are associated with outdated attitudes toward disability as well as with ideas about Divine judgement and faith and miraculous healing.

Whilst some people with disabilities understand this confusion, and have developed their own views, the negative effects of some interpretations of the Bible are widespread. A middle-aged woman, a wheelchair user working in the government service for people

4 Standards South Africa. 2010. *National Building Regulations Part S: Facilities for disabled persons*. Pretoria: South African Bureau of Standards (SABS).

5 Treolar L. L. 2000. Spiritual beliefs, response to disability, and the church – Part 2. *Journal of Religion, Disability and Health* 4(1):5-31.

with disabilities, said: “I have made peace with my paralysed legs, but in general disabled people don’t like to go to church [since they are despondent with the church].”

Another interpretation is that disability is seen as a punishment for sin and confession is required for healing. Some responses were: “They [church leaders] say people are disabled because of their sins, or their parents’ sins or God is punishing them for [...] doing bad things, that is why they are disabled, God is punishing them.” A mother of a disabled child brought her offering and was told: “You must confess your sin, why is the child disabled? Your offering will not be accepted until you confess.”

Bowers⁶ confirms that some people do hold the view that disability is a consequence of sin. She points out a case of parents who had a baby with disability. Their own immediate reaction, as well as that of their friends, revolved around a notion of retribution. They asked: “Who was guilty? Who was at fault?”

► Practices in faith communities that hamper the inclusion of people with disabilities

Practices in faith communities that hamper the inclusion of people with disabilities include lack of respect for the person, lack of effort to understand disability and patronising attitudes and behaviour.

Many people with disabilities say that they are not respected as persons. They feel that non-disabled people respond to them according to stereotypes that are out of touch with reality. These stereotypes are expressed in several ways.

- Labelling and generalising: “We are identified by our physical appearance. ‘Oh Sarah, the disabled lady’, is the way people refer to me”; “All wheelchair users are lumped together, as if we all have the same needs.”
- Regarding people with disabilities as incompetent and not recognising their competencies: “Some people overreact and want to do too much for you.”
- Using offensive terminology: People with disabilities do not like to be referred to in terms such as “the crippled”, “the handicapped”, since these terms define them by their disability and not their unique personhood. A further example of these derogatory terms is the Zulu word for a blind person, “*impumphuthe*”, derived from the verb “*phuphutha*” which means to fiddle around without direction. People with disabilities report that these terms are used in the church, making them feel worthless and unaccepted.

Watermeyer⁷ refers to this as “othering”, which is a way of classifying people according to their physical appearance and as different to a self-constructed norm.

The lack of effort by non-disabled people to know and understand disability is demonstrated by the following experiences of disabled people.

6 Bowers, F. 2004. Who sinned? *The Bible In Transmission*, Spring, 1.

7 Watermeyer, B. 2006. Disability and psychoanalysis. In Watermeyer, B., Swartz, L., Lorenzo, T., Schneider, M. and Priestly, M. (eds), *Disability and Social Change. A South African Agenda*. Pretoria: HSRC, 33.

- There is a perception that people with disabilities are unable to do anything for themselves: “*I am treated as an imbecile, as if I can’t think for myself*” (a woman who had a professional career).
- There is the view that church leaders are not open to learning about the disability: “*In my church, the leaders just don’t understand disability, they treat you as if you are fragile.*” A pastor admitted: “*We get too busy and don’t slow down to really listen to people*”, and another church leader: “*If pastors do not have the answers, they feel incompetent [and thus do not admit their ignorance].*”
- Non-disabled members of churches make no effort to understand and accommodate the needs of a person with hearing impairment. “*My Bible study leader does not consider my need that he should speak up clearly, he fiddles with his papers, and talks down to himself*” – this was the experience of a woman with hearing loss in her Bible study group where she struggles to feel included. With regard to this lack of effort to understand disability, Carter⁸ says that churches struggle to relate to unfamiliar situations, but challenges the church to be inclusive and willing to learn from people with disabilities.

Watermeyer⁹ points out that individuals are unaware of their unconscious motivations for doing certain things. In the case of non-disabled people interacting with people with disabilities, fears of vulnerability are projected onto the disabled person. This fear may be expressed by simply looking away from the person or overreacting to their disability.

People with disabilities experience patronising attitudes and behaviour from non-disabled people. Practical examples include unwanted sympathy: “*They pity me, they think my mind is also disabled*”; being insincere: “*People can be very patronising, telling me: ‘Oh, you are so wonderful’, I avoid such people*”, and making assumptions about the person’s needs and wishes: “*I don’t want people to think for me.*” The latter comment came from a woman who knows that she is dependent on others in some ways, but is confident in making her own decisions.

In his psychoanalytic perspective on this problem, Watermeyer¹⁰ writes about how non-disabled people respond in terms of their anxiety, and unconsciously assume certain things about living with a disability. For example, when meeting a person with a disability in society, an assumption is that the person needs help, based on the supposition that the person is dependent, has poor self-esteem, or feels unattractive and shameful. These assumptions influence the interaction between a disabled and non-disabled person.

8 Carter, E. 2007. *Including People with Disabilities in Faith Communities*. Baltimore, MD: Paul H. Brookes, 32.

9 Watermeyer, Disability and psychoanalysis.

10 Watermeyer, Disability and psychoanalysis, 34.

SUGGESTIONS TO ENHANCE INCLUSION OF PEOPLE WITH DISABILITIES IN FAITH COMMUNITIES

Besides their experiences of exclusion from faith communities, people with disabilities have suggestions to enhance their inclusion. These suggestions are grouped according to four themes outlined below.

Theme one: Strategies for inclusion

This theme includes sub-themes like the unconditional acceptance of people with disabilities, ways of relating to them, providing practical support and changing beliefs and practices regarding disability.

► Unconditional acceptance of people with disabilities in the faith community

Participants in the study gave some indicators of unconditional acceptance:

- Being allowed to be involved on their own terms: *“I go to church to thank God for my life, not to be healed from my disability.”*
- Display confidence in their abilities: *“A group of people with intellectual disabilities are part of our team who do maintenance of our buildings.”*
- Enable people with disabilities to take leadership roles: *“After my accident I came back to the church as a person with paralysis. The church made adaptations, and I could continue with my role as a deacon.”*
- Create awareness of disability in all situations: *“We include people with disabilities in the sacraments and rituals of the church. With this we say, we are all vulnerable, anyone can become disabled.”*
- Exercise patience: *“A person with a speech problem likes to give his testimony in church, they wait for him, until he finds his words, and he continues to testify.”*
- Practise hospitality through interaction and communication with the person with disability. A pastor said; *“We want people to feel at home with us, tell us what we can do to let you feel comfortable. If you need a better chair, let us find you one.”*

Referring to unconditional acceptance, Carter¹¹ mentions the importance of self-determination for people with disabilities and the interdependence of believers on each other's gifts. The invitation of the church to society can never be diminished by disability. Such acceptance leads to hospitality that goes beyond greetings and remembering a name once a week. It is instead demonstrated in authentic and substantial gestures like spending time together, celebrating successes, coming alongside one another in difficult times and nurturing close relationships.

¹¹ Carter, *Including People*, 23.

► Relating to people with disabilities as people with abilities and not helpless people

Relationships between disabled and non-disabled people should be cultivated and built on each person's contribution. A woman with severe physical disabilities, who is dependent on others for mobility, says: *"If you can get to know me, you will learn a lot from me."* She is confident that because of her maturity, she can contribute a meaningfully to a friendship.

Participants also described meaningful relationships as reciprocal friendships. *"I am their friend for who I am, they don't see my wheelchair anymore."*

In this context of relationship, friendship and reciprocity, Carter¹² emphasises that a church that wants to be inclusive will work for a balance where people with disabilities are not only recipients of services, but also have a chance to serve others. Clapton¹³ describes this as re-figuring relationships between people with disabilities and the church. Such relationships provide a rich medium for exploration which embraces new relationships with God, one's body and with "different" others.

► Providing practical support without being condescending

Support to people with disabilities should be respectful, based on their dignity. When offering help to people with disabilities, it is important to bear in mind their abilities. *"I am not able to carry all my bags myself, so when you help me, please don't make me feel that I am totally helpless"* was the comment of a mother with mobility impairment.

Carter¹⁴ says that people with disabilities should be included in existing support systems, rather than creating separate services.

► Changing beliefs and practices regarding disability

Several beliefs about disability need to change. These are:

- The belief that disability is abnormal and unacceptable. People with disabilities feel that their different life styles are simply part of the variety of life. *"That word 'normal', you better check what that means."*
- The belief that people with disabilities do not have any abilities. This should change to an understanding of their different abilities. *"A vote of confidence in me gave me the opportunity to take on more responsibilities."*
- Unfounded perceptions of the cause of disability. These need to be replaced with approaches that do not blame the person with disability, but liberate him/her to live to his/her full potential. One suggestion was: *"The Ubuntu philosophy has much potential to enhance inclusion and brotherhood."*

12 Carter, *Including People*, 33.

13 Clapton, J. 1997. Disability, inclusion and the Christian church: practice, paradox or promise. *Disability and Rehabilitation* 19(10):420-6.

14 Carter, *Including People*, 120.

- Accepting the person with disability as a spiritual being allows him/her to find spiritual nourishment, as expressed by a young Zulu-speaking woman: *“I come to church for my soul to be saved, not to be healed from my disability.”*
- Replacing views that blame the person with disability, e.g. the belief that sin is the cause of disability, with a liberating acceptance of the person. Meaningful spiritual help should be given to a person with disability by listening sensitively and giving support that liberates the person to find his/her unique purpose. *“It is about finding one’s purpose, finding how I [as a person with disability] can be creative.”*

Theme two: Suggestions for user-friendly buildings and liturgy

This theme includes suggestions for accessible buildings and disability-friendly worship services.

➤ **Develop awareness of the impact of an inaccessible physical environment**

When churches become aware of the impact that the inaccessibility of the church environment has on people with disabilities, it is more likely that action will follow. Inaccessible buildings result in people with disabilities feeling *“I am not thought about at this church.”* Asking people with disabilities what they need will avoid incorrect changes being made. *“Next time you make your place wheelchair friendly, you contact me”* was the comment of one participant. Churches need to understand the frustration that people with disabilities experience in an inaccessible environment as expressed by a motivated person: *“Many changes are not insurmountable; the holdup is that accessibility is not regarded as a priority.”*

➤ **Ensure physically accessible buildings by implementing the necessary changes**

Participants suggested that buildings be adapted in such a way that people with disabilities can enter the church and use its facilities independently. This includes parking areas, entrances, doorways, cloakrooms, etc. that should be wide enough for people who use assistive devices. These suggestions are described in the National Building Regulations Part S: Facilities for disabled persons,¹⁵ to which all buildings must adhere.

➤ **Accommodate the needs of persons with disability in the worship service**

The following suggestions will enhance the participation of people with disabilities in worship services. Wheelchair users should be able to choose where to sit, have space to turn their wheelchairs and be able to see words on electronic boards when others are standing while singing.

People with hearing loss need sufficient lighting and must be able to see the preacher at all times in order to lip-read. The preacher should not turn his back or walk around the podium. Also, these needs of people with hearing impairment need to be borne in mind when lights in the auditorium are dimmed.

¹⁵ Standards South Africa, *National Building Regulations*.

People with visual impairment also need good lighting. Blind people who use Braille hymnbooks need time to look up hymns in the Braille books.

People with intellectual impairments will benefit when the use of language in sermons is adapted to accommodate them.

Theme three: Suggestions on how to create awareness about disability

Suggestions for creating awareness included methods to use and the required knowledge about disability that will bring about inclusion for people with disabilities in faith communities.

► Methods that facilitate interactive processes between people with disabilities and non-disabled people

The suggestions for creating awareness and changing attitudes correspond with the views of Paolo Freire on conscientisation (as described by Hope and Timmel¹⁶). These include the use of dialogue, recognising the equality of all participants and allowing space for transformative processes. The following paragraphs refer to the key principles of Freire's work.

Opportunities for dialogical processes between disabled and non-disabled people need to be established. Participants emphasised the importance of dialogue to bring about change: *"If we want enduring change, it will take a lot of dialogue."* This implies an interchange of views and bringing deep-rooted beliefs into the open. A participant commented: *"Let us get together and talk straight about these things."*

Hope and Timmel¹⁷ present Freire's key principles of critical awareness in society. One of these principles is finding "generative themes", which are things that people feel strongly about. When brought to the surface, these issues release energy to work towards change. Disability in the church may be a topic that non-disabled people hardly speak about because of their feelings of uncertainty and fear. This means that their deep-rooted beliefs remain unchanged. On the other hand, people with disabilities may feel powerless and will suppress their feelings of not being respected and considered. Once a space for discussion is created, these views of both disabled and non-disabled people can be brought to the surface. This may release the energy that is needed to change attitudes, reconcile relationships and transform interaction.

The equality of all participants in the dialogue needs to be recognised. In order for this dialogue to bring the expected change, it needs to be understood that nobody is totally ignorant and nobody totally knowledgeable, and therefore all views are valuable for the debate. A participant who is a church leader with much experience of social issues pointed out that both disabled and non-disabled people may want to withdraw from such dialogue *"[...] because of feelings of insecurity from their respective perspectives"*.

16 Hope, A. and Timmel, S. 1996. *Training for Transformation. A handbook for community workers*. Book 1. Gweru, Zimbabwe: Mambo.

17 Hope and Timmel. *Training for Transformation*. Book 1, 17.

Hope and Timmel¹⁸ quote the view of Freire that no “expert” has all the answers. Dialogue that draws on the insights of all those concerned in a matter is required to bring about permanent change.

A further requirement for this interactive process is allowing space for transformative and challenging processes. Participants suggested that both disabled and non-disabled people need to make paradigm shifts when it comes to inclusive faith communities. A person with a disability spoke about the “*lack of emotional maturity of people with disabilities*”, which needs to change in order for them to participate in the inclusion process. Another referred to “*the pride of some church leaders, thinking that they cannot become disabled.*”

These problems have to be overcome. “*We all have to grow past our embarrassment and frustrations, towards embracing the realities of living together as human beings*” was the suggestion of a woman who has much experience in efforts to bring about social change.

This calls for a deep level of change in the thinking of all stakeholders, which corresponds with Freire’s view of radical transformation.¹⁹ For Freire transformation is based on the hope that life *can* change for the better, towards a more just society. However, radical change means going to the roots of problems and addressing the values held by society that cause suffering for others. Values such as greed, control and power over people need to be transformed into cooperation, justice and concern for the common good of all. It is also significant for faith communities that Hope and Timmel call this transformation process a spiritual process.²⁰

■ Knowledge required and important for understanding the reality of people with disabilities

The implied suggestion of participants is that non-disabled people in faith communities should learn more about the reality of disability. This would include a basic understanding of the different types of disability, e.g.:

- Communication impairments: speech or voice impairment that effects communication;
- Sensory impairments: including loss of sight or hearing;
- Physical impairments: including the limited use of upper and lower limbs, or chronic pain, which restricts independence;
- Intellectual disability: including difficulty in learning and/or understanding;
- Psychological disability: including emotional conditions or a mental illness where the person may experience problems in the way they think, feel or behave.

A recurring suggestion was that terminology used when referring to people with disabilities should respect their dignity. The person with disability should be emphasised more than the disability. This can be done by stating “the person” first, for example, “a person with paraplegia”, or “a person who is a wheelchair user” rather than the “paraplegic”.

18 Hope and Timmel. *Training for Transformation*. Book 1, 17.

19 Hope and Timmel. *Training for Transformation*. Book 1, 16.

20 Hope and Timmel. *Training for transformation*. Book 1, 16.

Mackelprang²¹ emphasises the “person-first” language as an important mechanism to re-define disability and embrace people with disabilities.

Theme four: Suggestions on how people with disabilities can contribute to their inclusion

People with disabilities can create awareness of disability and of their spiritual gifts.

► People with disabilities can be agents in (enhancing) their inclusion

Many of the people with disabilities participating in this study were open about their prejudices and fears, realising that these also need to change: *“If we are to give turning point education to non-disabled people, we are responsible for making it work.”* Others admitted that fear and a miserable attitude are not helpful to anybody. *“[We have to] outgrow our own nonsense, don’t get upset”; “Engage with people in a friendly way and take charge of the situation.”*

► People with disabilities have to take the initiative and contribute to creating awareness about the reality of disability

In a group discussion a woman who is a leader in the disability community said: *“We as people with disabilities need to get past our hurt and be ready to teach the church what they need to know about disability.”* This was confirmed by an older lady: *“I used to get angry about the silly things that people ask you, but then I realised, I was also ignorant about disability before my accident. The only way they will learn is if I talk to them directly.”*

► Faith communities have to recognise the contribution of people with disabilities

Having people with disabilities amongst the leaders of a church can bring a special dimension to the church. A comment was *“We need their sharp senses to represent the viewpoints of the disability voice”*; and a young man with mobility impairment said: *“Other people with disabilities in the church may relate more easily to a pastor with disabilities.”*

With regard to the role of people with disabilities in their inclusion in the church, Carter²² makes an important statement about their self-determination. Putting people with disabilities at the centre of their own life decisions is a key indicator of high-quality approaches. At best, others can support them to become assertive and skilful in presenting themselves to the faith community. This can lead to congregations being places “where people with disabilities and people without, are woven together in common community”.

21 Mackelprang R. W. 2010. Disability controversies: Past, present, and future. *Journal of Social Work in Disability and Rehabilitation* 9(2):87-98.

22 Carter. *Including People*, 23.

CONCLUSION AND RECOMMENDATIONS

The main conclusions reached through the research is that the inaccessibility of church buildings and worship services leaves people with disabilities feeling excluded. The National Building Regulations²³ that prescribe standards of accessibility are often ignored by church leaders and not enforced by regulatory bodies.

Some biblical interpretations and practices in faith communities have an oppressing effect on people with disabilities and make them feel excluded. A concerted effort is needed to change these ideas and practices.

Referring to the origin of this research, namely the need for contextually appropriate guidelines for South African churches to include people with disabilities, the findings contributed to materials published on a website towards the end of 2011.

Recommendations are:

- Faith communities should take cognisance of the experiences of people with disabilities in order for church leaders and task teams to accommodate people with disabilities;
- Guidelines should include a document that indicates all requirements for accessibility for people with disabilities, including the legal requirements of the National Building Regulations;²⁴
- These guidelines should include practical suggestions for an awareness programme in faith communities, such as:
 - Dialogue and interaction strategies as methods
 - The content of an awareness programme including information on different kinds of disability and some of their impacts on the lives of people with disabilities
 - The role that people with disabilities can play in an awareness programme and enhancing their inclusion in the church.

Including people with disabilities in faith communities can be seen as a journey. This research and the implementation of its recommendations presented an opportunity for church leaders, members of the congregation and people with disabilities to journey together. This journey can become a pilgrimage where we journey “as pilgrims, not as tourists; as learners, not as teachers; as receivers, not as givers; as listeners, not as talkers”,²⁵ in the interaction between disabled and non-disabled people, implementing a commitment to listen, learn from each other and journey together with one another. Journeying in this way is, I believe, a positive response to the *inclusive* invitation of Jesus in Mathew 11:28: “Come to me, *all of you* who are struggling and burdened, and I will give you rest.”²⁶

23 Standards South Africa, *The National Building Regulations*.

24 Standards South Africa, *The National Building Regulations*.

25 Hudson, T. and Kotzé, D. 2002. Journeying, a life-giving, ethical spirituality. In Kotzé, D., Myburg, J. and Roux, J. (eds), *Ethical ways of being*. Pretoria: Ethics Alive.

26 The Complete Jewish Bible. Online at: <http://www.biblestudytools.com/cjb/matthew/11-28.html> [Accessed: 24 June 2011].

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Part THREE

The complexity of the life of a disabled person as she/he navigates the journey towards reclaiming dignity and full citizenship

11

*Gubela Mji*¹

INTRODUCTION

As the Director of the Centre of Rehabilitation Studies of Stellenbosch University (CRS), I want to introduce in this essay three case studies to demonstrate the complexity of the life of the disabled person as she or he navigates the journey towards reclaiming dignity and full citizenship.

CASE STUDY 1: THE GUGULETHU CHURCH COMMUNITY

The Centre of Rehabilitation Studies of Stellenbosch University (CRS) was invited by a minister of a church in Gugulethu, Cape Town to assist with the integration of disabled people into church life and activities. The minister was aware that there were members of his congregation who had disabled family members who did not accompany their family to Sunday services. He wanted to understand the underlying reasons for the absence of disabled people in church activities. He wondered whether the reasons were structural or attitudinal.

The CRS approached the non-governmental organisation (NGO) Disabled People South Africa (DPSA) for assistance, and one of the DPSA activists joined the CRS/DPSA team. Several meetings were held with the church leadership to strategise an approach that would elicit the following information from the congregation:

- Were members of the congregation concerned that disabled people were absent from church's activities?
- If the absence of disabled people was a concern, what were the reasons for their absence?
- What steps could be taken by the church leadership to address the reasons why disabled people were absent?

¹ Gubela Mji is head of the Centre for Rehabilitation Studies, Stellenbosch University, South Africa.

It was decided to hold a church service facilitated by a disabled minister. After the service, there was to be an open discussion with the congregation, focusing on the above three questions. Both the service and open discussion proved successful, with the congregation identifying the general reluctance of families to bring their disabled family members to church. The congregation was enthusiastic about raising awareness about disability within the church through participation in small group discussions with the youth group, the women's group and the deacon's group.

A question arising out of this open discussion highlighted the issue of societal attitudes towards the disabled people. One of the deacons asked what should be done with disabled people who get drunk and fall all over in beer halls. This was an opportunity to discuss how disabled and non-disabled people engage in similar activities and behaviours. This led to a discussion about the general attitudes of humanity to itself, and how we tend to approach each other from a deficit critical standpoint rather than from an asset affirming one. People commented that when greeting others, we say, for example: "Hello, I have not seen you for a while. Oh, why have you gained so much weight?" or: "You look like you are frustrated, I can even see how out-of-colour you are", as opposed to saying: "Hello, I have not seen you for a long time and I have missed you so much. How is life?"

The church minister indicated his concern regarding the damage that is done through this deficit critical standpoint and pointed out that if this was damaging to the able-bodied, how much more so to the disabled person. An understanding was beginning to develop within the congregation that the families of disabled people and disabled people themselves might be justified in isolating themselves from others so as not to have to confront negative attitudes, even in situations when people were (or should be) welcoming and inclusive, such as in the church. Together with the church leadership, it was decided that the CRS/DPSA team would provide a short course on disability rights for the church community. The CRS/DPSA team felt that it was important not to undermine the fellowship of the church by advocating ideas contrary to its theology, and thus decided to invite the SU Faculty of Theology to join the team.

CASE STUDY 2: THE YOUNG DISABLED BOMVANE MAN

While undertaking disability research in the Eastern Cape on the extent of disabled people's access to health services, I interviewed a young disabled man from Bomvaneland on the Wild Coast.² The young man had fallen from a truck while returning from work and had sustained injuries which had left the lower parts of his body completely paralysed. He lived with his mother and two sisters, one of whom was older than him. As I approached his hut I realised what a struggle it must be for him to get to his home, as he lived up a hillock. Furthermore, in order to reach his hut he would have to negotiate uneven ground, strewn with stones. During the interview he spoke about only being able to use his new wheelchair inside the hut, as the outside terrain and his physical environment prevented

² This included conducting qualitative interviews in the homes of disabled people.

him from visiting friends and engaging in community-based activities. I wondered to myself how he was addressing his faith needs, or was he experiencing exclusion similar to the disabled group from the Gugulethu church?

He was also facing challenges on the legal front. The lawyer who had handled his case with the Road Accident Fund had disappeared with the R75,000 which the young man had been awarded as a result of his disability arising from the accident. Despite this, the young man had started a small business selling a few grocery items from his hut.

He explained his health challenges, including his struggle with pressure sores. His mother, a widow, praised her daughters for taking care of their brother, changing him and making sure he did not develop more pressure sores. She ended by saying that her daughters had become ‘the men of the family’. This was difficult for the young man to hear, because by cultural and birthright he was supposed to be the man of the family, but his disability has robbed him of this.

As I left this household I was concerned about the health and rehabilitation needs that the young man was struggling with. I also wondered if the lawyer who had disappeared with his money had received any orientation training with regards to disability and human rights during his years of study and in his work. It occurred to me that more than one discipline should have been involved in providing a collective response to the overall needs of this young man.

I believe that the newly-developed CBR guidelines would be the best tool to assist him in his plight, if they can be implemented in a collaborative manner in Bomvaneland.³

CASE STUDY 3: THE RELENTLESS YOUNG MAN FROM GHANA

It was during my research and educational visits to the Kwame Nkrumah University of Science and Technology (KNUST) in Kumasi, Ghana that I had the privilege of being exposed to this relentless disabled young man from Ghana.

Born in rural Ghana in 1977 without his right tibia, he explained to *Sports Illustrated* (2004) magazine that “in [this] deeply superstitious country [...] when you are a deformed child, people think your mother sinned”.⁴ His father was so ashamed of his new-born’s disability that he immediately abandoned the family. His mother was urged by others to kill her baby, but this proud woman had a deep sense of human dignity and was determined to nurture her son.

His family lived in a poverty-stricken home, which lacked the basic amenities of electricity or plumbing. His bed was the dirt-packed floor. Despite this, as a Ghanaian he had access to free public education. Disabled children rarely took advantage of this opportunity, but

3 World Health Organisation (WHO). 1994. *Community Based Rehabilitation and the Healthcare Referral Services: A Guide for District Health and Rehabilitation Managers*. Geneva: WHO/RHB; World Health Organisation. 2010. *Community Based Rehabilitation: CBR Guidelines*. Geneva: WHO.

4 *Sports Illustrated*. 2004. November. South Africa.

his mother insisted that he be educated. “She gave me the idea that I could go to school and become a great man.”⁵ His mother carried him two miles to and from school every day until he was old enough to go by himself, hopping on one leg. Of the 240 students, he was the only disabled child, and he endured the taunts and bullying of the able-bodied students.

At the age of 13 years his mother became ill and he dropped out of school against her wishes. He travelled to Accra, Ghana’s capital, to earn money and rather than join the disabled beggars, he decided to set up a shoeshine box and earned about R14.00 a day.

But this young man had a bigger vision for his life – with just one good leg, he decided that he would pedal around Ghana in an effort to make others aware that *disability* does not mean *inability*. His 380-mile journey made him an international celebrity. He featured in a documentary and was given a new prosthetic leg. He has since dedicated his life’s journey to transforming the lives of Ghana’s estimated 2 million disabled people.

In 2009, he was invited to give the keynote address on issues of human dignity and spirituality at the AfriNEAD symposium that was held in Cape Town. In his talk he emphasised the need of parents to affirm their disabled children’s abilities rather than to reinforce their disabilities.

DISCUSSION AND RECOMMENDATIONS

Case study one demonstrated the need of the faith-based community to be exposed to skills which would help them to better integrate disabled people into their activities. Faith-based leaders should have benefited from having an awareness of how to deal with disability and human dignity issues at curriculum level during their training. Failing this, the challenge for rehabilitation professionals working with the faith-based leaders is the lack of theological understanding that would enable them to work within or even challenge the parameters of the fellowship of the church/faith. The case study illustrated the overcoming of these challenges through a collaborative effort involving the church leadership, members of the congregation, various faculties from Stellenbosch University, and activists from an NGO.

The second case study demonstrated the vulnerability of disabled people at both societal and human dignity levels. The young man from Bomvaneland’s situation clearly demonstrated the need for an interdisciplinary approach when dealing with disability, both in the community as well as at curriculum level during the training of professionals.

It was encouraging to note how the young man from Ghana blossomed under the tutorship of his mother. However, the reality is that not all mothers or parents of disabled children are able to overcome the negative attitudes that they are subjected to after giving birth to a disabled child. A key informant from Ghana informed me that the negative prejudice of some community members towards the disabled child resulted in many mothers choosing to abandon their disabled children in the forest or drown them in a river.⁶

⁵ *Sports Illustrated*, November 2004.

⁶ Key informant, Kwame Nkrumah University of Science and Technology, Kumasi, Ghana 2008.

The community is the interface where abilities and disabilities become evident. Within this context, it is a matter of concern that the WHO CBR guidelines (2010) do not directly acknowledge these negative societal attitudes towards the disabled people, or the need for the re-establishment of their dignity by humanity.⁷ Disabled people as a collective have expressed their concern about the response of society towards the disabled body and its needs. They see this response as alternating between complete exclusion, on the one hand, and the desire to infantilise disabled people and take over the functioning of their lives, on the other. According to Mji *et al.* (2009), the following core statement reflects the role of society in further disadvantaging or disabling persons with disabilities: “In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society.”⁸

To reclaim their voice, the disabled community have coined the expression, “Nothing about us without us”. Judge Albie Sachs of the Constitutional Court of South Africa describes this expression as referring to persons with disabilities reclaiming the space of “democracy, human rights and human dignity”, not only for themselves, but for “the whole of humanity”, especially those who have been marginalised. “Nothing about us without us” is about all of us, as we are all struggling to find our humanity and gain an understanding of the structures that allow some to have so much, while others are struggling to put just one meal on the table.⁹

The three case studies demonstrated the need for the training of people to skill them to work with disabled people both at physical and emotional levels. It is important that this know-how should be underpinned by principles of hope, human dignity and human rights. The young man from Ghana has shown the importance of parental support. Many parents of disabled children are faced with insurmountable challenges. As a social response the SU needs to ensure that its students graduate with an understanding of how to relate to a disabled person and as future leaders they need to know how to facilitate equal opportunities for disabled people. An interdisciplinary discussion needs to be facilitated by disciplines that are already involved in the disability curriculum regarding which key concepts should be included in a curriculum that is disability responsive. The three case studies show the direction for what should be included in a social response curriculum that brings hope to all people.¹⁰

7 WHO, *Community Based Rehabilitation: CBR Guidelines*, 2010.

8 Mji, G., Geaza, S., Melling-Williams, N. and MacLachlan, M. 2009. Networking in Disability for Development: Introducing the African Network for Evidence-to-Action on Disability. In MacLachlan, M. and Swartz, L. (eds), *Disability and International Development towards Inclusive Global Health*. New York, NY: Springer, 69-89.

9 Sachs, A. 2008. Keynote address delivered at the Friday Mavuso Lecture, School of Health and Rehabilitation Sciences, Faculty of Health Sciences, University of Cape Town on 31 July 2008.

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My body and my faith belong together

A spiritual journey

12

Pieter van Niekerk¹

The understandable but regrettable distinction made between body and soul has deep roots in a philosophy that is removed from my understanding of the Bible, being particularly prevalent in the neo-Platonic (200-270 BC) and gnostic (200-400 AD) worldviews.² “The mind/body dualism that has long pervaded Western society has also found its way into the church. Such dualism in the church leads to an ignoring of the needs, abilities, and disabilities of peoples’ bodies.”³

People’s faith is as vulnerable as their bodies are. The biblical writer, Paul, uses two metaphors to describe a person: cracked earthen vessel and an earthly tent.⁴ He does not distinguish between body and soul, but refers to a single entity. Our bodies are prone to disease and disability; they are fragile and mortal. Likewise, faith is unstable and shot through with doubt. Faith is not cast in certainty, but received in doubt.

Since my diagnosis with a chronic condition five years ago I have gained a new perspective on faith: the fragility of my body emphasises the fragile quality of my faith; brokenness is the essential fabric of both.

1 Dr Pieter van Niekerk is a part-time minister of a small URCSA congregation and a research associate of SUSTEN at the Stellenbosch University.

2 Neo-Platonism is “a type of idealistic monism in which the ultimate reality of the universe is held to be an infinite, unknowable, perfect One” (Schaufenberg, G. W. 2011. *Building Blocks of Western Civilization: “What the founders did not tell us.”* Dartfort: Xlibris, 51). According to this philosophy, “The most perfect being was the least physical, and had the least to do with the physical; that the way of salvation necessarily leads from the body, from the earthly-historical, to a realm of pure spirit” (Berry, D. 1982. Seeking a Theology of the Finite. *Christian Century* 99(29):953-6). Gnosticism rejected the body and saw it as a prison for the soul and rejected “the doctrine of the incarnation. It declared that Christ could not possibly have a body: (1) because the absolute cannot enter into a real union with the finite; and (2) because matter is evil, and the spiritual world is ever in conflict with it” (Heick, O. W. 1965. *A History of Christian Thought*. Philadelphia, PA: Fortress, 72).

3 Harren, J. 2009. Bones and Bread: Knowing God in our Bodies through the Communion Table. *Journal of Religion, Disability & Health* 13(3-4):274-292 (274).

4 He reveals his “weakness, lack of eloquence, ordinariness, fragility, suffering, and hardships [...]. While Paul’s application of the image may have seemed outlandish, the image itself would have been familiar to Paul’s audience. Cheap, fragile, often unattractive, and readily discarded, clay jars were part of everyday life – much like the plastic container of today.” Ashley, E. 2008. *The scandal of weak leadership: Paul’s defense of ministry*. Online at: <http://www.lutterworth.com/pub/on%20eagles%20wings%20ch5.pdf> [Accessed: 9 May 2011]. Our body is vulnerable, exposed to the powers of nature, wind and weather; bodies that could be contaminated with viruses and venom.

My father was 70 years old when he was diagnosed with Parkinsonism. I was diagnosed 25 years younger than he was. It seems unfair to me that I should endure a so-called old-age condition at the comparatively young age of 50.

When I was about 40 years old I first became aware that I trembled when pronouncing the benediction to strangers. My brother, also a minister of religion, suggested a natural tranquilliser. A friend, a medical practitioner, did not seem to consider my symptoms in a serious light. After thousands of rands' worth of diagnostic tests (without the benefit of a medical fund) my conviction that the symptoms were not psychosomatic was proved to be correct: I was "labelled" with the disease.

My nightmare started with radiology. Unable to master the intricacy of tying the strings at the back of the theatre gown and unaware of the dressing gown behind the door of the cubicle, I sat on a bench for an hour with my entire backside showing through the open garment. The task-orientated staff moved up and down past me, seemingly unaware of my predicament. In the tunnel I had to lie like a mummy in a catacomb. Having fortunately survived that ordeal, I received the report three hours later – only after my account had been paid. It was a copy of the original, stamped: "NOT PROOF READ"! I had not even seen the radiologist – only the radiographer and the friendly cashier. The letter that I wrote to the radiologist later to complain about the impersonal service I had received, was not even dignified with a reply.

To top it all, I was subjected to a situation that bordered on the farcical during a Christian camp that I attended. At a session, the main speaker called those who wanted to be healed. A friend of mine tried persuading me to step forward. I refused. He really wanted to see me healed and told the faith healer about my condition. I then stood up and allowed him to pray for me. He laid his hands on me and prayed for total recovery – from Alzheimer's. I whispered that it was Parkinson's. No wonder no miracle happened, he prayed for the wrong condition. I realised more than ever before, illness, disability, chronic conditions, these are not necessarily things that can or should be healed by faith or the health sciences, and that suffering is not always to be explained or to be understood; sometimes you just need to accept it as part and parcel of life.

I think we need hugs or soft touches from dear ones, and solidarity from our friends, from fellow human beings their unconditional love and acceptance, and from God compassion – a partnership with everyone.

Sometimes this partnership comes in funny ways. The other day I went to an end-of-season sale at Woollies and tried on some clothes. I went out of the fitting room struggling to close my zip. A concerned assistant asked me innocently if she could help me. I felt the faith healer had viewed me as an object. Being treated as a patient and not as person by most medical professionals often makes me feel inferior. But the Woollies assistant's concern left me with a smile.

(My) church is a source of sadness to me. I am not angry with God, but I am frustrated at my own "disability" and upset with the church, or rather the representatives of the church. I am white, Afrikaans speaking, middle aged and am afflicted with a condition that adversely affects my chances to obtain permanent employment. I am too white for

“my” mainly black church and am considered too light-weight for the mainly white church. Moreover, my tremor requires explanation.

My personal experience seems to indicate that the Belhar Confession, which I confess and practise, does not apply in my case. In my experience God, who is uniquely the God of the needy and who appeals to the church to follow His example, by supporting and assisting the destitute, is not embodied by the church.

I am considered good enough to share my knowledge and experience with the church ministries and theological institutions without any compensation. Clearly, I shall not easily find gainful employment; of course, there are certain posts that other candidates are better qualified for. However, the “thorn in my flesh” torments me. Sometimes I deal with it inadequately and my faith trembles.

Having faith does not imply that the faithful never doubt. Julian Muller writes in *Om te Mag Twyfel – ’n Gelowige se Reis* (2011)⁵ that his faith is vulnerable and shaky, wavering between conviction and terror, completely honest and tentative. The combination of a broken body and vulnerable faith leaves the door wide open to a spirituality of imperfection.

The body is not merely a container in which the soul is incarcerated. “To discover who I am and who God is, is part of the same process, and who I am, is bound up with my body,” according to Vivien Naylor in *The Theology of Touch* (1996).⁶ It is for this reason that Eckhardt Tolle advises: “Do not fight against the body, for in doing so you are fighting against your own body. You are your body.”⁷ The established writer Nancy Mairs with MS writes:

I am *somebody*. A body. A difficult body to be sure, almost too weak now to stand, increasingly deformed, wracked still by gut spasm and headaches and menstrual miseries. But some *body*. Mine. Me. In establishing myself as writer, however modest my success, I have ceased to be *nobody*. I have written my way into embodied self, and here I am at home.⁸

My body says more than words. Dorothee Sölle writes:

My body tells me that I am in pain, hungry, have sexual needs. It is through my body that I know it is not so very good here on earth. The wrong way to relieve this tension is to deny and to suppress the body and its needs in favor of affirming an idealistic spirituality cleansed of all bodily desires. An idealistic spirituality is the enemy of a creational spirituality. It is based on the dualism of self and body, body-spirit dichotomy that we inherited from Greek philosophy (1984:29-30).⁹

The devaluation of human experience with no positive religious value and the emphasis on a “theology of the infinite” has a strong influence in Christian traditions. A theology of the infinite refers to “an inquiry into the identity and existence of divine beings, divine activity in history and nature, the purpose and destiny of human life as these are revealed by a being called ‘God’ to others called ‘persons’.”¹⁰ This dualism is antithetical to the reality of Christ, who had a body himself.

5 Cape Town: Tafelberg. (To be allowed to doubt. The journey of a believer.)

6 Online at: <http://www.franciscanarchive.org.uk/1996jan-naylor> [Accessed: 22 February 2011].

7 Tolle, E. 2005. *The Power of Now. A Guide to Spiritual Enlightenment*. London: Hodder & Stoughton, 96.

8 Mairs, N. 1989. *Remembering the Bone House*. New York, NY: Harper & Row, 271.

9 Sölle, D. 1984. *To Work and To Love: A Theology of Creation*. Philadelphia, PA: Fortress, 29-30.

10 Berry, *Seeking a Theology of the Finite*, 953.

Tolle (2005:95) is of the opinion that transformation takes place through the body, not away from it. He points out the significance of the fact that Jesus never relinquished His body. He ascended to heaven with it. Although, according to him, this is a myth with a “hidden meaning”.

According to Isherwood and Stuart, the traditional Christian view of the body is “viewed as something to be overcome in order to receive the joys of heaven. This is paradoxical since probably the most important article of Christian faith is that God became man”.¹¹ It is against the gospel of Emmanuel – Jesus is God-with-us.

The great mystery of God becoming human is God’s desire to be loved by us. By becoming a vulnerable child, completely dependent on human care, God wants to take away all distance between the human and the divine. Who can be afraid of a little child that needs to be fed, to be cared for, to be taught, to be guided? We usually talk about God as the all-powerful, almighty God on whom we depend completely. But God wanted to become the all-powerless, all-vulnerable God who completely depends on us. How can we be afraid of a God who wants to be ‘God-with-us’ and needs us to become ‘Us-with-God’?¹²

Eiesland refers to God as disabled:

In the resurrected Jesus Christ, they saw not the suffering servant for whom the last and most important word was tragedy and sin, but the disabled God who embodied both impaired hands and feet and pierced side and the *imago Dei*.¹³

I need to learn to accept my condition and to let go of my frustration in order to find peace and my body at home.

Willem Nicol uses the term “faith of the body” when he refers to silence with, and peace in, God. Your perception of your corporeal self is heightened.¹⁴ You realise that it is not only sensations of fright, tension and surprise that are partially experienced on a bodily level, but also awareness such as trust and peace in God. The peace that faith in God brings is felt not only in your heart, but also in your body. In this sense you experience God’s bestowal of faith to both the heart and to the body. You feel the working of God’s spirit in your body, from where it emanates to your heart.

The priest-professor Henri Nouwen’s theology of weakness and powerlessness – a spirituality of imperfection – is a good description of my faith. His journey of faith took him along situations that revealed his faith to be vulnerable and cracked. His pastoral ministry to mentally disadvantaged people who have to deal with the limitations their condition imposes on them lends credibility to his theology. Nouwen recognises the hope in, and spiritual importance of, the human body:

In Jesus, God took on human flesh. The Spirit of God overshadowed Mary, and in her all enmity between spirit and body was overcome. Thus God’s Spirit was united with the human spirit, and the human body became the temple destined to be lifted up into the intimacy of God through the Resurrection. Every human

11 Isherwood, L. and Stuart, E. 1998. *Introducing Body Theology*. Sheffield: Sheffield Academic.

12 Nouwen, H. 2007. *God’s powerlessness*. Cf. online at: <http://helenl.wordpress.com/2007/03/02/gods-powerlessness-by-henri-nouwen/> [Accessed: 26 July 2011].

13 Eiesland, N. L. 1994. *The Disabled God: Toward a Liberatory Theology of Disability*. Nashville, TN: Abingdon, 99.

14 Nicol, W. n.d. *Dring sy Allesdeurdringendheid tot my deur*. *Kruisgewys* 3(3):38-9.

body has been given a new hope, of belonging eternally to the God who created it. Thanks to the Incarnation, you can bring your body home.¹⁵

With this in mind, he later wrote: “A new spirituality is being born in you. Not body denying or body indulging but truly incarnational. You have to trust that this spirituality can find shape within you, and that it can find articulation through you.”¹⁶

A fragile faith, human weakness and a disabled body make a theology of vulnerability and finitude relevant. Donald Berry refers to a “A body theology” that

must, in short, include, in a non-masochistic way, a theology of pain and suffering, a recognition that time and the healing powers of nature are not always efficacious; indeed, that in the final analysis, they are never more than temporarily successful.¹⁷

I regularly go to the gymnasium. I am dependent on chronic medicine daily; without it I will not be able to live a life of dignity. But medicine and medical interventions are not necessarily a cure for healing. The outcome of prayer is not always in our favour. By the way, my faith is sometimes shaking like the tremor in my hands.

The spirituality of the body embodies imperfection. It is a faith that deals with growth and development, illness, degeneration and ageing. It nevertheless summons vulnerable believers to lead lives of faith, hope and love.

15 Nouwen, H. 1998. *The Inner Voice of Love. A Journey Through Anguish To Freedom*. New York, NY: Doubleday, 19.

16 Nouwen, *The Inner Voice*, 32.

17 Berry, *Seeking a Theology of the Finite*, 953.

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Cerebral palsy and a South African university

A life between smiles, tears and dilemmas of faith

Tatjana Metzger¹

INTRODUCTION

Only just very recently, early on a Monday morning, I wrote an e-mail. It was a desperate one, voicing immense frustration and calling for help. In the heat of the moment I strung together words. Most of them upset and appal me now, but some of them ring with truth. It is true that when I first decided on a university degree, when I first applied and when I first came to study, I did not think. I believed. Had I thought, had I reasoned, had I known, I would have certainly come to the conclusion that it was just better, easier, not to study at all.

As my brothers and I grew older, tertiary education was often mentioned and talked about in our home. Back then, it never occurred to me that I should not have one. Even though I have Cerebral Palsy, I have almost always been to a mainstream school, mainly for lack of another option in Namibia where I grew up. Also for lack of another option, I became a boarder at age seven. I fought my way through school and boarding school with minimal support. I finished my schooling in South Africa and by the time I reached Matric, I was a quite independent person, who felt pretty invincible. I felt there was nothing left to prove: I had mastered my life 1,600 km away from my family. I had passed Matric with a distinction. What more could people want? Who could bring me down now? Surely I had shown them all and they would finally leave me be! Little did I know ...! But be that as it may, at the time, going to university seemed like a natural step, the next thing in line, the right thing to do.

LIFE AT UNIVERSITY

So there I was in late January 2007, lined up to start my orientation weeks. Ready, or rather not so much, to start my life as an Education student at Stellenbosch University. Not only was I a student, I was an international one. I had left my support network in Namibia and was suffering through pointless initiation in one of the woman's residences. Many people

1 Tatjana Metzger is a primary education student at Stellenbosch University, South Africa.

argue for initiation and it may have some benefits, but in my case it was the worst thing that could have happened to me at that point. It was the last little weight that caused the scale of my life to tip and fall out of balance. Here I was faced with real, pressing problems: I had to learn how to drive my new electric mobility tool, my Shoprider scooter. I had to find accessible routes, all the while battling my very unique special orientation problem caused by my brain damage. Card readers were too high, ramps, if they existed, were too narrow and doors, for various reasons, were not conducive. The list goes on. Problems everywhere you look. In no time I was worn out on every imaginable level and lectures had not even started yet. As if my real problems were not enough, I was met by House Committee members who acted stern and unapproachable. From my point of view, they were wasting my precious time by telling me to paint banners and fold paper flowers. They drained my valuable energy with their fast-paced programme that continually accounted for almost every minute of my day.

It did not take me long to find out that my residence was utterly unaware of and unprepared for my disability. Apparently, when I first walked in on my crutches, I was thought to have broken my leg, even though I lacked a Plaster of Paris- or a moon boot. This lack of knowledge and preparation really perplexed me! I had done a lot of communicating beforehand. Over the previous months I had stated my needs in every which way. It seems, though, that these communications were lost in the mesh of hierarchy and the paper jungle that inevitably comes with an institution this size.

In terms of the residence, I did not need a lot of adaptations. I managed living upstairs, for instance. But, when after an exhausting day I got into the shower, things went from bad to worse. On my first day in the shower, I looked for the taps in a mad frenzy. I finally spotted them mounted to the roof of the shower, looking down on me at a 90-degree angle. Oh, great! Not even in my most perfect dreams would I be able to reach those. It was enough to have me melt down right there and then. Instead of bringing the taps down, people insisted on building me my very own disability bathroom downstairs. For the next three months, until I could finally move to my new room and bathroom, I had no choice but to co-ordinate my showers very carefully, as I always had to ask somebody to turn the water on and off.

Elsewhere on campus, things were hardly any better. I struggled with inaccessible faculties and lecture halls. I was overwhelmed by the vastness of campus and its human traffic jams. Above all, I had a very full timetable and never seemed to have enough time for anything. I slept little, did not eat much and regular bathroom stops were also a problem, mostly for lack of time and conducive facilities.

Late one Friday afternoon, it must have been late February or early March, I had a memorable meeting at the university's Centre for Student Counselling and Development. We came to the conclusion that what I needed most was more time in my day – time to eat, sleep and relax. It was decided that if I was to keep my sanity, I had to do fewer modules a year. So two psychologists and I went to see my course co-ordinator. That was another memorable meeting in the very worst sense!

I stepped out of that meeting knowing that I was at a crossroads in my life. Would I take heed of the course co-ordinators implicitly stated suggestions to leave the course, or would I become a teacher after all? I was hurt, I was angry, I was sad and then I became very,

very calm. I decided to stay. How many people had left before me? And if I was to leave as well, this faculty would never learn. Besides, one person cannot decide for an entire faculty. Somehow I knew that this was about so much more than just me and my little degree. Words of principle like “right and wrong”, “fairness and discrimination”, rang hard in my ears.

Now we are a good five years down the line and a lot has changed for the better since the day I decided to stay. I am still busy with my bachelor’s degree at the Faculty of Education and graduation is in sight. I have excelled academically. I have become part of disability awareness on campus. I have given motivational talks. I have touched many lives and the smiles have come back into mine. This is not to say that I do not head butt with Stellenbosch campus on a daily basis, but campus has shown me its beautiful side as well.

MATTERS OF FAITH

In all fairness, one has to say that I was raised by atheist parents. Nevertheless, through my broader surroundings and my circumstances I was exposed to the Christian religion at a fairly early age.

Over the years I have had the recurring, peculiar experience that once you show signs of disability, many people automatically jump to the conclusion that you must be deeply religious. I reckon that this comes, at least in part, from the fact that so many disabled people are indeed very religious. They take much of the courage and strength needed to face their days from their vivid relationship with God. I have often thought that it would be a relief to have God in my life – a higher power to rely upon, to share with and to collapse before. However, the issue of religious healing continues to wedge itself between me and God. It creates a dilemma, which to me is so unbridgeable that it keeps me from converting to the Christian faith.

To me, religious healing is not a distant, faded something that happens to other people. In my reality and over the years, it has become more and more real. It has gotten flesh, as people continually try to use religion to cure me of my Cerebral Palsy. Picture this:

I am having lunch in the Neelsie, the University’s student centre. All of the sudden a complete stranger sits next to me. By the way the person behaves and by what the person says, I already know where this conversation is headed. We eventually get to something like: “You know that Jesus can make you walk. He can heal you. Should we pray to start the process?” This is when I really start to struggle for every ounce of self-control within me. All the while boiling on the inside, outwardly I calmly reply something to the effect of: “Thank you, but no thank you.” I then look for ways to end the conversation fast and with as much politeness as I can. After all, these people truly believe that they are doing me a favour. Of course I could argue my point, but I am not up to it. You cannot win every battle, I am too agitated, and I really want to have lunch.

I will, however, argue my point now. Cerebral Palsy has been with me ever since the moment I was born. That was almost 26 years ago and by now my disability has infiltrated even the

smallest niche of my being. This is by no means an invitation to think that I am just and only my disability. I am a person with hopes, dreams, desires and ambitions, and yet I am a person with Cerebral Palsy. With time, the two have become inseparable. There is no telling where Tatjana ends and Cerebral Palsy begins. Now, if you were to take Cerebral Palsy away, if you were to heal me, I would no longer know who I am. By the same token, of course, there are days when I want out, when I want Cerebral Palsy to vanish into thin air. But then again, show me one able-bodied person who feels great all the time, every time! Having bad days is part of life, for all of us.

Secondly, the last I checked, we only heal or cure flaws, never assets. Or have you ever had someone walk up to you and say: "Excuse me, ma'am, can I heal your happiness?" Why is disability so commonly seen as a flaw? I am human, therefore of course I have flaws, but my disability at large is not one of them. On the contrary, my disability has given me direction and a unique perspective and I have employed it as my asset, to do good for others, many, many times. My disability is my asset. On most days, I do not want to get rid of it. On most days, I have absolutely no desire to be healed by any higher power, as I feel valuable just the way I am. And even more so, precisely because of the way I am.

CONCLUSION

My disability is integral to my identity and it is my asset. For most people to agree with me on this, society needs a significant paradigm shift. And so do our major religious doctrines. In my opinion, religion or its followers should not, in any way, intend to belittle or heal my disability. The way I see it, religion has to fully accept me, before I accept religion. Until such time, even though having God in my life would probably be a relief, and an enrichment considering my circumstances, I cannot let Him in.

On her blindness

Reflections on being blind in the world and associated issues of faith

Michelle Nell¹

A young blind teenage girl sits on a chair in a large room, surrounded by a significant number of individuals, including her hopefully expectant parents. Looking onto this seemingly intimate gathering are the remaining members of a charismatic congregation, excitedly yet respectfully holding their collective breath while the pastor of the congregation, his hand on the young girl's forehead, sounds the inevitable: "Do you truly believe, with all your heart and soul, that God will heal you of your blindness?"

Tension mounting, the eager congregation continues to wait with bated breath for her answer to break the unremitting silence. The pastor, assuming the girl to be understandably shy or possibly hesitant, reiterates his question: "Michelle, do you truly believe ...?"

A quiet, barely audible sob interrupts: "I'll try, but ..."

INTRODUCTION

In his 1985 publication entitled *Being Blind in the World*, author William Rowland puts the following phenomenological query: "[...] what in the life of a blind person is to be regarded as the result of blindness as such, and what, to the contrary, as the effect of nurture or circumstance?" Subsequent to this question, he explains that sometimes a single factor, more than any other, determines the course of existence and the quality of experience of an individual human being. "This may be so because of what that factor is, or because of the reaction it engenders, or because of the features of the encounter with the environment." The author furthermore elaborates by explaining that, similar to a psychopathological condition such as schizophrenia, or being part of a subjugated group, such as being black in a white supremacist state, it creates experiences of a very particular nature. Similarly, being blind creates a certain engagement or disengagement from the world of a particular kind, which could encompass a personal, social or political realm.²

However, the particular qualities of such a lived experience may vary from one individual to another. We cannot know, for example, what it is like to be healthy and not schizophrenic, or part of a subjugated group, in which case it should be grasped that a full understanding of what it is like to be blind, the phenomenological aspects of such a lived experience,

¹ Michelle Nell studies music at Stellenbosch University.

² Rowland, W. P. 1985. *Being Blind in the World*. Pretoria: South African National Council for the Blind, 57.

remains largely something that can not fully be grasped by individuals who do not suffer from visual loss themselves.

Nonetheless, it is the aim of this personal reflection to invite you, the reader, to engage alongside me in exploring this query of, as Rowland terms it elsewhere, the what-is-it-likeness of being blind in the world and the dilemmas with regard to issues of faith this holds for me.

A PERSONAL HISTORY

*Is my understanding only blindness to
my own lack of understanding?*³

As you possibly might have surmised by now, the girl featured in the prologue to this article is indeed my much younger teenage self, attending what might have been the umpteenth healing service up to that particular stage. The reason for interventions (as some might term them) such as these is the fact that I was born with the eye disease known as glaucoma which, as in my case, usually result in severe loss of vision. I choose to call it visual “loss”, since what proceeded from my diagnosis back then is rather akin to the onset of the five stages of grief in both my parents’ and my life.

The first stage of grief, denial, was first experienced by my parents following the diagnosis of my eye condition years ago. Far from accepting the status quo, conceptions such as “blindness is imperfection, so surely God must heal my daughter from this iniquity” continued to dominate their everyday lives and soon began to infiltrate my life as well. In addition, questions were asked: “Why my daughter?” “What have I/we sinned for this fate to befall us?”

As with many conceptual models of disability, such as the medical model, also not discounting the events in the long history of segregation, i.e. the witch hunts of the 1400s, or the era of institutionalisation, my visual impairment was viewed by both my parents, other parties such as family and faith healers alike, as well as myself, as an imperfection, even an iniquity, which promised a life of darkness, solitude and ignorance.

Following denial came the bargaining phase. Both my parents and I also shared this experience of bargaining with God. Conceptions such as living a good life on earth might reap positive benefits, particularly with regards to possibly restoring my lost vision, became an obsession, influencing every aspect of our lives. The constant questioning was gradually substituted with incessant bargaining, such as “if we live a life devoid of sin ...”, “if we continue praying as much as possible ...”, or “if I give enough money to the church ...”, then maybe I might be healed of my blindness.

As time passed my parents seemed to have made their peace with my situation, at least in some sense. For me, however, the battle with my visual impairment was far from over.

During the course of my adolescence I gradually became aware of the various conflicting attitudes toward my blindness, which indeed proved to be a complicating factor in my

³ Wittgenstein, L. 1975. *On Certainty*. Oxford: Blackwell, 424.

coming to terms with this loss of vision. Contrary to my parents' initial aversion regarding blindness, I gradually came to notice a shift in their perception of visual loss. Suddenly my visual impairment was viewed as a gift from God and I was believed to be imbued with abnormally keen senses, even possessing "special" psychic or spiritual powers. In my occupation as a young musician, I also encountered what I would like to term the "savant mentality", where my possibly mediocre or fairly acceptable level of musicality was exalted to being close to that of a musical genius.

I was told that my blindness is the will of God in order to show people true suffering which would serve the purpose of teaching and honing true gratefulness, or other features such as the exaltation of a deity.

However, iniquity or blessing, it gradually became clear to me that all these healing services, the incessant questioning and bargaining were in fact not paying off, contrary to many healers' optimistic promises, and I gradually grew frustrated and angry with all the unanswered questions and prayers, the conflicting ideologies around my visual impairment, and also life in general. Growing older I came face to face with my blindness, and I soon began to realise that it infiltrated practically all facets of my life. On a social level I felt isolated from the remainder of my peers, since I had to attend an ELSN school. My freedom was minimal, since my over-protective parents were not exactly bent upon honing the most independent blind girl there ever was, and I often found myself excluded from decision-making processes concerning personal matters – why, even at a restaurant the waiter would usually ask what "she" would like to have to drink.

Therefore, being in a "special" school removed from the broad community, and in addition then not being exposed to my sighted peers, created a sort dis-relationship with the world at large, or true reality as such. This was an environment particularly tailored to fit my every need, without keeping pace with the outside world. I felt out of touch with reality and I longed to experience it.

Meanwhile, life continued. The one day slipped into the next, and weeks became months, became years until it became time for me to enrol at a tertiary institution. Suddenly I was in a bigger, much more vast environment, both socially and academically. Attending university I experienced the overwhelming juxtaposition of my personal life, i.e. my visual impairment and my associated conflicting beliefs involving it, whilst being confronted by a new, fast-paced and potentially life-changing milieu. This meant that I had finally managed to step out of an extremely sheltered environment to find a world filled with new ideas and a great amount of freedom at my disposal.

However, I began comparing myself to my sighted peers, soon to realise that for all the given similarities, there were an equal number of differences. This included on an academic level slower work tempo, not always having access to explore printed academic texts, or on a social level having to contend with people's sometimes sceptical or uninformed views regarding my visual impairment, and I gradually grew frustrated and depressive at the realisation. Technically, I thus had access to the world, but not always appropriate access.

I faced a dilemma: is it me or the system? Regardless of the answer, how can the status quo be remedied?

I gradually became aware of the fact that it was a question of identity. Am I the exceptional blind individual and music student, incomparable and in her own league, or the student suffering from visual loss and constantly at a disadvantage, particularly when compared to others, thus always regarded as standing in the shadow of her sighted peers? I frequently found myself in what felt like a tortoise and hare race and I was squarely confronted by true reality of a constant conflict between my environment and my visual impairment. I discovered that the abovementioned conflicting ideas around my visual impairment had become internalised and I was left unequipped to find the right answer, or how to deal with it.

REFLECTION

*Doth God exact day-labour, light deny'd.*⁴

So real was this dilemma in my life that, with the undertaking of my Master's degree in music education, I chose a research topic concerned with the personal experiences of visually impaired music students in the higher education system. During the course of my research I came across a conceptual model developed by Howell and Lazarus (2003) to address the challenges for students with disabilities in higher education. This model is comprised of three imperatives, namely access, participation and success. The challenge in evaluating the status quo according to this model lies partly in the recognition that, as seen earlier with Rowland (1985), each imperative extends over various realms within the lives of students with a disability, namely personal, social and political. To embark on a comprehensive theoretical analysis or scrutiny lies beyond the scope of this personal reflection; however, it shall be applied to my own lived experience here.

Firstly, when referring to access, one can argue that I had sufficient access to schooling and that my primary educational needs had been taken care of. However, on a social level I did not have access to a full independent life and could therefore not fully participate in life itself. At university the degree of my access to the world increased. I had access to peers of my age, could even attend unsegregated classes, and I could participate to a greater extent. However, still there remained something lacking, something on a personal level. As a result of these unresolved issues, my level of success was thus minimal as far as my dealing with blindness goes (as well as the consequent quandaries it gives rise to, i.e. my acceptance of my visual impairment).

In retrospect, I discovered that my grieving process was not resolved yet. The refusal to make piece with my "imperfection", all the years worth of prayers and bargaining, as well as the anger and frustration and depression, none of those stages seemed to bring me closer to resolving my grappling – to accept the status quo for what it is.

As previously mentioned, this inner struggle also pertains to my identity. Is my blindness a blessing or a curse? Is it imperfection or divine intervention? Am I akin to the grovelling blind beggar condemned to live a life of darkness, solitude and ignorance, or am I in reality endowed with supernatural talents? Am I the special one, or in fact the excluded one?

⁴ Milton, J. 1939. On His Blindness. *The Oxford Book of English Verse*. Oxford: Oxford University Press, sonnet 318.

However, what I eventually came to learn about my life is the following. The emotional responses of, initially my parents, but also myself, unmistakably reflect the fact that my loss of vision inevitably set off a grieving process of some sort. The denial, bargaining, anger, depression – it’s all part of a process in which an individual mourns the loss or absence of something important, treasured and vital. Even though all these emotions are admittedly detrimental to one’s health and frame of mind, I learnt that it, the process, is an insurmountable fact of life for me. The resolution lies in the fact that one must accept this very insurmountability: the fact that I’m blind and the fact that I cannot be impassive about this reality. Thus, acceptance of the blindness as well as the conflicting emotions, questions, as well as personal battles it provokes – therefore, a work in progress.

We all have various characteristics: tall or short, shy or talkative, sighted or blind, creative or analytical, each one having his or her own personal history, characteristics, experiences, possibilities, hopes and aspirations which equip us with different abilities. However, what we do with what we have, therein lies the secret to a fulfilled life, a life where the involvement of work in progress becomes something to be admired and respected.

In the end I learnt that it is my own personal opinion and stance on my visual impairment that has the greatest impact. Yes, to be blind, with all the associated issues and hampering is less desirable, but as Helen Keller once wisely stated: “The only thing worse than being blind is having sight but no vision.” Similarly this statement pertains to my own life: being blind but possessing no vision or goal in life. And what is my vision then? To be sighted? In all honesty, I would rather be the most successful individual I can be, blind or sighted. In the end it’s not how much you have, but how much you “wheel and deal” with what you do have. Life, whether disabled or not, is all about choices we make, perceptions we adopt, chances we take, dreams we envisage. In that way we are all equal: constantly engaged in the process of negotiating our place under the sun, conceptualising who we are, chiselling away at our identity and our destiny. To aim for success in life.

CONCLUSION

*when we go home
with what we have got
when we climb the stairs reciting ancient deeds
the seas grow deeper
that we rose from⁵*

Seen in the light of the above-mentioned stance towards being blind in the world, this inevitably raises the question of the issue of faith. What is my true stance on being blind in the world, and what are my perceptions of the deity that ordained this cross to be borne by me? As much as I would like to reveal some deep-found wisdom in this regard, as much as I would wish to gushingly share an awe-inspiring account of thankfulness and gratitude, I must confess that I have not reached that point quite yet – possibly never will.

5 Merwin, W. S. 1991. Last People. In Minow, M. (ed.), *Making all the Difference: Inclusions, Exclusion, and American Law*. New York, NY: Cornell University Press, 121.

Regardless of this, however, for the time being, until I reach a new conclusion, or when I might be fortunate enough to have my sight restored by miracle or medical advancement, this will remain part of my work in progress. Until then, I place faith in myself: to gain as much independence as I can, to live a full and meaningful life, always reaching higher in life, always striving towards a better self and to make a conscious decision not to dwell incessantly on what could have, should have, or might have been.

In closing, the words of blind author Georgina Kleege:

Miracles happen. Or even without miracles, ninety nine per cent of my days are just fine. I get up, I go to work, I teach, I read, I write. The fact that I use aids and assistants to do some of these things is not really central to my consciousness. When everything works, I consider myself “normal”. My blindness is just a fact of life, not an insurmountable obstacle blocking my path. I work around it. I ignore it. On a lot of days, it matters less than the weather.⁶

6 Kleege, G. 1988. Blind Rage. *Southwest Review* 83(1):53-9 (59).

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This is a challenging book. It initiates some overdue debates about disability and Christianity in South Africa. Instead of editing out contributions with which they disagree or which do not easily fit into existing canons of writing on disability studies, the editors have produced a volume which challenges one's preconceptions and fondly-held beliefs. It is a fact that many people with disabilities (probably the majority in our context) are unlikely to ever in their lives engage directly with disability politics, but are likely to be profoundly affected by dominant religious views. For people with disabilities, many services, including schools, rehabilitation facilities and opportunities for social inclusion, are available only through religiously-aligned organisations. At the same time that religious groups offer much-needed services, disability is commonly viewed as punishment by God (or as a perverse 'gift' from God). People with disabilities have been viewed as objects of charity or pity, instead of as agents within our own lives, worthy of the same respect, rights and responsibilities. If we are serious about disability rights, we must be serious about robust engagement with the faith sector. This book, interspersed as it is with contradictions and differing opinions, constitutes an important start.

SHUAIB CHALKLEN

UN Special Rapporteur on Disability

This publication fills a unique gap in the theological and religious engagement with the issue of human disability in South Africa. Combining the contributions of scholars, practitioners and people living with disabilities, it stands out for the way in which it promotes an interdisciplinary debate on disability and human dignity from a theological point of departure and interest. The end result is a collective effort with a critical approach to the role of religion (and the Christian faith tradition in particular) in the social and life worlds of people living with disabilities. A forceful argument is thus constructed about ways in which religion and the Christian faith tradition should change their own discourses, practices and ideological presuppositions regarding the issue of human disability.

COBUS VAN WYNGAARD

Department of Philosophy, Practical and Systematic Theology, University of South Africa



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