

Conference Report

Theology, Disability and Human Dignity Conference 18-20 May 2011

DAY ONE: Wednesday 18 May 2011

Opening: Professor Nico Koopman, Dean Faculty of Theology, Stellenbosch University, welcomes all delegates to the Conference on Theology, Disability and Human Dignity which is co-hosted by the Faculties of Theology and Health Sciences. A special word of welcome is extended to visitors from outside the borders of South Africa, from Southern Africa and beyond – this includes a group of students on a study trip from Concordia College, Minnesota, in the USA.

At the request of Professor Koopman and the organising committee a moment of silence is observed in honour of Mr. Alexander Phiri, disability activist, chairperson of the Zimbabwe Federation of the Disabled as well as Director General of SAFOD (Southern Africa Federation for Disabled). Mr. Phiri passed away on 10 May 2011 and was to be one of the keynote speakers at the conference.

1. Prof. Arnold van Zyl, Vice-Rector Research, Stellenbosch University, welcomes all delegates on behalf of Stellenbosch University and its Rector and Vice-Chancellor, Professor Russel Botman. According to Professor van Zyl, this is a ground-breaking event. It is also in line with the broad vision of the Stellenbosch University. About ten years ago it was decided that the activities of the University should focus on serving the people of South Africa in very specific ways. The knowledge resources of the University were to be put at the disposal of South African society with regard to five specific themes: the promotion of peace and security, human dignity, a sustainable environment, democracy and human rights and fight against endemic poverty. About twenty projects were identified to form part of the so-called HOPE Project. Besides the fight against endemic poverty, the promotion of human dignity was chosen by the Faculty of Theology to form the focus of its activities as part of this project. This conference flows from this commitment. The issues identified as part of the vision of the Stellenbosch University cuts across various disciplines – as can be seen from the programme of and participants in this conference. This inter-disciplinary perspective affords all the opportunity of better understanding the issues and challenges at hand as well as the possible ways of addressing them. Finally, a conference such as thus also creates wonderful networking opportunities for all present and gives participants the opportunity to contribute to addressing the plight of people living with disability in three ways : by fostering respect and understanding, by combatting prejudice against those with disabilities and by acknowledging the latter's enormous potential.
2. Prof. Hans Reinders: (Professor of Ethics and Mental Disability, Free University of Amsterdam)

Theology and disability: what is the question?

There are three main concepts found in the title of this conference and the task given to Professor Reinders was to reflect on how these are related namely theology,

disability and human dignity. In this presentation the focus was on the relationship between theology and human dignity in particular.

There exists a worldwide growing interest in theology and disability. When one looks at the many publications on the topic it seems as if new field of inquiry is developing – think also of the work done by the European Society for the Study of Theology and Disability (ESSTD), and the Religion and Disability Studies Group of the American Academy of Religion, etc.

When one looks closer at the available literature, the main question seems to be on the issue of inclusion. The disabled and their families do not feel included in their communities and how can this be rectified? Theologians from are trying to answer this question from the perspective of their respective traditions.

One way of doing so is to answer the question from the perspective of pastoral care. This is a very practical approach which rests on the conviction that “we should practise what we preach”. A second approach is looking at the issue from a systematic theological perspective, an approach of critical reflection, of deconstructing existing practises of exclusion or, put it in a different way: “before one starts practising, make sure what you want to preach.”

What is the difference between these two approaches? In this regard one should start by mapping the field of what is involved in theological reflection on the issue. In virtually all literature on theology and disability experience comes first – the experiences of non-acceptance of persons with disabilities and their families (individual or collective) and testimonies are supplied of these experiences (in church and society). According to one author with disabilities, a variety of “theological” explanation, aimed at comforting him: “Do not worry, no one will be disabled in heaven”; “You are special. You were given a disability because you can cope with it”; “Disability is given to one in order to form one’s character.” All of these explanations/theologies were however inadequate to the persons personal experiences.

Behind these “theologies” lies the belief that there is something wrong with those with disabilities since God would not otherwise allow it, or they were chosen by God for to have a disability. In order to address these misconceptions two approaches or strategies are sometimes found:

- a) *A strategy of pastoral care* returns to primary sources of a tradition to see how those with disabilities are treated in and should be treated according to it. The New Testament is often used for this, especially emphasising Jesus’ interaction with those with disabilities. Then reference is made to how people with disabilities are treated in the tradition – usually people with disabilities should be completely accepted and respected in their tradition/communities. The problem, therefore, never lies with the sources of the traditions, but rather with the everyday practices of the communities/churches – not only those belonging to Christianity, but also to Judaism and Islam. There thus exists a difference between how people behave and the way in which their traditions say they should. This leaves one with an ethical problem and not a theological one.
- b) *A second approach or strategy* focuses on theology, since theology has everything to do with the exclusion of those living with disabilities, and these concerns some of its most central Christian doctrines. Raising human rights/human dignity awareness in religious communities has a long way to go. The first strategy (“a theology of access”) asks what we can do for them since it is felt that most people with disabilities suffer from their disabilities or from what we think of them. In

other words, this concerns what *we* think of *ourselves* or the position *we* take in the debate. However, the question to be asked is a simple one: what *in eyes of God* is the difference between those labelled “disabled” and those not? Many theologians strongly deny that there is any difference, that people with disabilities are not defective human beings. However many people still think so and in effect display the attitude of the crowd asking Jesus in the Bible: what has this person done to deserve this? From a Christian perspective the religious meanings commonly ascribed to disability are indeed on a whole negative: it is punishment, a curse for sin, a blemish, etc. and thus wounded people come to a community – even a church – to find only judgment. Positive responses – that disability is in fact a blessing in disguise, an opportunity for spiritual growth for the “little innocents, God’s little ones” – are equally inadequate. Whether curse or blessing, the underlying assumption is that disability is a “special” condition of humanity. Underlying this “special language”, however, is also the exclusion of people with disabilities by mainline communities. Therefore, one should be critical and suspicious of “special (blessing/curse) language” because it points toward exclusion since it assumes that disability is special problem which needs a special solution.

What have we to say *theologically* of disability? God is too often seen as on the side of “normal people” (us) to the exclusion of “the disabled” (them). What can theological reflection contribute without falling into same trap?

When one reflects critically on theological framework underlying these beliefs, one finds an implicit reference to Providence. Whether positive or negative, disability is seen as the result of Providence. Nothing in this perfectly ordered universe happens without purpose and disability is thus seen in terms of culpability or merit: every good/bad result must have a good/bad cause (for example, disobedience to God). This theology too is highly improbable. To attribute any (positive or negative) theological meaning to disability is to contribute to language of “special”. Furthermore, since we are not punished equally or in a similar way for what we have done wrong (even worse: only *some* seems to be punished!), this makes a mockery of divine judgement, for example. A second argument why attributing disability to divine judgement amounts to a highly improbable theology is because it would imply that people with disabilities cannot be good and it leaves no logical space for any contingency in our lives. This would mean that religious believer can never be in the dark as to why God allows good to happen to the bad and vice versa, and we have all experienced this at one time or another. Were it not for these contingencies in life the book of Psalms never would have been written. Providence is needed by the numbing experience of moral complexity, finding God in his apparent absence. Therefore, any connection between Providence and disability cannot stand test of critical reflection. The question of *what we think of ourselves* is closely linked to the whole issue. Thus it is perhaps rephrased as follows: *in the eyes of God* there is no difference whether *we* live with a disability or not, whether *we* are blessed or judged, whether *we* are “special” or not. God does not make distinctions between people – people do that. Thus ascribing religious meaning to disability in terms of either merit or judgement rests on a mistake.

This has important implications human dignity. The latter is not based on our distinct human capacities – for this makes people different – human capacities differ, this is true, for example from the elderly suffering from dementia or those with severe intellectual disability do differ from other people. Regarding human dignity

the question is a simple one: why should we respect people if they do not have certain capacities? Because human dignity is conferred *on each of us* because of *God's relationship with us* (NOT the other way around). According to Luther dignity is *Dignitas alienas*, alien dignity. It is dignity conferred on us by grace of God alone.

In the public domain human dignity demands respect for others it has implications for how we are to be treated by the institutions of society and by the community. Theologically it entails more: because *God bestows dignity on all*, it is hard to deny that he expects us to do the same. Therefore Christians are also expected to help those living with disabilities to regain their trust in life and the community. And how can that be done? Once again, with the help of God, through the Spirit of Divine Love (St. John) that will forge the bonds of friendship by inspiring love and kindness and friendship thus enabling us to help others.

3. Prof. Leslie Swartz: (Professor of Psychology, Stellenbosch University)

Is God disabled? Faith, scepticism and the problem of evidence in disability research training in Southern Africa.

Professor Swartz speaks on this topic with relation to his work with of SA Federation of the Disabled (SAFOD). SAFOD is an organisation which represents disabled people in Angola, Botswana, Lesotho, Malawi, Mozambique, Namibia, South Africa, Swaziland, Zambia and Zimbabwe. SAFOD has embarked on a research capacity development programme, known as the SAFOD Research Programme (SRP). Their aim is to become a powerhouse of information and research on disability issues in the SADC region. The goal of the organisation is to enable people with disabilities' organisations to undertake self-directed research and use its findings to influence policy and practice that is responsive to the needs of those with disabilities. Professor Swartz's presentation flows from his engagement in this project and questions arising from the training he is involved in as part of this programme.

Historically people with disabilities have been marginalisation – just think of the Franklin D. Roosevelt Memorial established in 1997 in Washington, DC which includes a statue depicting Roosevelt in his wheelchair. However, the latter is being obscured by Roosevelt's cloak! Furthermore, persons with disabilities have traditionally been seen as objects of professional scrutiny – the focus being on knowledge *about* mostly and not *by* those with disabilities. Disability has also often been seen as minority issue, losing sight, for example, of the close relationship between disability and poverty and the fact that while most families are confronted with disability in some form or the other. Factors such as these make the need for evidence/research such as that which is being done by the Social Research Programme necessary. Part of this programme is the use of 10 trainees with disabilities from widely differing backgrounds and training. Living with disabilities themselves, trainees such as these may either have been exposed to a life of exclusion or of feeling defective. This may result in turn in them becoming more and more "disabled", or it might result in such a person to become very critical and sceptic and thus a good researcher, someone that does not take anything for granted!

With regard to developing research capacity the following are important: a) Empirical Research (what is going on?) and b) Activism (what are we doing/can we do about it?). One of the interesting points emerging from the training of the SAFOD trainees is that people commonly see research as a very separate activity from

activism. However, one of the major challenges in the development of people with disabilities is the keeping of records of, for example, the number of people with disabilities, on which to base activism.

Regarding the issue of scepticism (the fact that all knowledge is provisional) Professor Swartz mentions this is an element built into research and it is necessary. Today one finds, for example, a great emphasis on the availability of “new sacred texts”, e.g. the UN Convention on the Rights of Persons with Disabilities. These, however, create platforms of solidarity instead of activism. Solidarity becomes quite difficult concept in this context. Part of struggle for developing research capacity is that while there is some comfort in solidarity (“I have a place despite not feeling accepted by mainstream”), solidarity may also breed a lack of willingness toward critical reflection. Part of mutual respect should be the ability to criticise and ask critical questions.

Finally, working with the trainees in the SRP opens one’s eyes to also critically reflect on the European idea and talk of independence of people with disabilities and the fact that African people do *not want* to be independent and *want* to be part of communities as one finds within the idea of Ubuntu. After all, a very important part of being human is being dependent.

4. Panel Discussion: (Mrs. Rachel Kachaje, Deputy Chair, Development and Underrepresented Groups of Disabled Peoples International; Mr. Mzolisi ka Toni, Deputy Director General, Department of Woman, Children and People with Disabilities)

Mzolisi ka Toni: The issue of embracing disability is a crucial one and Stellenbosch University should be thanked for acknowledging this. For every person the right to identity is very important – the fact that people decide what to call us without us having any say in it is one aspect that has been concern with me. We should, therefore, reflect on issue of language. It is also important to understand disability is *not me*; it is *an environment around me*.

We have to remain confident so that we not only to see the Promised Land but to enter it. I have been working with people with disabilities in South Africa for the last 20 years. I have seen and experienced many hurdles with regard to disability. I have also seen how Christians too perceive us. How we look at our bodies and how society looks at our bodies (black, white, disabled or not) are shaped by our societies. But for me, religion plays an important role in how people see themselves and their disabilities. Many charismatic churches today demonstrate their power by showing how they cure people with disabilities – I hope that during this conference we can reflect on this as well.

Rachel Kachaje: I was invited once to a discussion on the issue of theology and disability in Kenya – for me it was the first time to see disability being targeted with regard to issues of spirituality. Thank you for a similar opportunity afforded to me here once more.

I want to reply to this morning’s papers – a) regarding the theme of disability and theology an important issue pointed out was the one of inclusion and pastoral care. One may ask whether there is any difference between being invited to attend a church ceremony conducted in a foreign language, and thus being excluded from it, and not being able to participate in the ceremony due to one’s disability? Does

inclusion mean just being present, or really being part of something, participating in it?

We have also heard that “people do not suffer from disability, but from how society looks at them”. This too is a very important issue. We are all human beings (even the Declaration on the Rights of People with Disabilities speaks only of “human beings”), but we also need to be *effective* human beings. Professor Swartz’s paper this morning serves as an example of how a programme of SAFOD have proved that given the opportunity persons with disabilities can also become researchers, that they can in this sense be effective human beings.

However, despite progress on different fronts there negative experiences by and perceptions of people with disabilities persist around the word – even in theology and in churches. As we have heard this morning some people continue to see disability as a form of divine judgement and churches often include the issue of disability as a welfare issue, “doing something for the disabled”, the church being the one that does the work. This makes people with disabilities feel as if they do not belong, as if they cannot do anything, as if they cannot contribute.

Mrs. Kachaje also shared some personal experience with delegates. She was born into a family of 4 boys and 4 girls, contracted polio at the age of three and has been living with disability since. She shared her experiences of asking why such a thing happened to her, until she realised just how merciful God is. “Until I realised that every time I move, the glory of God moves through me.” “I am Rachel, not disabled Rachel. Today I am part of my church’s governing body – due to my efforts a ramp was built to give wheelchair access to the manse – now *anyone* has access to the manse as to the church. When I was asked to preach after being part of the congregation for years it was indeed a great challenge for me to get up on the pulpit – this is yet another challenge for people with disabilities, even in churches. And, on a visit to Stellenbosch Moederkerk during this week, I had the same realisation.”

Question from the floor: Regarding language – how would you want to be referred to?

Mzolisi ka Toni: Language is an emotive issue. One only has to think of the recent Julius Malema-“Kill the boer” saga. We have witnessed the disappearance of the term of “crippled” in the 1980s. The term “people with disability” still has kind of stigma – it influences my identity, my disability *forms* my identity. One consequence is that disabled people sometimes use this “to get away with murder”; saying that, because they have disabilities, they cannot do this or that. In South Africa we also find the “language of special” - people with “special” needs, “special education” etc. People living with disabilities also have a task to change this terminology, help to build communities of trust.

A comment that then followed from the floor and which clearly was appreciated by all delegates is that we are all in some sense “disabled”. We cannot all do everything equally well and there are some things that people with disabilities can do or can do better than so-called “non-disabled people”. The speaker refers to Mrs. Kachaje’s view that at stake is also being effective human being, being efficient. In light of this potential, employers should be encouraged to also employ those with disabilities for their special skills.

Another comment from the floor, this time by a deaf person underlines the fact that, in his view, he is not “disabled”, he does not make himself “disabled”, but other people do so. He feels that because he is deaf people do not ask him to do

things; they decide for him what he wants to do and what he can or cannot do. This frustrates him and he will keep on challenging this. "There is only one thing a deaf person cannot do and that is that he/she cannot hear, and even that I can do by 'listening' by way of sign language."

Another comment came from the floor from a deaf person from Umtata, now studying in Worcester to become a pastor. This was his experience as well. In Umtata are many deaf people and many hearing people believe that they do not want to work. This is simply not true.

Comment from the floor: Within the labour market yet another unfair phenomenon is referred to, namely that it is expected from people with disabilities to be superhuman, to prove themselves time and time again, to repeatedly prove that they can do their work efficiently, something which is not expected with other people.

5. Parallel Session: (Since the rapporteur was only able to attend one of the two parallel sessions at a time the report on those not attended by him is limited to the abstract supplied the presenter in the conference programme.)

5.1 Prof. Ignatius Swart (Huguenot College, Wellington) and Dr. Eddie Orsmond (Communitas and Dutch Reformed Church Simondium):

Disabled in the Drakenstein: engaging the new professionalism from and integrated practical theological interest.

This paper represents a next step in the authors' ongoing practical theological interest in developing perspectives on the agency role of actors of faith, including the Christian church, in promoting community and social development in the local Western Cape area of Drakenstein. Against this background, and in relation to a research focus on how a social agenda of human flourishing and inclusion can be promoted in the communities of this area, in this paper the authors seek to expand their focus to another group amongst the population whose daily life situation is characterised by the struggle to overcome exclusion and stigmatisation.

More specifically, in terms of this broad aim the authors' point of departure is to describe in some greater detail the new professionalism in delivering social services to people with disabilities in the area. Recognising thereby that a formal network of service to this group of people exists and is growing, this identification becomes the basis for a renewed relation to the authors' practical theological interest that, in this case, would in terms of a social agenda of human flourishing and inclusion reflect on how faith-based agencies could through their own (theological) discourses and action not only complement the new professional service but even play an innovative, critical role thereto.

Moreover, as the title of the paper suggests, this engagement with the meaning and existence of the new professionalism will be undertaken in a way that, from a methodological and hermeneutical point of view, reflects the authors' belief in the fundamental importance of an integrated approach to doing practical theology. Being geared to a notion of praxis that recognises the fundamental dialectical interaction between theology/theory and practice/action to develop any meaningful practical theological perspective, in this paper such

engagement will be reflected in a twofold manner: 1. the way in which a theological/faith-based interest does not merely juxtapose itself in relation to the wider social context of ideas and action (practice) but values the potential complementary relation thereof; 2. the way in which a broader, value-added faith-based contribution is conceptualised through an integration of non-theological, social scientific contributions in the academic conversation.

5.2 Dr. Pieter van Niekerk: (URCSA, Friemersheim)

Towards a Theology of the Body.

When the main speaker called those who wanted to be healed to step forward, I refused. A sincere friend then informed the healer of my condition, and I allowed him to lay his hands on me. When he prayed for total recovery of my “Alzheimer’s”, I whispered “Parkinson’s”. It was a disturbing, unsettling experience.

A theology of the body or finite should include, following a non-masochistic approach, a theology of pain and suffering, and the recognition that time and the healing powers of nature are not always efficacious. Too often, in a bias against the body, it is regarded as impure and distracting from the spiritual. But, who I am is bound up with my body. It is the locus of experience and meaning. However, in some way, becoming a full, self-expressive person is independent of the limits of the body.

We can speak of the body as sacrament: the outward and physical sign of inward and spiritual truth and grace. God’s most powerful statements about him/herself are made in silence through the body of Jesus: the baby, the cross, the bread and wine.

As one who lives daily with an irreversible physical handicap, it makes me sick to hear “If you choose to, you can be the master of every aspect of your life.” Touching one is not just a physical event of flesh meeting flesh, but a language for one’s very being; it is spiritual. If we take a person seriously, we are bound to take his/her physical nature and needs seriously.

5.3 Jan Oberholzer: (Head, Deaf Christian Ministry in Africa, Worcester)

A critical evaluation of Deaf Christian Ministry. Africa’s (DCMA) students after five years (2006-2011). A case study.

Several students completed their studies at DCMA. The questions were as follows: “How could you evaluate the DMCA four year training course?” “What were your experiences after completing your studies?” “What worked for you?” “What did not work?” “What were the challenges that you face in the first year after completing your studies?” “How did the fact that you are deaf influence your work as a pastor?” “To be excellent, is one of the noblest ideals, what do you think it takes to be excellent?”

The result of the evaluation was presented at the conference.

5.4 Erna Moller: (Social worker and Programme Manager, The Leprosy Mission, Johannesburg)

The experiences of people with disabilities in faith communities: a social work perspective.

This paper focused on the findings of a study undertaken in Pietermaritzburg, KwaZulu Natal in 2009 and 2010.

Some people with disabilities experience exclusion from faith communities. In order to address the problem in a culturally and contextually appropriate way, scientific knowledge was needed to explore the *experiences* of people with disabilities and church leaders regarding the inclusion in the church of the aforementioned in faith communities. The study further explored *suggestions* for practice guidelines to implement inclusion strategies for people with disabilities in faith communities. A qualitative research approach was followed using interviews and focus groups to collect data.

The paper presented the experiences of people with disabilities in terms of practices in faith communities that hamper their inclusion. These people are all on long journeys of the discovery of meaning in life, meaningful lives lived with disability. As one person put it: I have often asked: "why me?" Until I asked: "why not me?" Other important experiences are experiences of the role of significant others as well as experiences of the inaccessibility of church buildings, or even if the church building is accessible, the church hall where the congregation enjoys tea after the service might not be – even more of a problem is the accessibility of worship service activities themselves, for example when speakers walk around while speaking, something that seriously hampers the lip-reading abilities of deaf people. Other experiences include that of the perception that having a disability is to be not normal, to be abnormal and hence, that one needs to be fixed. People praying for those with disabilities may sometimes make the latter feel as if they are victims. In some traditions disability is seen as the result of sin and sin one should confess and will as a consequence one will be healed. People with disabilities also experience feelings of incompetence – or they may feel that other people view them as incompetent. To mention one other experience: the problem of marriage – people feel that people with disabilities are not supposed to get married and as such cannot always fill leadership positions even if have leadership skills since, it is sometimes felt, leaders should be married. However, it must also be kept in mind that not all experiences reported were negative. In the words of one person: "my paralysed legs are not the focus in my church, my heart is."

A further section of the findings is the suggestions towards inclusion, namely: changes in practices and the physical environment, creating a reciprocal learning process of inclusion, and enhancing the role of people with disabilities in the faith community (I am a spiritual being. Please, do not see me as a disabled person only, but as one with abilities). Mythical beliefs should be excluded and overcome by attitudes of embrace. Recommendations include a reciprocal and dialogical process to promote the inclusion of people with disabilities in faith communities. On a practical level this might include an annual disability awareness Sunday, something which was started in the area where the study referred to in this presentation took place. This will be one way of sensitizing people to the challenges faced by those with disabilities. Finally, in this whole process the role

of those living with disabilities is very important since they want to contribute and want to take responsibility for their own inclusion. In this way faith communities can become places of welcome and of real community.

5.5 Prof. Estelle Swart: (Department of Educational Psychology, Stellenbosch University)

This is my world – stories of battles and belonging.

Since 1994 the Department of Higher Education have embarked on the promotion of equity and access in higher education in South Africa. Higher education institutions are required to promote equal access to all qualifying students, including those with disabilities. The expectation is that these institutions create environments that accommodate the diverse needs of all students and facilitate their learning and participation. Within such a context we asked ourselves: what it is that is expected from educational psychologists? We are expected to live these values. However, even before that, we had to face the difficult issue of what exactly disabilities are and how we could classify disabilities? This was done by way of model of inclusive education, which represents a direct shift away from a medical model regarding disabilities.

A qualitative case study was designed using individual and focus group interviews to obtain an in-depth understanding of how a group of students with disabilities experience participation at a university. The study worked with multiple case studies: first very broadly, then narrowing it down, for example to specific disability groups. This resulted in collection of complicated data which revealed the tension between, for example, theory/policy and practice.

The presentation supports the notion that disability is an experience that develops out of the interaction between individuals with a functional limitation and the social attitudinal and physical environment in which they live. The focus was therefore on people's personal experience of living with impairment – both socially and individually. Using the constant comparative method of analysis, four main themes emerged: personal characteristics and self-determination, issues of social integration, the role of beliefs and attitudes and a need for a responsive curriculum. The feedback from the students with disabilities themselves included that while many people did emphasise physical barriers this was not the only barriers. Barriers also exist that allow or prevent people using their own abilities and strengths, self-advocacy and exposure. Students with disabilities have to be proactive and have to explain to their lecturers: "This is *my* world. I am/will be in your class and this is what I will need from you to make it possible for me to study." Many students find this process of disclosure is very tiresome since they repeatedly have "special requests" which have to be explained and justified again and again, in every new course, every semester and every academic year. In this regard self-knowledge is important, how will one, after all, know what one needs if one does not know oneself or one's needs? These students often have firm belief in their own abilities and potential and that is what others need to acknowledge as well: acknowledge my potential. The disabled student also needs a sense of humour as well as the ability to deal with conflict in relationships of power (heads of residents, deans, lecturers). Persons without disabilities need to realise that it demands extra energy from those with disabilities to convince

others of their capabilities and needs. In all of these relationships are very important, especially friendships, since this is the way we build a community.

5.6 Prof. Elizabeth S. Bressan: (Centre for Human Performance Sciences, Stellenbosch University)

Paralympic Sport evaluation of Deaf Ministry Africa's (DCMA) students after five years (2006-2001). A case study.

This contribution was on the Paralympic ("para" as in parallel, not paraplegic) Games. Elite level sport performance by Paralympic athletes has achieved increasing media coverage and raised the awareness of the general public about the extraordinary abilities of persons "with physical disabilities" – for this reason the Paralympic Games are often referred to as "a celebration of abilities". The Paralympics are, in terms of participants, the second biggest in the world (at Athens about 4000 athletes competed). The potential of high profile events and the iconic status of some Paralympic athletes may be particularly powerful in developing countries where the challenges to find effective strategies to transform stereotypes about disability are daunting.

This presentation described why Paralympic Sport is also explored in relation to affirming the dignity and rights of persons with disabilities, and its current status. It is not without reason that the values of Paralympics can be summed up as courage (to show what abilities are), determination (referring to the very hard road to travel to reach Paralympics and the aspiration to be the best) and inspiration (one only has to listen to the very many inspirational stories for those with or without disabilities). Paralympic Sport affords persons with disabilities the opportunity/right/luxury of risk – the right to try. There is also something such as the right to failure which is a right as any other right. People with disabilities should have this right as well. This becomes a new way also of identifying a new social group that does not depend on ability or disability. Finally alternative views do also exist about the value of Paralympic Sport especially with regard to claims that their very "separateness" undermines the concept of inclusion in its re-invention of the "separate but equal" justification for its continued existence. However, in the view of the speaker "the Olympics are the place where heroes are made; the Paralympics is the place where heroes come to".

5.7 Martha Geiger: (Centre for Rehabilitation Studies, Faculty of Health Sciences, Stellenbosch University)

Through the eyes of children: children living with severe communication disabilities doing theology.

The speaker is a Speech-Language Therapist working with non-verbal children (i.e. children with severe disabilities and little or no speech). However, even if these children cannot speak, they still can *communicate*. There are three aspects to communication when one looks at severe communication disabilities: people who are deaf and cannot speak but have ability and desire to speak. This is usually overcome with sign language. If the latter is impossible then such a person has a communication disability. Such a person does not have a problem

with communication content, though. Persons having problems with content of communication are, for example, those with an intellectual disability. Autistic children have both language and content but cannot communicate thought. They have language but cannot communicate with it.

The presentation aimed at generating future discussion on the need to recognise the spiritual assets of children with severe disabilities since in her work the presenter has had glimpses of some of the theological realities of such children. The presentation also hopes to highlight the possible role such children can play in challenging stereotypes and affirming the contributions they make to society and in this way to also put to rest fears people sometimes have when coming into contact with persons with severe communication disabilities. A series of case examples was discussed in the theological context of theology of childhood, child theology and children doing theology. One example is of a child who had the ability to speak, albeit with a severe tremor. The child attend group in which he declared that people that cannot speak have no spirit. This caused an outcry of anger from those unable to speak (literally screaming in anger at him). This not only shows that those without voices can communicate (not with words, but in other ways), but the child that made the comment also revealed a common perception, a kind of “theology”. A second example is of a cerebral palsy sufferer who recently passed away and could not speak. However he could communicate by blinking his eyelids – the only muscles he was able to use in his body – when being spoken to by way of questions being put to him. This happened while many people asked why people were talking to him, not realising that he had the ability to communicate and which once again reveals some common perceptions about those with disabilities. A final example is of another person with cerebral palsy – she cannot speak, but is very intelligent and gave the presenter an important lesson in children doing theology. While the child cannot speak, she uses one hand to communicate and declared that she speaks in *various ways*, including pointing at pictures and, even if she has a voice but no words, she can still *speak to God*.

Furthermore, the examples were discussed against their social and cultural backgrounds including attitudes to disability in general, communication disabilities in particular and social exclusion. Attitudes to different disabilities differ as do attitudes in different cultures, even within the same culture. In this regard the presenter referred to two cases she encountered while working in Botswana for many years. Children with disabilities lived in the city during school terms but went home for the holidays to their families. Two boys, both with cerebral palsy and intellectually impaired, lived in the same village and while one would be included and participated in the family circle all the time, the other was tied to tree.

It became evident that these children had an awareness of their relationship with God – with diverse ways of expressing it and/or communing with Him. Such information may assist in the training of professionals to enhance their recognition of persons with disabilities as fully human.

There is a need for a hermeneutical competence in engaging with children/persons with severe disabilities themselves and interpreting their awareness of their relationship with God to others in order to value and affirm them.

5.8. Prof. Daniel Louw: (Department of Practical Theology, Faculty of Theology, Stellenbosch University)

Virtuous suffering and the predicament of being handicapped and disabled: A theology of disablement and the puffing God in a wheelchair.

How does one approach ability or disability since these are categories we create? The Presenter's basic assumption and question is not how do we care for abilities or disabilities, but how do we care for *life* in order to help people hope and cross boundaries.

Theology mostly starts reflection on anthropology with the Fall; the flaw in creation. In order "to save God" we create an idea of some omnipotent God. Omnipotent comes from the Latin *omni potens*, but the Greek word for this is *pantocrator*, which was used with reference to the Greek gods that had to be omnipotent, immutable, omnipresent, behind and beyond all forms of vulnerability or disability. We want to link and justify God in terms of evil/suffering (the so-called theodicy). The following slogan by Oscar Pistorius challenges traditionally theodicy and *pantocrator*-theology: "You are not disabled by the disabilities you have, you are able by the abilities you have." Is it possible to use language related to God and then call God then the "disabled" God?

Unfortunately our understanding of (a) power and how we project it onto God and talk about it is not biblical, it is Hellenistic (the omnipotent God). *EI Shaddai* of the Bible refers to the way God is related to our vulnerability – this differs completely from how our disability is related to other gods. The Bible teaches us to enhance life and love our neighbour. We project our understanding into God. Our perceptions of strong and able people are also projected onto God: God almighty (this projection is a first big mistake). (b) Our second mistake is that we project a kind of knowledge and knowing into this God. We also want a kind of reason/principle (immutable-) involved so typically of Greek philosophy. This is thus also projected into God and, therefore, God becomes an omniscient God, an all-knowing God.

According to the presenter, the challenge to him as a theologian is to work with the Bible, but also with his own context. It is important to ask how the two relate. For this the presenter had to select some biblical texts and had chosen two texts, both from 1 Corinthians. The first (1 Cor. 1:25) refers to the foolishness of God (unlike the Greek gods, the God enfleshed in Jesus Christ is not perfect). Christ is related to an imperfect God. According to the verse "... the weakness of God is stronger than man" (in the Greek weakness here is *astinea*, which refers to weakness in all its forms also physical weakness, illness etc.). The other text chosen is 2 Cor. 5 which states that for our sake God "made Christ *to be sin*". God did not play weakness-weakness/disability-disability he was *truly* weak and disabled, not as pure and perfect as we usually see God (hence the "puffing God in the wheelchair" in the title of this presentation). Suffering, disability etc. are normal parts of the structure of this reality in which we find ourselves. According to the presenter, in a pastoral hermeneutics one needs to introduce the notion of a suffering, disfigured and handicapped God. In this regard one needs to deal with the vulnerability of a crucified God (*theologia crucis*). Because of God's identification with our suffering on the cross, the cross reveals the weakness and vulnerability of God. The cross is about stigma, impairment, disfigurement and

disability. Paul argues for the weakness of God in terms of a theology of the cross (1 Cor. 1:25). The cross is a theological reflection and a fundamental critique, even a protest and lament, on woundedness, weakness, disfigurement, ailment, vulnerability, marginalisation and stigmatisation.

Furthermore, one needs to move away from all-knowing to not-knowing realities – this is necessary if we want to link God to our realities of suffering and disability. This is what we see in the parable of the prodigal son; the father did not know the son was coming back. When God calls out to Adam and Eve: “where are you?” we find a God that is not all-knowing. Within the framework of the New Testament, the notion of “*el Shaddai*” is displayed and portrayed by *ta splanchna*. Power is virtually enfleshed in the bowel categories to describe the power of God as passion. *Ta Splanchna* reveals God as a Presence, a companion. In general Greek *to splanchnon* refers to the valuable parts, the heart, lungs, liver. Within the messianic context of Christ’s salvific mission, *ta splanchna* expresses compassion as an indication of God’s divine involvement with the human predicament of suffering. The bowel categories of *ta splanchna* should be understood as kind of ontology of space. The Father’s grief about the predicament of the prodigal son created a space of encounter; it created a space of hospitality; to come home and be accepted unconditionally for who you are without fear for rejection. This space of encounter was demarcated by the fidelity of the Father. The faithfulness within a theology of the intestines of God demonstrates the intention within the praxis of compassion, namely the mutual exchange of pain and grief. The grief of the Father is the pain of loss; that of the son is the pain of shame and remorse. Within the shared space of mutual exchange, making room for another, the being qualities of each are acknowledged and affirmed. And this is exactly what a compassionate theology of affirmation is about: respecting and affirming the vulnerable presence of another enough to abide with them faithfully that they are not alone.

Disability is not a fault, a mistake or a tragedy that has to be overcome by the individual with a kind of curative medical model. Disability is a reality of our being human within the vulnerability of life. With regard to a theology of the intestines, disabilities should be embraced as part of an affirmed being. Bowel categories designate hope as a new state of being beyond the limitations of disabled categories; it describes a spiritual ability within the new reality of *parrhesia* categories: the boldness and courage to be.

5.9 Prof. L. Juliana Claassens: (Department of Old and New Testament, Faculty of Theology, Stellenbosch University)

Job, Theology and Disability: Moving Towards a New Kind of Speech.

In the Book of Job one finds a classic example of a person moving from able-bodied privilege to disability by means of debilitating disease. This series of tragedies cause Job to become an outcast, alienated from his family/friends and relegated to the outskirts of society. Throughout 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 disabilities in today’s society have

to face – religion and theology quite often playing a negative role in transmitting and sustaining such harmful views.

In the Book of Job, though, one sees glimpses of a counter narrative that moves toward a new kind 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 rooted in values such as human dignity, inclusion, and hospitality.

- 5.10 Dr. Margaret Wazakili: (Post-doctoral Research Fellow, Stellenbosch University. University and Research Associate, University of Dublin, Trinity College, Centre for Global Health, Ireland)

Asexual Beings: Reflections of Young Women with Physical Disabilities.

What makes people say or feel that they are asexual beings? How do they reflect on it and put it into words? People with intellectual disabilities especially have often been accused of sexual deviance, but are also often the victims of sexual abuse.

Negative attitudes toward disabilities sometimes deny that those with disabilities have feelings. People want to see them as asexual since they are seen as being sick and unfit for sexual activity – especially when a person has a physical disability since sex is very physical thing and as such sex with a person with disabilities can even amount to cruelty! Child-birth too is believed to be the domain for women without disabilities. The legal emancipation of persons living with disabilities did not amount to their sexual emancipation as well. For many in Africa, this also means they cannot marry because they are seen as unable to have sex and, because many Africans hold very strong views against sex before marriage, if one cannot marry one cannot have sex anyway. Thus, according to many, the language of pleasure and desire should not and does not exist in the context of those with disabilities and young women with disabilities are torn between expressing their real need for affection, a sexual identity and sexual fulfilment in a society where culture and religion prohibit sex before marriage or for single women. Young girls with disabilities are kept in the house cannot be taken out by someone. They are also not expected to be beautiful and sexy. Furthermore, it is felt that since girls with disabilities are unattractive, not interested in sex, and will never marry, they do not need sexual education.

The presenter then shared some of the reflections from girls with disabilities that she has worked with regarding the issue of sex and sexuality.

One respondent complained that in African society sex only spoken of by and between adults. Another said that she was getting conflicting messages: she is a young woman and a sexual being, but as a woman with a disability she is seen as an asexual being. How is she supposed to choose between the two – could she not be both a sexual being as well as living with a disability? Another respondent pointed toward beliefs among certain Africans include the belief that engaging in sexual activity with a woman with a disability will make one rich and in view of that asked whether she thus is some kind of medicine prescribed by a sangoma? According to one respondent, a women in wheelchair, she has to be put to bed and cannot get up to close her bedroom door so anyone can come in and have

sex with her because her family does not protect her, they have, in fact, ostracised her. The marginalisation and exclusion of these women from communities are known to have resulted in them being used by various men in their communities for their own sexual gratification.

- 5.11 Elizabeth A. Martiny: (Jungian analyst and private practitioner, Johannesburg, South Africa)

Physical Disability. An Interdisciplinary search for Meaning: applying Feminist Theology and Analytical Psychology of CG Young.

Elizabeth A. Johnson, prominent feminist theologian, poses the question of what is the right way to speak about God. My question focuses on what images of God are prominent in those with a physical disability and how they influence self-concept and the sense of belonging in groups, including the self-confidence to contribute to society.

The paper employed an interdisciplinary perspective. Feminist Theology and the emerging Theology of Disability emphasize the importance of body, in addition, they reinterpret the meaning of perfection and suffering in understanding who God is and who we are in relationship with God. These are all relevant issues for those with disabilities. The Analytical Psychology of CG Jung offers an interpretation of images of a spiritual nature. Within both disciplines the physically disabled condition is not primarily considered a pathological burden, instead it is seen as a vehicle to bring about transformation which can result in psychological and spiritual transformation. Jungian tools, like active imagination, dream analysis, and image-work, enable those with disabilities person to creative express his or her disability for personal integration. In turn, imagining new self images can open up creative possibilities for interacting with others in the world. For example, the theme of “The Wounded Healer” provides a positive image of the disabled condition and can motivate persons with disabilities to expand their contribution to others.

This paper demonstrated with examples the interface of these two disciplines in understanding images of God of persons with a disability, for personal development and for the benefit of society.

DAY TWO: Thursday 19 May

1. Prof. Thomas Reynolds: (Emmanuel College, Toronto, Ontario)

Theology and Disability – Changing the conversation

Disability disrupts easy reassurances. The term is often used to signify that something is missing in a person, that something is present that makes one less human and these views touch on culture, on religion etc.

The speaker refers to his twenty-year-old son, Chris, who suffers from bi-polar disorder, obsessive compulsive disorder and is autistic. However, Chris’ way of being in the world is also a thing of beauty, he precious in his own way. Once talking to a

group of his students on the theodicy question the presenter realised that he has been on the wrong path the whole time. He has been thinking of Chris as someone with something missing, he presumed his condition was less than ordinary and he was suffering. The presenter realised that he had to reorient own perspective, not only on Chris, but also on theology. He realised that he would have to square the theology he was teaching in class with his relationship and experience of his son.

Encountering disability challenges our presumptions of disability: that it is “a cross to bear”, an opportunity for God to heal, a lesson for abled bodied people. These perceptions reduce people with disabilities to their disabilities and these perceptions are even found in biblical texts: disability is not normal, it is deviant. But what is disability and what is normal?

What we need is a change in the way we talk, in our conversations about disability. The presenter then makes some suggestions toward this. First, however, he notes that changing our conversation also implies changes to the way we act, changes to our practices. What we say influence the way we act. The speaker’s relationship with his son challenged him (the speaker) to change his conversation on disability. Our faith communities ought to be centres where this could happen. As the point of entry into a relationship with God, the body of Christ should not be barrier to community and to God. Words create barriers: blind, deaf, cripple. This diminishes the genuine humanity of people with disabilities when they are reduced to their disabilities. This access barrier is unjust and denies God’s presence amongst us.

So, how to change our conversation? In three ways:

- a) We have to move beyond seeing disability as a problem.
- b) We have to move beyond disability as something other than us (“our” idea of what is normal – who is the “us”?). We have to move from an “us” that “do for “them”.
- c) We also have to move away from seeing disability as something to be accommodated and tolerated, but rather towards relationships of mutuality.

With regard to:

- a) It is crucial to move away from seeing disability as flaw and tragedy, and equating it to reduced personal fulfilment, to not being able to be fulfilled on one’s own. Our culture makes caring for others a personal thing, the responsibility of families and not a systemic phenomenon of our culture. Disability to large degree is a social construct since it focuses on what a community values, what they see as normative and “normal”. Society disables. There is thus more at stake here than the abilities of individual bodies. In the same way the tem “impairment” / “impaired” body is a social construct and also reduces personhood to a person’s body.
- b) What is meant here is that we should move away from seeing disability as something which has to be “included” into us as if our society is noble and inclusive of “those outside it”. Such views contain the paternalistic issue of exclusion even if it endeavours to be inclusive. There thus is a problem with how communities “include”.

We have to deconstruct our views of what is normal and abnormal. Our vulnerability opens us up to something different: all of us are born, live and die as beings that need each other. Our mortality binds us to each other. The key in vulnerability is that we are exposed to others within a web of dependence. We have to challenge the “cult of normalcy”. We are brought up with certain values and later accept this as standard – e.g. the athletic sculpted body of the male and

the thin body of the female, the ability to think rationally, the ability to act independently. The cult of normalcy results in what we include and exclude in our community, what we exclude sometimes defines the identity of the (our) group and our language also reflects this.

However, human beings need each other. Mutual dependency is a fact of human existence and it runs contrary to our ideas that power and ability is dependent on our abilities. According to North American theologian Stanley Hauerwas our greatest strength is precisely the realisation that we are dependent on others and that we flourish within communities, that we need each other to become ourselves.

We come to judge the different and the strange as flawed, we want a scapegoat and this is also result of our fears, of the realisation of our own vulnerability and weakness. Thus, what often binds a group together is their sense of weakness/vulnerability and we then project our own vulnerability onto others and cut ourselves off of our own source of flourishing, mutual dependence. According to theologian Jürgen Moltmann a person with disability shows us what is most human to us: vulnerability is something we all share. It is not limited to certain classes, places, religions, etc. The same goes for suffering, joy, etc. The fact of the matter is that the line between giving and receiving/ in and out/ normal and abnormal/ able and disabled begins to blur when we start to think in terms of vulnerability.

Disability calls on us to recognise our own vulnerability. To live is to be vulnerable, this we see in Jesus Christ. Here God reveals divine compassion. Our redemption is a welcoming act of God and we share the radically inclusive love of God. Christ's body remains scarred after resurrection and in a similar way transformation does not do away with disability, but opens us up to others and our mutual vulnerability. Wholeness is not self-sufficient independence.

- c) The third shift in essence refers to compassionate respect (more speaking on an ethical level here). Compassionate respect pays attention of both equality and difference. Equality does not mean we are all the same. The difference is not deviancy or abnormality, but something that contributes to our communities. This is what it means to be church and community as well – being compassionate *and* making room for difference. Compassionate respect – difference and equality – seeing difference as a gift, the “gift of difference”, a gift towards our lives together. Differences here becomes a teacher: what can we learn from each other within a wider “we”? This does not mean one is romanticising disability, seeing others as “special”, but simply acknowledging the mutuality of our lives as gifts to ourselves.

2. Gubela Mji: (Director and Senior Lecturer, Centre for Rehabilitation Studies (CRS), Faculty of Health Sciences, Stellenbosch University)

The integration of disability concepts in teaching and learning in Higher Education Context.

The Centre for Rehabilitation Studies offers unique post-graduate programmes (Honours and MSc/MPhil) in the rehabilitation field to health professionals. Applicants are persons who are doctors, nurses, speech and occupational therapists, physiotherapists, social workers, etc. The approach is interdisciplinary, with emphasis

on development of leadership skills to facilitate development, management and evaluation and research into appropriate and cost effective rehabilitation and disability programmes. The Centre for Rehabilitation Studies is a unit of Stellenbosch University that offers opportunities for postgraduate study/research regarding rehabilitation. One aspect of the work of the Centre is the development of enabling curricula and learning environments for people with disabilities. The presenter then explained the in which this conference and the work of the Centre for Rehabilitation Studies fits into the HOPE Project of Stellenbosch University.

What is disability? This is a very complex phenomenon and defies easy definitions and easy models to explain it. However, all of us find ourselves on a continuum in life. Many factors can influence where one finds oneself, and some factors may cause one to be classified as “disabled” while other enabling factors might move you up on this continuum despite being classified as disabled. Society often excludes and impairs people and in this way society itself often disables people. The presenter then gives an overview of disability activism with reference to different statements and declarations, by for example the United Nations, since the 1980s. In all of this those living with disabilities say: nothing about us without us. They want to be part of these activist activities.

With regard to disability activism the presenter then highlights three important factors:

- a) The need to adopt a rights-based vision to guide such activism. Rights here refer to all kinds of rights – economic, environmental, political, cultural, social etc. When one speaks of these rights one must also speak of disability and the relationship between them. A rights-based approach demands that attention be given to vulnerable groups.
- b) Networking. There is a need for more activists. One should find out who can help one and how. Greater co-operation is also needed among different role-players.
- c) Must be positive – we should reflect on what has worked and what has not, count successes and acknowledge failures.

For the above conscientisation programmes are needed. The presenter explains by way of three case studies: 1) A pastor in a township in Cape Town wanted people with disabilities to attend his church. The CRS visited church and spoke to church council who then invited a pastor with a disability to speak and they held a conference on attitudes towards disabilities with an eye to integrating people with disabilities. 2) Another case is that of a young man who was involved in an accident is now in a wheelchair. Since his two sisters now had to help him, his mother repeatedly stated that they were now the “men of the house”. This shows insensitivity and amounts to humiliation, especially in Xhosa culture. The situation only grew worse when the man was awarded R75 000 compensation and could thus make a contribution to his family’s livelihood, but he lawyer kept finding excuses to hand it over. Such conduct shows that the latter clearly has no awareness of the financial and emotional situation this young man is finding himself in. (3) However, there are also success stories, such as one of a man living with disability who achieved much even though his father had difficulty accepting him. According to the young man, the reason for his achievements was his mother’s constant support and confidence in him. This shows what can be done. With regard to teaching and learning about disabilities there are many challenges but also many opportunities. We need to work together with others; we need a social contract with the

community and build communities of trust in order to overcome these challenges and make the most of the opportunities.

3. Prof. Anton van Niekerk: (Department of Philosophy, Stellenbosch University)

Disability and biomedical enhancement: conflict or co-existence.

Medical advances and enhancements are often not welcomed by people with disabilities (only think of the terrible experiments done in Nazi Germany such persons). It is felt that – underlying the idea of biomedical enhancement is that those with disabilities are abnormal, not wanted.

The presenter wanted 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, and disability are not irreconcilable concepts. In fact, much of what happens on the front of the development of new enhancement technologies, also of a biomedical (including genetic) nature, confers significant relief-possibilities on the plight of some people with severe disabilities. 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, debilitating or discomforting, does not imply any rejection of the individual people who live with these conditions. Motives for such enhancement are often morally and theologically grounded. Philosophically speaking one may say that there is a commitment to do good. Theologically speaking medical enhancement might be seen as part of a process of cosmic renewal and termination of suffering.

Disability itself remains a difficult term to define. A *medical definition* would be that it refers to a malfunction of part of a person's body or mind. *Social definitions* of disability may differ depending on the society. 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 (where there are, for example, all kinds of accessibility to people unable to walk this inability becomes much less of an issue). However, not all disabilities are social constructs and some cannot be cured – a blind person cannot appreciate a beautiful sunset, a deaf person cannot hear music and a lame person cannot climb stairs. In philosophical terms disability, unlike, for example, social constructs such as skin colour, refers to a condition only becomes a disability when it prohibits us from flourishing, from fulfilling our full potential. The presenter uses the following definition of disability: *disability is a physical or mental condition, characterized by significant functional impairment that someone has a strong rational preference not to be in.*

By “biomedical enhancements” the speaker refers, following a definition of Allen Buchanan, to “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”. Enhancement is an inherent characteristic of our species – we have always impinged on our natural abilities to enhance ourselves – glasses, the ability to read and write etc. are all forms of enhancement/improving ourselves. Inherent quest for perfection and improvement ourselves is part of us.

When one talks of biomedical enhancements one must remember that all inoculations and vaccinations are also enhancements of our natural abilities and no one will want people to be denied this.

But what is the relevance of enhancing for people with disabilities? The presenter explains this by way of case study, that of the PGD-technique (Preimplantation Genetic Diagnosis/ testing) and the choice made by deaf parents to choose whether to have a deaf child or not. This test amongst others shows whether a child will be deaf or not. Several embryos are created outside the body of the mother and one is then implanted to grow and develop into a baby. Sometimes deaf persons would prefer a deaf child, to ensure their child is deaf as well, to be part of so-called deaf culture. They expressly desire a deaf child to be part of their deaf world. The question now is whether there are any underlying moral problems in such a case? Does this result to a preventable harm to the child? When an embryo that will be born with the hearing function's hearing function is intentionally impaired so that the child will be born deaf (when embryo is harmed in order for it to be so), then it becomes serious moral problem. But if a "deaf" embryo is *chosen* amongst other "hearing" embryo's to develop then you are not harming the embryo. That is something different. Deaf parents will say it is the same as choosing between boy and girl and which is a choice often made by way of PGD. The baby thus not harmed, unless it can be argued deafness is such a terrible condition that it is unacceptable to bring such a child into the world, an argument few will say is valid. What one needs to be reminded of is that should the parents choose differently the child may become part of two worlds. He/she can learn sign language *and* hear, while the deaf embryo will not have this choice. The availability of cochlear implants today again changes the issue. Can the parents deny the child such an implant? Can they refuse it? The measure is the best interest of the *child*, and most will say then it is in the best interest of the child to become part of both the deaf and hearing world. According to the presenter, cochlear implants are clearly beneficially enhancements. This also serves as a good example of how enhancement technology can significantly improve the lives of people and that not all forms of medical enhancement should be frowned upon.

4. Wilhelm van Deventer: (Pastor in the Uniting Reformed Church, Potchefstroom)

Carefronting disability issues in the South African Labour Market.

People with and without disabilities experience the same challenges in the SA labour market, but the latter experience additional challenges and also unique challenges.

The presenter positions his contribution within a "theology of involvement" (pastoral involvement, pastoral community, prophetic judgement) and "carefronting" (caring enough to confront). The latter refers to caring and in this way also to be prophetically critical and confronting.

Various South African pieces of legislation, including the South African Bill of Rights and different labour laws, especially the Employment Equity Act provides for affirmative action on grounds of race, gender and physical disability. This policy is aimed at rectifying imbalances in the South African labour market. However the focus has thus far been on race and gender, while disability lags behind. According to the South African Labour Guide there is a 0.9% employment of people with

disabilities which in September 2010 declined to 0.5%, showing that numbers are in fact dropping.

How should this be addressed? The presenter identifies three problem areas:

1. What exactly is disability? How do we define disability – many views exist on what constitutes disability and this complicates the issue.
2. Absence of sufficient information from where to bargain with the public and private sector. The presenter mentions that for this paper alone he asked for relevant statistics from four different sources (including the Department of Statistics and the Society for the Blind and Labour Department) only to find four different figures. Such uncertainty has implications for the bargaining power of those living with disabilities.
3. The issue of recruitment: reasons given by employers why people with disabilities are not recruited include that they do not have the necessary facilities, cannot afford to make changes to accommodate them, and thirdly there are very few people with disabilities out there that have the skills/training they require. Regarding the first reason for non-recruitment (accessibility): This is about more than access to a building. We talk about reasonable access to offices, the offices of others, toilets, cafeteria etc. The second reason (not enough money/ too expensive to change): One only needs to ask how much is being spent on the company's end of year function to put this objection into perspective or what the possible financial implications (fines) will be for not complying with labour legislation regarding employing women, people of colour or with disabilities. The third reason is something that should indeed be addressed. It concerns issues of not only advertising the skills of the disabled but also access to training at universities and other institutions of higher education. At the same time this will help toward ending discrimination in the workplace, e.g., the view that a person in a wheelchair can only be a typist or receptionist, or that the visibly impaired can only work on a switchboard. This will prevent people with disabilities from only being found in lower categories of employment (the biggest decline in employment of people with disabilities is in the professional realm!), and fight the perception that they are only suitable for certain kinds of work.

5. Dr. George du Toit: (Gynaecological Oncologist, Stellenbosch)

Enabling the 'disabled' medical fraternity: Perspectives on the impact of medical training in the approach to the disabled.

Most of society do not even understand what is disability, how to define disability. Furthermore, widespread prejudice exists against disability. Recently the former Springbok rugby player Joost van der Westhuizen was diagnosed with motor neuron disease, a similar condition that Stephen Hawking, English theoretical physicist and cosmologist suffers from, thus dispelling a first prejudice, namely that those with disabilities are all stupid. This is clearly not true. Disability is also usually viewed as something negative and described with negatives (in Dutch, for example, as *onbekwaamheid* and in German the disabled are referred to as *Invaliden*).

Disability is a complex phenomenon. There exist different medical and social models of what it is (about 5% of the population live with disabilities) and the medical fraternity is often the first point of entry/contact with disability. The speaker

comes from the so-called medical model. Social models define disability according to society's expectations. Impairment is societal judgement not a medical one (both blind and seeing may wear glasses – but both are not viewed by society as having a disability). From the social side heated debate cautioning medical society not to keep medicalising disability, not to “keep it in the medical sphere”.

The presenter refers to research done with regard to attitudes towards those with disabilities people in which the medical profession fared very bad. Health professionals generally have, according to this study, bad attitudes toward those with disabilities and nurses, the worst of all. According to one study, conducted in 1989, not even occupational therapists showed a positive attitude toward people with disabilities! The medical fraternity thus has a far way to go. However, in another study with health workers participating in disability sensitizing the results showed better attitudes and these attitudes continued over time.

However, there is also a new approach among the medical fraternity, namely to see the patient as a whole person, and not only to focus on the patient's illness. What are the expectations of patients of the consultations? This is an important factor. The doctor is not only expected to give a diagnosis, but should also understand the patient's context. To explain this, the speaker uses an example from within the speaker's own field of experience, when a woman comes to gynaecologist for check-up for the first time in ten years, he *has to ask, why?* This might be because a neighbour or close family member has been diagnosed with breast cancer recently. If the doctor asks her why she came for the check-up she will tell you this. If not, then she will not and the doctor will have failed her, missed the point of her consultation. It the same with people with disabilities – health practitioners should do not only see the disability, but should also look past the disability to the patient as a whole person – not everything that goes “wrong” with such a person is related to his/her disability. For this reason medical training must pre-empt health care as patient-centred, according to a care/patient-centred approach and not according to a purely bio-medical approach (“Have you seen the liver in ward 5?”). This is dehumanising to people but, unfortunately usually also what people expect of them!

6. Panel Discussion: Students from Stellenbosch University living with Disabilities.

Tatjana Metzger is an undergraduate student. She studies primary education and admits that being a student with a disability at Stellenbosch University is rollercoaster, sometimes up and wonderful, but also sometimes leaving one down and in despair. Thus, it is difficult, but not all bad. Tatjana is a cerebral palsy sufferer due to injuries he mother suffered in a plane crash 7 weeks before her birth. She recalls that it was difficult as a child to make people realise that she does not have intellectual disability – those with cerebral palsy often do not. After a time attending a school for children with cerebral palsy in Cape Town, Tatjana, whose parents live on a farm in Namibia attended an ordinary school in Namibia and had to live in hostel, something that presented challenges of its own. Even coming to University in 2007 it was very difficult as not everyone understood her needs. By March 2007 someone actually suggested that she should rather leave and do something else. However she stayed, since on application form it was asked whether she has a disability and she stated that she has cerebral palsy, so she was adamant: “You cannot accept me and then deny me the right to study.” Tatjana was sad and angry, but stuck it out because of a strong sense of what is wrong and what is right.

Regarding problems she has to face with her particular disability, Tatjana mentions physical access (she cannot enter her faculty like others can from the front steps); the appreciation factor of her disability (she cannot open doors with electronic reader as it is sometimes too high with for her when on her scooter or in her wheelchair). However, this makes her grateful for small things, like doors that open or to find a parking space with enough room to take out her wheelchair. One should also start small and fix that which is wrong bit-by-bit. Finally Tatjana believes that having a disability also adds an educational factor to her being a Stellenbosch student since she teaches people about disability by just being herself!

Ntsakisene Mashele since birth has only had 10 to 30% vision, she is colour blind and cannot see detail. She hails from Limpopo then went to the school for blind in Worcester. It was a challenge for her simply to get people to understand that she wants to and was able to study occupational therapy. Some people told her she cannot do occupational therapy since it is for seeing people only. When she got to Stellenbosch she was eager to partake in all she could. She partook in initiation, but it was difficult to integrate in the beginning, especially socially. However, now she has many friends and is totally integrated socially. She also realised when at Stellenbosch that to be visually impaired very expensive. Challenges? First of all mobility – getting to her faculty across campus. Ntsaki also had to learn getting by at Tygerberg – she thus had to get to know two campuses (Stellenbosch and Tygerberg). Accessibility is also a problem. She tells of a test she had missed because she did not see that the question was written on the board and did not realise that the test had started. Accessibility of modules is another challenge. Ntsaki tells of her experiences during a practical class in biology, when she could not see the chicken carcass she was supposed to be dissecting and which other people take for granted. These experiences makes one realise that society needs to know what a disability is about and the influence it has on a person's life. People should be encouraged to ask person with disabilities what it is like to have their specific disability and what the impact of it is on his/her person's life.

According to *Michelle Nell*, a music student at Stellenbosch University it is important in disabilities studies to enquire into life-world of those living with disabilities. Others may never fully grasp her life-world, but they can try to understand it. Michelle was born with glaucoma. Immediately her parents asked, why our child? Michelle also asked, why me? She tells of also bargaining with God: if I live a moral life, can I please see in the afterlife – even now perhaps? She has experienced all kinds of radical healing rituals. It is difficult, when a pastor asks whether you believe God can cure you and you answer yes, and wait and wait and nothing happens. Then depression sets in – one realises one will not have the same life as one's peers. After a period of anger, one accepts one's condition. Michelle attended the Pioneer School in Worcester. At school everybody were acquainted with one's needs and one's needs are catered for. At university level Michelle's experience has been that lecturers were very accommodating and eager to learn from her about her needs and condition. She found that admitting a blind person to university was not a problem, but that participation part is more of a problem. As a music student she finds it costly, for example, to have music printed in braille. She realises that life is not only about what one wants, it is also about compromise. She has learnt from early age that one has to develop one's memory well if one is blind, as well as one's sense of hearing and

touch. Finally, according to Michelle, the student also has a responsibility to communicate more effectively, to work harder. It is important to focus on the negative points of the life-world of being blind, but at some point one has to start working together with others to not stay in one place, so that we all move on together.

6. Parallel Session:

6.1 Dr. Gerrit Brand: (Department of Systematic Theology and Ecclesiology, Stellenbosch University)

Teologie, taalgestemdheid en menswaardigheid.(Theology, language disability and human dignity)

This presentation is the result of the work of the association the presenter belongs to, i-MAG (Multilingualism Action Group) and which promotes multilingualism, amongst others in education, public broadcasting, and in the civil service. Members include speakers of most languages spoken in South Africa, including sign language. Before the speaker's own involvement with i-MAG he, like many others, did not really think that the deaf can speak. He was under the impression that sign language is simply the transcription of other languages and not that it is a language in its own right, with an own vocabulary and that speakers of sign language constitute their own language community. The speaker also realised that sign language can be creative, like other languages, a thing of beauty and of efforts for it to be recognised as the 12th official language in South Africa. At the same time the speaker realised that members of other marginalised and endangered languages also in a way are members of "disabled communities" and that the lives of *all* people are marked by disability although not all are defined that way (the inability to write with one's right hand, which the majority of people do, is not considered a disability...). This once again shows the extent to which disability is a social construct, a function of how societies work. An individual or group without cultural or intellectual capital necessary to function in a meaningful way within society and that has no realistic chance to obtain such capital, in essence find him/her/itself in a similar position as someone with a physical disability. However, such people seldom enjoy the same rights as those with physical disabilities.

Part of that what is often associated with indignity is social exclusion – also of language communities and the disabled. In this regard themes such as dependence and vulnerability are important – this is all part of the *imago Dei* reflected in humankind. We should not deny our own vulnerability and interdependence as if this denies us our dignity since it is God that bestows dignity on us. We answer on God's love by loving all the works of His hands. As human beings we ourselves exist within relational contexts, contexts characterised by vulnerability and interdependence. Our vulnerability and interdependence as reflections of the *imago Dei* should create societies marked by dignity, empowerment and friendship and the Church should never accept the denial of the dignity as inevitable. The Church must reflect the fact that an alternative exists and must also constitute such an alternative community.

6.2 Tim Stones: (Researcher with the National Institute for the Deaf, Worcester)

Hearing God Speak: A Critical Reflection of Mark 7:31-37.

Mark 7:31-37 talks of how Christ heals a deaf man, and enables him to speak in an audible voice, free from impediment. Some churches, particularly Charismatic denominations, interpret this passage as a literal call to “heal” the deaf person of his inability to hear, so that the deaf person can hear the Word of God, and thus receive redemption.

But is this really what this passage is saying? A closer inspection reveals that it was not the deaf man who came to Christ completely of his own accord, but rather “some people” who, for whatever reason, chose to bring him to Christ to be healed of his deafness, the story does not say how the man felt once he was no longer deaf. It is, in my view, significant that the passage indicates that it was the people in the crowd who spoke of the miracle to others, and gives no indication whatsoever of how the man at the centre of the story felt now that he could hear.

Perhaps just because he could hear does not necessarily imply that he could understand. Mark 7:31-37 in essence asks us to define what it means to hear the Word of God. Even those who can physically hear may be spiritually deaf to God’s word.

The presentation explored the meaning of hearing God’s Word, and sought to define the role of the Church in contemporary society with regard to the inclusion, or further marginalisation of people who experience hearing loss.

6.3 Prof. Nico Koopman: (Dean, Faculty of Theology, Stellenbosch University)

Hope vulnerability and disability. A theological perspective.

The speaker first offered a nuanced description of vulnerability. The latter is described in terms of the threat of unfulfilled needs. Humans always face the threat that our physical, social and spiritual or teleological needs are not 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 are discussed, namely anxiety and hope.

The three forms of anxiety proposed by Paul Tillich are discussed as ways in which we deal with vulnerability. Our physical vulnerability is accompanied by the anxiety of finitude and death, and our social vulnerability by the anxiety of guilt and rejection, and lastly our teleological vulnerability by the anxiety of meaninglessness and purposelessness. Over against anxiety as a way of dealing with vulnerability, the Christological hope of the heavenly solidarity of the cross, and the expectation of renewal of the open grave, is suggested as a faithful response to vulnerability. This hope is portrayed as realistic hope, active hope and resilient hope.

6.4 Dr. Tsitsi Chataika: (Postdoctoral Research Fellow, Centre for Rehabilitation Studies, Stellenbosch University)

Cultural and religious explanations of disability: A call for a rights-based approach to fostering of inclusive communities.

Our culture is the mirror in which we see the world, make sense of it, and ultimately influences our behaviours and interactions. Religion also plays a significant role in a culture. Religion and belief systems are dominant shapers of culture and many traditions, practices, stereotypes, hopes and fears of a community. To discount the power of religion on a culture is to ignore a fundamental part of that culture. Religion and culture provide explanations on why some people are disabled, how people should treat disabled individuals, and what rights and responsibilities disabled individuals are either entitled to or deprived of.

This presentation explored the relationship between culture, religion and disability; how people explain the occurrence of disability, and ascertains how communities respond to people with disabilities. It is from this understanding that I will ascertain various ways in which communities explain the presence of disability, which in many cases leads to segregation, isolation, stereotyping, blaming, pity, deprivation, and being 'special'; thus undermining the rights of those with disabilities enshrined in the United Nations on the Rights of Persons with Disabilities.

In conclusion, there is a call for a rights-based approach to understanding disability with the intention of fostering inclusive communities.

6.5 Isabel Murray: (IPSO – Institute for Psycho-Social Development)

Moving from dis-abling to en-abling: an equal partnership approach in working with people with disabilities.

The speaker is a social worker and shares some of her experiences by taking her cue from the day to day experiences of a father living with disability who has a child who has a disability and the former's view of to moving "from disabling to enabling".

In the speaker's own experience doctors, teachers and even social workers are often uncomfortable working with people with disabilities. And, even though disability has been with us forever, but each generation has to learn how to work and share with people with disabilities.

According to Nancy Lane, an author who is herself living with disability and with a ministry focusing on disability, it takes great faith to live with disability "because they [those living with it] live marginalized lives often far removed from work, church, marketplace... I did not need healing from my disability, what I needed is healing from the negative attitudes and responses of others and, like most of us, needed healing from the hurts that life may bring to any of us." Others with disabilities may feel living with disability opened up new perspectives and new spaces in life for them. They believe in a life without limits.

With the above in mind the speaker and her colleagues created a new way of interviewing for persons working at a centre for persons with disabilities. One needs to begin with the parent – "why do you want to see me today?" Then, "what I am going to do?" Then, "what is the background?" Then both parties plan the journey together. After they started using this method, the people working at the centre felt it really made a difference in their attitudes toward and experiences of those they worked with. Another empowering exercise the speaker and her associates tried was a game they developed called "Life without Limits". In terms of the rules of this game, participants were asked specific questions, such as: What are your dreams? What is your purpose in life? What makes you happy?, etc. The answers to the

questions then had to be *acted* out and the others then decide whether one can go on to the next question or go to jail. This is a great equalising game when those with and without disabilities play the game together, or when people with different types of disabilities play together. It shows one that we are all alike in important respects as well as that we are all useful within the group. In this way it helps one to look at others in different ways and to learn things from others that we never knew.

DAY THREE: Friday 20 May

(*Lewensruimte*, National Institute for the Deaf, Worcester)

1. Prof. Julian Smith (Vice-rector: Community Interaction, Stellenbosch University)

Professor Smit welcomes all delegates at the final day of the conference. According to him Stellenbosch University aims at making a significant impact on lives of our communities – especially the marginalised. The University works with knowledge and science and in this sense equipped to do so. Though it is not a welfare institution, it had decidedly deliberately to assist society to become decidedly better. Professor Smith is responsible for managing partnerships with other institutions and other structures in society. This joint initiative of the two Faculties (Health Sciences and Theology) demonstrates that the University also wants to be involved in rural communities. It wants to create hope (thus the HOPE Project), applying our knowledge and science to assist societies to create hope.

As a society we have to deal with a number of issues. One of these is issues from the past – memories and results of inequity and injustice of the part, also here in Worcester. We are living in a different age, also here in Worcester. There are opportunities for reconciliation, to peak out and learn from one another. When the Stellenbosch University thinks of disability at the University, it also thinks of compliance, human rights, using its science and expertise for the sake of society at large. Professor Smith expresses the hope that this conference at Worcester will become an important event regarding the issue of disability, that one will one might hear: “As was decided at Worcester”, “As was said in or as I learned that day in May 2011 at Worcester.”

2. Prof. Therese Fish: (Deputy Dean of Community Interaction of the Faculty of Health Sciences, Stellenbosch University). Apology on behalf of Prof. Fish for not being able to attend and to deliver her address “*Key points on Faculty Strategy direction*”.

3. Dr. HOFFIE CONRADIE: (Director UKWANDA Rural Clinical School)

Introduction to the UKWANDA RURAL CLINICAL SCHOOL

Dr. Conradie is a family physician at Worcester hospital, attached to US Faculty of Health Sciences, Stellenbosch University. He is also Director of UKWANDA Rural Clinical School.

Traditionally medical workers spend their training time at big hospitals attached to large education institutions. However, more recently views are changing and a new modelled has been suggested. There is a greater need to be trained by those working in the field. This because the majority of patients are not in hospitals,

but are served by primary medical institutions (clinics) and the nurses and doctors working there. Thus medical care workers in hospital do not get enough exposure to these kinds of illnesses. Training hospitals also are also becoming more and more super-specialised – experts and specialists work with cases that are not always relevant for doctors working in primary health care. Doctors, furthermore, see patients in hospital for a relatively short time only and not always over long periods and are often not in feeling with the context of the patient.

The imbalances in the distribution of health workers between urban and rural areas is a world-wide problem, as it the distribution of health workers working among the wealthy and among the poor. How can we address these inequities? Research has shown that students people from rural areas are more likely to return there – one must, therefore, make an effort to choose students (doctors and nurses) from rural areas. Another way is by training students *in* rural areas. Once again research has shown that the longer students are exposed to rural areas the more likely they are to return there. The Stellenbosch Faculty of Health Sciences has since 2002 tried to expose students to rural areas (currently only in Worcester and Ceres). All health science students have to spend two weeks of training in a rural medical environment (rural clinic or hospital). The Faculty realised that this short exposure might have a limited effect, therefore, students are encouraged to stay for longer periods via the UKWANDA Rural Clinical School. A couple of final year medical students also choose to do their final year at Worcester and Ceres hospitals. This happens under mentorship of superintendent of the hospitals. The students also write their exams also here. We, therefore, follow two educational models: one of rotation between different kinds of cases/wards with specialists (paediatrics, neurology, cardiology etc.) and another whereby two students stay for a whole year at Ceres hospital with only contact sessions in Worcester every Wednesday.

The students thus spend more time in context much more relevant for where they will end up and are exposed to the more common conditions patients are exposed to where they will one day work. More one-on-one teaching happens here – two- or one student per consultant instead of the usual six students per consultant at Tygerberg. There is also much more continuity with patients as they are seen more than once and over time. Since these students also live among the community where they work, they better understand their patients' lives and worlds and can thus provide much more relevant service. We hope the students will in this way also learn from the community; what it means to be sick in a rural community (access, for example, is often a problem). The students also do home visits and liaise with home-based care-givers.

This conference very important as the University is totally dependent upon the communities to make this kind of training possible. We use the facilities of the Department of Health, but also of the communities and NGO's for exposing students to the communities. We do not want to use communities for the training of students, but they have an important function of telling our students and showing them what it means to be sick in a rural community. This year six students will participate in this programme and next year in access of 20 students – not only doctors, but hopefully later also other health science disciplines.

4. Open discussion:

What are the needs of the community of people with disabilities to be addressed to be fully integrated into society?

This open discussion was facilitated by Claude Schroeder (Cape Winelands Municipality).

All participants were to choose a partner and discuss amongst themselves: What are the realities of those living with disabilities that lead to them feeling excluded from society? Each couple have to identify one reality.

Replies:

- Persons with disabilities do not really have a voice that is heard. There is a lot of talk and nothing happens. They are wondering whether their voices are indeed heard.
- When the community makes decisions about disability they do not always include people with disabilities. The latter are, therefore, not empowered to make decisions about themselves and can thus not fight for their own rights.
- We all have to deal with limitations, but often limitations suffered by those living with disability people are increased by economic the implications of overcoming their limitations.
- People with disabilities can do a good job and are capable of doing much and do it well, but have very little access to the open labour market.
- The ability of housing and the conditions of the roads creates mobility problems (the respondent was a blind person).
- People do not know how to handle or approach people with disabilities. Perhaps they are shy and, therefore, they do not know how to offer help or whether it will be accepted or not.
- Many people do have skills can still do certain forms of work, but are not considered, and this makes us (the respondent is a deaf person) feel bad about ourselves.
- Transportation remains a big problem in South Africa and even more so for those in wheelchairs. This makes it very difficult therefore to get around, to interact with others and leads to isolation.
- The visually impaired need, for example, bigger letter types and other forms of assistance – thus not only access to information, but appropriate access to information.
- People with disabilities need improved access to tertiary education institutions.
- There are many access issues in deeper rural areas – not only access to services, but also education, crèches, etc.
- Do we really know the needs of those with disabilities? Unless we go to the homes of people and see what they deal with on a daily basis we will never be able to address these issues. This is important because access for one person is not the same as the access issue for another person. We must then create a data basis and use expertise and resources together in a joint, concerted effort to address these issues. A proper assessment of needs and resources is thus crucial.

- People need to know more about disabilities and the needs of people with disabilities.
- Can students not also help NGOs?
- NGOs need support and funds from government.
- Working environments are also sometimes discriminatory against people with disabilities.
- Improved access to training for people *working with* people with disabilities

Claude Schroeder: *The Reality that faces Cape Winelands District Municipality (CWDM)*:

Amongst the 7 disability categories, the most prevalent in district is that of people with physical disabilities. Low public awareness cited as most pertinent issue faced by people with disabilities. There is also minimal employment of people with disabilities in the CWDM as well as insufficient funds allocated to service providers to address issues faced by people with disabilities. All of this creates a major threat to the well-being of the disabled in the CWDM.

The next part of the open discussion entailed delegates forming groups of 4 and looking at the above problems in terms of services, resources and policy.

Report back (one suggestion per group):

1. Do a community profile of each of the 7 disability categories (students might help with). This will at the same time be a process of raising awareness. Identify needs and work together (physical disability institutes with visible disabilities, hearing impaired etc.). With regard to public opinion, skills development etc., these institutes should work together with churches, universities, hospitals etc. Some institutes have no funds, others have millions. This is not fair and therefore one should not “build own kingdoms for blind, for deaf, for cerebral impaired” etc.
2. Partnerships should be formed with institutions such as the Stellenbosch University. There is also a need for appropriate legislation. There are gaps in legislation that excludes people at different levels. There, therefore, is a need for legislation analysis. Law students might help in this process.
3. Policy makers need to be knowledgeable of and exposed to the needs of those with disabilities. They, for example, need to know of the tremendous need for sign language interpreters.
4. Government services also need to be accessible and sensitised towards deaf or blind or disabled culture (There are, for example, no sign language interpreters at Tygerberg Hospital and one to explain to patients procedure, forms etc.)
5. Education is a priority. Policy needs to address access to primary education in rural areas for children with disabilities because education is the key to upward mobility. This includes the need for government financial support, for example towards mobility (how to get to school) and disability awareness (also important for parents to explain and motivate children that education is needed and important).
6. There is a Charter of Rights of the Disabled but not enough awareness and advocacy of these rights. Possible partnerships for this are universities, institutes for people with disabilities, internet, and churches.

7. One cannot start by looking down when formulating policies. Get information first from ground level and then start working up.
8. There is not enough protection for persons with disabilities. There is a need for an ombudsman to call government policymakers to task e.g. with regard to accessibility issues.
9. Rural areas are highly neglected. The focus should be on creating awareness not only with government but also among communities – only with awareness can we expect action. In rural areas it is also an issue of the affordability of things that may help those with disabilities. Thus access to medical aid very important, especially in rural areas where it is often completely non-existent.
10. Independence is important – how can we be helped? For example: how can the universities help blind persons with the development of electricity card that can tell one how much electricity is needed *and* that a blind person can actually load in the electricity meters.
11. Use churches/congregations to sensitise people to challenges of living with disability. Congregations are supposed to consist of compassionate people but able-bodied persons are often so afraid of offending that they feel uncomfortable around people with disabilities.
12. Why not introduce disability awareness in primary schools – life orientation classes and more contact between special needs schools and mainstream schools to promote this awareness.
13. Policies are not always very clear on who is responsible. “, for example, I know I have the right to voice my complaints to government, but at a meeting with government where I need a sign language interpreter, who responsible for paying the interpreter? Me or the government?”

Summary by Claude Schroeder:

Policy issues – have to do with National Government.

Resources issues – have mostly to do with provincial government. (Equity in funding is especially important).

Service has mostly to do with local government and issues – concrete specific issues (bad roads that impair mobility), accessibility of public service buildings.

Overall, and very important: there is a need for proper research to find out what are the needs and what are the most *important* needs (and where), what are the resources available and how is it utilised, where, and according to what criteria.

5. *Panel Discussion: Hans Reinders, Thomas Reynolds, Rachel Kachaje, Mzolisi ka Toni* – questions to be reflected upon:
 - a) How does an educational institute integrate students and staff with disabilities within the system?
 - b) What role does the religious community play in integrating people with disabilities within the area?
 - c) How should Stellenbosch University develop and sustain meaningful partnerships to address the needs of the community?

Mzolisi Ka Toni:

The speaker refers to the difficulties people have to define disability or how they should talk of disability. He admits that perhaps the way people with disabilities are referred to is a small thing, but reminds the audience of what Tatjana Metzger said the day before about the importance of small things, small gains, such as language. And we have to be honest with each other. One example, therefore, would be that some people here in Worcester, as was heard, work in institutions for “profoundly disabled” people. This “profoundly” divides, it elevates the disabilities of some above those of others. You cannot represent my issues because you do not understand it – in this way we undermine our solidarity.

Thomas Reynolds:

The speaker does not want to give answers to the specific questions above. However, he does appreciate references to “small things”. One word that we have often heard over the past few days is “integration”, the speaker prefers the term “access” since this is a process and not a point of beginning or ending, but a dialogue between those with and without disabilities. Real integration and access is a process of mutuality. Access presumes having been heard, welcomed, received by others and this presumes an attentiveness and openness to others. At this conference we have heard “addresses”. What if we should reverse this, if the “experts” are addressed (a moral enterprise)? This is what we experienced this morning. What would happen when people with disabilities address their communities in ways that call for responses, by telling their stories? There must be openness to horizons of experience, mutual addressing. For this we have to create a culture of reception where mutual addressing can occur and new relationships can be formed, also at universities.

With regard to religions – a) churches can help because they have access to resources that can galvanise and set in motion our imaginations in order to create new worlds, new horizons, transformation and change (at this conference we have seen such a sharing of resources within the university community – among different disciplines). b) Churches can also give a language of liberation and reconciliation. We need openness to language of freedom, dignity and reconciliation. Churches also have resources for genuine disagreement without faction and division.

Hans Reinders:

Professor Reinders tells the story of an occupational therapist that visits a client with a disability and sees on her bookshelf a book he has been looking for. When he asks whether he might borrow it the person stutters, astounded: yes, yes. Then tears appeared in her eyes. Asked why, she answered that this was the first time someone working at her home needs something *from her* or that *she* has something that the other person does not have. Our biggest need is to be needed – this is what the speaker often heard at this conference. One of the ways to do so is to stop using the “language of need”. To start to think and talk of people with disabilities not as people with needs, but people with abilities, resources if we want change and if we want all the suggestions made this morning to work. For people in the disability “industry” the question of how we can help those with disabilities is misplaced. We need a reversal of thinking. Therefore the question should be: what can people with disabilities do for *me*? How do *I* need *them*? If your society keeps telling you long enough you cannot, you at some time believe it. Empowerment is important,

but it does not mean *giving* someone power, rather it refers to *finding* our own power. The secret is indeed in the small steps. “Start where you are and use what you have.” It is the success in small steps that inspires you and empowers you to discover and use your own abilities. When we have the latter, then we can begin to fill in the answers to the above questions.

Rachel Kachaje:

a) At this conference delegates, many of them living with disability, had a voice, they have expressed their needs even if all has not been said. The first question above raises issues of access (curricula, buildings, braille, sign language etc.). When one finds solutions to these challenges one will have answered question 1. It, however, also concerns the issue of acceptance as equal members of communities. Thus it is also a question of equity. We differ (race is only one example of that). Art. 24 UN Convention on the Rights of Disabled People speaks of the right to inclusive education. What is expected of us in order to comply with this article? In many countries policies and legislation are inclusive on paper on paper only and is never implemented.

b) With regard to religious community we ask: treat us as any other. Not according to charity model as if we are people to be helped and treated. And help us to find our place in society; therefore, be welcoming to us. There are all types of people in churches from all walks of life and professions. Churches must seek out and welcome people with disabilities in their midst because we also want to praise God in church for what he has done for us.

c) This is a good start this partnership between US and disability institutions/associations such as this. We ask to be included and this will be to your benefit as well. For example, when you say it's expensive to cater for our disabilities, why not ask us our opinion when you build – not when it is too late when you have to demolish because you do not comply to building regulations regarding people with disabilities. If you included us from the beginning we would have saved you money, not cost you more.

Suggestion from floor: it does not sound as if there are any deaf students at Stellenbosch. Yesterday we heard that University of the Free State now employ one full time sign language interpreter and that person's time is shared between the 6 deaf students on campus. Is this not something Stellenbosch should consider?

6. Closure and way forward: (Gubela Mji and At Smit)

Rev At Smit gives a summary of both the challenges that were identified and the recommendations that were made by delegates over the past three days, especially during the sessions on the final day of the conference at Worcester. These will be discussed by the organising commission of the conference at a debriefing session which is to follow later and where the way forward will be discussed in light of the recommendations contained in this document. The document reads as follows:

Conference on Theology, Disability and Human Dignity

18 – 20 May 2011

The Way Forward

Introduction:

The faculties of Theology, Health Sciences and the Centre for Rehabilitation Studies of the Stellenbosch University, and participants from the disability sector, joined efforts over the past three days in a conference on Theology, Disability and Human Dignity to look into terminology, accessibility, awareness-raising and sensitization, and equal opportunities relating to study opportunities and interaction with people and communities with disability in society.

Recommendations:

- (1) A work group to be established to take forward issues and suggestions arising from presentations and discussions during the conference.
- (2) A reference group to be selected to ensure appropriateness and relevancy of draft policies, action plans and programmes.
- (3) A secretariat for the workgroup be appointed
- (4) the work group give attention to the following:-
 - a. clarify terminology
 - b. at least equal involvement of people with disabilities in future conferences as well as action plans arising from these conferences
 - c. content / curriculum of disability studies
 - d. include in early childhood development and primary education the support of parents to enrich parenting skills in raising their children with disability
 - e. include in curricula on all levels of education aspects of disability
 - f. listing of needs identified by conference participants, e.g. mobility matters, access to entire building and not just part of it, transport, interpretation preferences
 - g. needs assessment of persons with disabilities in rural communities involving municipalities and government departments
 - h. assessment of resources to address the identified needs appropriately keeping in mind the uniqueness of the needs of different disabilities
 - i. utilizing of knowledge, experience, skills etc. of people with disabilities in meeting training needs of service providers and students
 - j. sharing of resources between all stakeholders
 - k. research strategies to put theory into practice in a way that meet the needs of people with disabilities in rural areas
 - l. equal study opportunities for people with disabilities
 - m. join efforts with rural communities and NGO's for practical studies of students
 - n. accredited training for non-professional staff of centres and institutes e.g. in service learning programmes
 - o. explore opportunities for collaborative tailor-made training initiatives in communities

- p. join efforts in public education and training in communities regarding awareness and sensitization
- q. enter into memorandums of understanding with communities, organisations of persons with disability and service providers in the interest of people with disabilities in alignment with the United Nations Convention on the Rights of Persons with Disabilities
- r. issues of consent for treatment and admittance in hospitals
- s. co-hosting of conferences on an annual basis
- t. sensitizing and engaging (e.g. using disabled coaches, advocates, ect.) church communities and ministers/pastors to make it possible for people with disabilities to fully participate in all aspects and every level of church life (e.g. a ramp to the pulpit)
- u. continue to involve international experts in the conference
- v. look at the possibilities of establishing special interest groups for different fields and disabilities
- w. establish and maintain a database to be an source of information and an instrument of empowerment e.g. in negotiations for services and lobbying for rights
- x. establish a forum(s) of people with disabilities to share information and to speak collectively and in unity on needs and human right issues
- y. joint efforts by US and Free State University training *professional interpreters* to assist students with disabilities to gain access to training in fields they prefer
- z. assist and partnering with organizations working in the field of disabilities to achieve goals of empowerment
- aa. improving existing assistive devices and self-training toolkits (e.g. speech reading, lip speaking, electricity meters, etc.) for students with a diversity of hearing loss
- bb. promote the practice of universal access

(5) the conference declares its intention to work together towards equal rights, human dignity and full participation on all levels for people with disabilities moving away from the “us/they” mindset.

After the document was read, Ms. *Gubela Mji* closes the conference by reminding all that this is not the end. It is only the beginning. Powerful things were said at the conference. This included the issue of recognising others – if one allows a person to show one who she is and how one can relate to her. This is a sensible approach which we should allow room. In November 2009 the speaker visited the Worcester community together with others. In 2009 Alexander Phiri said he wanted an Afrinead conference in Zimbabwe. He is no longer with us, but still we continue. There will be an Afrinead Conference in Victoria Falls Zimbabwe in November (28-30) this year to which all are invited. With that Ms. Mji thanked everybody who attended the conference and especially those who have organised it and who have made it possible financially.