

# REPORT



## 3<sup>rd</sup> Mental Health and Deafness World Congress 2005 Worcester, South Africa

24 – 30 October 2005

### Mental Health and Deafness in a Caring Society



INSTITUTE FOR THE DEAF WORCESTER  
SOUTH AFRICA



## MENTAL HEALTH AND DEAFNESS IN A CARING SOCIETY

### REPORT: 3<sup>RD</sup> MENTAL HEALTH AND DEAFNESS WORLD CONGRESS WORCESTER, SOUTH AFRICA 24 – 30 OCTOBER 2005

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## MENTAL HEALTH AND DEAFNESS IN A CARING SOCIETY

### INTRODUCTION

It is a pleasure and privilege to present this report, which will be followed up by a CD containing the full proceedings of the 3<sup>rd</sup> Mental Health and Deafness World Congress.

In Copenhagen in October 2000, the World Contact Group agreed that the Institute for the Deaf should host the 3<sup>rd</sup> Mental Health and Deafness World Congress in 2005 in South Africa.

A full programme of meetings, conferences and special interest groups preceded the main congress programme. For the first time, users of services were involved in the Congress when residents from Lebenswelt in Austria and Lewensruimte in South Africa participated in a one-day pre-conference.

Two prominent mental health professionals who passed away during 2004, Dr Elsabé Smuts Pauw (South Africa) and Dr. Barbara A. Brauer (USA) were commemorated at the congress.

As an immediate result of the Africa Workshop hosted by the Institute for the Deaf in 2004 and sponsored by the Foundation Friends of Effatha in the Netherlands, 37 African countries were represented at this World Congress (a total of 57 countries were represented at the congress).

During the congress week, on 24 October, an Africa Contact Group was established and an Africa Committee on Mental Health and Deafness was elected.

At the end of the congress week, it was announced that the next ESMHD Congress will be held in the Netherlands in 2007 and the next World Congress in 2009 will be hosted by Australia.

Over the years the perspectives of the various world congresses have broadened from focussing only on Deaf Psychiatry, to Mental Health and Deafness, to Health and Well-being bringing us to the theme of this Congress: Mental Health and Deafness in a Caring Society.

The pre-congress programme consisted of two pre-conferences and a special interest groups' day.

The purpose of this report is to give an overview of the congress week programme including the pre-conferences, meetings and events that took place as well as recommendations arising from presentations and discussions.





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### PRE-CONGRESS PROGRAMME (22 – 26 October 2005)

#### **Saturday 22 October**

Residents from Lebenswelt in Austria and Lewensruimte in South Africa participated in a one-day pre-conference which concluded with the exchanging of national flags. A sports day rounded off the day and in the evening the residents were treated to a traditional "snoek braai".

This was the first time that users of services were involved in a world congress and allowed them to say how they experience services to multiply-disabled Deaf people. (see photo gallery on CD or website)

#### **Monday 24 October**

##### **Pre-conference on Mental Health and Deafness in Countries with Limited Health Services.**

Representatives from thirty-six (36) countries participated in this pre-conference which aimed to identify mental health and deafness needs in countries with limited health services, share knowledge and expertise, establish the existence, extent and appropriateness of services and also give delegates the opportunity to tell about their experiences.

Dr. A Karacostas, president of the European Society for Mental Health and Deafness, said in his opening speech that health care professionals rendering services to Deaf people need the support of Deaf professionals and that hearing and Deaf people should work together with the recognition of sign language as a true language when rendering services.

Drs Paul de Wet and Funeka Sokudela said in their introduction that integration of services and service providers is needed. Service providers are not necessarily specialized to work with Deaf people and require training and sensitising by Deaf professionals and organisations for / of Deaf people to improve accessibility of their services. Service providers in the health and mental health fields should network and complement each other in order to address both the physical and mental sides of well-being while more emphasis is placed on preventative aspects.

Three basic questions were asked and the groups gave feedback:

1. Where are you with regard to Mental Health and Deafness in your country?
2. Where do you want to be?
3. What do you need to do in order to get there?

In the feedback from the groups, the problems identified by the majority of countries were that of insufficient training, lack of skills, unemployment, poverty, exploitation and abuse, lack of opportunities, communication barriers, marginalisation, poor or non-existent health and mental health services. Special emphasis was placed on the plight of Deaf children living in desperate and traumatic circumstances. There is a great need to create awareness of mental health and deafness in all countries whilst lack of interpreters and resources aggravate the situation even further. HIV/AIDS awareness programmes for the Deaf are sorely lacking in most countries. Lack of hearing aids and assistive devices obstructs Deaf people in their efforts to utilise opportunities and access community processes to improve their quality of life. Insufficient government policies and legislations are also a big stumbling block in many countries and the cause of Deaf human rights is being neglected. In the majority of countries the lack of financial support and subsidies make it impossible for organisations for / of the Deaf to develop suitable services for Deaf people with mental health needs.

##### **Welcome Dinner**

A welcome dinner for participants of the first pre-conference was held at Moyo (Spier), a wine estate in Franschoek, where the delegates had the opportunity to socialise and relax.

#### **Tuesday 25 October**

##### **Network meeting**

A network meeting and sightseeing tour of Stellenbosch strengthened cooperation with the University of Stellenbosch while 80 professionals in the field of mental health and deafness had the opportunity to exchange ideas and contact details. Prof Pienaar, head of psychiatry at the University of Stellenbosch, and other speakers emphasised the role universities should play in ensuring appropriate and accessible mental health services for Deaf communities.

##### **Africa Contact Group meeting**

At this first meeting of the Africa Contact Group, a committee was elected by 71 African delegates representing 36 African countries. The committee was composed of 10 delegates, who were chosen from 5 different Africa regions, North, South, East, West and Central. Each region nominated 1 hearing and 1 Deaf representative active in the field



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### PRE-CONGRESS PROGRAMME (continued)

of Deaf services. The elected committee was tasked to (i) develop a structure or forum in Africa, (ii) update the Africa Declaration document and the Plan of Action drawn up at the Africa Workshop in 2004, (iii) appoint representatives to give feedback to the main congress of this contact group meeting as well as on the conference on Monday.

The contact group meeting concluded with an agreement by all delegates present to commit themselves to unite in their efforts to promote accessible mental health services for Deaf people throughout Africa.

#### **Annual General Meeting of the European Society for Mental Health and Deafness**

The European Society for Mental Health and Deafness held their Annual General Meeting for members. This was the last meeting for Mr Bob Clowes in his capacity as executive director of the ESMHD, a position he has held since 1997. After almost forty years of service in the field of mental health and deafness he has announced his retirement.

#### **Wednesday 26 October**

##### **Pre-conference on HIV / AIDS.**

The purpose of the HIV / AIDS pre-conference was to give health workers, health practitioners, social workers, occupational therapists, educators and service providers in the health and mental health fields the opportunity to:

- Learn about HIV / AIDS education for Deaf learners
- Understand the importance of Sign Language being an integral part of the programme
- Experience hands on training activities and demonstrations of lessons using Deaf learners
- Share an interactive skills development and growth experience

Professionals and other service providers in the HIV / AIDS and Deafness fields acquired knowledge and skills which will lessen communication barriers and enhance accessibility when rendering services to Deaf people. Networks were established enabling exchange of knowledge, skills and expertise in order to provide more accessible, affordable, appropriate and equitable HIV / AIDS services to Deaf communities in South Africa, Africa and other countries attending the congress. Fifty-seven delegates attended this conference.

##### **Special interest group workshops:**

###### **1. People with hearing loss later in life**

Presenters and delegates stressed the urgent need for the establishment of data bases of service providers and appropriately skilled professionals available to deafened people, assistive devices and suppliers thereof, adequately trained lip speakers, note takers and speech to text transcribers.

The group agreed on a plan of action that included (i) united efforts with service providers in drawing up policies and action plans on various issues including campaigning to government, business and commercial sectors, community integration and the special needs in adult education for deafened people, (ii) identification, initiation and empowerment of support and self help groups in the community, (iii) awareness regarding the utmost importance of ongoing research by service providers and universities, (iv) the active promotion of networking between service providers and interest groups in order to make existing mental health services accessible and appropriate for people with hearing loss later in life, (v) continuous appeals to educators and mental health professionals who must acquire sensitivity towards the trauma and challenges associated with hearing loss later in life.

The delegates agreed to keep in touch with each other in order to exchange ideas and support efforts by interest groups in different countries to improve services to and the quality of life of people with hearing loss later in life.

###### **2. Deafblind people**

The group appointed Rodney Clarke, former secretary of Deafblind International, to chair the meeting. Rodney Clarke, Andre van Deventer, (National Director of Deafblind South Africa) and Melette Els (National Development Co-ordinator of Deafblind South Africa) led the discussions and sharing of information. Information on and experiences of deafblindness as a dual disability and the complexity thereof was shared and discussed in depth by participants.

Discussions included (i) working towards a practical and social definition of deafblindness and a deafblind identity, (ii) diversity in deafblindness identifying the following sub-groups: (a) congenitally deafblind people, (b) deafblind people coming from a Deaf background, (c) deafblind persons coming from the blind community, (d) persons who became deafblind because of illness or accident, (e) deafblindness with the onset of old age, (iii) deafblindness and communication: (a) Oral interpreting or interpreting for hard of





### PRE-CONGRESS PROGRAMME (continued)

hearing deafblind persons, (b) tactile interpreting, (c) interpreting for partially sighted Deaf persons, (d) interpreting for deafblind persons with limited communication skills, (e) socio-haptic communication methods with deafblind people.

Participants agreed that a better understanding of deafblindness and the complexity of this dual disability resulted from this special interest group meeting. The group recommends that such a meeting should be included in future Mental Health and Deafness conferences and congresses.

#### 3. Medical Issues

Dr Ines Sleeboom chaired the meeting. A case study focussing on the importance of security and communication was presented and followed up by discussions on various health and mental health issues concerning Deaf people who need to access mental health services.

Discussions and sharing of information included (i) feelings of insecurity when a Deaf patient faces communication barriers in Deaf therapy, (ii) the necessity of health and mental health professionals to acquire sensitivity towards Deaf patients – this should become a professional skill for all mental health workers, (iii) research and training in techniques to stop violence (undertaken in Finland), which stressed that staff attitudes must change, not to look at the patient as a difficult person but as a person going through a difficult time, (iv) understanding of aggression as a symptom and not as a disease – understanding the context and cause of aggression before considering medication, sedatives must be seen only as an emergency measure, (v) in the absence of sufficient language with a Deaf patient, communication should be adapted by using pictures, photos, and drawings to explain all procedures, (vi) causes and consequences of tinnitus.

The chairperson informed the meeting of a SIG meeting which will be held in September 2006 at Laguna University, Tenerife and invited delegates to give topics for discussion / presentations. The meeting suggested the following topics: (i) Deaf questions about daily life, (ii) case studies, psychotherapy, (iii) problems related to having people with different degrees of hearing loss in the same ward or house, (iv) networking between countries, (v) communication barriers that Deaf people face, (vi) perspectives of Deaf professionals, (vii) tinnitus information for Deaf people, (viii) Deaf people in prisons have no access to or understanding of judicial procedures and processes resulting in longer incarceration, (ix) strategies for involvement of Deaf communities in mental health issues, (x) specialist training in mental health for interpreters, (xi) research and the difficulty to obtain questionnaires suitable for Deaf people, (xii) bullying among Deaf school children – causes and methods of prevention, (xiii) motivation of multi-disabled Deaf people towards self-reliance and a sense of well-being, (xiv) Deaf people with substance abuse, (xv) empowerment of Deaf people to take control of their lives.

Participants expressed their appreciation for the work done in this special interest group and urged that information must be passed on and that the special interest group should continue with its' valuable work in the field of mental health and deafness

#### 4. Children and families

The meeting was chaired by dr Tiejo van Gent supported by Kerstin Heiling, Woodi Oosterom-Bah and Bennie Steyn. Sharing of information and expertise focussed on challenges and issues from the perspective of the mental health professional.

Summary of discussions and sharing:

(i) Denial is a central theme: Both professionals, teachers and parents of Deaf children all too often deny mental health needs of Deaf children and young people. As specialist mental health professionals in this field we have a task to create awareness in the communities because parents struggle with denial as well as with overwhelming needs and powerlessness.

(ii) What impresses is the number of shared difficulties in the African countries – i.e. difficulties to get information. Parent movements must assist newly identified families of Deaf children.

(iii) Early identification of deafness, of mental health problems is critical to help Deaf children

(iv) Input on cochlear implants raised many concerns and worries to be addressed – a better understanding of the cochlear implant and its' consequences is needed, conflicting and different attitudes between professionals as well as different expectations carries the risk of a breakdown in communication between professionals with possible damaging effect for recipients.



**PRE-CONGRESS PROGRAMME (continued)**

- (v) Good parenting skills and communication are necessary to promote good mental health in Deaf children.
- (vi) Deaf people must be empowered by giving them language.
- (vii) It was striking to see that mental health professionals worldwide were dealing with basically the same mental health problems and issues. They are facing the same challenges though living in different situations and cultures. Attitudes of the parents are the same everywhere.
- (viii) Serious consideration and attention should be given to the dynamics in the family when a child with mental health problems is referred to mental health services.
- (ix) Contributions and sharing on challenges were made: (a) mental health standardized assessment tools should be translated in Sign Language and adapted for use in different cultures, (b) epidemiological research data should serve as a background for identifying both the mental health problems in the Deaf population and the priorities in the development of mental health services for the Deaf, (c) outpatient clinics should be established at schools for the Deaf, (d) existing mental health services should be made accessible to Deaf families and their children, (e) there is a great need for mental health professionals to be trained in Sign Language, (f) co-ordinated and multi-disciplinary action for the creation of awareness of the mental health needs of Deaf families and their children is needed – target groups are teachers in hearing schools and other medical service providers, (g) parents' and teachers' associations should be established for parents and teachers to support each other - strong parents' associations are needed for support and to help parents to come to terms with their Deaf child, and for awareness raising of other parents, (h) the main challenge is to improve the quality of life of Deaf children - this may be primarily met by influencing the schools, (i) teacher training and support is needed – provision of user-friendly educational material to assist teachers, (j) coping with severe behavioural problems in schools, (k) thorough knowledge of local cultural issues is needed, (l) special programmes for Deaf girls are needed to empower them against the risk of abuse, (m) early identification of both deafness and mental health problems in Deaf children is needed, (n) specialized professionals need to develop programmes for awareness raising in the medical field, (o) mental health professionals need to learn from experienced Deaf parents, (p) more work should be done on improving the self esteem of Deaf children adolescents – they can do everything and they do not have to feel different, (q) parents, health professionals and teachers of the Deaf must have high expectations of the Deaf child, (r) parents and service providers should be open minded to learn from Deaf children, (s) develop assessment material for Deaf children, (t) more needs to be known about the causes of Deafness so that we are able to develop early intervention strategies, (u) in-service training is necessary – in various specialised fields (psychiatry, psychology, parents' counselling and education) (v) short term courses and workshops will help to fast track the acquiring of knowledge and skills – do not forget to invite Deaf and hard of hearing professionals, keep in touch with interest groups like organisations for the Deaf, the deafblind, the sudden Deaf and hard of hearing people, (w) it is of the utmost importance that special interest groups be formed locally and internationally as platforms for the establishment and promotion of accessible mental health services for Deaf children and their families, (x) The group made the following recommendations: (a) create a platform to: discuss case material, share professional experience, explore challenges and issues in service development, support the development of an African Society for Mental Health and Deafness and/or more "special interest groups" regionally for mental health professionals and others involved in this field (b) key needs: training for the trainers, establishing resource centres, supporting interested professionals to acquire appropriate knowledge and communication skills, empowering interested groups and lobbying the authorities, recruitment of experts, (c) in-service training in various specialised fields including: psychiatry, psychology, parents' counselling, education.

**5. Health Forum meeting**

The Health Forum, chaired by Dr. Johannes Fellingner, discussed the health and mental health needs of the Deaf and was attended by approximately 50 people representing the five special interest groups. Con mental health policies in different countries, the special health needs of Deaf people and their integration in general health care systems.



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### PRE-CONGRESS PROGRAMME (continued)

The idea was to develop this forum into a special interest group on Public Health with the following aims: (i) to promote accessible education and health programmes that specifically address the special language, culture and learning needs of Deaf people, (ii) to hold a discussion forum for people with experience, special interest or concerns in physical/general health services for Deaf people, (iii) to provide a forum to: (a) network trans-nationally, (b) share mutual concerns, (c) exchange methods of good practice (d) develop more effective ways of making the full range of health services accessible to Deaf people in the language of their choice

The meeting agreed to the following vision: EQUAL ACCESS for Deaf people in their language of choice to: (i) health information, (ii) health education, (iii) health care, (iv) preventative health programmes. The meeting suggested the following ways to achieve equal access: (i) more health professionals who recognise the specific health needs of Deaf people, (ii) adequate professional time to facilitate the communication needs of the Deaf client, (iii) accessible health information for Deaf people, (iv) establish health data on the Deaf community to detect levels of need and help create appropriate accessible health services for Deaf people, (v) empower and enable Deaf people to take more responsibility for their own health, (vi) ensure that professionals are trained in Sign Language or have interpreters available.

#### Mayoral Welcome Reception

A reception hosted by the honourable Mr Clarence Johnson, mayor of the Cape Winelands District Municipality, was held at the KWV Brandy House to welcome all delegates to Worcester. Mayor Johnson put the coming 3<sup>rd</sup> Mental Health and Deafness World Congress in South African, African and world context referring to the importance of government authorities on local and national level to respond in a proper way to the needs of people with disabilities and especially so to the needs of the Deaf community. This congress is the result of years of planning and working in partnership with local, district, provincial and national structures, service providers in related fields, and community leaders. He expressed the wish that this congress will make a meaningful contribution towards empowerment of Deaf people and provide opportunity for networking and exchange that will result in actions to improve the life of Deaf communities around the globe.







### MAIN CONGRESS PROGRAMME (27 – 30 OCTOBER 2005)

#### Thursday 27 October.

##### Official opening ceremony and welcome

The 3<sup>rd</sup> Mental Health and Deafness World Congress opened with a colourful multi-media presentation introducing each of the 57 countries registered for the Congress. This was followed by a heart-warming rendition of the South African National Anthem in Sign Language presented by schools for the Deaf.

In his opening speech Mr Clarence Johnson, mayor of the Cape Winelands District Municipality, welcomed everybody present and expressed his best wishes for the success of the Congress. He stated that he believed that this congress was designed to bring people together to reflect, assess, plan, take note of what is happening on local level and to chart a way forward in all disciplines represented here. It is his sincere wish that South Africa as host country will benefit from the knowledge shared at this congress referring to two pioneers of the Institute for the Deaf in Worcester, South Africa who laid the foundation for services to the Deaf community 124 years ago. The mayor referred to specific socio-economic needs in Africa which have negative impact on living conditions and human rights. This includes the provision of mental health services to the Deaf community. It is important for Deaf and hearing to unite in their efforts to break the silence that isolates us from one another. He said "I look forward to the presentation of papers and the exchange of international best practices and also get a personal insight to the personal and human struggles that Deaf and mental health patients have in the various areas – both from developed and developing countries. This can give us new insight and knowledge in our approach towards issues related to mental health and deafness. I would like to see that this congress contributes to awareness raising in so far as the needs and human rights of people living with disabilities are concerned and that the world recognises the needs and priority of Deaf people and mental health patients. I hope that you will experience us as good hosts that will enable you to have a meaningful, productive, memorable and pleasant congress".

Mr Thami Mseleku, Director General of the Department of Health, represented dr. Mantombazana Tshabalala-Msimang, Minister of Health of the Republic of South Africa who, due to unforeseen circumstances, was unable to be present. He said that we, in South Africa are trying very hard to create an inclusive society, a society which embraces all of us as equal, irrespective of our different abilities. People with disability are still subjected to discriminatory practises and in extreme cases, even inhumane treatment. Inclusion of marginalized communities does not happen spontaneously, it is something we have to work through patiently and consistently. One of the fundamental prerequisites for inclusion and full participation is indeed a strong legislative framework that upholds the rights of people with disabilities. As a continent, we need to strengthen our laws to ensure that every citizen enjoys all the civil liberties of our countries. He continued by saying that one of the ways to break down barriers is approaching disabilities as human rights issues and understanding that disability rights are also human rights. There should be a push for a United Nations convention on the rights of persons with disabilities. Referring to mental health services in South Africa, he mentioned the implementation of the mental health act resulting in the upgrading and modernising of psychiatric facilities and the raising of awareness amongst the public. The result of this will be the improvement of the mental health of the population and the early detection and management of treatable conditions. He stated that health professionals and society at large do not fully appreciate the needs and difficulties of persons with multiple disabilities who suffer doubly in terms of exclusion and negative stereotypes, referring to deafblind and Deaf people suffering from mental disorders. He emphasised that particular support programmes and structures need to be identified so that people with multiple disabilities are able to be included in society. The department has endeavoured to reach people with sensory disabilities by using unorthodox methods, by putting messages on audio tapes for visually impaired people and producing video tapes in Sign Language to reach the Deaf youth. The department of health also started to train health workers in basic Sign Language enabling them to facilitate communication between Deaf clients and the rest of the health team. He concluded by saying that it would be wonderful to see all our children signing the National Anthem and that the deliberations at this world congress would contribute to a much more inclusive world and towards ensuring that South Africa adopts firmly, and in practice, Sign Language as one of its' official languages.

Mr Kobus Kellerman, board member of the World Federation of the Deaf (WFD), represented the President of the WFD who was unable to attend due to earlier commitments. He conveyed the greetings of the WFD and gave a short introduction of its' structure, aims and partnerships. The WFD is presently involved in the signing of the UN



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### MAIN CONGRESS PROGRAMME (continued)

convention on the rights of people with disabilities. This document aims to identify discrimination against people with disabilities as well as Deaf people. The linguistic identity of Deaf people is recognised. In this context, the 3<sup>rd</sup> Mental Health and Deafness Congress will have to look at how it can synchronise with all the work that has been done by the WFD, especially with reference to the congress in Montreal, Canada (2003) and the resolutions taken there. He highlighted some of the resolutions: (i) there was concern about mainstreaming education of Deaf learners and the mental health impact it has on these learners, (ii) special attention must be given to change the situation of Deaf women who are abused, (iii) the plight of Deaf children and care for elderly Deaf people, (iv) HIV programmes are not accessible to Deaf people and was identified as a priority – access needs to be provided through Sign Language, (v) health policies must ensure cultural sensitivity and accessibility through Sign Language, (vi) Deaf people who need access to health services in the mainstream are not recognised or respected and appropriately treated – the WFD wants this congress to look into this issue, (vii) the WFD wishes to improve the mental health services provided to Deaf people worldwide and hopes that this congress will make a significant contribution. The health commission at the congress in Canada made certain recommendations including the following: (a) criteria need to be drawn up to evaluate services and service providers who work with Deaf people, (b) the WFD needs to work with the World Health Organisation on various HIV programmes with special attention to the prevention of HIV/AIDS, (c) a commission was established to look at mental health and deafness – it was requested that all congresses on mental health worldwide should be made accessible to Deaf people in order to include the standard of services to Deaf people in the field of mental health. He concluded by expressing the wish that this congress will produce fruitful discussions and deliberations and unpacked the resolutions and recommendations made at previous congresses.

Mr Andre van Deventer, Secretary General of the World Federation of the Deafblind, conveyed a message of greetings and support to the congress on behalf of the President of the World Federation of the Deafblind. He expressed his appreciation for the inclusion of deafblind in this congress and urged participants not to forget the unique needs of deafblind people in their deliberations and planning. He went on to explain the diversity of deafblindness. The life situation of deafblind persons may also be further complicated by additional disabilities. All of these factors should be taken into account in the setting up and provision of mental health services for the deafblind. He referred to the existence of local self-help groups which are still very limited but with the potential to be of tremendous help to deafblind persons. He concluded by quoting the president of the World Federation of the Deafblind: "Dear colleagues, it appears more that ever that deafblind people are living in a society that is more and more made for people with sight and hearing, especially thinking about modern technology, mobility, mass media and social interaction. I hope that your congress realises the enormous barriers this development is creating for persons who are losing or have lost sight and hearing. I hope that future cooperation can help remove these barriers and improve the quality of life for all of us, fully participating in society."

Mr Fanie du Toit, Promotion and Awareness Manager for the National Council for Persons with Physical Disabilities, himself a person who became Deaf later in life, explained that the profile of persons experiencing hearing loss later in life must be promoted in terms of the following characteristics: (a) mild/moderate – difficulty in following speech without a hearing aid, (b) Severe – reliance on lip- / speech reading with a hearing aid, (c) Profound – reliance on lip-reading / facial expressions / signs (NOT SL). It is important to make the community aware that persons experiencing post-lingual hearing loss are persons with disabilities who need assistive devices, rehabilitation and support. He concluded by saying: "I would like to extend my appreciation to the organising committee for providing time and space in the congress programme to exchange information and experiences with international experts. I hope that this congress will be to the benefit of all persons with hearing loss."

Mr Brian Symington and ms Sandra O'Brien conveyed the following message on behalf of the President of Ireland: "It gives me great pleasure to send warm greetings to the Third Mental Health and Deafness World Congress taking place in Western Cape, South Africa. The island of Ireland, north and south, will be well represented at the congress by the Royal National Institute for Deaf People, and by the National Association for Deaf people whose partnership in working for common goals has improved the quality of life in so many respects for Deaf people and people who are hard of hearing. The recent creation of an all Ireland mental health and deafness service and the declaration at the 2003 European society for mental health and deafness congress are just two of the very welcome results of that cooperation. I wish you well in your conference deliberations".



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### MAIN CONGRESS PROGRAMME (continued)

Mr. Bruno Druchen, National Executive Director of the Deaf Federation of South Africa, expressed his appreciation to the Institute for the Deaf for hosting this world congress. He expressed his sadness for the passing away of dr Elsabé Smuts-Pauw who made an enormous contribution with regard to the acknowledgement of Sign Language, Deaf education and promotion of mental health in the Deaf community. He appealed to the department of health to make sure that mental health services as well as interpreters are provided in all provinces in South Africa. He urged delegates present to participate in all the deliberations and that papers produced by this congress not be shelved but be implemented for report back at the next congress. It is good to see so many organisations and structures together that can network and work together, in this field nobody can work alone. He asked all the delegates to distribute the knowledge that they will gain here in their countries and communities when they return home.

Dr Alexis Karacostas, President of the European Society for Mental Health and Deafness (ESMHD), forwarded the greetings of the ESMHD to the organising committee and participants and all those who worked to promote accessible health and mental health care for the Deaf population. He continued by saying: "The European Society for Mental Health and Deafness, always has been and will always be present besides those who fight against all forms of discrimination, for the recognition of the fundamental human rights of Deaf citizens, not only in health and mental health issues, but also in all other issues which contribute to good mental health, like the recognition of human rights for all, to get access to care in their language of choice, which is in Sign Language whenever necessary. Over the last 40 years, and especially with the creation of the European Society of Mental Health and Deafness in 1986, considerable work has been undertaken in many countries. The members of numerous Deaf communities and health professionals have joined together with many other stakeholders in society, in order to initiate new professional practices. In accordance with our campaigns for accessible health services, this resulted in the statement of some principles that I intend to summarize in a few words: First we need to consider the aims of our movement. We must consider separately the care towards deafness and the care towards Deaf people. I will explain how: Deaf people suffer also, like hearing persons, from diabetes, cancer, broken legs, schizophrenia or depression. Until now, most of these services are not able to take this fact into consideration. Wrong diagnosis, treatment error, and in many cases, lack of any kind of treatment are the rule. It is important when one meets a Deaf person, not to focus on his ear but to see him as a whole person with various needs that have to be satisfied and rights that must be respected. Among them specifically, this person has the right to express himself and to receive care in Sign Language, or whatever modality he or she communicates best in. Second, we consider that all efforts must be made in order to build bridges between Deaf communities and hearing society. In our case, this includes Sign Language training for doctors, nurses, social workers, educators, etc. This also includes the presence of interpreters, if possible specialized in health and mental health. Thus, the skills in Sign Language are of the highest importance. This can be best enabled when Deaf professionals participate in the teams' every day life and work. Deaf people are not only our patients, they must also become our partners. This means that they have to be trained in health and mental health issues; then, we never must forget that Deaf people need equality of access throughout their lifespan. Deaf children have special needs. Deaf adults have special needs and rights. As they become older, like all of us, Deaf elders have special access needs. This requires the creation of specialized services which will be the base of further national and international exchanges between professionals. These professionals will thus be able to network at every stage of the development - the links with Deaf professionals but also with Deaf community representatives and associations are required in order to ensure global social recognition. This is why such world congresses which give us the opportunity to meet and exchange experience and expertise, help us all to improve our understanding of specific needs and stimulate the development of local accessible health care services. This is why also the first African conference on mental health and deafness last year was an important event. The African declaration on mental health and deafness, as the 2004 declaration, recalls and summarizes some important aims of our movement. Obviously, these are only documents agreed between us. To be effective, you the delegates, have to take them back to your countries, present them to your government health departments, health service providers, and Deaf communities as the next vital step in the campaign to change these fundamental principles into the reality of more accessible services for Deaf people. Little did we think, when we held the first conference on mental health and deafness in Rotterdam in 1988, that we would be meeting in 2005 with colleagues from all over the world at this wonderful 3<sup>rd</sup> Mental Health and Deafness World Congress. ESMHD is proud of what we started in a small way all those years ago, and we now pledge whatever support we can give to you and your fight for accessible services for Deaf people in your countries. This world congress would not have



## MENTAL HEALTH AND DEAFNESS IN A CARING SOCIETY

### MAIN CONGRESS PROGRAMME (continued)

been possible without the initiative, commitment and hard work of Attie Smit, Deon de Villiers and all of the South African congress team. On behalf of ESMHD and all delegates I would like to thank them all for the hard work they have undertaken on behalf of us all. People like the team here in South Africa, show us all that there is a real commitment towards ensuring the rights of the Deaf linguistic minority. Having met so many of you during the last few days, I am now absolutely confident that our collaboration will lead to extending good practice in health and mental health care and services.

Dr Lauri Rush of Gallaudet University paid tribute to dr. Barbara Brauer, first executive director of the Mental Health Centre at Gallaudet, first Deaf psychologist in the USA (in the whole world?), pioneer in mental health and deafness and chair of the first mental health and deafness congress. Dr Rush said: "We honour dr. Barbara Brauer's memory through our continued work. The Mental Health Centre of Gallaudet would like to give a gift to this congress, in memory of dr. Barbara Brauer, the development of a CD to publish the proceedings of this congress to be given to all of the delegates. Barbara really was a lover of technology, she was a technology addict, so she will love the fact that this is the gift that has been given."

Mr Kobus Kellerman paid tribute to dr Elsabé Smuts Pauw, psychologist and pioneer in mental health and deafness. He said: "Elsabé Smuts Pauw was tremendously committed to improving South African Sign Language within the Deaf community and she lobbied very hard for the rights of education of Deaf learners. She co-ordinated a gathering of approximately 400 Deaf people to meet with policy makers from government for these Deaf people to tell government what their needs were in terms of education. This led to the needs of the Deaf being included in the White Paper on education in South Africa. Implementation always takes a very long time and Elsabé Smuts-Pauw did not have a lot of patience when it came to this, so she mobilised Deaf people in all the 9 provinces, with memorandums to march to the governmental offices, when she was getting too impatient. She found her way in to the South African qualifications authority in South Africa, and lobbied and worked very hard to get units standards recognised for South African Sign Language, to develop a curriculum and just one day after her passing away, the unit standards for South African Sign Language were approved and recognised to be on equal par with that of any spoken language in this country."

The tributes were followed by the unveiling of the Congress Memorial Wall by dr. Lauri Rush and mr Kobus Kellerman in honour of dr. Barbara Brauer and dr. Elsabe Smuts-Pauw. At the same ceremony, a tree was planted by dr Karakostas in his capacity as president of the ESMHD as a symbol of the continuous work to improve the quality of life of Deaf people worldwide.

#### Poster sessions (27 and 28 October)

Delegates were able to view some very interesting and informative poster sessions displayed throughout the day at various venues during the congress week. Posters were presented by professionals, non-professionals, and representatives of various organizations world-wide working in the field of mental health and deafness. Presenters and delegates took this informal opportunity to network with others in their field and to exchange contact details.

#### Plenary session 1

The chairperson of the first plenary session was dr Ines Sleeboom-van Raij. This session got underway with ms Wilma Newhoudt-Druchen with a paper on Mental Health and Deafness in a Caring Society. Ms Woodi Oosterom-Bah followed with her presentation on communication: With a Little Stick in the Sand. The last session of the day was devoted to report back from the Africa Contact Group delivered by mr Arssi Abdelaziz, rev Kamonyo Botanyi and ms Evelyn Mammopa Phae.

#### Workshops I, II, III, IV

Four simultaneous workshops were held at various venues on the campus in the afternoon.

The Health workshop was chaired by dr Funeka Sokudela, Education and Work chaired by mr Eugene van Vuuren, Family/Religion chaired by ms Anna-Marie Loftus and a special interest workshop chaired by mr Kobus Kellerman. Workshops I, II and IV consisted of four international speakers presenting papers and/or powerpoint presentations on topics related to the specific workshop whilst three speakers gave presentations at workshop III. Time was allowed after each speaker for questions and comments from the delegates.

#### Deaf Professionals and Deaf Community Meeting





## MENTAL HEALTH AND DEAFNESS IN A CARING SOCIETY

### MAIN CONGRESS PROGRAMME (continued)

inaccessibility at universities, work promotions and the difference between hearing and Deaf cultures.

#### **Meeting of the South African Society for Mental Health and Deafness (SASMHD)**

A meeting of the South African Society for Mental Health and Deafness was held. Three new members joined the society. The constitution was adopted by the interim committee of the SASMHD. A general meeting of all members and interested parties should be held within the next year, possibly to coincide with the re-union conference to be held by De la Bat School in June. At this meeting a new Governing Body and Management Committee will be selected.

#### **Friday, 28 October**

##### **Plenary session 2**

The second plenary session was chaired by Lauri Rush and opened with Gordon Chapman speaking on "For good health you must empower" and was followed by Ingrid Bodin and A Rassmussen with a paper on "Power and Powerlessness". Jan de Bosch Kemper followed with "But... we don't have Deaf here". This second session closed with Otilia Rodrigues and N Crittenden presenting "Silence is Golden – construing the world of Deaf people".

##### **Plenary session 3**

Alexis Karacostas chaired plenary session three and introduced Tiejo van Gent with his presentation on "The study of mental health in Deaf young people: what about ego-development and self-esteem?" Carla Shird and Debra Guthman followed with a paper entitled "Identifying, assessing and treatment substance abuse problems with Deaf and hard hearing individuals". The last speaker for this session was Brendon Monteiro who spoke on "Forensic Mental Health Services for Deaf People".

##### **Workshops V, VI, VII, VIII**

At the Health workshop chaired by Johannes Fellingner, three delegates presented papers. Ulf Müller chaired the Education/Work workshop where four speakers presented papers. The Family/Religion workshop was chaired by Anna-Marie Loftus and three speakers presented papers. Claudine Storbeck chaired the Special Interest workshop where four speakers presented their papers.

##### **World Contact Group Meeting**

A meeting of the World Contact Group took place. A declaration was drawn up at Bad Ischl in 2003 and a declaration also culminated from the Africa Workshop held in South Africa in 2004. Both declarations state the importance of a client being helped in the language of his/her choice. The first meeting of the World Contact Group was held in Washington DC in 1998 after the 1<sup>st</sup> Mental Health World Congress. These meetings are necessary and create opportunities to exchange knowledge and interesting events that may have happened in different countries. It is also of the utmost importance that people from Africa become involved. Information should be exchanged up to the next World Congress in 2009, to try and make health services accessible to the Deaf. A World Declaration should be considered. A spokesperson for the Africa Contact Group expressed the problem that no services are available in some Africa countries. The suggestion was made that a meeting between professionals in a specific country and their Deaf community could be initiated to help them to get to know and understand each other.

Consensus was reached that all African countries will be sent questionnaires to survey the situation regarding everyone's country, questions we share regarding data about services, statistics and communication with special attention to Sign Language proficiency. The questionnaire should be completed and returned to the contact group as soon as possible. The contact group will contact only the people who responded to the questionnaire.

Dr Funeka Sokudela announced that the South African Society for Psychiatry will be held next year in Swaziland and will focus on general psychiatry.

#### **Saturday 29 October**

##### **Plenary session 4**

The fourth plenary session was chaired by Paul de Wet. The first speaker was Guy McIlroy who discussed "Deaf Identity: A range of possibilities" and was followed by Ines Sleeboom van Raaij who spoke on "Family in focus, important factors in the family development – retrospection from adulthood". Sharon Kleintjes then presented her paper on "Hearing parents' experiences of raising their Deaf pre-school child in Cape Town: Findings and preliminary recommendations for improving health services". Liv Strand completed this session with her paper entitled "Look at my language: Program for parents of children who are Deaf".





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### MAIN CONGRESS PROGRAMME (continued)

#### Plenary session 5

Plenary session five was chaired by Francis Prinsloo and commenced with Jan de Jongh van Arkel presenting his paper on "the Role of (Christian) faith and religion in Mental Health". Kamonyo Botanyi then spoke on "Integration of the Deaf in the community" and was followed by the last speaker for this session, Johannes Fellingner discussing "The role of a signing community".

#### Plenary session 6

The sixth and final plenary session was chaired by Bob Clowes and opened with Deon de Villiers and Gona Nambiar speaking on "Equal access to Deaf people in job/career training in the community by means of Sign Language and with the support of technology and distance education". Anne-Marie Loftus and Marjon Dekker concluded this final session by discussing "The social competency approach in a learning and living environment".

#### Summary and closing ceremony

The closing ceremony began with a dance item by Deaf learners from De la Bat school followed by a video summary and credit scroll. Stephen Lombard said in his vote of thanks that he was stunned to see how many people were interested in this field. He added that knowledge of decisive importance was shared and made accessible to service providers of the Deaf and the Deaf community. He thanked the organizers for bringing this world congress to South Africa and expressed his appreciation to the delegates who came to attend and participate in this very important event and process for the Deaf communities worldwide. Various delegates then gave a word of thanks to the organizers and facilitators of the congress with special mention of the Foundation Friends of Effatha, without whose financial support the Africa delegates would not have been able to attend this congress. The congress chair conveyed a word of thanks to all participants, delegates and presenters, it is they who made the congress such a success. Each participant was presented with a certificate of attendance as a small token of appreciation. The next European Congress on Mental Health and Deafness in 2007, with the theme "Joining Forces", was announced by delegates from the Netherlands. The closing ceremony concluded with a presentation and the announcement by the Australian team, under leadership of David Harris and Damien Lacey, of the Deafness and Mental Health Centre of Excellence facility, that the 4<sup>th</sup> Mental Health and Deafness World Congress will be held in Brisbane in 2009.

#### Sunday 30 October

The congress week was concluded with a church service in the Deaf church on the campus of the Institute for the Deaf. Holy communion was shared with delegates participating in the worship service. Delegates from Africa shared their spiritual experiences and expressed the need for similar provision in African countries. Requests for networking and support were exchanged. The service was attended by more than 300 people, including members of the Deaf congregation and delegates of the congress. A brunch was served for delegates before their departure.





## MENTAL HEALTH AND DEAFNESS IN A CARING SOCIETY

### RECOMMENDATIONS

The organising committee followed up on suggestions and comments made by presenters and participants and present it in the form of recommendations.

The congress recommends that:

- 1 the Worcester Declaration 2005 be used as a lobbying document with governments, authorities and decision makers to promote accessible and appropriate services for Deaf people, the human rights of Deaf people irrespective of age, race, creed, gender or level of development
- 2 Deaf people and their community leaders be involved in the needs analysis, planning and implementation of services for the Deaf community based on the principle of "Nothing about us without us"
- 3 the Africa Workshop Action Plan be used as a guideline by associations and organisations whose main aim is to improve the quality of life for Deaf people (the plan is available in English and French on the website of the Institute for the Deaf as well as on the 3<sup>rd</sup> Mental Health and Deafness World Congress CD)
- 4 HIV/AIDS special interest groups be established on local, national, international regional and world level
- 5 the following interest groups be part of the structure of the Mental Health and Deafness World Congresses: Deaf and hard of hearing children and their families, Youth and education, Deaf professionals, People who experience deafness later in life, Deafblind, Multiple disability, HIV/AIDS, Medical issues, Health forum
- 6 a world coordinating committee on mental health and deafness be established to facilitate sharing and exchange of knowledge and expertise, networking and cooperation between role players and stakeholders on international level (it is suggested that this committee be elected by the World Contact Group – for the interim until the next meeting of the WCG, it is suggested that the organising committee of the fourth world congress act as a world coordinating committee with coopting of members of other countries as they see fit)
- 7 the Africa Contact Group Committee and its' secretariat selected during the 3<sup>rd</sup> Mental Health and Deafness World Congress be seen as the representing body for mental health and deafness in Africa
- 8 the organising committee of the 4<sup>th</sup> Mental Health and Deafness World Congress to consider the possibility of providing a time slot in a business meeting format for discussion, resolutions on policies and plans of action
- 9 associations and organisations give special attention to inequities faced by Deaf people of all ages with regard to communication barriers
- 10 regional resource centres to be established in developing countries to facilitate the recruitment of experts and professionals as well as training courses and skills development eg. training for the trainers (which should include training in the field of parent guidance, communication and Sign Language skills training in various service fields, HIV/AIDS, social competency skills), training opportunities for interested professionals to acquire appropriate knowledge and communication skills, empowerment courses for interested groups, training in skills in lobbying with authorities.
- 11 databases be set up of (i) persons with hearing loss later in life, (ii) appropriately skilled professional services, (iii) assistive devices and suppliers, (iv) lip speakers and note takers.
- 12 a programme be established to develop the skills of lip speakers and note takers for people who experience hearing loss later in life

This report was compiled by A L Smit on behalf of the organising committee.

More information is available on the website of the Institute for the Deaf: [www.deafnet.co.za](http://www.deafnet.co.za)

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## MENTAL HEALTH AND DEAFNESS IN A CARING SOCIETY

### ORGANISING COMMITTEE

President:	Mayor Clarence Johnson
Committee chairperson:	Mr Deon de Villiers
Congress chairperson:	Rev Attie Smit
Scientific committee:	Dr Paul de Wet
	Dr Elsabe Smuts-Pauw
	Dr Funeka Sokudela
	Rev Attie Smit
Deaf accessibility:	Mr Ernest Kleinschmidt
Africa delegates:	Mr Sanjay Beepat
Tourism and marketing:	Thebe Conventions
Finance:	Mr Deon de Villiers
	Mr Niel Hamman
Campus logistics:	Mr Natalie Roelofse
Stalls and exhibitions:	Mr Anton Rademeyer
Professional congress organiser:	Thebe Conventions (Ms Zelda Ingram, Renee Lukin, Caron Paulse)



END OF REPORT

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The organising committee would like to convey their best wishes to the Australian team, under the leadership of David Harris and Damien Lacey, for the planning, organising, hosting and success of the 4<sup>th</sup> World Congress on Mental Health and Deafness in 2009.