

The Conference Proceedings of the 2008 BAMENDA CONFERENCE ON DISABILITY AND REHABILITATION



Theme: “UN Convention on the Rights of Persons with Disabilities”

Njimafor Catholic Hall - Bamenda
North West Province, Cameroon
4th and 5th of December 2008



Cameroon Baptist Convention Health Board



International Centre for Disability and Rehabilitation
FACULTY OF MEDICINE
University of Toronto

FORWARD

This booklet contains the proceedings of the 2008 Bamenda annual conference on Disabilities and Rehabilitation that held at the Njimafor Catholic Parish Hall from the 4 to 5 December 2008. This conference was another step forward towards improving the lives of PWD and getting them included in the mainstream activities in the North West Region in particular and Cameroon at large.

On behalf of the conference planning committee, we wish to congratulate everyone who made significant efforts to ensure that this conference was such a success. Events such as this only succeed if everyone participates well, and the contributions were many and varied.

The Conference began with a welcoming note from conference planning committee and Lynn Cockburn of the University of Toronto Canada. After the welcoming address the rules and regulations of the conference was spelt out to ensure a smooth Conference.

The keynote address unlike previous years was delivered by a PWD Charles a lecturer at University of Buea. His presentation set the ball rolling for the Conference whose methodology included presentations, interactive sessions, group work exercises and question and answer sessions. This presentation set the stage for the discussion on "Dignity and Justice for us all" making the UN Convention a reality in the North West Region of Cameroon and the need for ongoing monitoring of what is happening within the region, the country and internationally. The remainder of the conference included several formal presentations, lively discussions and much networking. The expertise of the speakers was significant and contributed to the high quality of the event. We express our sincere thanks to each and every one for taking the many hours to plan their presentations and to answer the many questions and comments that participants posed.

The Conference was evaluated by the participants using the evaluation sheet provided to them by Conference organizers. From their responses the Conference was a huge success and beneficial to them.

Many people enjoyed seeing colleagues whom they had not seen for some time and also meeting new faces. Some say it was among the high points of the conference.

The full program is included here and a summary of the presentations is included in the following pages. A number of people worked diligently behind the scenes to make sure that participants had materials and food, to moderate and record sessions, and to deal with other details that allowed the conference to proceed. We express our sincere thanks to SENTTI students who moderated the sessions and acted as sign language interpreters and together with Takusi Daniel Watcha made sure that every participant had something to eat. Delicious food was provided by Mrs. Chia Gladys and we are very grateful for her efforts. Many, many thanks to all the others who had a hand in the

details of running this conference – whether photocopying at the last minute, arranging chairs or providing an encouraging word.

We hope that as you read through this collection of proceedings you are inspired to continue your own work in this area. There are several ideas and recommendations collected here, and there is no shortage of work to be done.

Please note that the information and ideas in each presentation are those of the author and have not been endorsed specifically by the conference planners or undergone a peer review.

Let us work together to ensure that this work is not lost and that future conferences are even more successful than this one.

The 2008 conference planning committee
Lynn Cockburn, Ezekiel Benuh, Francis Fokwang, Kat Chow, Heather Aspiras, Samuel Nyincho, Nungu Magdalene, and Julius Wango.

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SCHEDULE

The 2008 Bamenda Conference on Disability and Rehabilitation “UN Convention on the Rights of Persons with Disabilities”

This conference aims to bring together people with a wide range of perspectives to discuss disability and rehabilitation issues. The focus is on the UN Convention, on living with a disability, and on current rehabilitation practices, particularly in the North West Region of Cameroon.

Thursday, December 4, 2008	
8:00 – 8:30	Registration
8:30 – 9:00	Opening Prayer Welcome from Planning Committee: Mr. Francis Fokwang and Mr. Julius Wango, Bamenda Coordinating Centre for Studies in Disability and Rehabilitation Welcome from: Ms. Lynn Cockburn, University of Toronto
9:00 – 10:00	Keynote Address #1 Presentation topic: Making the UN Convention on the Rights of Persons with Disability a Reality in the NWR Presenter: Mr. Charles Nyuygap , Lecturer, Department of Education, University of Buea Additional Comments on the Convention Presentation topic: Full Integration of People Living with Disability at Family Level Presenter: Limen Florence
10:00 – 10:45	Session 1 Presentation topic: From Integration To Inclusion Presenter: Ngang Eric
10:45 – 11:15	Refreshment Break
11:15 – 12:00	Session 2 Presentation topic: The Use of Cognitive Behaviour Therapy as an Empowerment Tool for People with Disabilities Presenters: Kate Suffling, Jennet Seighe, Dickson Fambombi
12:00 – 2:00 Lunch and Networking Exercise Participants will read each organization’s poster on the wall and complete a small quiz)	
2:45 – 3:30	Session 3 Presentation topic: Stammering as a Disability Presenter: Joseph Lukong

Friday, December 5, 2008	
8:30 - 9:30	<p>Keynote Address #2: Presentation topic: The Right to Education of Children with Disabilities in North West Region Mme. Nungu Magdalene</p> <p>This presentation will describe who are the children with disabilities, what is education, what educational system will suit the needs of kids with disabilities, what is prevalent in the North West Region, what are the challenges. The address will conclude with suggestions for the way forward in the North West Region.</p>
9:30 – 10:15	<p>Session 4: Presentation topic: A Research Study on the Reproductive Health Experiences of Women with Disabilities in North West Province in Cameroon Presenter: Ruth Acheinegeh, Kim Bremer, Lynn Cockburn,</p>
10:15 – 10:45	Refreshment Break
10:45 – 11:30	<p>Session 5: Presentation topic: Investigation of an epilepsy epidemic in Momo division Presenter: Ambanibe Jerome, Irene Elliott, O. Carter Snead, Lynn Cockburn, Alfred K. Njamnshi, Innocent Takougang</p>
12:15 – 1:30 Lunch	
<p>Summary and Plenary Session: 1:30 – 3:00 As the third conference closes, this session will provide an opportunity for the participants to reflect on the two days, and the situation in the province. What have we learned? What are the questions emerging? Where do we go from here?</p>	
3:15 Closing Remarks and Evaluation	
4:00 Adjournment	

Our thanks to the students from SENTTI who have assisted to make this a successful conference.

Nketeh Lucy Mambo and Esomba Celestine (for Sign Language)

Ndikum Charles, Yvonne Nehfon, Nfor Victorine, Mboh Jones, Akomoneh Napoleon, Tchimou Kamdem Valerine, Achuo Anna Nnam, Njita Munshili, Precillia Mefor, Ngowah Margaret, Tosal Kelvine, Okole Annie Francine, PRricilla Awah, Kehla Mercy, Sirri Marie Louis, Tangyie Charles, Takoquen Gislaine and Mefire Rainat

ACRONYMS

CBCHB	Cameroon Baptist Convention Health Board
CBR	Community Based Rehabilitation
CBT	Cognitive Behaviour Therapy
CEFED	Centre for Empowerment of Females with Disabilities
CWD	Children With Disabilities
CWG	Cameroon Working Group
ICDR	International Center for Disability and Rehabilitation
ISA	International Stuttering Association
NGO	Non Governmental Organization
NWR	North West Region
UN	United Nations
PWD	People With Disabilities
PWS	Person Who Stammers
WHO	World Health Organization
WWD	Women with Disabilities

**KEYNOTE ADDRESS 1: MAKING THE UN CONVENTION ON THE RIGHTS OF
PERSONS WITH DISABILITY A REALITY IN THE NORTH WEST REGION**

Mr. Charles Nyuygap, Lecturer, Department of Education, University of Buea

SUMMARY OF THE PRESENTATION IS NOT AVAILABLE.

SESSION 1: FROM INTEGRATION TO INCLUSION

Ngwang Eric

The main purpose of this presentation was to show how actors in the field of disability and rehabilitation, together with the wider community of the NW province, can work together to create an inclusive society for PWD. This presentation permitted participants to have a better understanding of the merits of inclusion and highlighted some practical steps to be taken by various actors to make that to happen.

1. CONCEPT OF INCLUSION

a. Change in Perspective

- It is shift away from a deficit model, where the assumption is that difficulties have their sources within the PWD, to the social model, where barriers to free functioning of PWD stem from the attitudes and structure of the society.
- Inclusion is a sense of belonging, feeling respected, valued for who you are: feeling a level of supportive energy and commitment from others so that you can do your best
- Considers all disabilities
- It is about creating equal opportunities

b. The UN Convention

- The Convention declares that PWD have the same rights as all others
- Evolution from the medical model to the rights based approach
- Questions related to disability are now linked to the human rights agenda
- There are eight principles in the Convention:
 - Respect for the dignity, autonomy, including the freedom of one choice, and independence of people
 - Non-discrimination
 - Total and effective participation and inclusion in the society
 - Respect for diversity and acceptance of PWD as part of human diversity
 - Equalization of opportunities
 - Accessibility
 - Equality between men and women
 - Respect for children with disabilities and their rights to preserve their identities

2. AREAS OF INCLUSION IN THE NWR

a. Persons with Disabilities

- Develop self esteem
- Proactive: create initiatives for themselves
- Participate in community projects and programs
- Accept themselves and strive for autonomy and not dependence
- Advocacy: they must be able to come together and advocate for themselves
- Be self assertive: be able to go out to the community and make use of opportunities

- Raise awareness in their family's community, struggle to strive in their education no matter the difficulties

b. Families of PWD

- The family is the nucleus of every society and has a lot to contribute to make the process of inclusion work here in the North West Region.
- Acceptance
- Help develop good self esteem and confidence in PWD
- Participate in advocacy efforts
- Collaborate with service providers
- Ensure good communication
- Provide social needs of PWD
- Involve PWD in major family activities and decisions

c. Communities

- Promote the culture of inclusion and not of exclusion
- Accessibility: Make the society, geographically, socially, economically and culturally fit for living for PWD.
- Mainstreaming of PWD in development: PWD should be part of all community development initiatives.
- Equal opportunity: the community should offer equal employment opportunities to PWD.
- Acceptance
- Supportive

d. Medical and Rehabilitation Services

- Consult PWD: should involve PWD in designing and implementation of programs.
- Effective communication: enough information should be given to PWD and their families on the existing services available in their institutions.
- Human empowerment: vocational training given to PWD should be oriented toward livelihood
- Accessibility: medical services and rehab centers should be reachable to PWD
- There should be networking between services for complementarily services

e. Educational Institutions

- Inclusion in education is broader than formal schooling: it includes the home, the community, non-formal and informal systems
- Acknowledges that all can learn
- Adaptation of curricula: inclusion in education enables education structures, systems, and methodologies to meet the needs of PWD
- Accessibility: schools should be made physically accessible and positively friendly to PWD

- School culture should avoid bullying, name-calling and discrimination and stigmatization of PWD, it should promote conviction that all PWD have the right to attend and learn
- Restructuring the cultures, policies and practices in school so that they respond to the diversity of PWD

f. Government

- Provide legal framework
- Include PWD in planning, giving them the opportunity to advocate for themselves
- Public places should be built considering the needs of PWD
- Ensures inclusive education in Cameroon and in NW Region in particular.
- Provide Support for rehabilitation centers
- Protect the rights of PWD
- Ensure that legislation is respected

SESSION 2: THE USE OF COGNITIVE BEHAVIOUR THERAPY AS AN EMPOWERMENT TOOL FOR PEOPLE WITH DISABILITIES

Kate Suffling, Occupational Therapist, Cameroon Working Group
Fambombi Dickson, Social Worker, CBC Health Board
Jennet Sesighe, Chaplain, CBC Health Board

Cognitive Behaviour Therapy (CBT) is a method that focuses on the development of healthy thinking patterns and behaviours that promote better function and mental health, and thus, improve quality of life. This presentation discussed how if CBT is used appropriately, it can reinforce autonomy and choice, and has a direct application for people with both physical and mental health related disabilities.

1. BACKGROUND INFORMATION

a. Basic Theory Behind CBT

- CBT is a therapy approach used with a variety of mental illnesses and mental health problems
- It focuses on changing unhealthy thinking patterns and behaviours
- This is done to improve mood, decrease anxiety, and promote healthy behaviours that lead to better quality of life
- CBT is a collaborative process, where the client and therapist are exploring problems and solutions together as partners

b. Defining Mental Illness

- A psychological or behavioural pattern that seriously affects function
- There are many different diagnoses, e.g. Depression, Schizophrenia, anxiety disorders
- Disorders may affect mood, cognition, anxiety and/or sense of reality
- Mental illness is quite common around the world: more than 1 in 3 persons will suffer from mental illness at some point in their life

c. Mental Illness is a Disability

- Mental illness can cause impairments in cognition (thinking and perceiving), such as memory, planning, organizing
- Motor abilities (movement) can also be affected
- People may suffer from lack of motivation, fatigue, etc.
- Many activities of daily living can be affected, like learning, communicating, dressing, bathing, working, parenting etc. etc.
- All of this affects the ability to fully participate in society, making mental illness a disability!

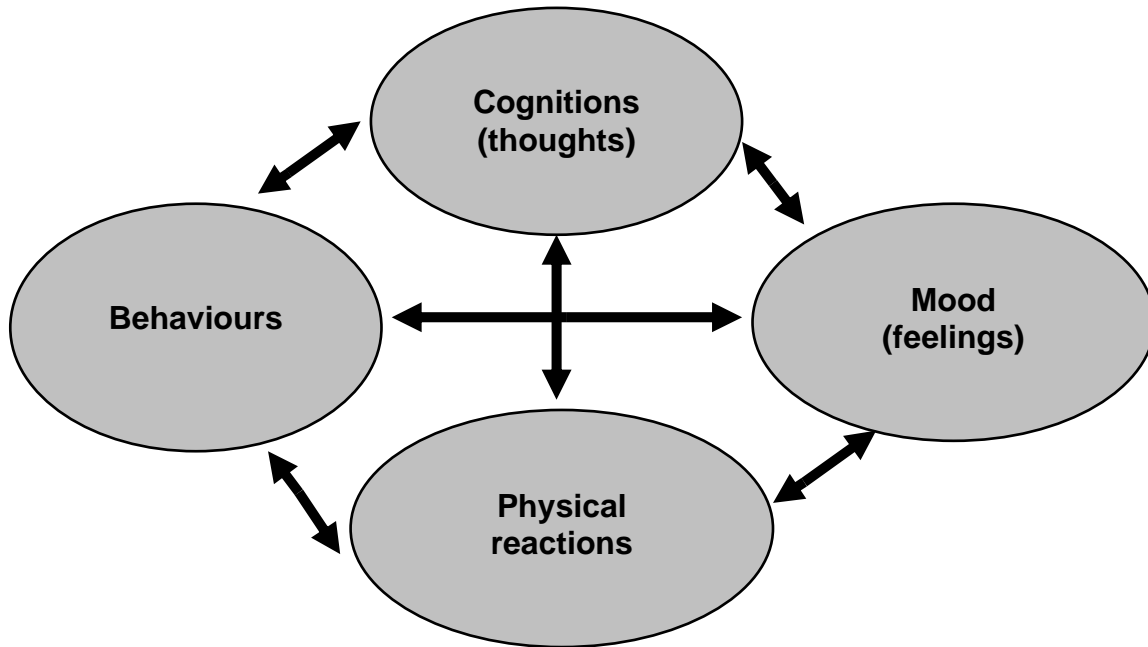
d. Stigma around Mental Health and Disability

- Attitudes to mental illness include the following: exclusion, abandonment, labeling, rejection, abuse, etc.
- Some common thoughts about disability:
 - PWD can't do anything (school, work, marry, have children, etc.)

- disabilities come from witchcraft, curses, parents' mistakes, etc.
- PWD are not intelligent
- PWD are not sexual beings (or shouldn't be)

2. THE COGNITIVE BEHAVIOURAL MODEL

- A positive change in any area will affect the other areas



a. Examples of Unhealthy/Dysfunctional Behaviours

- Aggressive behaviour
- Withdrawing from others too much
- Overuse of alcohol or drugs
- Being controlling of others
- Procrastinating
- Doing dangerous behaviours (e.g. driving drunk)

b. Examples of Unhealthy/Dysfunctional Thoughts

- *"I am not loved"*
- *"The world is a dangerous place – if I trust in others, they will harm me"*
- *"Since I have a disability, I cannot work"*
- *"There is no use in trying- everything I do fails"*
- *"I am only a valuable human being if I"*
- *We all have dysfunctional thinking patterns at times!*

c. Why Does Unhealthy/Dysfunctional Thinking Matter?

- It can negatively affect mood
- It can cause stress and anxiety
- It can lead to maladaptive behaviours (behaviours that do not help)
- It affects relationships

- It stops people from being free and reaching their full potential. (it is the right of everybody to be free unless a criminal. A philo once said “man by nature was born free but ever where in chains”)

3. THE APPLICATION OF CBT

a. How Does CBT Work?

- Clients learn about the relationship between their thoughts, moods, bodily reactions, and behaviours
- They learn skills to make changes in each area, which then affects the other areas
- E.g., thoughts - look for evidence that negative thoughts are untrue
- E.g., behaviour - try out new ways of doing things
- E.g., bodily reactions - learn relaxation techniques to relax the body

b. How Does CBT Empower People with Mental Illness?

- The relationship with the therapist is equal and collaborative; the client is seen as an expert on him/her self
- The focus is on learning skills to eventually manage one’s own thoughts and behaviours independently, so that one can continually improve and maintain one’s own mental health
- As the client is freed from dysfunctional patterns, he/she is free to reach his/her full potential

4. PROJECT

a. Purpose

- A partnership between the CBCHB and the CWG to discuss whether CBT is appropriate for Cameroon, and if so, how it could be used

b. Methods

- 30 Cameroonian chaplains and social workers in 3 locations participated in workshops to learn basic CBT and participate in focus groups to discuss the potential of CBT

c. Results

- The CBT model:
 - is also true for people in Cameroon and it is appropriate for the culture
 - people in Cameroon tend to focus more on emotions (rather than thoughts) as being the force behind behaviour
 - would be helpful for these individuals to learn more about how thinking plays a role in behaviour, through CBT
- How CBT can be used:
 - CBT approach may need to be simplified and/or modified for some clients
 - much of the language may need to be modified
 - many people will not have the literacy skills to do some of the exercises
 - many people will not want to do homework traditionally used for CBT, or won’t be able, but some will be willing and able

- might be useful for non-traditional problems (e.g., HIV/AIDS)
- The collaborative relationship in CBT:
 - some people in Cameroon are reassured by authority, and will feel uncomfortable at first with an equal partnership
 - once they get used to it, they may really see the benefits and enjoy the equality
- Learning and using CBT:
 - at personal levels, CBT helps us to fight our depressive moods, and also reduces maladaptive behaviours
 - our clients who successfully go through CBT turn to be useful not only to themselves but also to others in same condition.
 - when clients occupy their minds with activities during CBT, there is always decrease in depressive moods.(relaxation techniques)

5. CASE STUDIES

a. Comfort

- A 32 year old woman came to the hospital complaining of headaches, watery stool, dizziness, frequent fevers, and was looking worried, angry and aggressive. Expressed monetary hardship and had two children.
- Referral to SW for aggression and monetary hardship
- Recent Events:
 - husband just died few months ago (HIV + case)
 - brother in-law wants her as wife by force (or as tradition says)
- After CBT in 3 sessions with brother in-law the situation changed:
 - feelings – sad, worried, angry
 - behavior – withdrawn, aggressive, crying
 - physical reactions – dizzy, tired, headaches
 - cognition – I could die, I am unlucky, I will die, God hates me etc

b. 16 Year Old Girl

- A girl was taken to the hospital with the following complaints: dizziness, headache, loss of appetite
- Recent events:
 - had recently gone as a house help for someone else
 - had a scar on the face as a result of a fire accident
 - one child in the house was always running away from her
- She reported the following:
 - feelings – sad, worried, rejected, uneasy, angry
 - behaviors – withdrawing, complaining, weeping, aggressive
 - physical reactions – dizziness, headache, loss of appetite.
 - cognition – I look ugly, people run away from me, I'm rejected
- After going through CBT, she now feels that she can interact freely with others since she has the potentials of any other human being

c. Changing Attitudes about Disability

- E.g., A family where the parents do not send their child with a disability to school because they believe he/she could never work
- E.g., A person with a new disability who is very afraid of the future, so withdraws to his/her house
- CBT would work on changing these feelings/cognitions and lead to better function and participation for the PWD
- CBR workers at Mbingo Baptist Hospital also learned about CBT and are experimenting with its use for their clients and clients' families

6. CONCLUSION

- Effective use of CBT as an empowering tool for PWD enhances full participation and inclusion in society thus, fostering dignity and justice

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SESSION 3: STAMMERING AS A DISABILITY

Joseph Lukong, Speak Clear Association of Cameroon

Stammering also known as stuttering is a speech or communication disorder. The person who stammers (PWS) knows precisely what he wants to say but is sometimes unable to say it due to involuntary repetitions, prolongations, or cessations of sounds. It is universally accepted that 1 percent of a given population is made up of PWS. In our society speech is considered as one of the most important forms of interpersonal communications

The presentation highlighted some of the arguments in favour of this view by drawing on the presenter's experiences in working for PWS in Cameroon; heading a genetic research project on stammering that targets some families in Bui Division of the NWR; and from his involvement with the International Stuttering Association (ISA). The presentation also shared information from the Bill of Rights for PWS developed by the ISA in 2000.

1. WHAT IS STAMMERING?

a. Definition

- Is a communication disorder or disability
- Characterized by speech dysfluency affecting the rhythm of speech
- PWS knows precisely what he wants to say but is sometimes unable to say it due to involuntary repetitions, prolongations, or cessations of sounds

b. Prevalence

- Universally accepted that 1% of a given population is made up of PWS
- It occurs in all racial groups – but some groups have a higher population of stammering (e.g., some tribes in Central and West Africa)
- It is more common in males than females (ratio 4:1)
- There is a genetic contribution to this disorder
 - stammering runs in some families
 - first degree relatives of PWS have an increased risk for this disorder

2. STAMMERING IN CAMEROON

- Estimated ~160,000 PWS in Cameroon
- Difficult situation for PWS due to:
 - absence of Speech and Language Therapists or other professionals
 - lack of adequate information as to the causes and treatment of the disorder
- PWS resort to traditional and at times crude methods of treatment that are available
- Public is often insensitive to the plight of PWS
 - often the subject of ridicule by society or portrayed as fools or abnormal human beings by comedians
 - significant stigma and negative public attitudes towards stammering

3. IS STAMMERING A DISABILITY?

- General consensus amongst PWS, speech and Language Therapists, and speech researchers that stammering is a disability
- PWS consider their stammer as a disability which closes the door to them for interpersonal, academic and professional development and fulfilment
- *“As a person who stammers who has lived with this disorder for the past 38 years, I consider my stammer as a disability which has held me back from living the life I would have loved to. I am unable to obtain a job because of my inability to speak well under the stress of an interview.”*

4. THE RIGHTS AND RESPONSIBILITIES OF PWS

a. A PWS has the Right to:

- Stammer or to be fluent to the extent he or she is able or choose to be
- Communicate regardless of his or her degree of stammering
- Be treated with dignity and respect by individuals, groups, companies, government agencies, organizations and arts and media
- Have accurate information about stammering
- Equal protection under the law regardless of his or her degree of stammering
- To be fully informed about the therapy programs including the likelihood of success, failure and relapse
- Choose to participate in therapy, to choose not to do so, or to change therapy or clinician without prejudice or penalty

b. A PWS has the Responsibility to:

- Understand that listeners or conversational partners may be uninformed about stammering or may hold different views about stammering
- Advise listeners or conversational partners if one needs additional time to communicate
- Participate in any therapy of his or her choice
- Do what ever one can to overcome life handicaps that have occurred because of stammering
- Regard and treat others with disabilities or handicaps with fairness, dignity and respect
- Be conscious that he or she has the power to promote awareness about stammering and its ramifications

5. LEGAL FRAMEWORK

a. Is Stammering considered a disability in legislature?

- Stammering is a legally defined disability in many countries of the world
- In Cameroon, like many developing countries, this is not the case yet
 - viewing disability through the medical lens concede that PWS may face social exclusion, this however is not commonly viewed as a disability
 - the medical understanding of disability would include conditions such as blindness, deafness, being impaired in walking or having a diagnosis of epilepsy, diabetes, cancer, etc.

b. International Disability Movement

- asserts that people are disadvantaged not only by their impairments but by the limitations imposed on them by attitudinal, social, cultural, economic and environmental barriers to their participation in society
- Americans with Disability Act covers PSW
- United Kingdom Disability Rights Commission and the Disability Discrimination Act covers stammering
- British Stammering Association took the position that all PWS should be legally protected against unjustified discrimination due to their speech

6. ASSOCIATIONS THAT SUPPORT PWS IN CAMEROON

a. International Stuttering Association

- Umbrella organization for stuttering self-help and support groups from throughout the world
- Takes the view that stuttering IS a disability
- It is for individuals to decide whether the stuttering is seen as a disability to be lived with or a disability to be overcome
- Seeks to cooperate with various bodies to change governmental and social perceptions about stammering

b. Speak Clear Association of Cameroon

- Non profit organization of PWS in Cameroon
- Recognized by government services in Cameroon
- Has ~ 543 members in chapters across Cameroon (NWR included)
- Is a member of the International Stuttering Association
- Work principally on stammering awareness, self help, treatment and research
- Identified 3 large polygamous families in Bui Division of the NWR who have several members who stammer
- Engaged in a genetic research project on stammering with the national Institutes of Health and 367 members have taken part in this research

7. THE WAY FORWARD

- We hope that this conference is a start of a process of networking and collaboration with other sister disability organizations in Cameroon
- Stammering needs to be recognized as a disability and legislation needs to be enacted that recognizes the disability movement in Cameroon
- The objective of making the UN Convention on the Rights of PWD a reality in the NWR of Cameroon needs to be realized

“But stuttering becomes a disability or handicap as soon as it stops me from leading a satisfactory life. And what a satisfactory life may mean very different things than what it means to you! It may be getting your dream job ... it may also mean finishing your sentences by yourself, no matter how long it takes. Some of us PWS get bullied and some are totally socially excluded. Some of us simply give up on life.”

- Anita Blom, Chair of Swedish Stuttering Association

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KEYNOTE ADDRESS 2: THE RIGHT TO EDUCATION FOR CHILDREN WITH DISABILITIES IN THE NORTH WEST REGION OF CAMEROON

Nungu, Magdalene Manyi, Founder and Director, Centre for Empowerment of Females with Disabilities (CEFED)

The focus of this keynote address was on the right to education for children with disabilities (CWD) from 2 to 18 years old in the NWR. Education is any activity which impacts knowledge and skills, therefore, education could either be formal or informal. UNESCO states that 90% of CWD in developing countries do not attend school. Therefore 90% of CWD in NWR by implication do not attend school.

1. UN CONVENTION OF HUMAN RIGHTS

a. **Article 24: The right to education for persons with disabilities**

- This article states that all state parties should recognize the rights of persons with disabilities to education, without discrimination

2. EDUCATION SYSTEMS THAT SUIT THE NEEDS OF CWD

a. **Proper Assessment of CWD**

- Involves a multidisciplinary team of experts - a regular class teacher, student's parents, special educator, the student, speech therapist, occupational therapist, counselor, psychologist, principal, physiotherapist, etc.

b. **Individual Education Plan (IEP)**

- The multidisciplinary team will assess the child and develop an IEP which spells out a list of instructions on how best the child can learn and how best the teacher can teach, considering his unique educational needs

3. CURRENT SITUATION IN THE NWR

- The government through the ministry of social welfare has granted free education for PWD and their children
- Inclusive schools are still a far fetched phenomenon
- A few special education schools exist, some informal
- No multi-disciplinary assessment to assess the educational needs for CWD
- In the majority of schools, curriculum is not adopted to meet the needs of CWD
- School environments are Inaccessible
- Attitude and stigmas surrounding the education of CWD decrease the self esteem and motivations of these students
- Teachers are not trained on special educational principles and practices making inclusion difficult
- Little awareness on disability related issues on special needs.

4. THE FUTURE OF THE EDUCATION SYSTEM IN THE NWR

- Intensive training of teachers on special educational principles and practices should be done

- Proper assessment should be carried out by a multi disciplinary team in order to develop an IEP for individual students with disabilities
- The regular school curriculum should be modified, adopted or redesigned to meet the needs of individual students with disabilities
- The environment should be adapted to meet the needs of students with disabilities
- Lots of awareness on disability related issues should be raised so that attitudes, stigma and misconceptions be removed
- The government should revise the educational policies of Cameroon to be inclusive and to take care of all the educational needs of all the people group
- Sign language taught in all school as one of the official languages
- Braille resource rooms and experts set up in all government schools to enhance learning for the visually impaired
- Adequate research should be carried on disability related issues and findings disseminated

5. CONCLUSION

- Education is the fundamental right of PWD; denial of the right to education will lead to the denial of all the rights
- Need to increase efforts to put structures and policies in place, to enhance the education of CWD in the NWR
- This will give them an opportunity to gain knowledge and useful skills for job opportunities, earning an income, improving standards of living and independence
- It will also boost up their self images contributing in mainstream societal activities thereby bringing development in NWR

SESSION 4: A RESEARCH STUDY ON THE REPRODUCTIVE HEALTH EXPERIENCES OF WOMEN WITH DISABILITIES IN THE NORTH WEST REGION

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A woman's reproductive system is the sexual and reproductive parts of a woman, be it inside or outside of the body. These parts are the same for all women. Often people do not want to talk about reproductive health issues with women with disabilities (WWD) because it is seen as a private matter and it is not common to discuss these issues. This presentation stressed that it is important to discuss this topic and recognize the unique issues that WWD face.

1. INTRODUCTION

a. UN Convention On Human Rights

- Article 6: Women with Disabilities
 - countries will make sure that women and girls enjoy full and equal human rights and freedoms
- Article 23: Respect for Home and Family
 - countries will make sure that PWD have the same right as other people to marry, have children, to decide how many children to have and when to have them
 - countries will make sure that PWD get information and be educated on reproductive and family planning, and they should get help to understand this information

b. Background Information

- No known research in NWR that focuses on reproductive health for WWD
- An assessment of the strengths and needs of WWD in the NWR was conducted in 2007 (Kiani, 2007; Kiani, in press)
 - one of the outcomes of this study was the need for further examination of the experiences of WWD in specific areas of their lives, including reproductive health

c. Barriers to Accessing Health Information and Services

- Cultural norms e.g. beliefs about disability
- Service limitations e.g. few or no services available
- Lack of mobility aids
- Lack of communication skills by staff
- Inaccessible buildings
- Marginalization in the community
- Illiteracy and lack of education
- Gender inequality (Yousafzai *et al.*, 2004)

d. Why it is Important to Discuss Reproductive Health?

- WWD are just like other women (e.g., want to be healthy, have children)
- WWD tend not to talk about these issues with their families and health care providers - this potentially puts her health at risk
- Families of WWD may feel ashamed to discuss these issues
- WWD face sexual violence and other forms of abuse

2. PURPOSE

- To understand the experiences that women with physical disabilities have with reproduction and reproductive health care

3. METHODS

a. Participants

- 8 women with physical disabilities in Bamenda and surrounding area
- Basic demographic information was collected from each woman through the use of a check-off form
- Confidentiality was very important, no names will be disclosed
- Women who were not clearly competent to provide consent were excluded from the study

b. Data Collection

- Information was gathered through semi-structured interviews
 - participants were asked the same questions but there was also conversation about what the women said
 - interviews were transcribed verbatim (every word was written down so that there was an accurate record)
- The team had discussions with health care providers and completed hospital observations
- Researcher field notes were recorded

c. Data Analysis

- The codes were put together and then analyzed for key themes
- A composite description of the interviews and reflections was developed
- The composite was returned to the participants for review and discussion

4. RESULTS

a. Participant Demographics

- Age range: 27 to 45
- 6 Self-employed; 7 single and 1 married; 5 had children

b. Unique Reproductive Health Experiences are Influenced by:

- The reproductive health education and information they received
- Their feelings around their reproductive health
- Their social support network and community perceptions of WWD
- Their romantic relationships

c. Understanding of Reproductive Health

- “I did not really know much. In school we were not doing home economics.....I just learnt about [pregnancy] when it happened.....It was after I put to birth that they explained that to me.”

d. Sexually Transmitted Infections

- *“WWD don’t go for check ups, because of the way they grow up. They didn’t grow up with the education that you need to go and check yourself, they didn’t know about their self, they didn’t know. They pick up the information, ... so they don’t see it as important to go to the hospital to ask.”*

e. Pregnancy, Birthing and Motherhood

- *“I tell my mother when my pregnancy was already 6 months....I was afraid that they might beat me and send me out of the house.*
- WWD reported fears including whether:
 - they could successfully carry the pregnancy
 - their disability would affect baby’s growth and development
 - their disability would be transmitted to their child
 - the pregnancy or childbirth would kill them
 - they could afford the medical costs of having and raising a child
 - their partners would abandon them because they were pregnant
 - their parents would accept the pregnancy
 - their family’s reaction to the pregnancy caused them to keep their pregnancy a secret until they were in their second or third trimesters

f. Availability and Access to Supports and Services

- *“People were always around me to [help take care of the baby] for me. My mother, my auntie, my brothers and sisters, cousins, everybody was very excited. Everybody in the village they found out that I gave birth and they are coming to see what kind of baby that I have. So it made me to feel, it gave me a very big joy in me.”*
- *“Can you imagine a mature woman like myself being carried to enter the doctor’s office because I want to receive medical care? Which is very, very disgraceful and challenging”*

g. Impact of Relationships

- *“It is my condition that has hindered me from getting married.....because here in the village men will look at you and say that you cannot even work or do anything. When most women are going to farm, if they married me now, how will they be living? They will have to be the one to do everything for you. That is why I am with no one, that is the problem that causes them not to come”*

5. CONCLUSIONS

- Participants had narrow understandings of reproductive health
- Many girls with disabilities do not receive basic health education
- Some participants had knowledge of contraception, while others did not

- Unplanned pregnancy was common and pregnancy was often feared
- Respondents reported both positive and negative responses from family and community members, health care workers, and health care centers regarding reproductive health
- Most health care centers are physically and financially inaccessible to women

6. RECOMMENDATIONS

- Develop support and health education for girls with disabilities
- Encourage families to inform their daughters
- Education of health care providers about how to provide services for women and girls about reproductive health
- Need to broaden the scope of the research to better understand the experiences of girls and women throughout the divisions and region with respect to health and reproductive health

SESSION 5: INVESTIGATION OF AN EPILEPSY EPIDEMIC IN MOMO DIVISION

Ambanibe Jerome Akeneck, President, Association of Orphans and the Disabled

Epilepsy is a major problem and an important cause of mortality and disability in developing countries. The incidence of epilepsy in Ngie, Momo Division of the North West Province is about 40%, significantly higher than in many other areas. The epilepsy in Ngie appears to be an early childhood onset seizure disorder that continues into adulthood. An epidemiological case control research study is currently underway to learn more about this situation. The hypothesis of the study is that the increased incidence of epilepsy is caused by neurocysticercosis, caused by *Taenia solium*.

This presentation described the reasons for the study, how the team came together, some of the benefits and challenges of conducting the study, and what has been learned to date. Recommendations for conducting similar research studies in the NWP were also presented.

The following is information about the definition and treatment of epilepsy that was provided by the presenter.

1. DEFINITION OF EPILEPSY

- Epilepsy occurs when a person has a 'seizure' two or more times
- The world statistics show that 1 out of 11 people have epilepsy
- In the case of Ngie, 1 out of 5 people have epilepsy (this is especially common with people between the ages of 11 and 25 years old)

a. Causes:

- Only 25-30% of the causes of epilepsy are known
- These include:
 - Brain damage during delivery
 - Insufficient oxygen at birth
 - It could also be inherited
 - Poor water sources
 - Tape worm that can be gotten from a pig that is poorly cooked
 - After math of illness like meningitis

b. Types of Epilepsy:

- There are many types of epilepsy; e.g., partial and generalized
- Partial epilepsy affects one side of the brain and when the person has a seizure one side of the body normally shakes
- Generalized epilepsy occurs on both sides of the brain, which is why a person who has seizure, the whole body shakes
- $\frac{3}{4}$ of the patients under our care fall under the generalized epilepsy
- Some of them start by a simple twist of the face/finger and later develop to generalized epilepsy, which means that the epilepsy begins at one side of the brain and gradually spreads to the entire brain

2. FIRST AID TREATMENT FOR EPILEPSY

- Do not keep the patient near fire for a seizure may occur and he/she may fall into the fire
- Do not allow the patient to go to take a bath in a stream because he/she may fall and drown
- Do not allow the patient sleep alone for epilepsy may occur in the night and he/she will suffocate due to poor positioning
- If the patient must sleep alone. Let the patient sleep near a door and tie a small bell to the door so that people will be alert when he/she will have epilepsy
- Do not put anything into the mouth of the patient when he/she has epilepsy
- Turn the patient to the side when he/she is unconscious
- Refer the patient to hospital

3. PREVENTATIVE MEASURES

- Any child with an illness should be taken to the hospital for proper diagnosis and treatment
- Cook/boil your pork until it is no longer pink
- Wash your hands with soap or any other detergent before and after eating and after using the toilet
- Boil water well, allow it cool down before you drink for people who do not have good/portable drinking water
- Disinfect any standing water around your house with palm oil mixed with kerosene or any other disinfectant

4. ANTI-EPILEPSY DRUGS (AED'S)

- Generally Phenobarbital 100mg is effective, cheap to buy, easy to administer and can treat all types of epilepsy
- There are a series of other AED's that go with specific types of epilepsy
- Patients are encouraged to consult a physician for proper diagnoses, treatment and side effects of the medications
- Currently we are treating 1500 patients with epilepsy across the NWR
- Our greatest difficulty is insufficient money to purchase drugs so as to get the treatment continuous through out the year

FEEDBACK ABOUT THE CONFERENCE

There was a wide range of individuals who attended the conference including: people with disabilities, rehabilitation providers, rehabilitation and education students, family members, disability group representatives, and many others.

At the end of the conference participants were asked to evaluate the conference by responding to the questions below.

1. Please list the three things you enjoyed most about the conference.
2. Please list the three things you enjoyed least about the conference.
3. Is there any thing about the conference you would like to see changed for the future conferences?
4. Is there any thing about the conference you would like to see remain the same for future conferences?
5. What topics would you like to see addressed in future conferences?
6. Do you feel this conference has been beneficial?
7. Please provide any additional comments about the conference or the speakers.

After responding to the questions individually, the participants formed small groups of 5-7 people to discuss their answers.

From the evaluation by the participants the conference was an overwhelming success.

In all, 94 participants evaluated the conference. Comments are presented in the table on the next page. Numbers in brackets represents the frequency of the answer.

Three things you enjoyed most	Three things you enjoyed least	Things you would like to see changed	Things you would like to see remain	Topics for future conferences	Was the conference beneficial?	Additional comments
The presentations were enriching and varied (92)	Question time was short (63)	More time for questions and answers after each presentation (63)	The mode of presentations (87)	Mental Health (34)	Learn much about disability issues (87)	Some presenters were fast thus making comprehension difficult (18)
Participants were active in asking questions (60)	Conference was not well publicized (32)	Contact churches to inform faithful about the conference (9)	Diversified nature of topics (71)	How people with disability can have access to jobs (18)	Learn that PWD have the same rights like able body persons (54)	Language used by some presenters was difficult to understand (13)
Time was respected (62)	The venue was out of town	The venue should be in central town (17)	Venue should be maintained (13)	HIV/AIDS and disability (24)	Learn to live with my disability (31)	Children of PWD should be invited (19)
The hall was spacious (50)	Only one type of meal was cooked (7)	Government officials should be persuaded to attend (23)	Organizers should be the same (55)		Learn proper terminology of addressing PWD (37)	Enlightened us about the UN Convention (29)
Power point presentations (16)	The microphone was faulty (41)	More partners and organizers should be included (12)				
Inclusion of medical students (24)		Conference days should be added (34)				
The organization was good (67)		Handouts should be given to participants (32)				
Made new friends (66)						

