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# RIGHTFUL REPRESENTATIVE

## Editorial

A few months ago, I had a conversation with Hannah whose twenty-two year old son Andrew has a moderate mental disability. Hannah and Andrew live in one of the East Africa coastal towns where festivities of all kinds ranging from weddings, birthdays, religious and public holiday communal parties are a common feature. Such parties are largely open to members of residential neighbourhood who are expected to assist in such chores as welcoming guests, serving food and at times entertaining visitors. It is often expected that each household in the neighbourhood should be represented in such a party. Hannah told me of an incident a few weeks before when such a wedding festive occasion had taken place in her neighbourhood. She was personally not able to attend but Andrew, in his usual stroll had found himself among the celebrants. Andrew, a neatly dressed and well trained young man in respect to such basic hygiene practice as washing hands after toilet, before meals and brushing his teeth was not afraid of mixing up with the neighbours who all knew him well. He was adequately socialised but his mental capacity did not enable him to understand order and programmes. During this particular occasion, the programme was rather long with speeches and entertainment before the meals. Andrew was hungry and could see all the food lined up on tables covered in serving dishes. Responding to the dictates of his hunger, Andrew stood up, walked to the front and greeted the bride and the bridegroom before turning to the master of ceremony with a request to be served with food. Someone from the crowd walked up to restrain him but realising that this was not going to be easy, one of the people responsible for serving quickly interjected and did according to his request. In the meantime onlookers who did not know Andrew could not understand this interference with the programme. Undisturbed, Andrew took his meal after which he again walked to where the soft drinks were kept and requested for one. One lady thinking that this is too much of interference run to Andrew's mother and requested her to come for him because he was interfering with the programme. Hannah asked the lady, "What has he done?" The lady explained exactly what Andrew had done and to her amazement, Hannah asked her, "What is wrong for anyone to



**Sam Kabue**

request for food if he is hungry?" She continued, "I see nothing wrong with what Andrew has done. Let it be understood that Andrew is there as a full and rightful representative of this family in the function. Unless there is anything else that he has done other than requesting to be served, let him enjoy the function like any other person there." Explaining her action to me, Hannah underscored the need to get the society understand the situation of people with intellectual disabilities. They are part of the human creation and have all the human needs including the need to belong and to be included. Andrew is one of the many thousands and thousands of people with mild, moderate or severe mental disabilities. Few have a mother with the kind of understanding that Hannah has. She is confident of the training she has given to Andrew and has accepted that he has the right to self-expression and a measure of

freedom. Whereas advocacy and activism by people with physical or sensory disabilities are features of the modern times, many of those with mental disabilities remain voiceless and unable to understand their world. Those with severe and to a large extent those with moderate disabilities do not understand that they face problems unless those problems have to do with hunger or pain. This has often been a reason for their being neglected and ignored. Our neglect for such people is not only on the basic needs of food, shelter and clothing. Their need for belonging is never a factor in their care. The spiritual realm is also a problem especially in the way spirituality has been intellectualised in our churches. The procedures for spiritual initiation call for intellectual activities like attending baptism and confirmation classes. Those unable to undergo these processes tend to be seen as though they are less deserving of the grace of God and unable to reach God's acceptable standards. Self-confession as a basis for acceptance in the Christian faith tends to leave out those in this category. If the Bible says that we are all created in the image of God, we cannot change this fact for the reason that one does not have adequate intellectual capacity to confess and partake in the initiation processes. The church in its theology will have to seek the answer and hence the ways to deal with the spirituality of those who lack the capacity to intellectually understand these processes. In the meanwhile, these are part and parcel of God's people and the church will not be complete without them.





# Summary report on EDAN Reference Group meeting

## Word from the Director

In his address Rev. Samuel Kobia said that WCC recognises the difficulties EDAN encounters in trying to bring about understanding and that a lot more need to be done in this area. He pledged that WCC will listen with interest recommendations coming from that meeting and EDAN in general. Sighting the recent attack on the world Trade Centre and Pentagon he said that WCC recognises the vulnerability of people with disabilities during such events of violence; for instance what happened to people with disability as everyone was running away? Rev. Kobia posed adding that, the greatness of a nation is or should be judged by the way they treat their people with disabilities, and this include the church as well. He noted that the formation of EDAN at Harare was a historical point in the way ecumenical work on disability with WCC was to go and he promised that WCC would continue to support this work.

He pledged that WCC would increase its efforts to provide an ecumenical-enabling environment if this work is to be carried out. Rev. Kobia also promised to take upon himself to do some fundraising for this work to rise up against the challenge of financial difficulties and avail funds for the planned work. He reiterated that EDAN has full support from the council and the staff.

On behalf of Reference Group members Kathy Reeves thanked WCC through Rev. Kobia for their support to EDAN.

## Regional Reports

### LATIN AMERICA

By Noel Fernandez, EDAN co-ordinator Latin America

Since a meeting in Nairobi, Kenya from December 1<sup>st</sup> to 8<sup>th</sup>, 1999, in which I was given the responsibility of working in the co-ordination of the network in Latin America, I assumed the task with joy and decision.



Noel Fernandez

## Contacts Carried Out

I have sent letters informing on the objectives and projects of EDAN to:

- Rev. Israel Batista, General Secretary of the Latin American Council of Churches (CLAI).
- Rev. Dr. Walter Altman, President of the CLAI, until January 2002
- Rev Dr. Hector mendez, Cuban Presbyterian pastor and member of the Central Committee of the IMC
- Rev Carlos Emilio Ham, Vice president of the Christian Conference of Churches of the Caribbean and at the moment Executive of the director of Mission and Evangelization Commission of IMC
- Dr. Ofelia Miriam Ortega, principal of the evangelical Seminar of theology of Matanzas, Cuba, and ex official executive of the IMC
- Dr. Reinerio Arce Valentine, president of the Cuban Council of Churches
- MA. Elio Munoz and Lic. Antonio Mendoza, leaders of United Biblical Societies who were very interested in the work of EDAN in Latin America and they accepted us to send them work projects to materialise their collaboration.

With all these people, also, I have sustained personal conversations to make them aware of our objectives and how important and necessary their support is to us. Some of the activities that have been carried out jointly with other groups include:

### Second Latin American Meeting of Christian Deaf Persons and Interpreters for the Deaf

We were able to develop this event in Cuba attended by Christian deaf persons and interpreters for the deaf from Chile, Venezuela, Dominican Republic, a host country delegation and visitors from United States. It was favourable opportunity to state the objectives of EDAN.

### Visit to head quarters, Latin American Council Of Churches, Quito, Equador

During my visit to that country in September 2000 I had the opportunity to visit the offices of the Latin America Council of Churches in Equador and talk to the General Secretary, Rev. Israel Batista and other leaders, about the project of making a Latin American Consultation on the disability, role of the churches and future strategies.

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## Interview

An interview carried out by the engineer Manuel Quintero, director of Communications of the CLAI, to me appeared published in the *Rapidas* (Quick), CLAI magazine on February 2000. In which I talked of EDAN.

## EDAN Consultant visit

In July 2001 we had the privilege of having Mr Samuel Kabue visiting with us in our country together with Dr. Gordon Cowans and Miss Anjeline Okola, where we took part in conversations and activities that were to reaffirm what is known about EDAN in the country.

## Official Conversations

I have had official conversation with Dr. Reinerio Arc Valentine, president of the Cuban Council of Churches and with other leaders of that institution and with Dr. Hector Mendez, member of the central committee of the IMC.

I have had also wide exchange of experience with the president of the three associations NGO, s for people with disability in the country: Association of the blind, deaf and physically handicapped persons. Also I had fruitful exchanges with pastors and leaders that work with people with disability from some churches in the country.

## Activities

We participated in worship services in the First Reformed Presbyterian Church of Havan and in the William Car Baptist Church of this city. In both of these visits we explained about EDAN.

Mr. Samuel Kabue preached and offered information about EDAN in the weekly worship service that the officials, leaders and employees of the Cuban Council of Churches have every Monday. A visit was made to the Cultural and Recreational National Centre of the National Association for Blind Persons of Cuba.

I had the privilege of travelling together with Mr. Samuel Kabue and Miss Anjeline Okola to the Caribbean where Dr. Gordon Cowans welcomed us and organised an excellent program of activities that included the visit to the institutions, churches and people related with the disability in Jamaica, Trinidad and Tobago. Later on we travelled to New York, United States to sustain important conversations in the head quarters of the National Council of Churches of Christ. There we were assisted by Rev. Joe Leonard,

official of this institution who also programmed a wide plan of activities, very profitable for the development of EDAN in the region.

## Latin American Consultation on Disability, Role of the Churches and Future strategies

With the support of the General Secretary of the CLAI and their office in Quito, Ecuador we set ourselves to the task of organising this event.

### First trial

Originally it was planned that the consultation would be carried out parallel with the General assembly of the CLAI, in Barranquilla, Colombia, from January 13<sup>th</sup>-19<sup>th</sup> 2001. This would allow also a space of around 15 minutes in the Assembly to disclose objectives and plans of EDAN. Due to communication difficulties we were unable to achieve such goals.

### Second Trial


The consultation was planned to take place between 8<sup>th</sup>-9<sup>th</sup> of May 2001 in Caracas, Venezuela. The difficulties in granting Visas for some of the participants forced us to cancel it 48 hours before its beginning.

### Third Trial

To the suggestion of CLAI office, Quito was chosen for the celebration of the Consultation. They accepted all responsibility in the internal organisation of the event, visa arrangements etc. The consultation was scheduled for 18<sup>th</sup>-21<sup>st</sup> July, 2001.

I should acknowledge that the presence in it of Mr samuel Kabue, Consultant of EDAN, Dr. Gordon Cowans, co-ordinator for the Caribbean area, and Miss Anjeline Okola, EDAN administrator offered to the event a substantial support that all the participants appreciated.

The presence of Rev. Israel Batista, General Secretary of the Latin American Council of Churches, his valuable information on the objectives and the programs of this council and the political and religious position of Latin America that he referred about constituted a valuable contribution as well as meritorious recognition of EDAN in the region.

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The Consultation has been a magnificent starting point to work deep in Latin America area, and especially in the evangelical and/ or protestant churches in defence of people with disability.

### Future projects

- i) **Christian Indigenous Blind People’s Meeting**  
For the first week of July 2002, we scheduled to celebrate in Riobamba, capital of Chimborazo province, in Ecuador, a meeting of Indigenous Blind men and women of the Evangelical Churches located in the mountainous area, especially of the Quechua ethnic group that is the most extended in the region. This will be the first event of its kind in Latin America.
- ii) **Second Latin American Consultation on Disability, Role of the Churches and Future Strategies**  
A project has been elaborated that is already circulating for the celebration of the second Latin American Consultation on the Disability, Role of the churches and future strategies, to be held from 11<sup>th</sup>-14<sup>th</sup> September 2002 in San Leopoldo, state of Puerto Alegre of South, Brazil. The realization of that one will have support of the Evangelical Church of Lutheran Confession of Brazil and the southern diocese of the Anglican Church of the same country, who will co-operate in the organisation and the financing of the event.
- iii) **Second Latin American meeting of the Deaf Christian Persons and Interpreters for the deaf**  
We will offer all kind of help to the organisation and realisation of the second Latin American meeting of the deaf Christian persons and interpreters for the deaf that will be held in Cuba, in the second half of November, 2002.

### Latin American Network

A Latin American Network comprising of 18 people is now in place.

### Difficulties

For better acting of my role as co-ordinator for Latin America I have confronted difficulties in the area of communications, not having an own electronic mail box, so depending for the communications on the good will of other people. This matter has slowed in certain occasions the communications. This situation is on its way to be solved.

### The Caribbean

by Gordon Cowans, EDAN co-ordinator, Caribbeans

Working with Noel has been inspiring in the way this could bring about the breakdown of language barriers. Turning to the Caribbean, there has been lack of co-ordination of the

islands getting the contact across these small many islands. Working out an approach has been one of the pre-occupation. One way is to develop strong linkages between the disability and the various islands. Even in a



Gordon Cowans

small country like Jamaica, there has been fragmentation of the disability movement and Dr. Cowans has started working on bringing these groups together and bringing awareness on the Churches, the government and various boards that deal with disability. The approach to deal with disability work includes activism. Dr. cowans has been involved in development of the National policy. Six islands in the Caribbean’s have policies and part of collaboration is to see how these policies are operating in different islands. Although for instance Trinidad and Tobago has been working on their policy since the 1980’s but has not been discussed in Parliament as they are thinking in terms of the potential cost of accepting these views. Trinidad does not want to participate in a policy that does not have the budgetary support to meet its obligation. Jamaica on the other hand has gone rather quickly without considering the financial implication. Awareness on increasing awareness has been another concern and deepening Churches response. The focus for Caribbean is not just by churches but also within the secular organisations. There is a need to create a network between various organisations of the disabled. The work of the Caribbean conferences has also been important. In July, the visiting team called on the conference senior staff in Jamaica and Trinidad. The visit of the consultant coincided with a wide range of activities and meetings that had been organised before.

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Discussion with the United Theological College of the West Indies was started during the visit. This is our plan towards the effort for theological reflections with Africa and Europe. Response from different denominations is another step in our work

## North America

by *Kathy Reeves, EDAN co-ordinator North America*

Churches in US have started articulating disability through theological statements. There is even an association of physically challenged Ministers. In the United Methodist church, there are four yearly conferences. Through these a lot of documents have been written on faith statements. A lot of Churches have been doing some work and the argument that access need not be made because there are no people with disabilities in that particular church has been going on. The development of the American with disabilities were not quite involved in the development of the legislation. The secular communities felt that the Churches were not doing much. The National Council of Churches has now established an annual forum where various denominations get together to share and discuss what they are doing. This group has started working with schools of theology to start building a faith based approach to disability work. In general, people have felt less accepted by the Churches. The disability community has gone through the ADA (American with Disability Act) and has noticed that it is not quite relevant to the churches because of the separation between the Church and the society. There is a formation of network of Church leaders with disabilities. There is a national Committee on deaf ministries as well. One concern is the decline of the work on disability from the early 1990's as compared with the present situation. The decline is related to funding and this is something we need to examine. The question is how we can ensure that Churches do not use the excuse of funds to ignore work with persons with disabilities. The globalisation and market economy is relegating the justice work to less importance and this needs to be taken to the Churches



*Kathy Reeves*

through WCC. EDAN could use what the Churches and theological institutions in the US have achieved to network it with the rest of the regions.

## Middle East

by *Elie Rhaban*

The appointment of the Middle East region began after the identification of Mr. Elie Rhaban early in the year. There has been very little knowledge about the network and how it should work. Rhaban has travelled to Syria to promote the network. There were wars in the region and this is a hindrance to the work. A number of meetings have taken place but not much has been covered. A lot of what has happened is attributable to Lina Muckeiber. It will be necessary for WCC to work out some networking possibilities.



*Elie Rhaban*

There are about 40 thousand disabled people in Lebanon alone. A meeting has been held with different groups. The meeting would like to see these groups come to EDAN and more knowledge is required to understand EDAN and how it works. The need for EDAN to be a barrier breaking frontier between disability organisations and this affects not only Middle East but also other regions. The idea is to integrate the many fragmented situation of the disability movement. We need to understand what brings about these barriers and how in openness we can deal with these barriers.

## Africa

by *Abraham Berinyuu, EDAN co-ordinator, Africa*

Not a lot can be said in Africa mainly because of the heavy responsibilities that the co-ordinator has. He was unable to come to Nairobi for the Eastern Africa Federation decade meeting. The secular groups are well organised and we need to see how we can work with these groups. The co-ordinator however feels the

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need to give attention to the Church leadership. In this respect, some contacts were made during the All Africa of Conferences of churches. The problem is also the way Churches seem to ask as to why disability issues are being brought in today in



*Abraham Adu Berinyuu*

a different way from in the previous years. What this indicates is that the issue needs to be seen at the level of a social issue. The co-ordinator is of the opinion that there is need to deal with specific individuals since letters only end up in files. A database has been prepared for Council's of Churches and church leadership. There have been attempts to get contact persons even in these churches and Council of Churches. The division between English speaking and French Speaking countries has brought a language barrier. The co-ordinator has tried to collect information on Councils of Churches in French speaking countries. The decade to overcome violence has been another concern. The co-ordinator has participated on a luncheon to launch the decade and this was to take place and at the same time address peace issues. The idea of raising the connection between violence and disability is another concern. The co-ordinator however missed the luncheon as he was in Sweden on a scholarship on peace and reconciliation. The Council of Ghana is having its own internal problem which it is not able to address. The hope is that during the General assembly of AACC next year November, we could bring these issues to the Conference. The issue of influencing theological institutions has been in his mind and it is hoped that the issue can be brought in as a social ethic issue rather than just a counselling issue. In terms of Church networks dealing with disability, there has not been any particularly in West Africa. All we need to know is that at educational level, there seems to be not much differentiation between people with disabilities and others. They go through the same processes and do the same examination. We need however, to know that access in Churches and Church institutions is a problem. Awareness on access is a major issue in our Churches in Africa.

## EUROPE

*by Pal Gado, EDAN Co-ordinator of Europe*

He began by confessing that not much has been done. He is overwhelmed by the size of the European member Churches. Pal's opinion is that in our work, we should begin with the standard rules and more specifically rule

12 on how the church should organise themselves. We also have the European Union with 11 countries with more having chances to enter. They have been discussing the standard rule, which could be placed in the



*Dr. Pal Gado*

centre of the activities. There was a meeting in Hungary in July this year where standard rules were again the subject. As EDAN representative, the Co-ordinator admits that he has not done much. It was recommended that a consultation in Europe be organised to bring people together to discuss. Such a consultation should be held here in Geneva to interest The Conference of European Churches in this respect. It is also important that Simone and Arne get involved to bring together their efforts into this work. The first most important is to get the four persons from Europe together at the earliest possible time.

## ASIA

*by Joseph Ying Bo, EDAN Co-ordinator, Asia*

He had already sent a CD containing his work over the last 5 years. They convinced the Presbyterian Church to have a day of the Disabled and to have the Church consider persons with disabilities on this day. The Presbyterian Church is the biggest denomination in Taiwan. A letter was sent to the over 2000 churches. Some materials were prepared from a booklet from Joni and Friends. These materials included Bible study materials. The Co-ordinator spent a lot of time translating these materials into

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Chinese. A lot of work was done to prepare these materials into Chinese and to make them official document for the Presbyterian Church. These materials were to be distributed to the Churches. The Church in Taiwan is still viewing disabilities from the perspective of charity where the Church thinks that giving people money is enough. The Co-ordinator has just received a report from the Government on statistics. There are 711,000 people with disability out of about 23 million. This is 3.23% of the population. There is 9 years compulsory education. More than 903 people have more than 9 years of education. Among people with disability, those under 9 years are 74 per cent. This is because most of the schools are not accessible. In Taiwan, less than 20 per cent of people with disability have jobs. Specifically only 19.1 per cent have jobs. Thus most of the people with disabilities are unemployed. This means that the living conditions of people with disabilities are very poor. The situation is getting worse because many companies are moving to china because of the high wages in Taiwan. The Christian



*Joseph Tsai Ying Bo*

population in Taiwan is only about 2 to 3 percent. The people with disabilities who are Christians are even less. The co-ordinator has tried to get those people together but it is very difficult because they are few but also political situation between Taiwan and China has created a problem because every meeting is seen in a very suspicious way. Thus organising the network for Christians is rather difficult. Language is another problem between the Asian countries. Not as many can communicate in English. Those which can include Philippines and Malaysia. The first thing here will be to put together a network and then try extending to other countries. The co-ordinator is in touch with a lady in Malaysia who is on wheelchair and there may be opportunities to share EDAN in that country. The Co-ordinator has been to Philippines where he tried to share about EDAN and there did not seem to be a lot of enthusiasm on this.

## RESOLUTIONS

The Reference Group meeting resolved to have 3<sup>rd</sup> of December as a day for the disabled in the churches to coincide with the International Day of the disabled. It was agreed that a communiqué to all churches and ecumenical organisations be released calling upon them to have some celebrations on this day. Activities for the day were suggested to include visiting persons with disabilities and inviting people with disability to participate in the churches. Pal Gado was requested to put an advert in the DAA newsletter for people in Europe who could be interested to work with EDAN.

# EDAN ACTIVITIES HIGHLIGHTS FOR YEAR 2001

The end of the year 2001 marks the second year since EDAN was formally incepted in Nairobi, Kenya. Since then the network has expanded as has its operations around the world. So far regional structures have been put in place complete with a volunteer Regional Co-ordinator in each of the seven regions namely: the Latin America, the Caribbean, North America, Middle East, Africa, Europe and Asia. We have continued to co-ordinate various activities at global, regional and local levels as the following highlights reveals.

## Theological Rationale

Every aspect of human life has relevance to the people with disabilities and this explains why disability concern as an agenda has been included in the World Council of Churches' work. Advocacy is needed to have this same agenda incorporated into the work of the national and regional ecumenical organisations as well as to the entire church. It is often believed among Christians, that people with disabilities are a weak group that needs help and who have no contribution to make in the church life. The New

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Testament however teaches us that that is not the case. In the first letter to the Corinthians Paul notes; “those organs of the body which seem to be more frail than others are indispensable.” (12:22). If the church has to be truly the body of Christ, it would need to carry with itself, even those members that are seemingly weak as they are indispensable. They have gifts and contribution without which the body of Christ cannot be complete. The issue of rights as opposed to charity is very vital as traditionally, most societies tend to view people with disabilities as recipients of charity. These attitudes are prevalent among individuals, institutions and even ecclesiastical Structures.

People with disabilities are still largely excluded from mainstream society thus hindering their full participation. We need a conversion within the churches to see that people with disabilities have a mission and they can contribute in understanding what the gospel means in practice. The inclusiveness of all people of God in the church life includes those with a disability and enhances the credibility of the church. This is why we need to work on all levels of the church: local, national, regional and global to raise awareness, advocate and network on this important issue. The work at the global level is important to build a network between people in the world that are involved in this work, to inspire and challenge the churches to see how important this issue is in every aspect of the churches’ life. This is aimed at increasing our commitment to promote an “inclusive community”.

### Activities and Outcomes:

#### EDAN Newsletter

The production of the EDAN Newsletter remained a major activity of the Network. Four issues are produced yearly. So far six issues have been produced since the last Advisory group meeting.

The newsletter remains the main communication and information dissemination tool for EDAN. It has served to maintain the fellowship between the EDAN members, to disseminate

information to churches, national and regional EDAN bodies as well as other key people whose contact has been essential. The demand



for the newsletter has continued to increase since the first publication and now 1000 copies are produced and distributed. This was done with the first issue in the year 2001. The newsletter has also been placed in the WCC web site, which has also widened our readership.

#### OAU Africa Decade for Persons with Disabilities

EDAN attended the 1<sup>st</sup> planning meeting of the Africa Decade for Persons with Disabilities in Harare in March, 2001 which was hosted by the Pan African Federation of the Disabled (PAFOD) and the African Rehabilitation Institute (ARI). The meeting in Harare requested EDAN to help them host the second planning meeting in Nairobi before the end of the year and EDAN agreed on condition that the meeting would be funded by both PAFOD and ARI.

#### Visit to the Middle East Conference of Churches (MECC):

This visit that was held from June 28 to June 30, 2000 came up as a follow up of the recommendation of the Nairobi consultation that highlighted the non-participation of Middle East Region in EDAN. The main purpose of this visit was to introduce EDAN, share its vision, enjoin the conference in EDAN’s work and identify a representative for EDAN in the Middle East Region. We were able to introduce EDAN and to share our vision with both the staff of the Middle East Conference of Churches and the various organisations that we visited. We are convinced that important contacts were made and that there will be need for follow up to ensure that they are maintained. We have finally been able to identify a Co-ordinator who has already started working in the Region.

#### EDAN Reference Group Meeting

The first EDAN Reference Group meeting was held in Geneva from 6<sup>th</sup> to 11<sup>th</sup> August 2000. The Reference Group met to discuss the internal management of EDAN and the implementation of the disability work in accordance to the objectives set both by EDAN itself and by WCC. A strategic work plan was tabled for discussion.

The following recommendations emerged out of the meeting regarding the internal management of EDAN:

- The issue of the regional co-ordinators was discussed as pertains their work and some funds were allocated to cater for their communication cost with the network offices as well as the

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travelling expenses to other areas in the region, to enable them do their work effectively.

- It was agreed that a co-ordinator be identified for the Pacific region, which at that time had no representative in EDAN.
- There is a need to identify one person from the network to be co-opted to the DOV working

committee to represent EDAN's interests. Issues to be addressed in relation to disabilities include violence against women with disabilities, impact of systematic violence



as well as wars and disabling violence caused by landmines.

- It was recommended that the WCC calendar of activities be availed to EDAN so as to identify the activities that EDAN needs to be involved in. This will facilitate early lobbying for participation and enable the WCC member churches and staff to know more about EDAN.
- It was recommended that a database be developed to enable the EDAN office to know areas of strength for each of the members. Such information will be necessary when making decisions on who is to represent EDAN on various activities.

On Theological Reflections, the main focus points identified were:

- To prepare the leadership to play a nurturing role. In this regard, JPC/EDAN will work with Education and Ecumenical Formation on the pastoral preparation of clergy. Additionally, the EEF Team needs to be encouraged to bring the concern of people with disabilities into Christian Education, Sunday school materials and into the work of Lay Training Centres. Discussions have already begun towards a co-curriculum on disability issues at the St. Paul's Theological College in Kenya, Stockholm School of Theology in Sweden and United Theological College of the West Indies in Jamaica.
- In conjunction with the Faith and Order Commission, to move towards the adoption of a second interim theological and ecclesiological statement by the churches as a framework for the advocacy and pastoral role the churches need to play in the present changing environment. To include the new theological, ecclesiological and ethical challenges that confronts the churches in

the context of disabilities. LWF has been invited to join this process at every stage.

### African Union of the Blind General Assembly


EDAN was also represented in the African Union of the Blind General Assembly held in Addis Ababa Ethiopia between 4<sup>th</sup> - 6<sup>th</sup> October 2000. Besides the usual business of the Assembly, the key issue discussed was the implementation of the African Decade of Disabled Persons. It is in this context that EDAN was invited to bring the perspective of the Church to the Assembly and it was agreed that the Church is a vital player in the implementation of the decade plans and all efforts made to ensure collaboration and networking.

### International Conference entitled "From Principles to Practice"

EDAN participated in a conference entitled "From Principles to Practice" held in Washington DC from 22<sup>nd</sup> - 26<sup>th</sup> October 2000. The US Government organised the conference with participation from 40 different countries. The main aim was to bring together lawyers, disability advocates and service providers to discuss the way forward in respect to legislation and policies in different countries. The conference also deliberated on the strengths and weaknesses of disability legislation in different countries and underscored the need to change the attitude of national governments towards disabilities as a way of enhancing the implementation of policies and legislation.

### Eastern Africa Disability Consultation

Eastern Africa Federation of the Disabled (EAFOD) and Ecumenical Disability Advocates Network (EDAN) jointly organised a disability consultation held in Nairobi, Kenya from 7<sup>th</sup> to 10<sup>th</sup> November 2000 under the theme "The concept of Universal Design and the UN Standard Rules in the African Decade of Disabled Persons". This brought together key leaders and personalities in the disability sector and representatives from the Councils of Churches in the Eastern Africa sub-region. The aim of the consultation was two fold; one, to develop a plan of action for East Africa in implementing the African Decade of Disabled Persons and two, to conduct the business of EAFOD as a General Assembly. Through a participatory process, participants identified key concerns specific to the sub-region and recommended

Continued on page 11 



ways of addressing their concerns during the African Decade. Some of the key issues identified revolved around policies and legislation, women rights, awareness creation, sustainability, capacity building and the development of strategic alliances. Drawing from some of these concerns, participants came up with a draft plan of action for the African Decade in which they built a framework and developed a strategic plan for the decade.

### World Blind Union General Assembly

EDAN participated in the World Blind Union Conference held in Melbourne Australia from 20<sup>th</sup> – 24<sup>th</sup> November 2000. The key issues raised in this forum were:

- Participation and inclusion of people with visual impairment in decision making in all aspects of the society.
- Communication and technology development that have on people with visual impairment.
- The place of visually impaired women in society and the use of Braille as a medium of communication.

There was a pre-assembly forum for Visually Impaired pastors, which the Consultant missed but was able to make valuable contacts with them during the assembly. The main speakers included the special rapporteur for the UN Standard Rules on Equalisation of Opportunities, who highlighted the development of legislation on the impending UN Convention on the rights of people with disabilities.

### Central Committee Meeting in Berlin

EDAN had three advisors in the last Central Committee. The need for EDAN's participation in the central committee despite the pressure on finances was borne during the meeting of the EDAN reference group meeting in Geneva. This arose out of the need to sustain the visibility of persons with disabilities in this key governing organ of the WCC. Other issues included the need for a Padare in Central Committee of 2002 and support for the idea of a special plenary in the Central Committee meeting of 2003, where EDAN will present the interim statement of the theological reflections on the issue of disabilities.

The key recommendation that was made by the programme committee during the meeting was a call to the: "Central Committee to have a padare offering at the 2002 meeting reflecting on issues of disability

led by the Ecumenical Disability Advocates Network (EDAN), and a special plenary be held at the Central Committee meeting in 2003. The plenary would present the theological and ecclesiological statement being prepared for the churches by the EDAN/JPC with the Faith and Order Commission as a framework for the churches' advocacy and pastoral role with the disabled."

### Ministerial Formation and ECHOES Magazine Publications

During the EDAN reference group, the members agreed that EDAN should be contributing articles in the major WCC publications starting with the Ministerial Formation. The January 2001 issue of the Ministerial Formation was dedicated to issues on disabilities and all the articles were contributed by EDAN members and their associates. The ECHOES magazine issue of July 2001 was also dedicated to issues on disabilities and all the articles too were contributed by EDAN members and their associates.

### EDAN visit to the Caribbean, Latin America and North America

As a follow up of the recommendation of the EDAN Reference Group meeting to visit REO's and the churches the first visit was made to the Caribbean, Latin America and North America from the 5-29 July 2001. The program of the visit included meeting with Churches leaders, Councils of Churches and organizations of persons with disabilities.

### Coming Events

- EDAN Central Africa Consultation - November 28, 2001
- May 2002, National gathering on disability, spirituality and Faith in Aotearoa, New Zealand
- September 2002: A Padare with the Central Committee of WCC, Switzerland.
- November 25<sup>th</sup>-29<sup>th</sup> 2002, Reflection on Disability at Bossey







# RALLYING FOR SUPPORT

## IID: REQUEST FOR URGENT ACTION

October 29, 2001.

Dear Friends:

All of us involved with the defence and promotion of the human rights of people with disabilities are fully aware of the momentous importance that would have the approval, from the United Nations, of an International Convention that protects such rights.

This is a dream that has been forged within the International Community, since the end of the 70's. Twenty five years later we have a valuable instrument (the UN Standard Rules), but insufficient to improve, with effectiveness, the situation of human rights of more than 600 million people that today represent the population with disabilities in the planet.

The Inter-American Institute on Disabilities (IID), joining in support of all efforts being made by the international organisations representing people with disabilities, puts all its energy to the service of the cause of the UN Convention.

We act now with the same commitment and inspiration that we did during the process of the adoption of the Inter-American Convention for the Elimination of All Forms of Discrimination against People with disabilities, adopted by the Organisation of the American States (OAS), in 1999, in Guatemala, now ratified by 7 countries in the Region. We want to offer the experience that we accumulate then, to the service of an urgent and exciting process that is now going on in the UN.

Right now, there is a valuable opportunity for us all to make advance the process toward the approval of that important international instrument. A few days ago Mexico has presented to the Third Committee of the United Nations, a proposal of a resolution that supports the adoption, by the UN, of an International Convention for the Rights of People with Disabilities.

If Mexico receives the necessary support and co-sponsorship from the simple majority of the country members of the UN, this proposal of a resolution is approved by the Third Committee and is automatically included in the Agenda of the next General Assembly Meeting.

The Disability Rights Movement and, all other sectors of society identified with social development, should take this opportunity to advance the process and to strengthen all the initiatives that have been taken by the international organisations from many years now, to develop the basis for an International Convention.

Since the Third Committee is meeting in New York right now, we have **ONLY FEW DAYS TO ACT**. The **DEAD LINE IS NOVEMBER 20th**. We can make a difference taking two parallel actions as follows:

**ACTION I:** to send a letter directed to the UN Secretary General Koffi Annan, in support of the Mexican proposal to the Third Committee Meetings, of a resolution for the adoption of an International Convention on the Rights of People with Disabilities.

**ACTION II:** to lobby with your governments, particularly, with your country's permanent missions to the UN, to gather their support and co-sponsorship to that resolution proposal, during the UN Third Committee Sessions that are going on in November. The Mexican staff person directly working on the subject is: Berenice Díaz, Mexico Permanent Mission to the UN.

To complete that task, we will send, as attachments to this request for urgent action, information on the resolution initiative presented by Mexico. We will also keep you informed on progress developments during the process toward the Convention.


It is a crucial time to ACT and give a strong and definitive impulse to the International Convention. With it, we all win a fair, inclusive and accessible world for peoples with disabilities - a better world for the whole humanity.

Best Regards,

Rosangela Berman Bieler  
President,  
Inter-American Institute on Disability  
Headquarters - Washington, DC



*Following this request EDAN wrote a letter (see separate article) to the UN secretary General in support of our colleagues in Mexico; their agenda is very much ours!*

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## Mexican Document on the Convention

### Comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities

#### The General Assembly

*Considering* that the Universal Declaration of Human Rights proclaims that all human beings are born free and equal in dignity and rights and that everyone is entitled to all the rights and freedoms set out therein, without distinction of any kind,

*Reaffirming* the principles and purposes of the United Nations Charter and the obligations contained in relevant human rights instruments,

*Recalling* its resolutions 37/52 of 3 December 1982, by which it adopted the World Programme of Action concerning Disabled Persons, 48/96 of 20 December 1993, by which it adopted the Standard Rules on Equalisation of Opportunities for Persons with Disabilities, and 54/121 of 17 December 1999,

*Recalling* also Economic and Social Council resolution 2000/10 of 27 July 2000 on Further promotion of Equalisation of opportunities by, for and with persons with disabilities, as well as other relevant General Assembly, Economic and Social Council and functional commissions resolutions,

*Affirming* the outcomes of the major United Nations conferences and summits and their respective follow up reviews, in particular they pertain to the promotion of the rights and well-being of persons with disabilities on an equal and participatory basis,

*Noting* with satisfaction that the Standard Rules play an important role in influencing the promotion, formulation and evaluation of policies, plans, programmes and actions at the national, regional and international levels to further the equalisation of opportunities by, for and with persons with disabilities,

*Recognising* that despite different efforts made to increase co-operation and integration, and increasing disability awareness and sensitivity to disability issues, since the adoption of the World Programme of Action concerning Disabled Persons by governments, bodies and relevant organisations of

the United Nations system and non-governmental organisations, these have not been enough to promote the full and effective participation and opportunities of persons with disabilities in economic, social, cultural and political life, on the basis of equality, to achieve a society for all,

*Encouraged* by the increasing interest of the international community in the promotion and protection of the rights and dignity of persons with disabilities in the world under a comprehensive and integral approach,

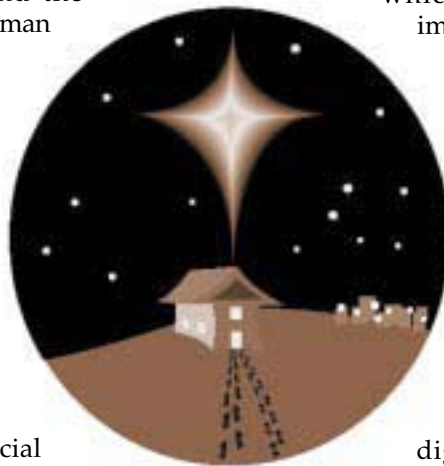
*Deeply* concerned about the disadvantage and vulnerable situation faced by 600 million persons with disabilities around the world, and conscious that such situation makes it imperative to advance on the elaboration of an international instrument which will permit a substantial improvement on the quality of life of persons with disabilities on an equitable basis with other vulnerable groups,

*Welcoming* the recommendation of the World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance to the General Assembly to consider elaborating a comprehensive and integral International Convention to protect and promote the rights and dignity of persons with disabilities, including special provisions that addresses the discriminatory practices and treatment that affect them,

*Decides* to establish an ad hoc Committee open to the participation of all Member States and observers to the United Nations, for the purpose of elaborating a comprehensive and integral International Convention to protect and promote the rights and dignity of persons with disabilities,

*Decides* that prior to its fiftieth-seventh session the ad hoc Committee shall hold as minimum three meetings, each of ten working days,

*Invites* relevant bodies and organisations of the United Nations, including relevant human rights treaty bodies, regional commissions, the Special Rapporteur for Monitoring the implementation of the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities of the Commission for Social Development, as well as governmental and non-governmental organisations interest in the matter to make contributions to the work entrusted to the ad hoc Committee based on the practice of the United Nations,



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**Requests** the Secretary General, with the support of the Office of the High Commissioner for Human Rights and the Division for Social Policy and Development of the Secretariat, to submit to the ad hoc Committee prior to its first session a compilation of existing international legal instruments, documents and programs which direct or indirectly address the situation of persons with disabilities, including those of conferences, summits, meetings or international or regional seminars, convened by the United Nations and non-governmental organisations,

**Calls** upon States and regional commissions, in co-operation with the High Commissioner for Human Rights, the Division for Social Policy and Development of the Secretariat and the Special Rapporteur for Monitoring the implementation of the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities of the Commission for Social Development, to hold regional meetings or seminars to contribute to the work of the ad hoc Committee with recommendations, regarding the content and practical measures that should be considered in the international convention,

**Requests** the Secretary General to provide all financial resources to the ad hoc Committee to discharge its responsibility and to promote voluntary contributions to strengthen the work of the ad hoc Committee, in particular to facilitate the participation of experts from developing countries in the work of the ad hoc Committee,

**Requests** also the Secretary General to submit a report to the General Assembly, at its fiftieth-seventh session regarding the work of the ad hoc Committee.

## **TALKING POINTS REGARDING DRAFT RESOLUTION ENTITLED “; COMPREHENSIVE AND INTEGRAL CONVENTION TO PROMOTE AND PROTECT THE RIGHTS AND DIGNITY OF PERSONS WITH DISABILITIES”**

### **1. Background**

The Universal Declaration of Human Rights, adopted in 1948 by the General Assembly, proclaims that all human beings are born free and equal in dignity and rights and that everyone is entitled to all rights and freedoms set out therein, without distinction of any kind the efforts carried by the United Nations to protect the rights and dignity of persons with

disabilities had been translated into a wide range of initiatives, activities and mechanisms throughout the years. They include: the adoption of the Declaration on the Rights of Mentally Retarded Persons of 1971; the 159 ILO Convention on Vocational Rehabilitation and Employment (Disabled Persons) of 1983 and the Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care of 1991.

Moreover, the General Assembly proclaimed 1981 as the International Year of Disabled Persons, adopted in 1982 the World Programme of Action concerning Disabled Persons; and proclaimed 1983-1992 as the Decade for Disabled People. Also in 1993 it adopted the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities and designated a Special Rapporteur for monitoring the implementation of the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities of the Commission for Social Development, who is assisted in his work by a Panel of Experts.

Given the disadvantage and vulnerable situation faced by persons with disabilities throughout the world, it is important to emphasise that all major United Nations conferences and summits (Vienna, Cairo, Beijing, Copenhagen and Istanbul) that took place during the last decade and their respective follow up reviews have included in its Declarations and Programmes of Action provisions pertaining the promotion of the rights and well-being of persons with disabilities on an equal and participatory basis.

### **2. Elements in support of the draft resolution**

The number of persons with disabilities around the world is approximately 600 million and they constitute a vulnerable group that requires priority attention from the international community.



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Even though the 1993 Standard Rules can be considered as one of the most important achievements on issues pertaining disabled persons at the international level, taking into consideration that these norms have played an important role in influencing the promotion, formulation and evaluation of policies, plans, programmes and actions at the national, regional and international levels, they do not have a legally binding nature.

The general acceptance of these norms and the great interest shown by the international community on this issue, makes it imperative to advance in their codification in an international instrument in order to protect this important sector of the world population. Besides, the elaboration of this international instrument will give the international community the opportunity to develop progressively new norms of international law in favour of persons with disabilities.

It is important to emphasise that even though persons with disabilities are subject to the rights contained in international instruments such as the Universal Declaration on Human Rights, as well as in other international human rights instruments, there is no specific reference to the condition or rights of persons with disabilities, making them invisible or ignoring them.

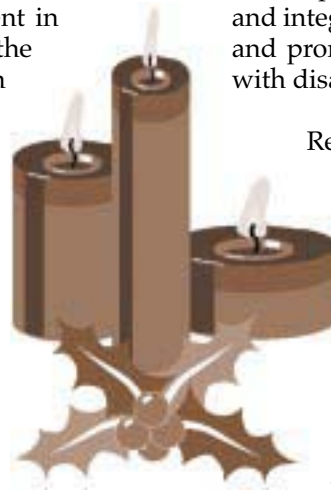
To this respect, it is important to underline that despite different efforts made to increase co-operation and integration, and awareness and sensitivity to disability issues, carried out by governments, bodies and relevant organisations of the United Nations system and non-governmental organisations during the last twenty years, these efforts have not been enough to achieve the full and effective participation of persons with disabilities in the economic, social, cultural and political life. Moreover, persons with disabilities are victims of violations of their rights, prejudices, stereotypes and discrimination, besides the physical, social and cultural barriers they encounter.

All these elements justify the elaboration of a comprehensive and integral International Convention to promote and protect the rights and dignity of persons with disabilities, as recommended to the General Assembly by the World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance, if the international community truly wishes to achieve the objective of “a society for all”, where persons with disabilities, men and women either young, adult or elder can develop their possibilities to participate fully in society on an equitable basis.

The Mexican initiative does not pretend to be a substitute of or duplicate with other efforts or initiatives carried out within the United Nations but to complement them and fill the gap, as well as to make justice to a legitimate demand of civil society that has raised its voice in favour of an important and numerous sector of the world population.

### 3. Content of the Resolution

The proposal consists on the establishment of an ad hoc Committee open to the participation of all Member States and observers to the United Nations, for the purpose of elaborating a comprehensive and integral International Convention to protect and promote the rights and dignity of persons with disabilities.



Relevant bodies and organisations of the United Nations, including human rights treaty bodies, regional commissions, the Special Rapporteur for Monitoring the implementation of the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities of the Commission for Social Development, as well as governmental and non-governmental organisations interest in the matter are invited to make contributions to the work entrusted to the ad hoc Committee based on the practice of the United Nations,

It also calls upon States and regional commissions, in Cupertino with the High Commissioner for Human Rights, the Division for Social Policy and Development of the Secretariat and the Special Rapporteur for Monitoring the implementation of the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities of the Commission for Social Development, to hold regional meetings or seminars to contribute to the work of the ad hoc Committee.

The ad hoc Committee will meet three times as minimum for ten working days each period, and will submit a report on its work to the General Assembly at its fiftieth-seventh session.

In the elaboration of this international instrument, all existing international legal instruments, documents and programs which directly or indirectly address the situation of persons with disabilities, including those of conferences, summits, meetings or international or regional seminars, convened by the United Nations and non-governmental organisations will be considered.

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## Letter From EDAN to Kofi Annan

Your Excellency  
Kofi Annan  
UN General Secretary

Dear Sir

We wish to register our interest and therefore appeal for the support for the Mexican Proposal of the Third UN Committee of Resolution for the adoption of an International Convention on the Rights of People with Disabilities.

The Ecumenical Disability Advocates Network (EDAN) is a programme of the World Council of Churches whose mandate is to address disability concerns. The EDAN office is based in Nairobi, Kenya but the programme operates with volunteer co-ordinators who are organising regional networks in their various regions. These regions include Latin America, North America, the Caribbean, Europe, Africa, Asia and the Pacific. In line with the general mission and operations of the World Council of Churches, EDAN is very keen in respect to inclusion, participation and observation of rights for persons with disabilities.

We are happy with the UN Standard Rules on Equalisation of Opportunities but we believe that the UN need to go a step further in influencing member nations not only to concern themselves with the rights for persons with disabilities as an option but to have disability legislated and to have such legislation enforced where necessary. It is in this light that we believe that a Convention is long overdue.

We are, therefore, in full support of the Mexican Proposal and wish to kindly urge you to support it.

Looking forward to every co-operation from you I remain,

Yours faithfully

Samuel Kabue (Mr.)  
EDAN Consultant

**Note to the EDAN family:** EDAN is in full support of this Mexico initiative as it is in tandem with Network objectives. We therefore urge you to do whatever you can to support this call, which is very much our own.  
-Editor

The following is a reply to the above letter

Date: Monday, November 19, 2001 9:06 PM

Mr. Samuel Kabue  
EDAN Consultant



Dear Mr. Kabue,

Thank you very much for your communication dated 2 November 2001 concerning your support for the initiative for an international convention on the rights of persons with disabilities. The United Nations commitment to promote the human rights of persons with disabilities is deeply rooted in the Charter of the United Nations, international human rights instruments and other international commitments for global action for a society for all. The programme on disability of the Division for Social Policy and Development has closely

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collaborated with the Governments, the non-governmental community and the academic institutes to promote the rights of persons with disabilities in the broad human rights framework. We are very pleased to invite you to visit our home page <http://www.un.org/esa/socdev/enable>, especially the report of the Informal Consultative Meeting on International Norms and Standards related to Disability held in New York, 9 February 2001 available at <http://www.un.org/esa/socdev/enable/consultnyfeb2001.htm>, the report of the United Nations Consultative Expert Group Meeting on International Norms and Standards relating to Disability held at Berkeley, 8-12 December 1998 available at <http://www.un.org/esa/socdev/enable/disberk0.htm>. For further reference, International Norms and Standards Search Engine <http://esa.un.org/socdev/enable/search.htm> provides technical information on international norms and standards relating to disability.

Yours sincerely,

Akiko Ito  
Chief Programme on disability  
Division for Social Policy and Development  
Department of Economic and Social Affairs  
United Nations

## PERSPECTIVES

### **There... we are received: A theological view of disability by Rev. Jan Van Buuren.**

Alongside the sheltered accommodation for the homeless stands a church. But the inmates of the shelter almost always go instead to the other church, some ten minutes walking distance away. Asked why all this extra effort on a Sunday morning, Arie-Jan replies: "There we are received!" The emphasis is on the last word.

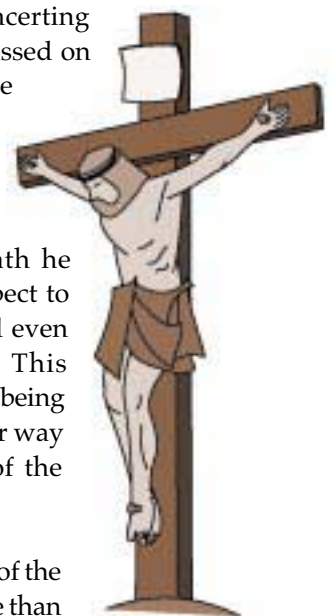
We talked about this amongst ourselves later; what exactly did Arie-Jan mean by the words: "There we are received?" At last we understood. It is like this. The church next to the shelter is a beautiful church and the vicar there is very kind. That is not it. But the church is just a little too big for the congregation. So on Sunday mornings there is plenty of room. When the inmates of the shelter arrive at church at five to ten, sometimes eight of them, they can easily find room to sit in one pew together. In the other church it is not like that. There things are a bit cramped and almost all the places are taken for the morning service. If you arrive just before the service it is hard to find somewhere to sit. But then some lady or gentleman will stand up and give you a nod and a wink that near them there is just one place free for you. "You see, there you are received!"

### **Central to the Church is the Cross**


When Jesus was laughed at and mocked on the cross, the paradox of the Gospel was upon the lips of his

persecutors: "He saved others; himself he cannot save." (Matthew 27:42). And so indeed did Jesus live, always looking towards others, never directed towards Himself: the Redeemer can not redeem Himself.

In an extension of this disconcerting reality of God, the task was passed on to his followers: live in this same vulnerable manner. When Jesus sent out his disciples he empowered them to heal the sick and to drive out evil spirits. But in the same breath he warns them that they may expect to be imprisoned, persecuted and even put to death (Matthew 10). This ventured vulnerability is part of being a follower. And there is no other way for Christians than the way of the cross.



Thus, then, the central position of the cross to the Church. This is more than simply the symbol for Christ's suffering for our sins on that day at Golgotha. The cross is for the congregation simultaneously the sign of its own weakness, its own powerlessness, of the surrender of each individual's being to the world of today.

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What was applicable to the disciples in Matthew 10 is applicable to the congregation time without end, both in its dealings with the outside and the inner world. The unattractive self-identification with he who has fallen behind is not simply a token of deep humanity or of impressive compassion (as an incidental and valued occurrence), it is much more: it is the only valid manner wherein the congregation becomes the congregation, body of Christ. There is no other way!

### The World Made Straight

A church may be judged as to its fidelity to this valid form of congregation by the numbers of its disabled persons. The attitude towards the disabled persons in the church is indicative of the validity of the congregation. In other words: to enquire after those with a handicap in the church is to enquire after the health of the church itself. (Newbigin in *Niet zonder elkaar*, page 22).

To be a Christian, to belong to the congregation, is to be taken up in that world of God turned around and made straight: the love of Christ sanctifies the godless, the sinner may live, death is no longer ultimate.

To be a Christian is to share in that turning around and being made straight. Was it not the most shocking thing about Jesus' presence in Palestine that He talked with tax collectors and that He challenged the pious to love their enemy? Jesus made equal the unequal. He mirrored the rich man in the poor Lazarus (Luke 6). He asked Simon the Pharisee to look out for the sinner in the city (Luke 7). He presented the Samaritan as an example to the lawyer (Luke 10). So is Jesus recognised by them and they follow him, as they who in the days of the Old Testament knew all the particular cares visited upon them by Israel's God; the people of Psalm 146, the oppressed, the hungry, the imprisoned, the blind, the righteous, the stranger, the orphan and the widow.

However, to choose their side is, soon or late, to fall prey to the opposition. They who can not live with the turned around, the just, the unexpected. They who feel threatened in what is for them most important: their power, their sense of righteousness or their comfort and safety. In Jesus things are different.

### Members of One Body

It is suggested (by C.P. van Andel in *Een vergeten schakel* page 47) that besides the three classic characteristics of the Church, namely, preaching the Bible, the sacraments and the discipline, a fourth distinguishing feature might be postulated: are there present people with one or other handicap? God chooses always for the weak, the have-nots and for those who are impotent. And therefore it should be characteristic of the congregation that it be extremely generous in the space allotted to these same people.

Paul has one or two things to teach us about this. In his care for the congregation of Corinth he has left us the magnificent image of the congregation as the body of Christ (1 Corinthians 12:12-31). After his departure from Corinth, much went amiss in the congregation. All sorts of groupings stood in opposition to one another and competition even arose between what we should call the various types of work within the congregation: preaching, management, healing, speaking in tongues and explanation of the Word. And the greatest matter of dissent involved which of these was paramount.

To counter the animosity amongst the Corinthians, Paul sets before them the initial question: how are your relations with one another within the congregation? Then: how do you regard one another within the congregation? Paul then compares the congregation with a body. The unity of the body exists by grace of the contributing parts. Each part has its own function and only together do the parts form the one body. With great humour, Paul sketches how the eye might get into an argument with the hand and how the head might look down upon the feet. So were things going in Corinth, were they not? But at the same time Paul was introducing the idea of the creation of order within the diversity of the congregation; nobody can be missed, everyone has their own place and their own task.

### ...a specific place

Upon further elaboration, the boundaries between this image and reality begin to fade. This happens as Paul writes: "God hath tempered the body together, having given more abundant honour to that part that lacked;

*Continued on page 19*



that there should be no schism in the body but that the members should have the same care for one another” (1 Corinthians 12:24b-25). Paul sees here not so much the human body as the solid image of the congregation. She is the body of Christ. And without further ado, he associates the congregation with the deprived, the latecomers and those who remain behind. It is these people who take their place as choice members of the universal congregation. To fail to see this, to neglect the deprived within the congregation – this, according to Paul, is the deep reason underlying the rivalry between the parties in Corinth.

God has placed the deprived at the centre of the congregation ‘so that there should be no schism in the body’! People with a handicap have a task, a function within the congregation that may not be underestimated. According to Paul, they are the cohesive factor, they make whole, they prevent the congregation from falling apart and are the cause of its unity. Precisely this diversity, if allowed, leads to unity. Just to avoid misunderstandings, this means not that the disabled occupy a position of special honour, but simply that place which is theirs by right.

### Creating space

There is more applause heard in our churches today than in former times and often it takes only a little to get a congregation laughing together in a relaxed way. Happily, children contribute more and more in little ways to the liturgy and sometimes the mentally disabled are even recruited to do the collection.

And yet.... roughly ten percent of the Dutch population is disabled. The numbers of disabled churchgoers is not in proportion to this statistic. And the number of disabled office-bearers fades away into insignificance.

I am well aware that deafness may be experienced as a nuisance, and that blindness brings with it limitations, and that a wheelchair makes demands upon the church building in terms of space and meeting accommodation.

I am also aware that sometimes the simplest technical alterations may reduce, or even remove, such problems. The question is: what have we as congregations and as church councils done to ensure

that the entire body of the congregation is present in church? I don’t suppose that we leave parts of our own body at home when we come to church?

Fortunately, prejudice in relation to the disabled is on the wane. However, it remains a daily task to think and rethink about the composition of the congregation in terms of its component parts. How does the congregation need to look if it is to appear to the outsider as the Whole Body of Christ? And where do we begin to address these questions?

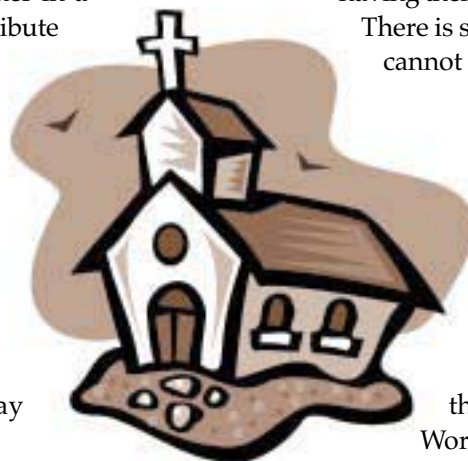
The first question we need to ask ourselves is whether we dare create such space within our congregation!

*Ref. Biblical texts taken from the King James Authorised Version of the New Testament*

*Rev Jan van Buuren is member of International Working Group Theology and Disability in the Netherlands.*

### The Interdenominational Study Group Theology and Disability – Who we are and what we do

The Interdenominational Study Group Theology and Disability realises that sometimes it appears to reproach those who are sympathetic for being sympathetic and those who have good intentions for having them. And sometimes this is really true. There is something unkind about this. But it cannot be helped.



Years ago, the International Study Group Theology and Disability described its goal thus: “To develop a theological view of the position of disabled people in the church and in society with respect to Gods salvation.” This goal was established in 1985 after the international conference of the World Council of Churches on disabled people and the church. The theme of this conference was “Being watched without being considered”. The position of disabled people can still be characterised in this way.

History shows us names of famous people who achieved much for disabled people. The churches have developed a respected tradition of charity with regard to taking care of and understanding disabled

Continued on page 20



people. However, the Study Group has concluded that a theological view of this subject has not been established and described until now.

The Study Group consists of theologians and people who are interested in theology. Most of them have a handicap. These people represent several denominations. They do realise that they are not the first to think about this subject. And, of course, they do not pretend to establish the only truth about being disabled, after all those who preceded them. Moreover, they are not that self-confident that they want to define a sort of special theology of the disabled.



However, the Group conscious of the fact that through their handicaps they have had special experiences which are often neglected. They also know that for a long time disabled people did not get the opportunity to express their own opinion. This also holds for disabled people and the churches. Or stated more precisely, especially for disabled people and the churches.

Furthermore, they know there are still disconcertingly few disabled incumbents despite a considerable emancipating effort through and on behalf of people with disability. The churches do not comply with the five-percent regulation, which is used in trade and industry.

Therefore, for many years the study group has tried to find words that express “the position of people with a disability in society and the church with respect to Gods salvation”. Thus, they want to explain that people with and people without a disability may learn from each other, learn something essential, learn something about God and mankind.

Moreover, the Group tries to find ways of making its own especially defined contribution to theology truly understood. For throughout history disabled people have often been discussed by people without a disability. But disabled people themselves were hardly listened to.

For this reason, the Interdenominational Study Group Theology and Disability makes exegesis of Biblical stories. For theologians with a disability often work from a perspective and with a sensitivity that differ from the approach of the average theologian. This appears from the questions they ask and the issues they take into consideration. They publish their own exegeses in order to make people without a disability familiar with this valuable and special sensitivity.

The Group can be contacted at:

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## Grace Down Under

*by William Gaventa*

It was 1998 when I went to Australia for the first time, an amazing trip that introduced me to a small corner of the country, from Melbourne down the Great Coast Road to Adelaide and back to Melbourne. It felt in many ways like a magical country: the spirit of the city, the spirits in each gum tree out in the countryside, a visit to the Twelve Apostles, and a small corner of that continent that seemed to go on and on in its own right.

At one of the first stops on the journey, a presentation for an audience of about one hundred at an agency that supports people with mental illness, I was given a gift, a book; *The Sacred Edge: Transformation in Australia*, by David Tacey. I read the book during the rest of the journey, a book about the national character of Australia. Tacey describes the settled circumference of Australia, where most of the population lives, in a primarily Western order and structure, and the ambivalent relationship with the untamable, complex, and huge interior, where other people, the Aboriginals, had lived for thousands of years in a rhythm of life wedded to the spirits of the land. He compared that to psychoanalytic model of an individual person, with an ordered ego sitting on the boundary around a primitive and uncontrollable id.

The paradox was and still is that in the sacred edge of those relationships, people and civilisations are transformed by the very forces they presume to conquer and control. It is a move away from a fear of the other towards interdependency and community,

*Continued on page 21*





and a move towards a more healthful balance of order and chaos, meaning and mystery, reason and feeling. Tacey, in effect, served as a spiritual guide to my journey.

That journey led to a sermon entitled “Grace Down Under,” a sermon not just about that trip, but about one of my own, three years earlier, in, down, and through a major depression. It was as if this trip to Australia had been an outward form of an inward journey, one leading to an experience of profound grace as the depression ended, for reasons beyond my understanding and control. It had been a trip that also left me with a deep sense of appreciation for the gift of everyday, the miracle of hope, the mystery of my own life, and the capacity of deep feelings to shape and bend my own illusions of control.

This month, October 2001, I was invited back, by old friends and new colleagues. The primary event was Australia’s third national conference on spirituality and disability, entitled “Exclusion and Embrace.” The conference used the title and themes from a book by that same name by Yugoslav theologian Miroslav Volf. Volf explores the relationship between personal identity, the other, and the process to reconciliation. He explores how and why people and cultures exclude the other, the ways in which identity is shaped in what can be a deadly dance between the self and the other, and the difficult process of an embrace or reconciliation in which truth is also told and justice is done. I left one month after September 11, hearing about the initiation of the bombing on Afghanistan as I drove to JFK airport in New York on a fall Sunday afternoon.


Part of the grace of this trip was that I got to go to some other parts of Australia, with stops in the amazing Sydney Harbor, the bustling city of Brisbane, and a two-day adventure into the Queensland hinterlands. I spent an afternoon and evening in a “farm stay” beef ranch in the hills, spent an early morning hour by a stream at that ranch watching three platypus (platypi?), saw kangaroos and wallabies by the side of the road, visited a koala rehab and preservation centre, and ate lunch on the top of Mount Tambourine with 10+ lorikeets eating out of my hand and plate. Amazing once again. Close encounters with three or more Australian animal icons and one



architectural one, the Sydney Opera House, in the space of about three days.

It was, however, the hospitality of my hosts and sponsors, in whose homes I stayed, that made the deepest impression. Trevor and Marie Parmenter and their two daughters, Natalie and Sophie in Sydney. (It was the girls who helped me figure out how to email home.) Dr. Parmenter heads a training, technical assistance, and research centre much like The Boggs Centre in which I work, an Australian version of a University Affiliated Program. In Brisbane, Trish Murdoch and her husband Brendan not only put me up but introduced me to the Australian “barby.” (Outdoor cookout) Trish is a disability ministry resource staff person for the Catholic Education Centre of the Archdiocese of Brisbane. In Melbourne, back to the guest bungalow in the back yard of the home of Andy Calder, Julie Perrin, and their children, Ben and Anna, where I had stayed three years before. Open hearts and homes, engaging conversation, shared ideas, and even the trusting loan of a car for an American to drive for two days on the wrong side of the road.

Then to Melbourne, for the Exclusion and Embrace Conference. On the Tuesday before it started, the Melbourne City Mission, one of the conference sponsors, sponsored a news conference, with the head of Mission, Ann Turley, the co-ordinator of the conference, Andy Calder, and the imam at the Melbourne City mosque, Sheikh Isse Musse, originally from Somalia, and me, the invited foreigner. As we drove to the Melbourne City Mission for the press conference, we passed a sidewalk full of accountants and brokers and a street with emergency vehicles, outside the Melbourne stock exchange, where they were having their first anthrax scare. The reporters who came to the press conference were partly interested in the conference, but as you might imagine, they also wanted to know our views on the wider range of interfaith issues related to the war on terrorism. We did a few contortions after the press conference so the absent photographer from the major Melbourne daily could find us for a picture the American minister and the Australian/Somali iman. It happened on the “footpath” (Australian for sidewalk) outside the mosque where the imam had gone to participate in midday prayers.

*Continued on page 22* 





The crowds outside the Melbourne stock exchange were by no means the first evidence of Australia's connection to the wider world of issues involving other forms of exclusion and embrace. At every stop, people had inquired about how we in America were doing. There were prayers. There were expressions of gratitude for my coming. "Was I afraid of the flying?" was the frequent inquiry. On the way to the Sydney airport, a construction site had professionally made signs all around it on the fence in a series of alternating titles: "We Mourn" and "We Pray," with four times listed under each...the four times of the September 11 morning when the planes had hit their targets or the ground.

I was touched, in numbers of ways, by those signs and gestures. I had also found September 11 hard to talk about, for at every telling of my version of the story in public gatherings, the feelings would well up in my throat and voice. Part of that came from feeling like the messenger or representative, trying to assure foreign friends that the spirit of the US was alive and, if not well, coping and supporting others in amazing ways. Part came from my feelings of gratitude for prayers and poems sent to me from my Australian hosts on the Wednesday, Thursday, and Friday after September 11. I found myself tearing up when reading those emails in the immediate aftermath, and found those tears again as I talked, in person, to those who had sent them.

### Inclusion and Embrace

Then came the conference. It began late on Thursday afternoon with an opening ceremony in a hotel conference room brought to life with Australian and aboriginal symbols of welcome, embrace, and exclusion. A tribute to Elizabeth Hastings followed, an incredible woman in Australia, a wheelchair user because of polio, first Commissioner of an office for Disability Rights, and a person of deep faith and beauty whom I had met three years before, and who died far too young soon thereafter from a recurrence of cancer. "Inclusion," Elizabeth had once said, "was a false premise. God has already included me. Why is it that others think they can exclude, or try to?" Phillip Adams, one of Australia's premier film and radio hosts and producers led a moving tribute. We all toasted her memory and contribution with an imagined glass of her favourite Australian sherry.

As the guest keynoter, I got a chance to say "hello," bring greetings from America, and to preview my talk for the following morning. Again, I had moments when the feelings overwhelmed, but clearly in the company of a community who deeply cared. Earlier

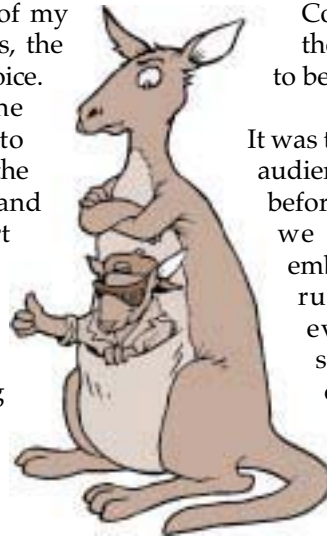
in the week, I had told some of the Conference Committee about some of the people with disabilities who had gotten out of the World Trade Towers, and some who did not. From my work in New Jersey with congregations working on inclusive ministries, I just happened to know one of them who was guided down some 50 floors by his seeing eye dog. Rabbi Aviva Kippen, who had also helped organise a first ever government encouraged and funded, interfaith community memorial at the Rod Laver Tennis Centre after September 11, told me I had to tell people that story. I did, but it was not easy.

Then came Friday morning. It began with an opening greeting from a number of government and religious leaders: the Victoria state commissioner on human services, the Executive Director of the Victoria Council of Churches, and the rabbi, head of the interfaith forum. All of them happened to be women.

It was then my turn. The keynote went fine. The audience and I had already bonded the evening before. I used Volf's book, and looked at ways we might move beyond exclusion and embrace. I looked at the polarities that often rule in the world of disability and everywhere else: normal or disabled, science or wrong, good or evil, oppressor or victim. I then explored some of the perils and paradoxes that we must move through carefully if we seek to move towards what Volf calls "the will to embrace." Finally, I looked at some of what I have learned from others and

my own experience in community building, and the ways that third persons, third places, shared (third) interests and activities, and shared spiritual visions and calls can move us toward hospitality to one another, the stranger with or without disability.

One of the people who came to speak to me afterward was Sam Ginsburg. After morning tea (Australian for coffee break), and a moving presentation by Don Ludlow via an Internet presentation (He is a poet "confined" to the island of his home because of multiple chemical sensitivities), it was the turn for the Imam and Sam Ginsberg. They were speaking as representatives, respectively, of Islam and Judaism, for fifteen-minute perspectives on inclusion and embrace from their personal history and religious tradition. They were preceded by a short word from Rabbi Kippen, with an invitation for participants to write a prayer or thought about September 11 which I could take back to share with others in the States.





Sheikh Isse Musse was terrific. A gentle, compassionate voice who led the audience into core Islamic perspectives, and left us all hanging to hear the end of the only story where the prophet Muhammad was known to have been engaged by a woman with a disability. To hear the end, he said with a twinkle in his face (he became blind at age 5), “You have to come to my afternoon workshop.” The title of his talk: “Insight from Islam”.

Then it was Sam Ginsberg’s turn. His title: “Can a Jew Embrace the World?” He confessed saying “Yes” to the invitation to present a Jewish perspective without really thinking about what he was doing. He is a psychologist, and works for the agency which co-ordinates Australian volunteers overseas. He talked about his late night struggles with what to say, whether to share key concepts, or key authors who had been important to him. As he walked around the speaker’s platform, he talked about the importance of asking questions in Jewish tradition. Following in the best traditions of Job, the psalmists, Lamentations, and the other writers from other traditions who had been important to him, including Buddhist, Taoist, and philosophical traditions. He talked about the embrace of the covenant relationship, one in which his people believed God would not let them go. He then turned back to his place at the speaker’s table, pulled out a little sack, and started sharing some central symbols from rituals of that covenant. Again, a gentle spirit and voice that embraced the whole room and let everyone in.



One was a cup (chalice), given to him by a Christian, which they used in their family for Friday Shabbat dinners. The shared cup, the shared meals, the sacred family hours on Friday, all formed the environment where a young red headed Jewish boy learned that he was loved in a world which made fun of him for reasons of religion and hair colour.

A second was a yarmulke, the head dressing worn by men. This one he gave to Sheikh Isse Musse.

The third was a prayer shawl, worn for years by his father. It was blue and white silk, obviously handled with care for years, fingered with dedication and love, and grey with age. Sam talked about how his father, a doctor, had taught him about compassion as he went around with him on house calls in his youth. He shared how his father, dying with cancer, had fought to stay alive till his bar mitzvah. His father made it, by two days, and while he had not been able to come, the synagogue had allowed a first ever videotaping which was shown to his father in the hospital room before his death two days later.

Sam Ginsberg then turned towards the side of the audience where I was sitting in the first row and said in words that I could not believe I was hearing, (and which are not fully recaptured here): “I would like to give this shawl to Bill. I would like him to take it back to the States, and find a Jewish boy in New Jersey or New York who lost his father on September 11. Give it to him, on my behalf. I would like that boy to know, at this time, that he has a surrogate father in Australia.”

It was as if the air had gone out of the room in a collective response of astonishment and awe. I could not speak for the tears welling up inside of me, and I was not sure I could stand and walk over to receive it. But I did, and could only manage a simple bow in response. And I still cannot write about it, as I am now, or talk about it, without tears. I now think I should have taken off my shoes, for it was holy ground.

I will not say much more. His gift and gesture is still reverberating around within me, as it did around the conference for three days. I know that I will

never be able to think of September 11 without thinking of this gift. Tears of amazement and awe sit right beside the memories of that day. I came to Australia conscious about being one form of messenger from America. I now know something about the sacred and awesome duty of being a messenger with tidings of embrace and a specific story yet to unfold, its participants unknown. A simple act with a small piece of cloth that embraced an unknown child and countless strangers, halfway around the world.

But I know for certain that two trips to Australia led not to grace added to grace, but grace multiplied and squared. This had to be written, as another form of message back to friends in Australia, America, and around the world. Share it with whom you will, but in your own way, find ways to let in and give out the grace as well.

And may God grant, through us, shalom, salaam, and peace.

*William Gaventa is a member of the Working Group on Disability and Theology of the National Council of Churches, USA;*

*Co-ordinator, Community and Congregational Supports; co-editor, Journal of Religion, Disability, and Health, and Executive Secretary, Religion Division, AAMR*





## The Unseen Disability

by Caroline Kisakye

I have been attending to children with mental retardation since 1996. I am currently working in Mengo hospital in the occupation department. It takes a lot of devotion for one to train persons or children with mental retardation. This is simply due to the wide range of behaviour they display. Such behaviour may include violence, self-injurious behaviour (SIB), withdrawal tendencies, hyperactivity, hypo-activity to mention but a few.



Caroline Kisakye

According to my observations many writers, politicians, the church and the world in general either knowingly or unknowingly marginalise persons with mental retardation. This is mainly because the world is deceived that handicap refers to that which is visible and evident like physical handicap, blindness and deafness. People with these handicaps have always been identified when they use devices like the clutches, wheelchairs or other language (s)- sign language. Persons with mental retardation may not use any of this unless mental retardation is coupled with another handicap. They may seem to have no problem until one interacts with them. Mental retardation refers to generally low intellectual functioning. Till much later in their lives, persons with mental retardation remain "children". "A child is a little person without a sense of value, information, skills, attitude, character patterns but just waiting to be trained"

Persons with mental retardation normally have their mental age far below their real age. In training however, children and other persons with mental disability can learn. It needs to be repetitive as they master by frequency. Proverbs 22: 6 say "teach a child how they should live and he will remember all his life" Children are therefore capable of learning as long as they are taught with consistence.

Psalm 139:16 carries a message that God knows each of us deeply. This includes persons with mental retardation. God therefore knows each one of them individually and has a plan for them. In Uganda there are few units caring for children with mental retardation. In each of these, the awareness of God's presence is emphasised and persons with mental retardation have also been told and taught to live in ways acceptable in the sight of God. This knowledge has been quiet a psychotherapy and a source of comfort in the lives of children with mental retardation.

In John 9:3 when Jesus healed a man born blind he said "neither is this man or his parents sinned, but this happened so that the work of God might be displayed in his life." The church should therefore take it as an opportunity to extend God's service.

A lot of effort has equally been made by the Uganda government in catering for persons with disabilities in general. In the country's constitution Article 35 Section 1 page 31 states that, "Persons with disabilities have a right to human dignity and the state and society shall take appropriate measures to ensure that they realise their full mental and physical potential" In support of section 1 section 2 of the same article (35) states that, "Parliament shall enact laws appropriate for the protection of persons with disabilities.

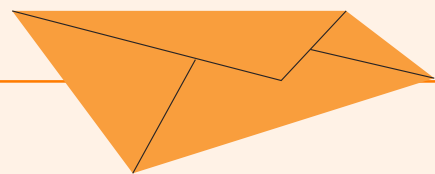
Much as the constitution supports persons with disabilities in general people still need to be sensitised heavily about mental retardation, as it may be the "unseen" disability.

*Caroline Kisakye works at Mengo hospital in Uganda as an occupational therapist. She can be reached on Mengo Hospital, P.O. Box 7161 KAMPALA, UGANDA. Tel 041 - 270222*





## EDAN MAIL BAG



November 6, 2001

Dear Friends:

We would like to thank so many of you that have already taken the actions recommended in our "request for urgent action" sent out last week.

As promised, please find the proposal enclosed of a resolution that supports the adoption, by the UN, of an International Convention for the Rights of People with Disabilities, presented by Mexico to the Third Committee of the United Nations.

As you may know from our past message, if Mexico receives the necessary support and co-sponsorship from the simple majority of the countries members of the UN, this proposal of a resolution can be approved by the Third Committee and be automatically included in the Agenda of the next General Assembly Meeting.

Also enclosed, are some of the "talking points" regarding the draft-resolution that can help clarify some of your questions on this process.

Please notice the correct e-mail address for the Mexican delegation mentioned in our past message. We ask you to replace it before taking further action:

Victor Hugo Flores  
Oficina de la Presidencia de Mexico para las  
Personas con Discapacidad  
vflores@presidencia.gob.mx

It's time to think strategically and negotiate with all actors involved, the best way of getting disability issues in the world development agenda.

Thanks for your support!

Rosangela Berman-Bieler  
Presidente, IID

To: The Editor,  
EDAN publication

Subject: Request for permission to reproduce article.

My name is Stella Etemesi and I am the editor of CHAK Times, the newsletter for Christian Health Association of Kenya (CHAK). I recently came across your publication, Edan, which I read with much interest. We are in the process of preparing the next issue of our publication which will focus on "Disability," and the reason I am writing is to ask whether we may reproduce your editorial that appeared in the July-September issue - "Rejection or over protection which way"

Briefly about CHAK & CHAK Times: CHAK is an umbrella body for church-run health facilities in Kenya and currently has about 300 members facilities (hospitals, clinics, dispensaries, etc.) around the country. CHAK Times is the network newsletter that we circulate to our members and other partners both locally and abroad. Our current circulation is 1000 copies. The content of the newsletter covers both medical and social issues, such as domestic violence, Malaria, Early marriages, HIV / AIDS. CHAK Times is a not-for profit publication and our main audience is all cadres of clinical and non-clinical staff in health facilities, medical students in MTC at our facilities as well as interested lay persons.

I look forward to hearing from you.

Best wishes and blessings,  
Stella Etemesi

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## EDAN MAIL BAG



Dear Samuel,

I want you to know that I began to build up the European network of EDAN. As a first step I sent EDAN News and questionnaires to ten addresses of WCC member churches in the countries around Hungary. I am looking forward to their reactions. Depending on that I plan to organise a small sub-regional meeting with disability representatives from these countries.

With kind regards in Christ

Pál Gado

Dear Sir / Madam,

Subject: Mailing List

Amaudo UK is a registered charity working in Nigeria with the Methodist Church focussing on the needs of people with mental health problems and learning impairments.

We tackle issues of homelessness, human rights abuses and service provision. Our goal is to implement sustainable structures of healthcare and

information which is affordable and accessible to all and to encourage people to form alliances to demand the support and services they require.

We work with federal and local government, local communities and the church to achieve our goals.

We have enjoyed reading your newsletter in the past (we were able to borrow a copy from former work colleagues) and would like to receive it in the future. We often pass it on to our partners in Nigeria who also find it very informative and interesting.

We hope that you will be able to add us to your mailing list.

Best regards

Kate Lumley  
Project manager

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