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REJECTION OR OVER PROTECTION WHICH WAY?


EDITORIAL

A few years ago, I was visited in my office by a young blind woman from a middle class Asian family living in a town not too far from Nairobi. She was accompanied by her father who wanted me to get her daughter some reading materials in braille. The father explained that her daughter had never gone to a formal school but had learned how to read and write braille through a private teacher hired by the family. She had mastered braille and English with time and could therefore read and write. Enquiring as to why she had not been taken to school, the father explained that being from a minority community generally perceived in the country to be very wealthy, he and the girl's mother had come to a conclusion that it would not be good to subject their daughter to humiliation and mistreatment she would have likely gone through in a predominantly Kenyan black school for the blind. Since such were the only schools available they had decided to keep the girl in their house and have her taught how to read and write through a private teacher. As Shanani the twenty-two year old woman listened to her father, she burst into tears accusing her parents for restricting her from any social activity interactions both in the house and outside. She lamented that the mother would not even allow her in the kitchen for the mistaken reason that she might either burn herself or cut her fingers in trying to use the Kitchen knife. The father did not have any response to these accusations and he looked very surprised if not ashamed. All he could say was that they had done what they had considered best for their daughter.

As I later reflected on this encounter, I wondered how many people who, like Shanani had nobody to share their frustrations with and who lived worse life than this particular girl. My observation today is that the birth of a child with a disability or the onset of a disability in a child within a family is always a great disappointment. The early reaction to this is either resignation, denial or attempted over-compensation. At first, the disability is treated as a disease and all attempt is made to ensure that any possible cure is tried. When all these fail, there are in both extremes two possible conclusions which are largely unconscious. These are either rejection or over-protection.

Rejection results from a sense of guilt on the part of the parents. They somehow consider that they are in a way or the other to blame for the disability and that the rest of the society are aware of this factor. The parents get uneasy especially with every comment made about the child whether positive or negative and as such they all the time look for ways of avoiding such comments. A child who is rejected may either be closed up within the house to conceal him or her from the public view. Such a child will be denied any form of social interaction including going to school. In the past, where boarding schools for such children existed, a good number of them were taken there and abandoned until they themselves are of age to retrace their parents. I remember thirty years ago when I joined a blind school after the loss of my sight finding such children who never went for school holidays and wondering why that was the case. I later learned that the parents of these children did not collect them when it was holiday and the school was in most cases unable to trace them. The mindset of such parents is that they have no need for such children as they are a bother, a constant reminder of their guilt and certainly a liability that has no eventual cost benefit.

Over-protection on the other extreme results either from love and lack of knowledge as to how to bring up such children but could also unconsciously result from a sense of guilt and hence the need to compensate. Among some communities, the presence of a disability in the family is a punishment from God and it has to be executed lest God should strike in a different way. A child with a disability has therefore to be cared for, nurtured and protected. The over-protection may take the form of doing everything for the child and ensuring that he or she is safe from any form of danger be it the fire in the kitchen or the kitchen knife as was the case with Shanani. The whole idea may be stressed to the point where parents are not ready to let go the child even if it means going to school. Over-protection tend to ignore the normal stages of growth and their psychological consequences such as search for knowledge, identity and belonging. It results in restrictions which inhibit these psychological developments. A number of people with disabilities do manage to get out of these situations but as can be expected, one has to have a

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very strong ego and natural drive to assert themselves out of these restrictions. Unfortunately, such assertion is often delayed manifesting itself when it is either too late to go to school or to have the necessary psychological foundation in life.

Rejection and over-protection have many negative things in common. They result in lack of exposure which in turn leads to lack of motivation, stimulation and life goals to aim for on the part of the one subjected to them. Both alienate and isolate those subjected to them from their peers, relatives and to a great extent their own families. Consequently, they restrict the natural cognitive and affective processes thus resulting in otherwise less intelligent and socially mal-adjusted personality. They prevent the individual from reaching their potential in social, spiritual, educational and developmental achievements. It has to be borne in mind that if the family has rejected you, it is very difficult for the rest of the society to accept you. Equally, if the family over-protect you, those around you will tend to treat you the same if not worse. The sum total of all these is loss of necessary opportunities in life.

It is necessary for parents to understand that they are not responsible for the birth of a child with a disability or for the onset of disability later in life. They should therefore not be ashamed of such children and should offer them all opportunities to overcome the restrictions that may be imposed by the disabilities. The ideal situation is where parents understand that in the first place, whether the child has a disability or not, he or she needs to go through the normal stages of growth being given opportunity to play, interact with peers and have education in the least restrictive environment. Exposure to psychological and social skills should not be any different from that of other children. Love should not be allowed to inhibit normal growth and search for identity.

A child who is given the right growth environment will be socialized and may reach the same potential as any other in similar environment. Both rejection and over-protection inhibit such potential.

It is necessary that there be institutions in the society that could help parents who find themselves with children with disabilities whether at birth or later in the lives of their children. As can be seen from

the foregoing, reactions to the birth of a child with a disability or the onset of a disability in a child may be associated with beliefs, customs and traditional practices. They go far back in history as can be seen in the Judeo-Christian culture as in the Gospel according to St John 9: 1-3. In this passage, the disciples of Jesus are seen grappling with the question as to whose sin had caused a blind man to be blind. Some of these reactions by parents have also to do with lack of understanding and limited exposure on the part of such parents. As such, they may not know where they could go for help to understand how to go about helping such children.

There is no institution in a better position to help parents who find themselves in such situations than the church. Although the church has in many parts of the world helped to set up institutions for children with special needs, it has not in many cases been able to address the social and emotional needs of parents who suddenly find themselves with children with disabilities. Theology has not stimulated discussion in this line to enable pastoral care and counselling to include these needs. Thank God that owing to years of awareness and visibility of more persons with disabilities in the society, attitudes are changing especially towards the provision of learning opportunities for children with disabilities.

However, education could still be provided within the context of rejection and over-protection. It is therefore necessary that the church seek to address not only the provision of learning facilities but also stimulate theological reflection and discourse on the whole subject of disability. It has to take upon itself to provide early social support for parents with children who have disabilities based on sound biblical foundation. One way will be to ensure that our theology curriculum for trainee ministers and the continuing education for practicing ministers have core-components that address these needs. Let it be understood that at least 10 per cent of all parishioners both children and adults have one form or the other of disabilities and that these affect parents and other members of the family and close relatives. Thus, the number affected by disabilities warrants the need for part of the training for the ministry to include components on how to deal with disabilities and their consequences on parishioners.



FOCUS ON THE CARIBBEAN

EDAN IN CARIBBEAN (5TH – 29TH JULY 2001)

INTRODUCTION

During the EDAN planning meeting held in Geneva between 6th to 11th August 2001, It was agreed that solidarity visits to Regions would greatly enhance the fellowship, sharing of experiences and awareness building among Churches, National and Regional Ecumenical organizations in as far as the work of EDAN is concerned. It was recalled that the impact of such visits had been evident at the mid Decade on Churches in Solidarity with Women. People involved in those visits were referred to as “Living Letters” and were considered to have carried forward the objectives of the decade much more than the various consultations held for that purpose. The Geneva EDAN planning meeting, therefore, recommended that this approach be tried as part of the Network programmatic work. It was agreed that the first visits be made to the Regional Ecumenical conferences with an aim of formally introducing the Regional Coordinators and to share the vision of the World Council of Churches (WCC) in regard to people with disabilities. Opportunity was also be taken to share the specific objectives of EDAN. A substantial budget was allocated to enable this important aspect of the work.

The first visit was planned to cover the Caribbean, Latin America and North America. The motivating factor for the timing of this particular visit was the fact that Rev. Noel Fernandez Collot in conjunction with the Conference of Churches had planned a Consultation for the Latin American Region in which it was necessary for some of the other EDAN members to give him support through a practical show of solidarity. Other Regions were included in the visit due to their proximity to the Latin America Region. Include in the visit were also the National Council of Churches in Cuba and Jamaica where our two Regional Coordinators reside and through where we had to go to get to the two Conferences of Churches which were the targets for the visit. The programme of the visit included meeting with Churches leaders, Councils of Churches and organizations of persons with disabilities.

Included in this visit were Rev. Dr. Gordon Cowans the Caribbean Region Coordinator and Rev. Noel

Fernandes the Latin America Region Coordinator who was accompanied by his guide and Spanish language interpreter Mr. Eduardo Gonzales. EDAN Consultant was accompanied by Angela Okola the EDAN Administrative Assistant. Rev. Kathy Reves the Coordinator for the North America Region was only able to join the team in New York towards the end of the visit though not before we had a very fruitful meeting with the National Christian Council of Churches in USA General Secretary. This was helpful because Rev. Gordon Cowans could not join the New York sector owing to prior commitment in Belize where he went after the consultation in Quito Ecuador.


The specific objectives of the visit were:

1. To participate in the Latin American Consultation in Quito, Ecuador.
2. To meet with the leaders of the Caribbean, Latin America and North America regional ecumenical bodies as “living letters” in order to formally introduce EDAN, its Coordinators, WCC vision regarding work with persons with disabilities and to elicit support for this work.
3. To meet the National Ecumenical Organizations in the countries to be visited with an aim of sharing the vision of EDAN and learning what they are doing in regard to work with persons with disabilities.
4. To meet individuals with disabilities and representatives of organizations of and for persons with disabilities in the countries to be visited to share in their experiences and achievements.
5. To encourage the Regional Coordinators in their work and to offer inter-regional exchange for exposure purposes.

STOP AT CUBA

The EDAN team arrived in Cuba from Jamaica to meet our Jamaican counterpart, Rev. Dr. Gordon Cowans whom we were to travel with to Cuba. On arrival, we were met by Rev. Noel Fernandez with his Assistant Eduardo Gonzalez who took us to El-Baroque Hotel in Havana where we were to stay.

On Sunday, we went for a church service at the First Presbyterian Church of Havana whose pastor, Rev. Hector Mendez is also a member of the WCC Central Committee. During the service, the EDAN team was given a chance to tell the congregation about disability work. After sharing on accessibility, it occurred to many that the sanctuary was not in itself accessible to

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wheelchair users. Rev. Mendez pledged to consider this to ensure full access. A member of the congregation who is a Civil Engineer by profession volunteered to ensure that this pledge is fulfilled.

During our trip, we had a meeting with the staff of the Cuban Council of Churches and various persons working together with the churches on the area of persons with disabilities. A lot of disability work has been done in Cuba. For instance, the churches have sponsored sign language training for interpreters who are in almost all the big churches in Cuba. This is particularly impressive because the deaf people can worship in various churches which have interpreters. This ministry for the deaf has also come up with a sign language dictionary of religious words. Another achievement is that the Bible Society Commission which is one of the Commissions under the auspices of the Council of Churches has been providing churches with Spanish Braille Bibles, audio tapes and Bibles for the deaf. Rev. Noel Fernandez who is in charge of the Commission for Persons with Disabilities champions the cause of inclusion in the church for persons with disabilities and together with others working have written a book entitled "Pastoral care for Persons with disabilities" which they distribute to pastors. The President of the Council asked for closer cooperation with EDAN and asked the team to always consider them as their focal point in Cuba.

In the visit to the National Secular Associations of the Disabled we met leaders of the 3 main National organisations of the disabled who shared with us their experiences. It is worth noting that the Cuban government is very supportive of their activities and they fund these organisations' activities and administration. The government has for example built a sheltered workshop which employs persons with disabilities. Their salaries though are paid by the government and so the profit is put back to the establishment.

JAMAICA


The first appointment in Jamaica was with the Minister of Health in his office. The EDAN team was able to tell him about the WCC and EDAN's work. He appreciated the fact that WCC had gone into Advocacy for persons with disabilities. The question of access for instance to practical things like toilets, placement of obstacles on side walks and public buildings needs to be addressed by establishments.

These are issues that could be dealt with through awareness building and advocacy. The Ministry of health is very much involved in prevention and care service especially on blindness and deafness. The issue of road accidents is very crucial as most of the disablement are due to this physical disabilities.

When we visited Baptist Church in Jamaica we realised that they have done a lot of work on the deaf as they had interpreters for the deaf in some of their churches. They also have a mission among the deaf through the school they sponsor for the deaf. The EDAN team however challenged them that they have to look beyond the deaf community and think about the blind, Mentally Handicapped and the People with Physical Disabilities among their congregation. One of the members of the board however, challenged the church to look more on the area of counselling, to persons with disabilities and access in all public and private places. The church promised to take this seriously and include it in the one week symposium that they will hold this year to create awareness on the issue of persons with disabilities. The symposium will be held in the first week of December which is set aside as the disability week in Jamaica.

During our meeting with the United Church of Jamaica and Cayman Island, the EDAN team talked about their objectives and goals. It was moving when a pastor confessed that one of the many things that their church has taken for granted is the presence of persons with different disabilities. There is no training at the theological colleges on how to respond to the needs of these people and so faced by this challenge, the pastors fail to know how to handle it. The church promised to take this up and look at inclusion in a more holistic way to the entire people of God.

In the meeting between the President of the United Theological College of West Indies Dr. Howard Gregory, who is also the President of the Jamaican Council of Churches, two things emerged. These were the theological discourse in theological colleges on the issue of persons with disabilities and the issue of scholarships for these persons to study. He stressed that there is a need for a curriculum on disability. He pledged that UTCWI will be ready to converge a forum of people with disabilities, church leaders and theological students to brainstorm on these issues. From the Jamaican Council of Churches front, he promised to look into the scholarship possibility for persons with disabilities who would wish to pursue further studies. This came up from the meeting that was held with the Caribbean Conference of Churches'

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officer in Jamaica who informed the team that the mandate of awarding scholarships lay with the National councils of churches when approached on this issue by the team.

TRINIDAD AND TOBAGO

Trinidad and Tobago which hosts the program Office of the Caribbean Conference of Churches and so this was our next stop from Jamaica. Our appointments in this place were to institutions that care for children with various disabilities and Centres for Persons with disabilities.

One such centre was Princess Elizabeth Centre for Physically Handicapped Children. This Centre was started in 1952. On the engagement of Princess Elizabeth to Prince Phillip, Lady Dos Santos who was then President of the Red Cross society of Trinidad and Tobago mounted a fundraising programme to buy the princess a suitable wedding gift from the people of Trinidad and Tobago. The princess, however requested that the money raised should be used to build a home for children with physical disabilities and this home should bare the name Princess Elizabeth. The government donated land for the home and the Anglican church erected a school and hence the present Princess Elizabeth Centre. The centre has a school, a workshop and an operating theatre to correct physical disabilities among children so that they can pursue further education in any other institution.

The National Centre for Persons with Disabilities of Trinidad and Tobago is a big pride in the Caribbean. The Centre that was began in 1964, is headed by Ms. Beverley Beckles provides vocational training and employment opportunities for the deaf, blind and physically handicapped. The Centre offers courses in tailoring, computers, agriculture and carpentry. It has production units for various goods which are either produced on order or sold to various companies in the island. Due to its popularity it attracts many students from other countries in the region. The Centre also carries out awareness and sensitization to people in service providing areas through the media.

During the meeting with the various church leaders of the Trinidad and Tobago Council of Churches, the delegation was informed that the churches here have been very much involved in the disability work

though however it was clear the approach to this work was that of provision of service, education and training without involvement of persons with disabilities themselves in the social life of the church and community. As such it was clear that more awareness needed to be built to encourage inclusion in the churches. Discussing this with Dean Knolly-Clarke who is incharge of the programme, he promised to include modules on disability in the curriculum under preparation, which the CCC is organising on lay training, pastors continuing education and pastoral programme which could be avenue for awareness through which a curriculum with a disability awareness could be developed.

ECUADOR

The key reason of this trip was to attend the Latin America Consultaion on Disability. The consultation brought together people working with the churches in the area of disability from the region. During the discussions, the main issues dealt with were: integration, inclusion, situation of persons with disabilities in the region and lessons learnt in this field. The greatest challenge thrown was for the churches to get involved in elimination of discrimination of all forms. A participant from the indigenous tribes in Ecuador, who was blind, gave an account of the work among the blind in the indogeneous groups. He pointed out that segregation is a major problem of these people. There are no roads in the areas, where the indogenous people live, no electricity and no schools either. Even though one third of the population in Latin America is believed to be from the indeginous tribes, yet the Churches seem not keen on alleviating this problem. The very first indigenous blind person to go to the University who was at the time a law student, gave us an insight on how hard it is to get education in Ecuador for the indeginous people. It was even more difficult as he said to get education when one was blind. He had to leave his home and look for a school in the city where he stays with his brother. The church therefore needs to have a greater outreach especially in the remote parts of the country. He told us how he has experienced sick people literally having to be carried for long distance to get them to where transport can be. In situations like this, going to church for people with disability is very difficult and unless more work to encourage all those concerned is done, the situation will remain very gloomy.



IS THERE EQUALITY OF HEALTH OPPORTUNITIES FOR PEOPLE WITH DISABILITIES?

‘On the occasion of the International Day of Disabled Persons, 3 December, the World Health Organization (WHO) will publish a report on the health of disabled persons. Its main purpose is to identify the various government policies on disability and problems with implementation of strategies in order to meet the needs of people with disabilities and ultimately to give them equality of opportunity.

WHO estimates that between 7% and 10% of the world’s population lives with disabilities which means almost 500 million people. The vast majority of them, about 80%, live in developing countries, where only 1% to 2% have access to the necessary rehabilitation services.

“In matters of health, everyone should be treated equally. Yet, people with disabilities have been discriminated against throughout history. Their participation in life and social activities has been restricted. This has to change.” Dr Gro Harlem Brundtland, Director-General of WHO, stated.

In 1993, the General Assembly of the United Nations adopted 22 Standard Rules on the Equalization of Opportunities for Persons with Disabilities; four of those rules are directly related to health: medical care, rehabilitation, support services; and personnel training. Those rules form the basis of the questionnaire that WHO sent last May to all its Member States and to the many Disabled People’s Organizations (DPOs) through its six Regional offices and its hundred or so National offices. One hundred and four of the 191 Member States of WHO responded as did 115 DPOs).

This report shows that at least 95% of the 104 countries who responded claim to offer medical care to disabled people and 30% have no rehabilitation services at all. 46 out of 95 countries do not cater for disabled people in primary health care services, which goes against WHO recommendations on the subject.

One third of countries who responded do not provide adequate training for staff who work with disabled people. Many countries do not cover disability in training curricula for health professionals. General practitioners in 20 countries, nurses in 21 countries,

paediatricians in 26 countries and social workers in 12 countries receive no such training. WHO recommends that this be rapidly remedied, at least for nurses, since they are the ones who provide most of the medical care and rehabilitation services for disabled persons.

There are major disparities between countries (industrialized and developing) and within countries (urban and rural areas) as regards access to medical care including the presence of qualified staff. Apart from general practitioners, nurses predominate, while specialists such as orthopaedists, speech therapists, psychologists and paediatricians are few and tend to be found in the cities. Disabled people, therefore, often have to travel great distances to centres with the appropriate human and material resources.

Participation of Disabled People’s Organizations (DPOs) in the planning and evaluation of health services is inadequate: only 3 out of 103 countries involve them fully, and 12 countries report that they never consult them. The report also stresses the personal involvement of disabled people and their families in managing disability, while most of those families are poor...

WHO maintains that disability should not be seen as a matter of concern to the disabled and their entourage alone. Disability concerns the whole of society, in terms of the legislation, education and services which should be promoted if the disabled are to be fully integrated; the environment should be adapted to their needs whenever necessary. The report advocates that countries increase their efforts to ensure that children and adults with disabilities gain access to better medical care, which will help them to participate in the life of their community.

WHO intends to publish another report soon based on responses from the DPOs.’

Downloaded from the Disability Awareness and Action (DAA) website.



DISABILITY MARCH:

1500 COSTA RICANS DEMAND EQUAL OPPORTUNITY

On Friday 1 June 2001, nearly 1,500 people with disabilities marched on Second Avenue in San Jose, Costa Rica. Our demand: **Equal opportunity.**

The Wide Avenue was filled with a picturesque group of people that moved on wheelchairs, walked on crutches, were using white canes, or were guided by dogs, or had someone translate what was said into sign language.

The successful and enthusiastic demonstration was organized by **FORO POR LOS DERECHOS HUMANOS DE LAS PERSONAS CON DISCAPACIDAD**, the Human Rights Forum for People with Disabilities. The main goal of the demonstration was to celebrate the five-year anniversary of Law 7600, the law on equal opportunity for people with disabilities, passed by the Costa Rican congress in 1996.

Moreover the march wanted to show the Costa Rican society that people with disabilities movement had the will to pursue its rights and remind Costa Ricans that law 7600 had not been enforced.

And five years later enforcement is still mostly nonexistent. There have been gains. But they have lacked depth. They are reversible and have not any impact upon the lives of 400,000 people with disabilities. As the Bureau of Civil Rights says, we are still the most excluded population in the country.

Underestimating & Overprotecting

Costa Rican society has two dominating traits: it underestimates and overprotects. In the daily lives of people with disabilities, this translates into exclusion and passive discrimination.

Hundreds of people from different parts of the

country answered the call of the Human Rights Forum for People with Disabilities, convinced that real change demands active participation not only from people with disabilities, but from all social groups seeking equal opportunities for all.

This socially and politically significant effort made itself heard through hundreds of voices and boards, all screaming slogans such as

“Law 7600: Enforce it”

“Equal opportunity for all people, for all ages”

“Woman with disability, twice discriminated”

“Costa Rica listen, we are risen”

“Baruch, you’re not a Liberal, then liberate our money” (Baruch is Minister of Finance)

One slogan, however, was taken up in chorus by the vibrant crowd. It became the official slogan for the March for Equal Opportunity:

“If Costa Rica is not accessible, democracy is impossible”

The diverse and hopeful crowd gathered at the Merced Park. The group walked for a mile under a scorching afternoon sun and stopped opposite the Legislature Building, chanting its demands for justice. There the Majority Whip, Ovidio Pacheco, listened to the Open Letter to Costa Rica (see annex)

The March finale was full of songs. Violeta Parra’s “Gracias a la vida” (“Thanks, Life”) was the closing point of the March. Its optimistic message rekindled hope, and like an electric current, it went from one end of the crowd to the other, forever imprinting on it the seal of justice and hope.



OPEN LETTER TO COSTA RICANS

*From the Organizations of People with Disabilities
To the People of Costa Rica:*

On 29 May 1996, the Official Gazette published Law 7600 of Equal Opportunity for People with Disabilities. The main goal of the Law is to serve as a tool for People with Disabilities to reach their full potential, achieve full social participation, and exercise their human rights as per the Costa Rican Constitution and international treaties.

A group of organizations that belong to the movement for people with disabilities decided to commemorate with a march the fifth anniversary of Law 7600. The occasion presents a good opportunity to reflect upon the enforcement of this law. The degree of enforcement offers no consolation. According to the Annual Report of the Bureau of Civil Rights, people with disabilities are among the most excluded social groups in Costa Rica.

We still hope to attend a school that is near our home. We still hope to use public transportation, just like our friends and family. We still hope to obtain a decent job, one at the level of our training and talent. We still hope to enjoy health and rehabilitation services according to our needs. All this, nonetheless, is as precious to us as it is distant. Enforcement of Law 7600 is in its infancy, is painfully slow, is inconsistent, and is reversible.

It is imperative that the government, public institutions and Costa Rican civic society at large truly commit to the effort of strengthening the living conditions of people with disabilities

On account of the above, we declare:

To our legislators: We demand deep changes in regulations so as to secure equal opportunities for people with disabilities. Currently a bill is being reviewed, the General Collective Transportation Law, that clearly represents a setback to accessibility in buses, which are used not only by people with disabilities, but by other people with mobility problems such as pregnant women, senior citizens, children, obese individuals, small people, and so

forth. We ask that the bill be modified to comply with the principles of Universal Accessibility in public services.

To the President: We demand that measures be taken to fully insure the human rights of people with disabilities. This means strategies, policies programs and services should subscribe to the principles of equal opportunity and accessibility. Furthermore, financial resources should be assigned to them to secure their satisfactory implementation.

To the authorities: We demand a watchful attitude, so that the Law of Equal Opportunity for People with Disabilities is fully enforced. To this effect we believe it is indispensable that the officers who enforce the law are trained to clearly and correctly interpret it in accordance with the needs of people with disabilities.

To those who want to become our leaders: We demand real political will to improve living conditions for people with disabilities. Disability should be an issue of state and it should not be left to the agenda of the First Lady or philanthropical associations. This would limit the issue to a problem for social assistance, which in turn would strengthen prejudice that restricts the full appreciation of people's true value.

To the media: we request that you air a positive and dignified image of the people with disabilities that helps eliminate stereotypes that make us the recipients of pity and charity. These two are obstacles to our social, cultural, political, and economic growth.

Five years have gone by since the signing of Law 7600 and its level of enforcement does not give us high expectations for the people with disabilities in Costa Rica. We want a country with equal opportunities for all with no distinction of any kind. This is the fight we will never give up.

"If Costa Rica is not accessible, democracy is impossible"

San José, Costa Rica. Friday, 1 June 2001



HUMAN RIGHTS FORUM FOR PEOPLE WITH DISABILITIES IN COSTA RICA:

Social Activism for a Necessary Change Throughout history, as people with disabilities, we have had to face off all daily aspects of a socio-cultural ambiance that underestimates and overprotects us, discriminates and marginalizes us.

A more than a century old, Costa Rican democracy, under its gains and limits, has not even been experienced by the thousands of citizens with a disability.

Inaccessibility to the different existing services has been more a norm than an exception. Although filled with good intentions, public assistance and private charity have dominated the national scene, thereby, limiting autonomy and development for people with disabilities.

Advanced Legislation; but...

In Costa Rica, as people with disabilities, we enjoy an advanced legislation that protects our rights. The Bill for Equality of Opportunities for People with Disabilities, Bill 7600, was published in May, 1996). Included in this Law is the American Convention for the Emancipation from All Forms of Discrimination (ratified by Costa Rica).

In spite of this, there is an enormous void between the legal aspects and reality, and the daily experiences of an immense majority of people with disabilities.

Access to education, jobs, health services, transportation, architecture, communication an information, culture and sports, as to other spheres of social life is restricted and, in many cases,

impossible.

For a majority of the nearly 400 000 people with disabilities living in Costa Rica, development is at the end of a road dominated by inaccessibility.

No one has denied there has been progress, and we are not pushing for immediate or impossible changes. Absolutely not! What happens is that changes generated up until today are shallow, prone to be changed back, and inconstant throughout public institutions.

A Weak Social Movement

In spite of the progress, as people with disabilities organizations and as people with disabilities ourselves, and our presence, we have not been able to lead the way it corresponds to perform the necessary changes.

Concerning this, it is timely to recall the words by the United Nations' ,Special Secretary on Disabilities, Bentg Linqwist, who, while visiting our country in 1999, spoke about the weaknesses he perceived in the people with disabilities' movement.


Such a worry makes a lot of sense, because all countries showing significant advances in these matters are those, which show strong and active social movements of people with disabilities.

A Permanent Forum

To solve this need, by the end of last year, a group of people with disabilities started building an open, democratic and inclusive space formed by individuals and organizations committed to the Human Rights of people with disabilities.

Such is the purpose for the **FORO POR LOS DERECHOS HUMANOS DE LAS PERSONAS CON DISCAPACIDAD** (Forum for Human Rights of People with Disabilities).

What this Forum for deliberation and action intends is that from civil society itself, to join organizational and individual efforts of those interested in advocating for the actuality of civil and political, and economic,

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social and economic rights of people with disabilities.

Our assured unswayable decision and goal is to contribute to the development and strengthening of a social movement by people with disabilities in Costa Rica so as to reach the social, economic, political and cultural empowerment of this social group.

To understand this effort, the statement by Nobel Prize for Economy, Amartya Sen, is as just as inspirational: "Development means to build people's capabilities for them to attain freedom to build a dignified life."

"Nothing about us, without us."

San José, Costa Rica, March 7, 2001.



INTRODUCING FRANKLIN DELANO ROOSEVELT INTERNATIONAL DISABILITY AWARD

The Franklin Delano Roosevelt International Disability Award is named from the 32nd President of the United States who contracted polio at age 39. Although he was unable ever to walk or stand unassisted, Franklin Roosevelt was four times elected President and lead his nation through the two gravest crises it has faced in the twentieth century: the Great Depression and World War II. Roosevelt was also a principal founder of the United Nations and was preparing his speech for its opening conference when he died in 1945. This Award was created to strengthen commitment and action by all nations toward expanding the participation of people with disabilities in the life of their societies as called for by the United Nations. In addition, the Award projects worldwide FDR's legacy of social justice and his spirit of optimism.

FDR's world changed the moment he contracted polio in 1923 on Campobello Island, Canada. Born to wealth and privilege, FDR was faced with the greatest struggle of his life – to triumph over his disability. He had to learn how to stand, how to move on his own, and how to rely on both the support – physical and moral – of others. And, he had to learn never to give in to despair, to self-pity or to discouragement. He not only championed America, but he embraced a desperately troubled world and gave it hope. He provided the vision for the United Nations, the commitment to collective security, the determination to end colonialism, and the framework of an economic plan for a prosperous world. He changed the course of history, and all citizens of the world are beneficiaries.

FDR overcame his disability not by diminishing his life to what was readily manageable, but by enlarging his life to embrace all the risks the greater world had to offer. He challenged the world to triumph over its advertises – war, poverty and hatred – just as he challenged

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himself to triumph over his adversity. From his wheelchair he inspired people everywhere. He continues to do so today.

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SPONSORSHIP OF THE AWARD

World Commitment on Disability

The World Committee on Disability promotes the full and equal participation of people with disabilities in the life of their societies. It works with the United Nations, world leaders, and international organizations to further the goal of the United Nations World Programme of Action Concerning Disabled Persons. The World Committee is the international arm of the National Organization on Disability, a Washington DC based non-profit organization that itself is a direct outgrowth of the United Nations International Year of Disabled Persons.

FRANKLIN AND ELEANOR ROOSEVELT INSTITUTE.

The Franklin and Eleanor Roosevelt Institute is a non-profit organization headquartered at the Franklin D. Roosevelt Library in Hyde Park, New York. Its mission is to inform new generations of the ideals and achievements of Franklin and Eleanor Roosevelt, and to inspire the application of their spirit of optimism and innovation to the solution of current problems.

**In Memory of
Je H. Kim, Ph. D
1937 – 1998**


A dedicated scientist and humanitarian, who, later in life, overcame the adversity of visual

impairment with courage and strength. As a Korean-American, he took pride in Korea becoming the first nation to receive the FDR International Disability Award. His understanding of people with disabilities and enduring generosity makes possible the annual publication of the FDR Awards booklets.

A SILENT CRISIS

According to the United Nations, there are a half-billion men, women and children with disabilities in the world. They are unable to participate fully in the life of their societies because of one or more major disabling conditions. Disability knows no political boundaries. Eighty percent of people with disabilities are in developing countries and are further disadvantaged by poverty and discrimination. Counting family members who also are directly affected, a fifth of the world's population lives with disability on a daily basis. The numbers are increasing dramatically. Population growth, medical advances that preserve and prolong life, war injuries, landmines, accidents, malnutrition, disease, substance abuse and environmental damage all contribute to this increase. Anyone can join the disability community in an instant. No one is immune.

The United Nations has recognized the need to confront this "silent crisis" and through a series of measures has raised awareness and increased action to improve the lives of people with disabilities worldwide. In 1976, the U.N.

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SPONSORSHIP OF THE AWARD

proclaimed 1981 the International Year of Disabled Persons. The U.N. General Assembly in 1982 adopted unanimously the U.N. World Programme of Action Concerning Disabled Persons as a global strategy. This was followed by the U.N. Decade for Disabled Persons (1983-1992). This U.N. commitment is continuing into the new millennium.

UN ACTION

The United Nations World Programme of Action Concerning Disabled Persons is a global strategy. Its goal is the full and equal participation of persons with disabilities in all aspects of life in their respective countries regardless of the level of development. It was adopted unanimously in the U.N. General Assembly December 3, 1982. The World Programme prescribes how nations, communities, organizations, religions and people of goodwill everywhere can and must expand the participation of people with disabilities for economic, humanitarian and social reasons.

National governments bear the ultimate responsibility for improving the lives of their citizens with disabilities. Through the World Programme, member states of the U.N. are called upon to: enlist the participation of people with disabilities and their organizations in all activities affecting their lives; provide rehabilitative services and technical aids to persons with disabilities; ensure that people with disabilities have opportunities for education, employment and economic, social and cultural life equal to those of other citizens; support community action programs; provide training to those who offer services to disabled persons; and disseminate information and promote public education to ensure a broad understanding of the issues.


The World Programme serves as a guideline for community, national and international action. Its goal continues as a beacon of hope for the disability family, and indeed for all humanity.

WHY THE AWARD

The Franklin and Eleanor Roosevelt Institute and the World Committee on Disability announced the establishment of the Franklin Delano Roosevelt International Disability Award on the fiftieth anniversary of the United Nations on October 24, 1995 at Hyde Park, New York, the home of President Roosevelt. The Award recognizes and encourages progress by nations toward the fulfillment of the goal of the United Nations World Programme of Action Concerning Disabled Persons.

The Award was established to elevate the U.N. World Programme of Action on the agendas of nations throughout the world and to encourage further action and commitment by leaders and governments to expand the participation of people with disabilities in the economic, social and cultural life of their countries. It is presented annually to a nation that has made noteworthy progress toward this goal. The Award is accepted by the chief of state.

Nations nominate themselves for the Award. Selection of the nation to receive the Franklin Delano Roosevelt International Disability Award is made by the Board of Directors of the Franklin and Eleanor Roosevelt Institute with the advice of the World Committee on Disability and individuals from throughout the world who are knowledgeable about international disability, the World Programme of Action and FDR's commitment to social justice.

The Award consists of a bronze bust of Franklin D. Roosevelt by the distinguished artist, Jo Davidson, and a \$50,000 prize from the Roosevelt Institute. The monetary prize is then awarded to an outstanding non-governmental disability program in the selected nation. 

EDAN MAIL BAG

I received the message that you would like to make contact with our group. We thank you for that and on behalf of our group I will try to introduce ourselves to you.

Dear Mr. Kabue,

I received the message that you would like to make contact with our group. We thank you for that and on behalf of our group I will try to introduce ourselves to you.

Our group “Theology and Disability” started in 1985, as a result of the international meeting on disability and the churches, that was organised in Holland by the World Council of Churches. We are a group of theologians, or people with a theological interest, who themselves have a disability or chronic illness of any kind. We think it is important that we can *speak from the perspective* of persons with a disability, rather than to *talk about* them. This is our principal basis. In the past years we have also admitted some people who don’t have any disability, but would like to commit themselves to our work on the basis of equality and solidarity.

We are an ecumenical (though mostly protestant) group, and are supported by the Reformed Churches in Holland. We also have contact with the ICIG, the group that Simone Poortman is a member of. She gave us a copy of your newsletter, and that is where this contact started

We mainly are a studying group. For example, we have written several articles on Bible-pericopes regarding disability, sickness and healing. (I would like to send you some of these, but we first would have to translate them in English...) We try to get these articles published in (theological) magazines or newsletters that appear in our churches. In this manner, we want to open the eyes and ears of churchmembers for the situation of people with a disability, and try to establish real communication on this subject. We also do this by giving information in local or regional meetings, or by organising seminars.

As for myself, I am a woman of 43 years old. I have worked as a minister in several communities, together with my husband, who also is a minister. I also worked for a few years as minister (or pastor) in a hospital. At this moment, I don’t work as a minister anymore, but I take care at home for our children, and I participate in the work of “Theology and Disability”.

I hope you now have an idea of who we are and who I am. We look forward to getting to know you better, and hope that we can help each other in our activities. In case you want to answer my mail, it is good to know that from July 1st I will be on a holiday for about three weeks. So I won’t be able to read your messages then.

Sincerely Yours,

Willy Rullmann.

E-mail: w.rullmann@planet.nl

FINAL DECLARATION OF THE FIRST LATIN AMERICAN ENCOUNTER OF PEOPLE DISABILITY, PAPER OF THE CHURCHES AND STRATEGIES OF FUTURE

-Quito, Ecuador, 18 at July 21 the 2001-

“But when you give banquet invite the poor, the crippled, the lame, the blind and you will be blessed..”. Luke 14:13

Gathered by the Ecumenical Disability Advocates Network (EDAN), which is a programme of the World Council of Churches and with the collaboration, participation and commitment of the Latin American Conference of Churches, we have met in the city of Quito, Ecuador, from July 18 to 21, 2001 as brothers and sisters involved in the work with carriers of disability, coming from Cuba, Brazil, El Salvador, Nicaragua, Venezuela and Ecuador. Honoring us with his participation we have among us Samuel Kabue, (Kenya), consultant EDAN and of Dr. Gordon Cowans (Jamaica), Coordinator for the Caribbean Region of the same network, as well as Anjeline Okola (Kenya), EDAN Administrative Assistant.

Taking in consideration that:

1. Although the percentage of people with disability, according to the World Health Organization (OMS), is 10% out of the world population, in some countries of Latin America this percentage is higher.
2. Some years ago people with disability were seen as second class citizens who lacked legal rights and they were considered as a social burden.”


3. There are laws; agreements and ordinances that favor people with disability.
4. Regrettably, the economical policies that we suffer as a consequence of the indiscriminate application of non-liberal and globalized initiatives, have made people with disability lack, more and more, accessibility to employment, education, medical and law services, among others.
5. This policy has made stronger emphasis on the productivity of humans beings than in the human value, which causes that non capable population (people with disability, old persons, women and children, among other) are excluded and they are denied the opportunity to achieve an appropriate social and economic well-being.

In spite of the limitations, we acknowledge that social advances have been reached in the attention to the population with disability. But in the particular case of churches, this people with disabilities have not been given the same treatment they have been receiving from the society, in the secular sense of the world. It is a shame, taking into account that the command and our Lord Jesus Christ’s example of preaching the gospel to all creature” (Mark 16:15) it is clear and overwhelming for our communities of faith. The disobedience to this principle, it has turned churches in a more discriminatory place than the society they should minister to.

Many are the factors that have caused the churches not to develop the work of love that has been commended to them, but none of them is strong enough so as not to disobey the biblical command.

It is objective of this consultation to motivate, to sensitize and to promote the change toward an effective, appropriate and pertinent Pastoral work for blind, deaf, deaf blind, limited physical and people with mental deficiency. Among others allow the integration from these sectors to the full life of our churches, without leaving behind the importance of support from their families.

Because of these, listening to the clamor of this sector,

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FINAL DECLARATION OF THE FIRST LATIN AMERICAN ENCOUNTER OF PEOPLE DISABILITY, PAPER OF THE CHURCHES AND STRATEGIES OF FUTURE

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we make a call to the churches and Christian institutions to make the Great Commission come true, so that the salvation message gets to persons with disabilities so that they can be able to enjoy the abundant life that Jesus Christ came to bring us. This can be achieved by giving to people with disability access to all the activities of the church and to positions of leadership in accordance with their gifts and capacities.

For what is necessary:

1. To eliminate the architectural barriers that not only will be of benefits to people with disability, but also to the old persons, pregnant women, children and others.
2. To promote means that allow blind, deaf and deaf blind persons not only participation in worship services, but in church life.
3. The use of an inclusive and appropriate language and liturgy in church that does not exclude them.
4. To use accessible materials that facilitate the understanding of the Gospel to all the people that need it.
5. To promote the training of church leadership on the appropriate pastoral care of the population with disability.
6. To eliminate the over protection and sorry feeling and to provide persons with disabilities with training that will allow them to rise up to positions of leadership.
7. To set special interest in the pastoral care to people with disability in the indigenous sector.
8. To facilitate, according to the necessities of each country, the development of Disability Prevention Programs.

9. Whenever the conditions allow it, this work should be based on an ecumenical effort.

The participants in this consultation feel committed to walk with you for the achievement of this aspiration, assuming that we are sent by The Lord to build a better world. “..Again Jesus told them: peace be with you. As the Father has sent me, I am sending you” (John 20:21).

EDAN STOPS OVER IN NEW YORK CITY

Our host the National Council of Churches, arranged all the meetings in their Interchurch House in New York City. From our encounter with Rev. Joe H. Leonard who is in charge of disability work and who also planned the programme for our trip, we realised that a lot has been done by the Council of Churches. They have developed and implemented a policy on disability and have a very strong committee on disability.

During the meeting with Rev. William (Bill) Gaventa who coordinates faith groups on spirituality for developmental disability at Boggs Centre through building of advocacy groups. after discussions with the Boggs Centre on Disability was appointed on the board of editors of a journal on Religion and Disability. A lot has been achieved in this field by the member churches. Through the work of this committee, many of these churches now have programmes on disability. The EDAN programme requested to be enjoined in the various activities that the council is involved in as pertains disability work.

We also met with the General Board of Global ministries where we met the staff in the Health and Ministries Department which houses the disability work.

A courtesy call was made to the World Council of Churches USA Coordination Office which Coordinates the work of the WCC in North America. Other Organisations visited were John Milton Society for the Blind who have a long track of producing Biblical articles in Braille.



EDAN NEWS

"POLE" TO USA

Following the horrendous terrorist attacks in New York the EDAN fraternity sends our sincere prayers and "pole" (Swahili word for sympathy) to our brothers and sisters in USA. We stand behind you in this difficult time - Terrorism is a great contributor to the increase of disability cases - an enemy of EDAN. We are in prayer with you.

Bye and Welcome

Anjeline Okola the EDAN Administrative Officer leaves for studies at the University of Leeds, beginning 20th September 2001. Jane Ngari will stand in while Anjeline is away. we wish Anjeline well and welcome Jane to EDAN Board.

- EDAN Reference Group and Regional Coordinators meeting will be held in catigny, Geneva, Switzerland from 30th September to 5th October 2001.
- Mr. Samuel Kabue has been appointed a judge for the Fredrick Delano Roosevelt Award.
- Mr. Samuel Kabue appointed and Editor of the journal of Regional Disability and Health, published by the Howard Press.
- Simone Poortman will attend the Justice Peace and Creation Advisory meeting from 6th to 16th October 2001.

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