

# CONTENTS

<b>EDITORIAL</b>	<b>2</b>
<b>ONE BODY? CHURCH, DISABILITY AND CREDIBILITY</b>	<b>3</b>
<b>YING-BO'S MEETING AT MANILA</b>	<b>5</b>
<b>PRESIDENT CLINTON HONORS DREDF'S PAT WRIGHT</b>	<b>6</b>
<b>JOHN HULL'S INTERVIEW</b>	<b>7</b>
<b>EDAN IN CENTRAL COMMITTEE</b>	<b>8</b>
<b>WCC LAUNCHES DACADE TO OVERCOME VIOLENCE</b>	<b>10</b>
<b>INFORMATION PACKAGE ON DISABILITY STUDIES</b>	<b>11</b>
<b>EDAN NOTICE BOARD</b>	<b>12</b>
<b>HUNGARIAN PERSONS WITH DISABILITIES ACT</b>	<b>13</b>
<b>RAZAKA'S INTERVIEW</b>	<b>19</b>
<b>EDAN DIRECTORY</b>	<b>20</b>
<b>EDAN PIX.COM</b>	<b>23</b>

**EDAN is a quarterly publication of the WCC Programme on Persons with Disabilities within the Cluster on Issues and Themes, Justice Peace and Creation Team  
Issues and views in this publication are by the members and contributors and not necessarily of EDAN**

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# EDITORIAL

## THE STRANGER

They were all alike on wheelchairs in their city. Everything was made according to their needs and comfort. Their wheelchairs were a source of delight and not symbols of confinement. The wheelchairs made their users “normal” and as such nobody could imagine life without the wheelchairs. The architects, city planners, doctors, social workers and opinion leaders were all on wheelchairs. Streets were designed with the necessary pavements, buildings were fully accessible, medical services were in line with the needs of the users and social workers conducted their work objectively according to needs. Everybody went about their affairs happily in an environment free of all physical barriers.

The ‘beautiful’ architecture designed to match aesthetics as conceived and understood by the wheelchair users. Doors were wide enough for the wheelchairs to go through but low to the extent that no materials were wasted beyond the necessary height for the wheelchair to go through.

Life was all happiness until a “stranger”, a person on his feet towering high above everybody else joined the community. The “stranger” did not fit because he was “different”. He was too tall to go through the doors as they were not designed for people walking upright. He had to bend down to switch on the lights and the pavements were too slippery for his comfort and safety in walking. The physical and social environment was “disabling” to him as his needs had not been put into consideration. The doors were especially a problem because he kept on hitting his forehead on the frame whenever he was getting in. This made him to have a permanent wound on the forehead with which the doctors were most unhappy about just as the stranger himself was but for different reasons.

To the doctors, the man was careless and did not deserve their attention. To the ‘Stranger’, the wound was a constant reminder that he did not belong. The failure to fit kept the stranger socially down most of time making the work of the social worker hard as attention to him was needed most of the time.

A meeting was held between the architect, the social worker and the doctor to discuss the problem of the stranger. The problem was identified as that of being “different” from “us”. Being “different” from “us” meant not fitting. To solve the problem, the stranger had to be integrated. He had to be “normalised”. He had to be made to live like “us”.

The conclusion was that in order to fit and make him appreciate life in the city, the social worker suggested that the stranger should have his legs amputated and then provided with a flash new wheelchair which he would be “happy” with. The assignment to carry out the surgery was given to the doctor who agreed that this would be a solution in that the wound on the forehead would heal and thus give the stranger a “better” look. The architect was very happy about this solution because he was saved the possibility of having to adjust the door as this would have interfered with the architectural aesthetics. ■

*By Sam Kabue*

# ONE BODY? CHURCH, DISABILITY AND CREDIBILITY

*By Arne Fritzson*

**Because there is one bread, we who are many are one body** (1 Cor 11:17). We use these words in our tradition almost every time we celebrate holy communion. Which claims do they make? Are these claims that we as a church can meet?

In this text we are going to put some questions out of our experiences as members of congregations with disabilities. Questions about our longing for participation but also about disappointment, exclusion and pain. We can see how persons with disabilities do not get the inclusion in the life of the churches as they need. This raises questions to do with the whole faith and life of the churches. Let us illustrate this with an example that touches the very centre of the faith.

A congregation that builds a house and plans their room for devotion does this out of their picture about the future use of the facilities. They often do this with the advice of an architect. They visualise the people that will come to this room, what they will do there and how they are going to move around in the room. That means that the shape of the room is a statement about how the people who have designed it look upon the church fellowship and faith. It is seldom we talk about such issues as we are not always aware about it.

In the front of many churches there are some steps to the altar, the pulpit and the place where the choir stands - but mostly there is no ramp. Those steps are a theological statement, done unconsciously: This is how far for people sitting on wheelchairs or have difficulties to climb steps can come. At least without being lifted or assisted in some other way that causes them to be more dependent on others.

When the congregation climbs those steps to take holy communion can those who can not reach the table get the bread and wine carried out to them to a place outside the fellowship? The exclusion becomes

obvious in such a service. A room for worship with steps and without a ramp is a statement of an excluding theology.

We are all welcome to the church. No parish says clearly that their community can not include people with disabilities. But if such generous welcome is not supported by, for example, accessibility to the room where the congregation gathers for worship, the welcome loses on credibility. The staircases but only one example, out of many, of how the parishes can make people feel excluded. It is not possible here to give a complete list of all things that makes a community exclusive towards people with disabilities.

We should be able to meet in the church regardless of the fact that different factors separates us such as social background or age. We meet there because our faith reaches beyond boundaries. But does our way of living out that faith reach beyond those boundaries? It does not matter how much we would like to welcome all, it does not give a true picture of reality, though when the map differs from reality, reality counts, regardless of quality of the map. Even if the church tells us that everybody is welcome it's possible for people to feel shut out. This exclusion can make us think of the church's message excluding or even hypocritical.

The problem is not how to include people whose way of being, think and feeling are the same in a community. The challenge is to go beyond the

*Continued on page 4*

## Are We Really One Body ?

*From page 3*

framework that gives us a feeling of security, to see that people with different experiences have a contribution.

When you feel an exclusion, when one's knowledge and experiences are not respected and you are not given a real opportunity, one can experience pain. That pain hurts even if it was not given with intent. If someone were to step on your toes when you are standing in a queue it is probably by accident. That person tells you that they are sorry and you understand that it was not their intention. Even so you have to live with the pain for a while. But you might have a bad day and someone else steps on your toe.

The pain increases in spite of the fact that, that persons had no ill intentions whatsoever. If this happens many times you finally lose patience and scream: Watch out! It is no longer possible to smile and say that it does not matter. It does not matter that you do understand that no one had the intention to hurt you. It hurt so much you had to express what you feel.

When we are causing pain to someone in our congregations, we are causing pain to the whole body. If we are one body that means that we are also causing pain for ourselves. To care for every member of the congregation is to care for the whole community. We can say that we lack knowledge about ourselves when we are hurting one another, for instance when we do not give ourselves time to get to know our selves. To have a good knowledge of our own body is necessary for a congregation that wants to stay alive.

In order to get a better knowledge about its' own body a congregation has to see which factors work towards exclusion for different persons. We have to be open and see our own prejudices. That means that it is not enough to make small changes on the surface but to a deep consideration of our way of looking at each other. It is an act of love to include your fellowmen in the community.

This challenges us to make a difference. A process of changing is both exciting and promising, but it also painful. To become aware that this is lacking in our own community should make us feel sorrowful. Because of that there is a risk that the challenge to change wakes a defence that stops us from seeing that

those changes are needed. It is more comfortable to choose to not understand.

To not make a difference is not an alternative for a congregation that has got the vocation to make God's love and care known among its fellowmen. The love of Christ controls us (2 Cor 5:14). But with the vocation God always gives a promise. If our community opens up we will get to know the richness of plurality and the truth in the words of the apostle: **"When you come together each one has a contribution (1 Cor 14:26)."**

Such a change will lead to a new and deeper way of understanding what we are as human beings. We will get a new understanding of what it can be to live as a human being in God's world. This will definitely have consequences for our faith, for our way of understanding God, for our understanding of humanity and our understanding of God are always connected. God's church needs to listen to experiences from persons that sees life from different perspectives. Without such experiences the church can not conceive parts of who God is. Because it is only when all who belongs to Christ come together that we have the power to comprehend the breadth and length and height and depth and to know the love of Christ which surpasses knowledge, that you may be filled with all fullness of God (Eph 3:18-19).

The vision of the church becoming one body is part of the church's life that we can not lose. This vision is both a reality, it has been given to us in Christ by grace, and an ideal that we should try to reach. We need to work towards the goal that our way of being together is a manifestation of the love of the gospel that finally is the life of the church. ■

# YING-BO'S MEETING AT MANILA

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It was a nice trip to the Philippines . I met the President of Autism Society Philippines, Inc. , Mrs. Conchita M. Ragragio and Medical Doctor Alexis L. Reyes, one of the organizers of this G.A.P. Conference. I gave them the EDAN Newsletters and shared our vision. They are going to organize an Asia Conference on Autism and try to build a network around this area in October this year and they also asked me to participate in it.

On 27 February, a lady with physical disability from Malaysia came to see me and my work. She is the Director of Beautiful Gate Disabled People Caring Center supported by the Methodist Church in Malaysia. I also shared EDAN with her and she was very interested and even wanted to be a volunteer to facilitate the Network within Asian countries.

We also talked about the possibility of organizing a consultation by the end of September 2001. We agreed to write a proposal and try to get some funds for it. The name of this lady is Sia Siew Chin, a very active pioneer in this field in Malaysia and running 3 centers now.

I am still working so hard and trying to do my best to raise awareness among the churches to look at people with disability around our society . Before the International Day of the Disabled last year, I had written 3 articles, more than 5000 words, concerning about the situation and perspective of theology of the people with disability and been published in the Church News of the Presbyterian Church in Taiwan and produced a video tape and VCD to introduce our work. We have reproduced more than 2000 copies and sent them to all Presbyterian churches in Taiwan and try to send them abroad.

I am proud to mention that the Presbyterian Church in Taiwan has set aside December 3rd of every year as a day for the disabled from last year. I think it is a small step but an important start though there is a long way to go . May God lead us and bless us. ■

*Ying-Bo Tsai*

# PRESIDENT CLINTON HONORS DREDF's PAT WRIGHT

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On Monday, January 8, 2001 President Clinton awarded the Presidential Citizens Medal to Patrisha A. Wright, Director of Governmental Affairs for the Berkeley-based Disability Rights Education and Defense Fund (DREDF). Honored alongside Pat were 27 other exceptional Americans, including Muhammad Ali, Archibald Cox and Elizabeth Taylor. Only 128 citizens have ever received this medal.

Pat's citation says:

The President of the United States awards this Presidential Citizens Medal to Patrisha Wright, widely regarded as "the general" guiding the campaign to pass the Americans with Disabilities Act. Patrisha Wright has been a driving force in the battle against discrimination based on disability. Through her tireless efforts to forge relationships with the civil rights community, defend disability rights, and promote progressive legislation, she has helped break down barriers to equal opportunity, enabling people with disabilities to participate more fully in our society.

*January 8, 2001  
William Jefferson Clinton*

Wright also coordinated the legal, legislative and grassroots campaigns to enact the Fair Housing Amendments, the Civil Rights Restoration Act and the Handicapped Children's Protection Act. She has worked for two decades to establish disability civil rights in the traditional civil rights communities, the traditional disability communities as well as the halls of Congress and multiple administrations. She has received many

awards including the Distinguished Service Award from President Bush, and was the first person with a disability to receive the Hubert H. Humphrey Civil Rights Award given by the Leadership Conference on Civil Rights.

DREDF, a non-profit law and policy center, promotes the civil and human rights of people with disabilities to secure their full integration into society. Founded in 1979, and managed by people with disabilities and parents of children with disabilities. DREDF fulfills its mission by providing training, technical assistance, policy analysis and development, advocacy and legal representation. An integrated education for children with disabilities is the corner-stone for independent living; DREDF devotes considerable resources to empowering parents in self-advocacy. DREDF has been significantly involved with every major disability legal reform in the US, and is closely connected to grass-roots disability groups in the US and worldwide. DREDF recently presented the first-ever federally-funded international disability law and policy symposium, with participants from 58 countries. ■

# John Hull's Interview to BBC Radio 4 'Sunday'

**Sunday 25 February 2001**

*Transcript of interview with John M Hull by Roger Bolton about Hull's new book In the Beginning there was Darkness, published by the SCM Press in London March 2001.*

**Radio BBC (RB)** "Your publishers claim that your interpretation of the Bible is entirely novel, is it"?

**John Hull (JH)** "Well I think that it is the first time that anybody has interpreted the Bible from a blind point of view. This is not simply a book about the theme of blindness in the Bible. It actually reads the Bible from the point of view of a blind person, and I think that is new".

**RB** "Now there is a great deal of anger in your book at the way the Bible, and Christians, have treated the blind. What do you find particularly offensive"?

**JH** "Well you see in Matthew Chapter 23 Jesus uses the word 'blind' as a term of abuse. He speaks of blind fools, blind guides and when I read that passage I find myself saying "Oh you know, my dear Lord why couldn't you have stupid fools or stubborn guides, ignorant teachers, why must the word blind be used as term of abuse in that way".

**RB** "Well you go a bit further. You say you were angry with Jesus and you say he shared the prejudices of his age towards the blind".

**JH** "Yes undoubtedly that is true. You see there is one place reported in two of the Gospels where Jesus says "how can the blind lead the blind, won't they both fall into a ditch"? Now this is a typical sighted persons attitude towards the blind peoples mobility. Many times I have lead around blind people in familiar territory and been lead. We have never fallen into ditches. I admit to the occasional confrontation with a rose bush. It is when I am being lead around by sighted people I suddenly go flack into a tree ... "sorry John, forgot you are blind".

**RB** "Well in the end you say you forgave Jesus. Some might think that's a bit heretical, now forgiving the Perfect Being"?

**JH** "I am not angry with Jesus but I must admit that I found the symbolism in which blindness is always regarded as indicative of sin and darkness and unbelief; that symbolism which does run right through the Bible, I found it distressing. However, when I found that my imagination was drawn to the passage where Jesus himself was temporarily blinded .. you know when they blindfolded him. Then I found that my anger diminished and then I came to regard Jesus as my blind brother".

**RB** "When reading your book it is difficult not to feel angry with the evangelist who pretended to heal you. Was he a complete fraud do you think, and is this a really dangerous tendency amongst some evangelicals"?

**JH** "I think that the image of Jesus as a healer of blind persons has created a kind of desire to imitate him literally, although this is mistake I am sure because when you read how Jesus treated blind people he always treated them with courtesy and respect. He never, as far as I read, went out of his way to invite blind people to come to him and be healed. It was the blind people who called upon him. But in that connection, one of the things which distressed me was the thought that there wasn't a blind person amongst the Disciples of Jesus. There was no blind person amongst the disciples for the obvious reasons that Jesus healed the blind person. But where does that leave blind Christians today"? ■

*End of interview.*

# EDAN IN CENTRAL COMMITTEE

need to sustain the visibility of persons with disabilities in this key governing organ. other issues included the need for a padare in Central Committee of 2002 and support the idea of a plenary session in the Central Committee of 2003 where EDAN would present the interim statement of the Theological Reflections.

JPC was asked to facilitate this and the General Secretary consented to the request. The 3 Advisors representing EDAN were; Mr. Samuel Kabue, Rev. Kathy Reeves and Rev. Dr. Gordon Cowans.

One of the key recommendations made by the Programme Committee was that:

The Central Committee have a padare offering at the 2002 meeting reflecting on issues of disability led by the Ecumenical Disability Advocates Network (EDAN), and that 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. ■

The Central Committee of the WCC serves as the chief governing body between General Assemblies. It meets every 12 to 18 months. Its meeting in Potsdam, Berlin began January 29 and concluded on February 6.

This was the first time that the WCC Central Committee met in united Germany. Three Central Committee meetings though had been held previously in Germany during "the ideological and military bloc confrontation of the cold war".

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 last August. This arose out of the

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## CHURCHES DECADE TO OVERCOME VIOLENCE

In preparation for the event and for the Decade to follow, several members addressed the Central Committee to describe situations of violence and hope in their homelands.

His Beatitude Archbishop Anastasios (Orthodox Autocephalous Church of Albania) said the key to the Decade's success is faith in Christ's power to bring peace to hearts.

On the eve of the launch of the Decade to Overcome Violence (DOV), members of the World Council of Churches (WCC) Central Committee shared their worries about a brutal world and their hope for the future.

*Continued on page 9*



## CHURCHES DECADE TO OVERCOME VIOLENCE

*From page 8*

"The future belongs to him who is the mighty God, the prince of peace," Anastasios told the Central Committee. "He is our peace, he reconciles us to God and to each other and gives us the ministry of reconciliation."

Anastasios described the increasing energy of the church in Albania to intervene in the midst of violence. In 1999, when NATO was bombing Yugoslavia, "hundreds of victims of violence overran the country," he said. "The church responded in love without asking about the religious identity of the victims" who were mostly Muslim. "We strongly protested the war in Kosovo. No one has the right to use religion to justify violence."

Bishop Margot Kaessmann (Evangelical Church in Germany) noted that church-sponsored childcare programmes in Germany had devised ways of helping people resolve conflict non-violently and teach their children to do the same.

She also acknowledged humorously that children can put parents in touch with their own violence. "Take it from me because I raised four children," she said "I know they can drive us so crazy we feel the violence rising inside us. Go out the door, count to 10 and calm down!"

Kaessmann also acknowledged that because of a "small minority" of violent persons in Germany, hundreds of minority persons had been killed or injured in the past eight years. The statistics include 64 deaths because of racist attacks, 119 who died in their efforts to emigrate to Germany, 92 who committed suicide rather than be deported, 10 killed by German police, and 13 killed in their home countries after being deported, according to Kaessmann. Churches must reassert their commitment to non-violence if the Decade is to be a success, Kaessmann said.

Dr Hermen Priyaraj Shastri, general secretary of the Council of Churches of Malaysia, walked among the circular tables with a microphone, interviewing

members of the Central Committee.

Dr Richard Grounds (United Methodist Church), professor of anthropology at the University of Tulsa, Oklahoma, USA, who is a member of the Seminole and Uchee nations, said he hoped indigenous people would benefit from the Decade.

"It may surprise some of you to realise that in the US, levels of police brutality and assault on our people continue at an unprecedented level," Grounds said. He told of an unarmed Kiowa woman who was shot repeatedly by police in Oklahoma.

Ideological violence by the United States against the people of Cuba was cited by the Rev. Héctor Méndez (Presbyterian Reformed Church in Cuba). "For 40 years we have been . . . in war, not with guns so much but 40 years of ideological war," Méndez said. "I want to tell you how terrible it is to live in such a situation."

Churches in Cuba "have sown a seed of reconciliation and this is the only bridge that exists between Cuban society and North America," he added. "All the churches, Roman Catholic and Protestant, and our seminaries are full. We thank God for the work of reconciliation that we are able to do in our situation."

Psychological violence is as destructive as physical violence, said Mrs Rosebelle Thu Lay Paw of the Myanmar Baptist Convention. "People are frightened to speak the truth," she said. She cited instances of violence against churches in Myanmar and said the churches have formed a peace and reconciliation committee to confront the situation.

The Rev. Dr Maake J. Masango (Presbyterian Church of Southern Africa) said the media was the cause of much violence in the world. "We need to fight the media that (are) producing 'Rambo'," he said, referring to a popular but violent film. "It's hard to do anything about it because the media are more powerful than we are. We may have to destroy the media through prayer - we pray that the TVs just blank out." ■

**"The church should become a body that genuinely incarnates the peace of Christ rather than equally contributing to the world's brokenness"**

*By Cynthia Yuen,  
Christian Conference of Asia*

# EDAN PARTICIPATES IN ANTI-VIOLENCE CAMPAIGN

People everywhere were invited to join in the celebrations in Berlin on Sunday 4 February. The international launch of the WCC Decade to Overcome Violence: Churches Seeking Peace and Reconciliation (2001 - 2010) was a colourful and festive occasion for the people of Berlin and Brandenburg, many of whom took part.

The Decade launch service was preceded by an all-night vigil in memory of children who had lost their lives as a result of violence of one form or another. The programme began with a televised ecumenical service in the Kaiser-Wilhelm-Gedächtnis-Kirche, which started at 10 a.m. Christians around the world had been asked to give the WCC names of children known to them who have been victims of violence in their community, their country or region or in other parts of the world.

The launch then continued with a varied programme of music and dance, speeches and interviews in Berlin's House of World Cultures, which started at 12.00. During the Festival in the Foyer peace groups and initiatives presented their work, projects and programmes. The first highlight of the afternoon, at 13.00, was a presentation of the WCC's dance theatre production "Peace to the City", with the Brazilian company Marcia Milhazes Dança Contemporânea, the Aquarius Trio and the soprano Juliana Franco. With the composer Nestor de Hollanda Calvalcanti, these artists from Brazil had created a modern music theatre production vividly depicting the experience of violence and work for peace in cities.

Prominent guests from Germany and abroad were present, including the Nobel Peace Prize-winner, José Ramos-Horta, from East Timor, and the chairperson of the German Parliamentary Committee on Immigration and former President of the Bundestag, Rita Süßmuth. Both talked about aspects of violence and their visions of peace. The moderator of the WCC central committee, His Holiness Aram I, Catholicos of Cilicia, then outlined what is involved in the Decade and invite the churches to participate.

To conclude the event, there was a candle-light match whereby the marchers carried small votive candles

inside red, green or yellow cups - the colours of the Decade to Overcome Violence. They marched through the snow past the dark Reichstag building toward the Brandenburg Gate, the famous gate at the site of the former Berlin Wall. The marchers then placed their glowing candles in the shape of the red heart and green and yellow globe of the DOV logo.

The General Secretary of the WCC, Dr Konrad Raiser, stood bareheaded on a makeshift platform and addressed the shivering crowd. "This gate has already witnessed many processions of protest with torches and candles," Raiser said, speaking in his native German. "The Brandenburg Gate itself is a symbol that stands for many things - lust for power and violent division, reunification and reconciliation."

Although the aims of the Decade are lofty, Raiser said it is not being launched out of starry-eyed idealism. "For us, the Decade journey must start with repentance for the violence that Christians and churches have tolerated or even justified. We are not yet the credible messengers of non-violence that the gospel calls us to be."

Raiser paid homage to martyred peacemakers. "Here in this place we remember the way travelled by Dietrich Bonhoeffer, who would have been 95 years old today. We think of Oscar Romero, Martin Luther King and Mahatma Gandhi." He concluded with a passage from Hebrews (Heb. 12:1-2), "Therefore, since we are surrounded by so great a crowd of witnesses... let us run with perseverance the race that is set before us, looking to Jesus the pioneer and perfecter of our faith."

The participation of EDAN was highly significant as they were able to contribute in the various committees that they had been selected in. The participation also reflected on the visibility and contribution made through the ratification of 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

*Continued on page 11*

## WCC LAUNCHES DECADE TO OVERCOME VIOLENCE

*From page 10*

churches by the EDAN/JPC with the Faith and Order Commission as a framework for the churches' advocacy and pastoral role with the disabled. ■

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# INFORMATION PACKAGE ON DISABILITY STUDIES

PREPARED BY

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August 1998

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(Downloaded from the web)

This information package includes a reprint that we are unable to produce here on our web site. We have indicated contact information for this resource, or you can obtain a complete copy of this information package by contacting [Center on Human Policy](mailto:thechp@sued.syr.edu). [thechp@sued.syr.edu](mailto:thechp@sued.syr.edu)

This information package was prepared with support from the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR), awarded to the Center on Human Policy, Division of Special Education and Rehabilitation, School of Education, Syracuse University under Cooperative Agreement No. H133D50037. The opinions expressed herein are those solely of the authors and do not necessarily reflect the position or the policy of the U.S. Department of Education and no official endorsement should be inferred.

Over the past several decades, what we now refer to as "disability studies" has been a powerful influence on policy and practice in regards to people with disabilities. Disability studies has evolved as a means of addressing how people with disabilities have been treated historically and how they continue to be treated.

Once seen through a medical model as people who are sick and in need of a cure, through a sociological model where people with disabilities are labeled and stigmatized by others, or through a psychological model where their experiences have been individualized and pathologized, people with disabilities are now being seen through different perspectives.

Although medical and psychological models are still present, they are being resisted by a relatively new field called disability studies, its philosophy being that disability is a social construction. While disability studies does not deny that there are differences, either physical or mental, between people, they argue that "the nature and significance of these differences depend on how we view and interpret them" (Bogdan

*Continued on page 12*

## INFORMATION PACKAGE ON DISABILITY STUDIES

*From page 11*

and Taylor, 1994). Therefore, rather than seeking to “fix” a person or to separate him or her from the rest of society, a disability studies perspective would seek to problematize society rather than the individual. The solution therefore lies not in the person, but rather in breaking down the barriers that limit people with disabilities from full participation in their communities and in society in general.

Disability studies seek to examine the social, economic, and political forces that for years have served to marginalize and oppress people with disabilities. The field has emerged over the last several years, drawing on theories and perspectives from sociology, social science, women’s studies, cultural studies, and education. It often focuses on the idea that people with disabilities are a minority group who has been discriminated against. In this sense, the study of disability is similar to the study of race, class, and gender inequalities. In addition, disability studies provide the intellectual and methodological tools needed to create disability research and policy. The theories and philosophies of disability studies can then be applied to real issues in the law, in community inclusion, and in public policy.

The field of disability studies continues to grow and change. Recent additions to the field such as feminist disability studies and cultural studies have challenged “traditional” disability studies, and have forced the field to be more inclusive of different perspectives and positions in society. Moreover, disability studies most often focuses on issues around people with physical,

rather than cognitive disabilities. One major challenge for the future of disability studies is the inclusion of the experiences of people with cognitive disabilities and how they shape this emerging field.

This package provides current information about the field of disability studies. In order to address this next challenge to disability studies, we have annotated very recent books (and just a few journal articles) about disability studies. They are divided into the following sections: disability studies texts, feminist disability studies, personal narratives/ autobiographies, and movies and documentaries. **(not included in this newsletter)**

Next, we have included a number of academic programs around the country which offer coursework and degrees in disability studies, as well as a list of journals and magazines and membership societies all pertaining to disability studies. Following this is a small section on Internet resources on disability studies. At the end, we have included an article by Steve Taylor from Disability Studies Quarterly regarding the construct of mental retardation and disability studies. Also included in this reprint is a selected annotated bibliography that includes information on a number of books that address the same issue. The last section is a reprint of several articles from Radical Teacher, which recently devoted a large section of its publication to the field of disability studies. ■

### *Reference*

*Bogdan, R., & Taylor, S. J. (1994). The social meaning of mental retardation: Two life stories. New York: Teachers College*

## EDAN NOTICE BOARD

- \* Latin American EDAN consultation, Venezuela 8<sup>th</sup> May to 12<sup>th</sup> May, 2001
- \* Samuel Kabue’s visit to the Latin America Conference of Churches and the Caribbean Conference of Churches, 8<sup>th</sup> May to 23<sup>rd</sup> of May, 2001
- \* Decade to Overcome Violence Launch West Africa in Accra, Ghana 3<sup>rd</sup> to 6<sup>th</sup> May 2001
- \* Decade to Overcome Violence launch Swiss Churches 26<sup>th</sup> April 2001
- \* Decade to Overcome Violence launch/US Conference annual meeting 23<sup>rd</sup> - 24<sup>th</sup> April 2001

# HUNGARIAN PERSONS WITH DISABILITIES ACT

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## **Act No. XXVI. of 1981 ON PROVISION OF THE RIGHTS OF PERSONS LIVING WITH DISABILITY AND THEIR EQUALITY OF OPPORTUNITY**

Persons living with disability are members of society with equal dignity and equal standing who are able to exercise the rights and opportunities to which all are entitled only with considerable difficulties or not at all. In the interest of easing the disadvantages of persons living with disability, to lay the foundations for their equality of opportunity and to shape the attitude of society, Parliament - in harmony with the Constitution and the generally recognized rules of international law - adopts the following act:

### **CHAPTER 1**

#### **GENERAL PROVISIONS**

##### **The aim of the act**

###### **Section 1**

The aim of this act is to define the rights of persons living with disability and the instruments for the exercise of these rights, further to regulate the complex rehabilitation to be provided for persons living with disability, and as a result of all these, to ensure equality of opportunity, independent living and active participation in the life of society for persons living with disability.

##### **Basic principles**

###### **Section 2**

(I) The state, the organisations of society and their members, must carry out their activity in such a way that it cannot cause damage leading to the development of disability, and they must create conditions in which persons living with disability are able to live a fuller life and the burdens arising from their disability can be

eased.

The act was passed by Parliament at its session - last day- on 16 March 1998. (The votes: 309 for, 0 against, 0 abstentions).

- (2) In the course of behaviour and activity related to persons living with disability action must be taken in such a way that it prevents deterioration of the state of disability and eases its consequences.
- (3) In the course of planning and decision-making processes the special needs of persons living with disability must be given particular attention and it must be taken into account that persons living with disability are able to take advantage of the possibilities available to all only if special solutions are applied.
- (4) In the course of decisions affecting persons living with disability it must be taken into account that persons living with disability are equal members of society and the local community and for this reason the conditions enabling them to participate in the life of society must be created.
- (5) The state must provide for the respect of the rights of persons living with disability, and for the operation of a system of institutions compensating the disadvantages of persons living with disability, in harmony with the possibilities of the national economy at the given time.

### **Section 3**

Due to their condition, persons living with disability are less able to exercise the rights to which they are entitled in the same way as everyone else and it is therefore justified that they should be given priority in every possible way.

### **Explanatory provisions**

#### **Section 4**

For the purposes of application of this act:

- a) person living with disability: anyone who is to a significant extent or entirely not in possession of sensory - particularly sight, hearing - locomotor or intellectual functions, or who is substantially restricted in communication and is thereby placed at a permanent disadvantage regarding active participation in the life of society;
- b) rehabilitation: a process realised in the health care, mental hygiene, education, training, retraining, employment and social welfare systems, aimed at developing or maintaining the level of capability of the person living with disability for participation in the life of society, and at promoting independent living;
- c) aid: means serving to partially or fully make up for the partial or full lack of physical or sensory capability in persons living with disability; 3
- d) supporting service: service aimed at promoting independent living for persons living with disability, at meeting their everyday needs and realised through personal participation; e) residential home: form of residence for a small community, promoting independent living for persons living with disability .

## **CHAPTER II**

### **Rights to which persons living with disability are entitled Environment Section 5**

- (1) The person living with disability has the right to a man-made environment that presents no obstacles, can be perceived and is safe.

- (2) The right set out in paragraph (1) above applies particularly to possibilities for orientation traffic and the man-made environment.  
Communication

### **Section 6**

- (1) Persons living with disability, their family members and helpers must be ensured the possibility of access to information of public interest, as well as to information related to the rights to which the disabled are entitled and the services provided for them.
- (2) Information is accessible if the person living with disability can perceive it and if it ensures for him or her the possibility of appropriate interpretation.

### **Section 7**

The conditions for mutual information must be made possible when persons substantially impeded in communication make use of the public services.

### **Transport Section 8**

The transport systems, further the means of public transport and passenger traffic facilities - including signals and information installations - must be made suitable for safe use by persons living with disability.

### **Section 9**

Mobility for persons substantially impeded in transport may also be ensured by operating a network providing transport, from the place of departure to the destination.

### **Section 10**

Provisions must be made for the creation of parking spaces of suitable number and size in public parking areas for the use of persons with disability impeded in transport, in keeping with the separate regulation.

## **Supporting Service, aids**

### **Section 11**

Use of the supporting service appropriate to the needs justified by the disability, and aids must be provided for persons living with disability. A separate regulation shall determine the range of aids-obtainable at subsidised price, the manner and extent of support.

## **CHAPTER III**

### **TARGET AREAS FOR THE EQUALISATION OF OPPORTUNITIES**

#### **Health care**

##### **Section 12**

- (1) In the course of providing health care for persons living with disability - in harmony with Act CLIV of 1997 - the needs arising from their disability must be taken into account.
- (2) Persons living with disability must be provided - in conjunction with the disability - with regular and efficacious health care needed for the improvement of their condition and to prevent the deterioration of their condition. Persons caring for persons living with disability must be ensured the possibility of special training and further training.
- (3) In the course of health care for persons living with disability, efforts must be made to ensure that the care promotes rehabilitation and social integration and does not strengthen the sense of illness.

#### **Education, training**

##### **Section 13**

- (1) It is the right of the person living with disability to take part in early development and care corresponding to his or her condition and depending on age, to kindergarten training, school training and education and development preparation for such education, in keeping with the provisions of the act on public education.
- (2) If it is advantageous for development of the capabilities of the person living with disability - in keeping with the opinion of the expert and rehabilitation committee set up for this purpose

the person living with disability shall take part in kindergarten training and school education together with other children and pupils, in the same kindergarten group or school class.

##### **Section 14**

The kindergarten and school providing the kindergarten training and school training and education of a child living with disability shall be chosen by the parent on the basis of the opinion of the expert and rehabilitation committee.

#### **Employment**

##### **Section 15**

- (1) Person living with disability are entitled to integrated employment or, in the absence of such employment, to sheltered employment.
- (2) The employer providing employment must ensure the workplace environment to the extent required to perform the work, in particular ensuring the suitable modification of tools and equipment. Applications can be made to the central budget for support to cover the costs of such modifications.

##### **Section 16**

If employment of the person living with disability cannot be ensured within the frame of integrated employment, as far as possible the right to work must be ensured for him or her through the operation of special workplaces. The central budget extends normative support to such sheltered workplaces.

## **Place of residence**

### **Section 17**

Persons living with disability have the right to choose a form of residence - family home, residential home, institution - corresponding to their disability and personal circumstances.

## **Culture, Sport**

### **Section 18**

- (1) It must be made possible for persons living with disability to visit educational, cultural, sports and other community facilities.
- (2) The use of sports and leisure facilities must be made accessible to persons living with disability in order to create the possibility for participation in sports.
- (3) Leisure and mass sports for persons living with disability are supported by the Miklós Wesselenyi National Youth and Leisure Sport Public Foundation and competitive and elite Sport by the Aladar Gerevich National Sport Public Foundation.

## **CHAPTER IV**

### **REHABILITATION**

#### **The right to rehabilitation**

##### **Section 19**

Persons living with disability have the right to rehabilitation. The exercise of this right is ensured by rehabilitation services and care.

##### **Section 20**

The Government shall set up a public foundation to carry out the state task set out in Section 21 below. Acts or government regulations may set further tasks for the public foundation.

#### **The rehabilitation service and care**

##### **Section 21**

In the interest of achieving the rehabilitation of persons living with disability, the public foundation shall provide the following services:

- a) publication of a system of criteria for the elaboration of drafts for a suitable program corresponding to the existing or developable

capabilities of persons living with disability, comprising the regular measurement of the development of capability achieved in the course of the rehabilitation process and making possible the amendment or further development of the rehabilitation program as required;

- b) organization of access to the services and benefits specified in the rehabilitation program;
- c) co-operation with the organizations and persons taking part in the process of rehabilitation, monitoring their rehabilitation activity;
- d) elaboration of the directions for development of aids and the supply of aids;
- e) elaboration of the considerations to be taken into account by the helping services and in creating a network of such services;
- f) elaboration of professional-methodological recommendations based on the experiences gained in the rehabilitation process;
- g) gathering data and information related to the organizations providing the service and the rehabilitation services they provide, in the interest of informing persons living with disability, their family members and helpers.

## **CHAPTER V**

#### **The disability support**

##### **Section 22**

Persons above the age of 18 years with serious disability are entitled to disability support to cover in part the additional costs arising from the disability, as set out in a separate act.

##### **Section 23**

The monthly sum of the disability support shall be equivalent to 80% of the minimum old-age pension at the given time.

## **CHAPTER VI**

#### **National Disability Affairs Council**

##### **Section 24**

- (1) The National Disability Affairs Council (hereinafter: Council) shall assist the Government in carrying out its tasks related to disability affairs.



*From page 16*

- (2) The Council
  - a) takes initiatives, makes proposals, gives opinions and co-ordinates in decision-making related to persons living with disability ,
  - b) carries out analysis and evaluation in the process of implementation of decisions.
- (3) The Council
  - a) gives its opinion on draft regulations affecting persons living with disability;
  - b) makes proposals for decisions, programs and legal regulation affecting persons living with disability;
  - c) takes part in the coordination of activities affecting the affairs of persons living with disability; d) regularly informs the Government on trends in the life situation of persons living with disability .
- (4) The Council elaborates the National Disability Affairs Program and monitors its implementation.

### **Section 25**

- (1) The members of the Council:
  - a) deputy state secretaries of the Ministry of the Interior, the Ministry of the Environment regional Development, the Ministry of Transport, Communications and Water Management, the Ministry of Culture and Education, the Ministry of Labour , the Ministry of Welfare, the Ministry of Finance;
  - b) Four persons delegated by national organizations representing the interests of the
  - c) Physically disabled, the deaf, the blind and the mentally disabled persons;
  - d) Two persons delegated by the organizations of sheltered workplaces;
  - e) One person delegated by the federation grouping national bodies representing the interests of local authorities;
  - f) Two persons delegated by non-profit organizations operating in the interest of persons living with disability .
- (2) The president of the Council is the minister of welfare.
- (3) The Council holds its sessions as required, but at least quarterly.

- (4) The Council has a quorum if more than half of the members are present.
- (5) The operating costs of the Council must be ensured by the central budget as an item in the budget of the Ministry of Welfare.

## **CHAPTER VII**

### **National Disability Affairs Program**

#### **Section 26**

- (1) In the interest of laying the foundations for the measures needed to create equality of opportunity for persons living with disability, Parliament shall draw up a National Disability Affairs Program (hereinafter: Program). The contents of the Program must be taken into account when making decisions in the areas of planning for health, employment, education and transport, in regional development and in other state planning.
- (2) The Government shall provide for elaboration of the Program and for submitting it -through the minister of welfare - to Parliament in the form of a draft Parliamentary Resolution.
- (3) The Program shall contain the following
  - a) a presentation of the social situation of the population living with disability;
  - b) identification of the aims related to rehabilitation;
  - c) tasks needed to bring about a favourable change in social attitudes affecting persons living with disability;
  - d) identification of the system of conditions needed for improvement of the quality of life of persons living with disability and their families;
  - e) plans promoting the active participation in social life of persons living with disability;
  - f) definition of the justified extent to be attained in transformation of the transport systems (public transport means, passenger traffic facilities ), transport and the man-made environment, and in the target state of special education and special employment, in line with the number of persons living with disability and their socially recognised needs;
  - g) specification of the necessary means and institutions, and the necessary financial sources for attainment of the goals set.

*Continued on page 18*

- (4) The Program shall be adopted by Parliament. The Government shall report annually to Parliament on its implementation. Parliament shall re-examine the resolution at least once every four years.

## **CHAPTER VIII**

### **Protection of the rights to which persons living with disability are entitled, responsibility for the tasks arising from the act**

#### **Section 27**

Any person suffering an unlawful disadvantage because of his or her disability shall be entitled to all the rights which apply in the case of violation of individual rights.

#### **Final provisions**

##### **Section 28**

This act shall enter into force on 1 January 1999, with the provision that legislative provisions related to the disability support must be created by 30 September 1999.

##### **Section 29**

- (1) Transport systems, public transport means and passenger traffic facilities- including signals and information installations- already operating at the time of proclamation must be gradually, but by 1 January 2010 at the latest, brought into compliance with the conditions set out in Section 8 above.
- (2) The network providing transport regulated in Section 9 of the present act must be built up gradually, but must be completed by 1 January 2010 at the latest.
- (3) The objective and staffing conditions for the special education of persons living with disability regulated in Section 13 above must be created gradually, but must be completed by 1 January 2005 at the latest.
- (4) The conditions set out in Section 16 above for the employment of persons living with disability in special workplaces must be created gradually, but must be completed by 1 January 2005 at the latest. (This is the non-discrimination paragraph. The para. refers to the Civil Code. The 76 § of the Civil Code prohibits any kind of- negative -

discrimination on the ground of sex, race, nationality or religion. (But it does not mention disability, this is why it was necessary to refer to it in the law.). The Section 84 of the Civil Code says that in the case of violation of any individual rights, the aggrieved party may bring the question before the court in order to let the court decide the infringement etc.

- (5) Institutions providing long-term residence for persons living with disability must be altered gradually, but by 1 January 2010 at the latest, in such a way that care for persons living with disability capable of independent living with personal help are housed in residential homes for small communities, further that humanised, modernised institutional care must be provided for persons living with serious disability who are in need of such care.
- (6) Public buildings already existing at the time of proclamation of this act must be made obstacle-free gradually, but by 1 January 2005 at the latest.
- (7) The National Disability Affairs Council shall be set up within three months of the time this act comes into effect.
- (8) The Government shall submit the Program to Parliament by 30 April 1999 at the latest.

##### **Section 30**

- (I) The Government is authorized to set out the following in a regulation:
- a) detailed rules for determining disability;
  - b) rules for the award and payment of disability support;
  - c) rules for the operation and financing of special workplaces.
- (2) The minister of welfare is authorized to set out in a regulation the professional rules for the establishment and operation of supporting services. ■

# A MODEL FOR DISABLED PEOPLE

## INTERVIEW CARRIED BY THE DAILY NEWSPAPER "MADAGASCAR TRIBUNE" BETWEEN RAZAKA WHO IS A MEMBER OF EDAN AND THE PRESIDENT OF JOURNALISTIC ORDER, WHEN SHE WAS GOING TO PIETERMARITZBURG, SOUTH AFRICA

*At Ivato Airport, we have run into Mrs. Ralphine Razaka who who was about to board an international flight. We have always known her as a teacher, a former bulwark of the MFM Party. But she belongs to the Lutheran Church Revival Movement called Fifohazana, of the Ankaramelaza Centre. Despite her disability, she is an active member of the Malagasy Lutheran Church and contributes to the good works of the Protestant Federation 's for Revival Centres. Just before leaving, she told us a few words:*

**Madagascar Tribune (MT):** You have recently been seen a few times at the international departure lounge.....

**Mrs. Ralphine Razaka (MRR):** That was when I was leaving for an English training course in Nairobi and also when I went to attend some meetings of EDAN

**MT:** And what about today?

**MRR:** I am going to South Africa to prepare a Ph.D in Geography at the University of Natal in Pietermaritzburg. By the way that is why I needed to have the English training course in Kenya.

**MT:** Tell us more about EDAN

**MRR:** The Ecumenical Disability Advocates Network (EDAN) is an Ecumenical Network advocating the rights and concerns of disabled persons throughout the world. It is an NGO linked to Justice Peace and Creation Team of the World Council of Churches (WCC) in Geneva and coordinated by the National Council of Churches of Kenya (NCCCK).

**MT:** Are you a member of EDAN?

**MRR:** EDAN's Board is comprised of 13 Network members and I am one of the 4 Africans representing it, by the same token, I represent Madagascar and the FFRM.

**MT:** Are you then sponsored by EDAN for this trip?

**MRR:** No. This is a post-graduate scholarship

offered by the World Lutheran Federation after they accepted to fund a future project which I had submitted to Geneva. The project title is "Towards a better social Insertion of Disabled People in Madagascar" and it is the concrete implementation of the Theology paper I had presented at the FJKM Lay Theological Training Centre, 'The Contribution of Disabled People to the Church', as inspired by Judges 6:14b 'Go in this might of yours.'

My future project might create jobs for among others, educated but unemployed disabled people. This is why I need to have this Ph.D EDAN will however remain for me an inescapable entity an unavoidable partner, more so because the topic I have taken for my Masters is about disabled population of Madagascar, and my Ph. D dissertation will probably deal with the disabled people in Sub-Saharan Africa in the wake of colonization.

**MT:** What have you already achieved in this country?

**MRR:** Concrete measures will be taken in four years time upon my return. I have already met the FFKM Heads of Churches to acquaint them with the activities and aims of EDAN. I also requested them to start sensitising their respective flocks to this matter and to take part in the African Decade for Disabled Persons. Rest assured that I shall still attend all EDAN summits in all the five continents, excluding exam period in Pietermaritzburg.

**MT:** What about teaching and political commitment?

**MRR:** (With a smile) Rest assured that I am keen to be back with my flock, my students whom the Lord has asked me to look after.

**MT:** And the Fifohazana Spiritual Revival Movement?

**MRR:** No Comment. It is a lively part of the Protestant Church which has nothing to do with sects and remains compatible with any respectable intellect pursuit. It has greatly helped me to overcome many barriers and problems while respecting Christian Ethics and principles?

**MT:** What will be the best memory of our country?

**MRR:** Mmm.... So many things but the prayer meeting on New Year Day and the Manandafy Rakotonirina family's residence along with the farewell party held for me by the Soatanana Revival Centre. ■

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