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## EDITORIAL



*Sam Kabue*

It is yet another year, the third since we began the EDAN publication. We have kept to the schedule of producing the newsletter quarterly and publishing as much as possible of what our network members and other readers have contributed. We have everything to thank God for in our work and in building bridges between churches, national and regional ecumenical organizations and disability work through our established disability networks.

Our publication has remained the major meeting point and means of sharing experience, fellowship and information. This would not have been possible without the contribution of those who have either written articles, made comments on the various issues that we have published or simply requested to be included in our mailing list. The World Council of Churches; Justice Peace and Creation team led by Aruna Gnanadason has been extremely helpful. It is through this team that the entire operation of EDAN including this publication has been financed. It is also through this team that the publication has been placed on the WCC website. Besides the financial support, EDAN in general has

received a lot of moral support from both Aruna herself as well as the entire JPC advisory group.

We have not been without challenges. In the first place not as many of our readers or our network members have shared with us their experiences and their work. We have therefore had to rely on just a few of these as well as searching for information from various other sources. If our newsletter has to be truly an instrument for sharing experiences and fellowship, it is necessary that each of our readers make their contribution by writing articles on what they consider important to share with the rest of the readers. We are especially challenging all our original network members who came up with the vision of this instrument to keep to their promise of maintaining it by ensuring regular contribution and sharing of their work and experiences. Noel Collot Fernandez has been exemplary in this. Finances too have been a challenge in that we have several times been requested to publish the newsletter in other WCC official languages like French and German but this has not been possible. We look forward to being able to do so once finances allow.

As I say this, it is necessary to note that these are very difficult economic times for many organizations and therefore many of our supporters. WCC itself is facing serious financial cuts in all its operations. We thank God that the EDAN publication has not been affected by this. This is very encouraging to us when we consider that in many organizations, including the WCC in the past, disability work has been the first to be considered in the cut-downs. We want especially to hail the efforts of both Rev. Dr. Samuel Kobia, the Director, Issues and Themes and Aruna Gnanadason for their commitment to maintain the work of EDAN even in these very difficult times.

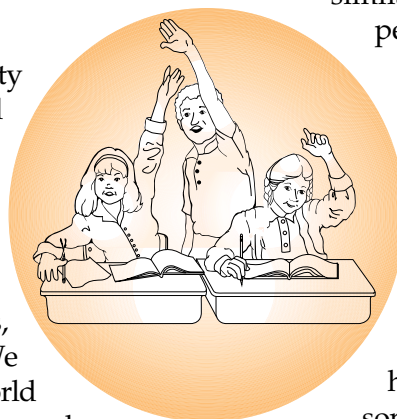


# Focus On Children With Disabilities

## How Children are Learning about Disability by Barbara Kolucki

We know that in many countries today, children with disabilities are included in more mainstream classes than ever before. How are non-disabled children being prepared for these experiences? How are they learning about their peers? Are they learning in ways that prejudice them or in ways that keep them open-minded for perhaps their first first-hand interaction?

This is the first in a series about a variety of ways school-aged children around the world are learning about disability today. We will present actual projects taking place, associated educational products such as new disabled dolls and appliances, guides on how children can critically analyze books, contests for teenagers, etc. We encourage readers from around the world to write in with their examples and suggestions.



## The Berkeley Pioneer Disability Rights History Curriculum

Berkeley, California has been at the forefront of just about every aspect of the disability rights movement. They have continued this trend with a project that was piloted in November and December 2000. The target audience was fifth and sixth grade classes who also happened to be learning about civil rights history as part of their curricula. The project was run by the Disability Rights Education and Defence Fund (DREDF) in Berkeley and funded by California's Department of Rehabilitation. The project co-ordinator was Kenneth Stein, who was an early staff member of the Berkeley Center for Independent Living. Kathy Martinez, Deputy Director of the World Institute on Disability (WID), and Gerald Baptiste, Associate Director, Berkeley Center for Independent Living, were co-instructors for the classes.

In November of 2000, a letter was sent to the parents, guardians and caregivers of all children in the fifth and sixth grade classes at Jefferson and Martin Luther King Middle Schools. The letter explained the project and how disability rights would be part of the larger "rights movement" that was being studied in school.


Parents were briefed on various assignments for the class and asked for permission to take and use photographs from the project for DREDF publications and website.

One of the instructors, Kathy Martinez, was no stranger in teaching children about disability. Ten years ago, she worked on a project called "Keys to Introducing Disability into Society", also known as the KIDS Project. Here children learned about both similarities and differences. A number of people with disabilities were invited into the classrooms over the six week project, and the disabilities ranged from those visible, such as blindness or cerebral palsy to invisible ones, such as learning disabilities. During the final week of the KIDS project, audiocassettes were made where children talked about what they learned and how they felt. They also had to experiment with inventing something that would help a person with a disability in an activity of daily living. And they were asked to write and/or draw something based on this experience. Ms. Martinez's personal experiences as a blind person and her professional experience teaching about disability were central to this 2000 DREDF project.

## The Book: Cornerstones of Freedom: The Disability Rights Movement

All students participating in the project were asked to read a 1996 publication by Deborah Kent called *Cornerstones of Freedom: The Disability Rights Movement* (Children's Press, A Division of Grolier Publishing, New York). The book is written for children with about a Grade Three/Four reading level. It includes numerous photos of children and adults who are disabled.

The book tells the story of Ed Roberts and Judy Heumann, two of the first pioneers in the disability rights movement. It also informs readers that disabled people have been Presidents, composers, poets, as well as many millions of ordinary human beings. Historically, discrimination kept them from school, work, play and basic communication opportunities. It covers the birth of the first Independent Living

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Centers and the first organizations formed to bring about political change to improve the lives of people with disability.

The actions of the first disability rights advocates were similar to those who fought for change in the civil rights struggle in the USA. These included peaceful demonstrations, sit-ins, demands for new non-discriminatory legislation and, plenty of press coverage. And as was also the case in the civil rights struggle, the attitudinal barriers were as powerful and damaging as those that denied access to buildings or schools.

The book details the key laws passed since the 1970s in the USA. It also highlights some of the strides that have been made with regard to mainstream/inclusive education, physical accessibility in communities and new disabled leaders in the field. The appointment of King Jordan, the first deaf president of Gallaudet University (the world famous university for deaf students in the USA) was a landmark event - and one that again, was brought about after a mass protest and shutdown of the University in 1988.

I personally think that this book is a welcome addition to the literature about the disability rights movement and similar struggles. However, educators and authors of books for children have learned a great deal about several principles and guidelines that can enhance the potential of such books with readers. I would have liked to see the book be more interactive



and encourage critical thinking skills in the readers. I would have liked the book to include a section on how other types of discrimination can affect all of us. I would also have preferred if there were some first person stories

where the person who is disabled speaks directly to the reader. Perhaps there will be a Revised Version or second part on this important topic!

## Work with the students


After students had read the book, the presenters spent time with them discussing civil rights struggles in general as well as the relationship between the disability rights and civil rights movements. They viewed a video on laws passed in the disability field. The two presenters with a disability provided personal stories as well as a discussion of their daily lives and any adaptive aids they used. Sessions were interactive and students were encouraged to ask as many questions as they wished. Each of the three presenters were activists themselves in the disability rights struggle and so they could put a human face on what students read in the book.

Each student was then asked to interview a person with a disability. Interviewees were pre-selected and they welcomed a phone call or visit from the student. In some cases, students interviewed parents of children with a disability. Sample questions were provided but each student was encouraged to be open and ask what was "on their own mind". Students and presenters discussed these interviews. And finally the students were asked to write a letter about what they learned from this experience.

## Project Report and Next Steps

A final report has been written by Ken Stein of DREDF. It is available at the DREDF website (<http://www.dredf.org>). The report highlights how much the students both enjoyed and learned from this pilot project. There are a few specific examples from this project and report that are fundamental to the true understanding of Disability Rights. These include:

- "Although the independent living/disability rights movement sprang directly out of the experience and lessons learned from the struggles of other minority groups (in the USA) and is at its heart a civil rights movement, the passage of the ADA (Americans with Disabilities Act) and other disability civil rights laws were accompanied by no such public education or media awareness; neither of the history of discrimination against people with disabilities, nor the wrongs being righted by the passage of these laws. As a consequence, the laws protecting disability civil rights continue to operate in a traditional cultural and attitudinal context of charity and pity, and in

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a mass media context of “helpless cripple” and “inspirational super-crip”. This view of persons with disabilities persists, in spite of the fact that the disability rights movement was based on an entirely different perspective, that is, on the disabled person’s right to full and equal participation in society, and a recognition that the primary barriers to societal participation are discriminatory attitudes and architectural barriers”.

• About 25 years ago, I began working at an organization called the Center for Independent Living. I know that many of you (the students) have seen the movie ‘Pay It Forward’, the movie with the boy who starred in ‘The Sixth Sense’. What happens in that movie is that the teacher gives his class the assignment of doing something ‘to change the world’. When I started working at the Center for Independent Living, I had no idea at the time that this was an organization that was literally going to change the world: it would change the way that people had thought about people with disabilities for centuries; and it would change the way that people with disabilities thought about themselves. What we’re going to be talking about this week and next (with the students in the project) is what happened here in this city (Berkeley, California) back then, that literally changed the world.

These two quotes illustrate points that should be part of any project or activity aimed at educating children (or adults) about disability. First, we see the similarity between disability rights and the struggles of other groups confronting prejudice and discrimination - this is often a prerequisite for moving toward understanding and accepting others as equals. Second, we see that even laws are not enough. The public needs to be sensitized and educated if true implementation of the law is to occur. And third, we need to see what we can do to make a change in this world. We need to be challenged to make a positive difference in the lives of others.

The report provides an overview of what happened in each session with the children. The descriptions and details are clear and could definitely be adapted to other countries’ efforts to bring disability rights education to children.

In the project evaluation, feedback was both positive and constructive. From a curricula standpoint,



adaptations might need to be made with regard to developmental appropriateness (especially for Class Five students) as well as use of media (books and videos) that were of greater interest to this age group. There are numerous books for children (from pre-school to teens) that are creative, sensitive and educational. Recent issues of Disability World include a review and listing of many of them. Many can serve as examples for adaptation and production elsewhere in the world.

### Reactions from the Children

What follows are some quotes from children who participated in the project. Of course, we can see their honestly, practical suggestions and humour:

*“I’m glad the ADA program came to our 6th grade class. I enjoyed learning about disability rights. I’m glad I got the chance to be the first class to meet Mr. Stein and Ms. Kathy Martinez! My favorite part of the program was calling a disabled person. I called Suzanne.... A very nice, enjoyable, likeable woman. For me, the movie we saw about disability rights was an interesting movie, but a little slow. Slow, for children, I mean. I think the part about disabled men and women going to a sit-in was the most interesting part in the movie. I still think you could use that particular video, but most kids will like a different one. Me included. Thanks for coming to our class, and teaching us about disability right”.*

**Olivia**

*“I think a fun activity (for us kids) would be to write Braille. Maybe a few sentences per person”.*

**Julia**

*“I like the way those gadgets (Braille watch et al) worked”.*

**Marc**



*"My auntie might get her left cut off so she can't walk. The reason why she can't walk is she had surgery three times. I was going to give her advice about disabled people but I didn't know about anything. Now you taught me stuff about disabled people and I can give all the advice I learned. Thank you.*

**Anthony**

*"I learned a lot from your class like that disabled people can survive on their own, and that the movement helped them. Speaking of movement, I learned that there was a movement. I used to think that people with disabilities were helpless (I know, I know, I was pretty stupid) but now I know how wrong I was".*

**Gabrielle**

*"I much enjoyed those two disability rights classes! I must say, some of the kids who usually never were intrigued or elated about any kind of work were interested in participating! I felt prized to be able to learn about an important subject that is rarely brought up! You may (for future references) want to have some sort of activity or game to get kids excited, if you unfortunately are asked to teach a class with lack of manners and listening skills. Besides that, I liked having you here to present an important subject that hardly any people (children and adults) are exposed to deeply understanding".*

**Catalina**



The students also expressed a wish to be introduced to people with other types of disability. Their comments reflect interest, candour but also the fact that this one event is just a beginning. Some of the students continue to concentrate on "the people that are not disabled need to help disabled people" and "people with disabilities have it hard". Others were able to see both the obstacles but also the resilience and creativity that are part of the lives of disabled people and their families.

## **The Future**

It is hoped that this pilot will serve as a model for the inclusion of disability rights history as part of the overall curriculum on human rights struggles in other schools. In addition, DREDF hopes to use this pilot as a springboard for a broad media awareness campaign to introduce children (and adults) to the issues, key players and legislation in the disability rights movement.


Will children someday know the names of Heumann and Roberts in the same way they know about Martin Luther King? Will they remember Ms. Martinez and Mr. Baptiste as the first persons they met who taught them that people with disabilities are talented, intelligent, contributing and "awesome" members of society? Will they meet a new student with a disability or an adult in the community and feel comfortable speaking with them and learning from them? Will they understand that persons who are disabled vary in the same ways as all human beings?

This project is one example of how children can come closer to learning about and integrating these attitudes into their daily lives. I hope that it is one among several models designed to integrate disability rights as an integral part of human rights history.

## **Questions from an 8-year-old nephew**

Ms. Martinez knows that projects like this one are extremely important. And she also knows that it is the daily interactions and responses individual to individual that make a difference as well. And reaching children is the best way of making a difference for the future.

The DREDF project was aimed at children in fifth and sixth grade. I personally think that although this is a good place to integrate disability rights history into their existing curriculum, it is too late in some cases to begin to educate about people with disability. The pre-school years are when children's attitudes are formed and when they begin to learn about similarities and differences. The first grades in school are when they often begin to act in a way that might discriminate. Yet it is also the time when they will show extraordinary kindness, ingenuity and bravery. Ms. Martinez was recently asked by her eight-year-

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old nephew if he could “interview” her. Of course she said yes. And how she responded to Kyle’s questions will not only impact him but also his teacher and other school friends who might read and learn about his interview. Here are a few excerpts from Kyle’s interview:

“Thank you Kyle for considering the subject of disability for your interview. I would like to give you some information about disability:

1. In the USA there are approximately 54 million people with disabilities - this is about 20% of the population.
2. Before, people usually died if they had a severe or moderate disability. Now they are living longer because of the advances in medical treatment and technology. Now they are out in public and participating as active members in their community.
3. In the past 30 years, there have been many laws passed to both protect the rights of disabled people as well as to make society more “accessible”. This means that if the government or business wants to build a new building, for example, they have to construct it so that people in wheelchairs can get around, so that blind people can read the elevators and they have the proper equipment in order to communicate with deaf people.

**Question: Do you wish you could see?**

*Answer: Because I was born blind, being blind is normal to me. I have never been able to see so I don’t miss it. Sometimes it’s hard being blind when I can’t read something or I don’t know how to get somewhere. Mostly it’s not hard.*

**Question: Are you treated differently because you are blind?**

*Answer: Sometimes I am treated differently because I am blind. Mostly it’s when people don’t understand that blind people want to be treated like everyone else. Sometime people don’t know what to do - if I need help or how to help. This just means that they haven’t been around blind people and that they’re not sure how to act.*

**Question: What has helped you to be successful?**

*Answer: The thing that has most helped me to be successful is the confidence given to me by my family when I was young. Grandma and Grandpa and your mom and others*

*treated Peggy and me (Ms. Martinez’s sister who is also blind) like regular kids. We had to clean up, wash dishes, do our homework and participate in all the household activities. Another thing is that we were both lucky because when we ere your age, we had teachers who wanted us to succeed in our education. We had access to Braille, we learned to type on a regular typewriter when we were about eight years old and we had lots of friends who were very honest with us about how we acted and presented ourselves.*



**Question: Who are the biggest influences in your life?**

*Answer: Many people have been major influences in my life. My parents and brothers and sisters come first. There have been a number of teachers and also many mentors in the disability rights movement who have taught me a lot about being proud of who I am. You and Sarah have played a very important role too. Like when we go to San Francisco and you want to help guide me. That’s a big deal, because it means that you are comfortable having a blind aunt.”*

I particularly love the last answer. Ms. Martinez demonstrates a sensitive knowledge about children when she helps Kyle understand that kids can be influential too! I would bet that Kyle passes on this knowledge and ease to his friends. Yes, it is important for us to teach the masses. The media can be particularly effective here. But it is also the individual “Each One, Teach One” that gives us confidence to pass.

**From: Inter- American Disability web-site  
[www.disabilityworld.org](http://www.disabilityworld.org)**







## PAN - AFRICAN CONFERENCE ON THE AFRICAN DECADE OF PERSONS WITH DISABILITIES - 1999 - 2009

EDAN through its consultant, Mr. Samuel Kabue attended the Pan African Conference on African Decade of Persons with disabilities from 4th to 7th February 2002 in Addis Ababa, Ethiopia.

The Conference brought together representatives from the African Member States, UN Agencies, Disabled Persons Organisations (DPOS), NGOs, Inter-governmental Organisations and other International and Regional Organisations as well as Experts and Resource persons.

In his Opening Ceremony Prof. C.A.L Johnson, the Director of the Community Affairs Community of the OAU welcomed the participants and gave the background on the African Decade of Disabled Persons (1999-2009) proclaimed by the Heads of State

In his address, Mr. Khalfan H. Khalfan, the Chairperson of Pan African Federation of Disabled Persons (PAFOD) recalled the Seminar on disability that took place in South Africa which recommended that 1999-2009 be proclaimed as the African Decade of Disabled Persons. He also referred to the UN Decade of Disabled Persons (1983-1992) and underscored its successes and failures. He stated that since the African countries could not implement the World Programme of Action adopted by the UN Decade, the Disabled Peoples Organisations (DPOS) took the initiative to have an African Decade.


He informed the participants that PAFOD has already developed a business plan to implement the African Decade, which could be used in drafting the Plan of Action. In this regard, he proposed that the following



*Participants of the Pan African Conference in Addis Ababa, Ethiopia, 4th - 7th February 2002.*

of Government as well as the Declaration which was adopted. He stated that the Conference was being convened within the framework of the Decade with a view to adopting a Plan of Action to guide Member States to implement the activities to be undertaken during the Decade.

issues be included in the Plan of Action to be considered by the Conference: human rights; recognition and support of organisations of people with disabilities; strategies towards poverty reduction; education; integration of people with

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disabilities in social and economic development.

### GOAL OF THE DECADE

The goal of the African Decade of Persons with Disabilities is the full participation, equality and empowerment of people with disabilities in Africa.

### OBJECTIVES

The Declaration of the Decade calls upon Member States to study the situation of persons with disabilities, with a view to formulating measures favouring equalization of opportunities, full participation and their independence in society.

Among other actions, Member States are called upon to:

- Formulate or reformulate policies and national programmes that encourage the full participation of persons with disabilities in social and economic development;
- Create or reinforce national disability co-ordination committees, and ensure effective representation of disabled persons and their organisations;
- Support community-based service delivery, in collaboration with international development

agencies and organizations;

- Promote more efforts that encourages positive attitudes towards children, youth, women and adults with disabilities and the implementation of measures to ensure their access to the physical environment.
- Develop programmes that alleviate poverty amongst the disabled people and their families;
- Put in place programmes that create more awareness, conscientisation of communities and governments on disability;
- Prevent disability by promoting peace and paying attention to other causes of disability;
- Mainstream disability on the social economic and political agendas of the African governments;
- Spearhead the implementation of the United Nations (UN) Standard Rules on the Equalization of opportunities for people with Disabilities and ensuring the use of the Standard Rules as a basis for policy and legislation to protect the interest of disabled people in Africa;
- Apply all UN and OAU human rights instruments to promote and monitor the rights of persons with disabilities.

## ECUMENICAL PROJECT ON DISABILITY ISSUES

**The open conference to explore disability, spirituality and faith.**


Planning is well underway for the inaugural national gathering on Disability, Spirituality and Faith in Aotearoa New Zealand to be held in Wellington in May 2003. The aim of the conference is to explore issues of disability and faith within and beyond churches and other faith communities in Aotearoa New Zealand. It is hoped that this conference will be an opportunity for people who live with disability to explore faith and spirituality as well as joining others in addressing disability issues within faith communities and beyond. Possible topics include justice, pastoral issues, theology, and spirituality-the search for meaning, church structures, bio-ethics, honouring stories and cross-cultural issues.

From July to mid September 2001 the planning group sent out "registration of interest" forms (originally the conference was to be held in second half of 2002 but this timeframe proved unrealistic) throughout church and disability networks. As of November 2001 we have had over one hundred responses. This is very heartening and shows that there is great interest in issues to do with disability and spirituality.



There have been three similar conferences in Australia. The convenor of the planning group has been to all three conferences and others have attended the other conferences. New Zealanders attending these conferences have been our inspiration. There is much enthusiasm and encouragement from people in Australia for a conference in New Zealand.

While the New Zealand conference will seek to offer

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a similar range of content to Australia we intend to stamp "a New Zealand flavour" on it by having involvement from the three tikanga by including maori and polynesian perspectives of disability and spirituality. Another crucial difference between New Zealand and Australia is that the impetus for the movement in Australia came from those working on disability issues in academic institutions and in the church whereas the impetus in New Zealand has come from the planning group who have experience in organising gatherings in the disability sector, this hopefully means that the conference will cater better for the needs of people with disabilities than the Australian conferences have done to date.

Conference of Churches in Aotearoa New Zealand (CCANZ) has made a commitment to disability issues by endorsing the planning group to organise this conference by "acting as an umbrella organisation of the member churches to those organising a faith and disability conference in Wellington in 2002/2003..." CCANZ has committed \$1,000 over two years to this end.

At the suggestion of CCANZ's General Secretary, the planning group is applying to EDAN for a contributions toward the running costs of this conference. It is proposed that the income will come from conference fees; sponsorship from the churches and from the community. We are seeking sponsorship in order to lower the Registration costs for individuals to ensure access to all who wish to attend. We are seeking sponsorship particularly in the area of facilitation. We suggest that you may like to sponsor a particular item and this will be acknowledged at the conference.

Vicki Terrell, Convenor  
November 2001

### Send us your ideas and thoughts:

*Open Conference to explore Disability, spirituality and faith.*

A first-time ever national gathering to explore the issues of Disability, Spirituality and Faith will be held in Wellington in the second half of next year. The conference is for people who have a connection to disability (through personal experience, work/ministry, close relationships) and an interest in spirituality and faith, whether that is through formal or informal structures.

A planning group has been set up, of people from a range of spirituality and church/faith backgrounds, the majority of whom have a disability. The gathering has the support of the Conference of Churches in Aotearoa New Zealand.

We're keen to hear what themes and issues people would like to explore at such a gathering. This is your chance to let us know your ideas and thoughts! Please also distribute this letter to other people/organisations you think may be interested. At the moment possible topics to be covered include - justice, pastoral issues, theology, spirituality - the search for meaning, church structures, bio-ethics, honouring stories, cultural and bi-cultural issues.

Thanks for your help in making sure this gets to as many people as possible.


If you would like paper copies of this letter please let us know, email: [vterrell@actrix.gen.nz](mailto:vterrell@actrix.gen.nz) or phone/fax Vicki Terrell 04 934-3792. We look forward to hearing from you.

## NEW GENDER AND DISABILITY REPORT AVAILABLE

Mobility International USA releases groundbreaking report on gender and disability within the international development community.

Mobility International USA (MIUSA) is proud to announce publication of Gender and Disability: A Survey of InterAction Member Agencies. The survey was the first attempt to systematically document the extent to which US-based international development organizations include

people with disabilities, particularly women and girls, in policies, employment, programs and services. One hundred and four members of InterAction, a coalition of international relief, development, environmental and refugee agencies based in the US, participated in the research project, which was sponsored by the United States Agency for International Development (USAID) Office of Women in Development.

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Findings from the survey point to the need by development agencies for training, education and technical assistance to bring people with disabilities, in particular women with disabilities into the development assistance process. Most organizations collect little or no data about the participation of women and girls with disabilities in field programs. The data which are available support anecdotal reports that very few women with disabilities are served in field programs, including gender-specific and disability-specific programs. Obstacles cited to inclusion of women and girls with disabilities include lack of training, information and resources for effective outreach and disability-related accommodations. Less than 1% of staff positions in responding agencies are filled by people with known disabilities. Respondent organizations indicated that they need assistance to implement equal employment opportunity policies for recruitment and job accommodation of people with disabilities in the US and overseas.

Recommendations from Gender and Disability include the need for InterAction member organizations to seek out appropriate technical assistance to develop Plans of Action to implement InterAction's Private Voluntary Organization (PVO) Standards on Disability. Adopted in 2000, the

Standards provide guidelines for inclusion of people with disabilities in governance, management, human resources, programs, material assistance, and child sponsorship.

MIUSA, founded in 1981, is a US-based non-profit organization working to ensure the inclusion of people with disabilities in international exchange and development programs. Nearly 1,000 people from 80 different countries have taken part in MIUSA's unique cross-cultural disability rights and empowerment programs over the last 20 years. A member of InterAction, MIUSA recently began a new three year project sponsored by the US Agency on International Development, to provide training and technical assistance to InterAction member agencies, based on the findings of the gender and disability survey.

Gender and Disability: A Survey of InterAction Member Agencies - Findings and Recommendations on Inclusion of Women and Men with Disabilities in International Development Programs is available to download at no cost from the MIUSA website, [www.miusa.org](http://www.miusa.org).

For more information, contact MIUSA at (541) 343-1284 (V/TTY), e-mail at [development@miusa.org](mailto:development@miusa.org), or visit the website, [www.miusa.org](http://www.miusa.org).

**PROFILE**

# Introducing ... W.A.S.E

## (World Association for Supported Employment)

**SUPPORTED EMPLOYMENT**

Supported employment has proved to be very appropriate method to secure employment for persons with disabilities, regardless of cultural context and labour market founded in 1995 with the purpose of promoting and disseminating information specific to the supported employment methodology in all parts of the world.

Employment is a basic need in people's existence. Self-identity economic security and social relations are strongly related to employment. Persons with disabilities find several barriers in finding a job, like lack of work place accommodations, inaccessible transportation, negative stereotypes, lack of training and possible loss of benefits.

Despite being confronted with these barriers, persons



with disabilities have demonstrated a strong desire and ability to be full participants in open labour market.

During the 1980's an employment strategy entitled Supported Employment was developed in the United

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States. With proper supports, even individuals with severe disabilities are capable of securing employment in integrated work settings. Supported Employment therefore is a total new approach, which leads to better outcomes compared to traditional methods of vocational rehabilitation such as sheltered workshops.

In the United States more than 100,000 individuals with severe disabilities have secure employment in a regular job and persons with long histories of being unemployed are now receiving regular wages, as a result of being assisted using the supported employment methodology.

### Supported Employment defined

The world association of Supported Employment (WASE) developed the following definition: Supported Employment can be characterised as paid work in integrated work settings with ongoing support for individuals with disabilities in the open labour market. Paid work for individuals means the same payment for the same work as for persons without disabilities.

Who is the supported employment methodology meant for? Supported employment methodology is intended for individuals with more severe disabilities, who without the necessary support would likely encounter difficulties to secure employment in the open labour market. Individuals with difficult learning, physical, intellectual, psychiatric or psychological disabilities, requiring job support, benefit from supported employment.

### Identifying features of supported employment

Supported Employment defines characteristics, which set it apart from traditional approaches to vocational rehabilitation.



**Immediate job placement:** A guiding principle of the supported employment methodology is that

the person is placed in the work site once a suitable work environment has been located.

**Employee on site training:** Integrated work settings are optimal learning environments. The reason being

that individuals often experience difficulties generalising knowledge acquired in one setting to another. Additional benefits of on-site training are that it promotes social integration and raises staff awareness on how to support a co-worker with a disability in sustaining employment.

**Competitive work:** The worker with disability receives the same pay and benefits as workers without disabilities performing similar job functions. There is also the job expectation that the worker will engage in full or part-time work, which translates in to a minimum of 20 working hours per week.

**Employment in integrated work settings:** Placements where individuals with disabilities work in job sites amongst individuals without disabilities are referred to as integrated work settings. Economic integration occurs when an individual obtains paid employment. When presented with opportunities to interact and perform job tasks with co-workers, meaningful relationships can be established.

**On-going Support:** Unlike other methods of Vocational Rehabilitation, the supported Employment methodology involves the provision of on-going support to persons with disabilities and their employers.


**Individualised Support:** A specialised individualised approach to vocational rehabilitation is necessary for ensured job retention. Only the amount of support that is necessary, nothing more.

### Five Phases of Supported Employment Methodology

Client can give five forms of assistance:

**Job finding:** Researching the open labour market to identify suitable job placements for clients with disabilities. The central criteria for suitability is that the job is consistent with clients interests and the client receives regular wages. When searching for suitable employment possibilities, the focus is always on specific clients. Not only should existing jobs be evaluated, but the possibility of creating new positions should also be assessed.

**Job analysis:** The various elements of a job are thoroughly examined with the purpose of identifying those able to be completed by the client with a disability. A precise understanding of each aspect of the position and the work environment is necessary so that a comprehensive job description can be formulated.

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**Assessment:** For successful job placement, a clear understanding of the employee ability to perform a particular task is necessary. This is determined through formal and informal, measures commonly administered during the job-finding phase. Special consideration is given to the interests of disabled person and how they relate to the specific job tasks. The person's abilities are determined, rather than disabilities.

**Job Matching:** In this phase, the determination is made of the degree to which job demands match the abilities of prospective employee. A perfect match between an employee's skills and the demand of the position is impossible.



**Job Coaching:** The job coach initiates and facilitates systematic learning, on the part of the employee, of the social and practical skills necessary for the position. The job coach is also intended to be a resource for employers and co-workers. Before the individual with a disability can begin work, the job coach can be familiar with all aspect of the job placements. As the employee adjusts to the job, the job coach gradually fades off.

In our globalized world, people cannot work in isolation: clients, service providers, researchers, family members and policy makers must be apprised of developments in other parts of the world. Supported Employment methodology is a method of vocational rehabilitation that can be implemented in all parts of the world, provided that it is. Thus, WASE provides guidance and support to countries interested in implementing the supported employment methodology in their given region.

*Reference: Egers, J. (2001) Supported employment.*

*Unpublished manuscript*

*For more information, Contact:-*

*Ad Wiese - Holland*

*E-mail: [Wiese@zuidwester.org](mailto:Wiese@zuidwester.org)*

## Introducing the World Federation for Mental Health...

### The federation is unique

- The only worldwide, multidisciplinary, grassroots advocacy and public education organization concerned with all aspects of mental health.
- Accredited as a consultant to the United Nations and its specialized agencies, working especially closely with the world Health Organization, the UN High Commissioner for refugees and the U.N Commission on Human Rights.
- The federation has the influence and broad membership base to facilitate collaboration among governments, non-governmental organizations, Scientists, mental Health workers, consumers of mental health services, and others.

### Our mission


The World Federation for Mental Health is an international non-profit organization founded in 1948 to advance, among all peoples and nations, the prevention of mental and emotional disorders, the proper treatment and care of those with such disorders and the promotion of mental health.

### The Federation's Work Approach

- Educate the public about and improve public attitudes toward mental and emotional disorders.
- Promote the development of regional, national, and local voluntary and governmental organizations for mental health work.
- Identify widespread mental Health issues and develop and disseminate strategies and materials for international, national and local efforts.

### Primary Program Activities

- World Mental Health Day, held each year on 10th October, which uses a variety of activities throughout the world to bring out public and government attention to mental health issues.
- World Congress on Mental Health, held biennially. 2003 Congress: Melbourne, Australia.

Continued on page 14 



- International Committee of Women, leaders for mental health.
- Program Committees on key issues that impact mental health.
- Research through Collaborating Centers at leading universities worldwide.

### **Join the Worldwide Mental Health Movement!**

Our efforts to prevent mental disorders and to ensure access to appropriate mental health care are possible only with the support of concerned individuals and organizations around the world.

We seek financial and membership support to reduce the world wide personal, social and economic losses associated with mental health problems. Your contribution in any amount will help.



With a contribution of \$35 or more you can become an individual member of the World Federation for Mental Health which will involve you in the worldwide mental health network.

Members of the world Federation for Mental Health receive:

- Newsletter, published quarterly
- Reduced-price invitations to regional conferences
- Reduced-price invitation to the biennial world congress on Mental Health
- Annual Report of Federation activities
- Membership card

Organizational membership in the federation offers additional benefits. If your organization would like to consider membership, please request an organizational membership kit.

### **The Need for Mental Health Advocacy**

Mental health issues are critical problems for millions of people all over the world. Depressive and anxiety disorders, suicide, domestic violence, political violence, substance abuse, and schizophrenia are just a few of the concerns. People with mental disorders are still being mistreated and stigmatized in many parts of the world, but many places have seen the changes that mental health advocacy can bring. The World Federation for Mental Health is at the forefront of the worldwide mental health movement.


### **The Mental Health Bells and the National Mental Health Association (NMHA)**

Nearly 50 years ago, the National Mental Health Association, U.S.A. issued a nation-wide call for chains and shackles that had been used to restrain people in asylums. NMHA then took these tools of mistreatment and forged them into a powerful beacon of freedom: the 300-pound Mental Health Bell.



Today as the symbol of NMHA and its affiliates, the Mental Health Bell continues to ring out hope for the millions of individuals living with mental illnesses.

For more information, contact:  
The World Federation for Mental Health  
1021 Prince Street  
Alexandria, VA 22314 USA  
E-mail: [wfmh@erols.com](mailto:wfmh@erols.com)  
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or [www.nmha.org](http://www.nmha.org) for NMHA

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# Brazil: The Taizé Brothers and The Talking Hands Club

And Jesus Said, "let the little children come to me, and do not hinder them, for the kingdom of heaven belong o such as these." Matt.19: 14

## One of the Taizé brothers living in the North East of Brazil writes:

In our neighbourhood there are twenty-five children and young people who are deaf. They have always taken part in the different activities we have for children. The total number of deaf people in our city of 120,000 inhabitants is unknown.

It was in 1994 that we realised that nobody in the city knew the sign language for the deaf. This meant that deaf children were learning nothing in school, and consequently remaining completely marginalised. So we started searching all over the State of Bahia - which is a big as France) - for someone who could teach us the sign language. We discovered Tadeu, who is a great friend of the deaf in the state capital, Salvador. He taught us our first steps, and in 1995 began the "Ecole Vendo Vozes" (School of "voices that look at each other"). It started off very small, and today it has thirty-five pupils and eight teachers. The lessons last for eight hours each day, including some professional training courses.

In 1996, began a mixed group of deaf and non-deaf young people, "the talking hands club". This group organises extra-curricular activities, like Capoeira e o Makolêlê (handed down from the slaves from Africa), celebrations and excursions, a theatre group and a silent choir. They also organise sign language courses for other young people. To date there are sixty young people who have obtained the certificate that attests their proficiency.

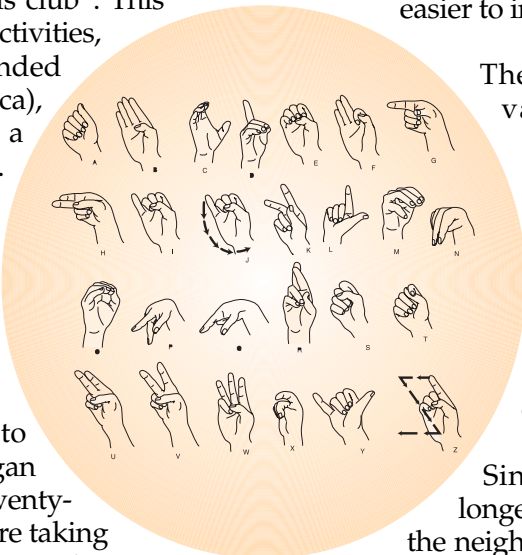
In 1997 the first young people to complete the language course began catechism for the deaf. Today twenty-five children and young people are taking part. Some have asked for baptism and some have made their first communion, and the oldest are now preparing for confirmation. From 1998, members of the "talking hands club" started making visits in other cities of Bahia to help those who want to begin schoolwork or catechism.

Before going to school some of the deaf take part in the brothers' Morning Prayer. There is always

someone present to ensure the translation. After school, the deaf group organises "Capoeira" training (a traditional African dance for self defence) for other children of the neighbourhood. Other deaf young people help in the "children's hour" that brings together 100 to 150 children from the neighbourhood every day. Some help to lead the Sunday Eucharist, with theatre presentations or the silent choir. From time to time the mass is in the sign language, and translated for the non-deaf. At weekends, there is work to be done among the families, teaching the sign language to the brothers and sisters and mothers.

Once a year, all the young deaf people from the town, including those who do not study in our school, are invited with their families for a "day for the deaf". Exchanging experiences, language courses, theatre and so on, these days bring together between 150 and 200 people.

So that the children may communicate with their families, we try very hard to get the families interested too. It is not always easy for the mothers to take part in these activities. The fathers are practically non-existent, so the mothers have to find money to feed their families and as they are all poor their time is very limited and they are tired. Members of the "talking hands club" visit the homes, and prepare something to celebrate with the mothers. It is much easier to integrate the brothers and sisters.



The role of the Taizé brothers is varied: finding out what is happening elsewhere, getting things started, finding young people motivated enough to take on this work; helping to obtain or defend on an administrative level the rights guaranteed to the deaf; maintaining an active presence; making sure that the daily prayer is always translated.

Since we began, the deaf are no longer treated as outcasts and fights in the neighbourhood have diminished. The deaf have become respected and they are less aggressive when they have to defend themselves. (Before they started studying in our school, some appeared to be gravely maladjusted.) The classes for the deaf are integrated into a school where non-deaf children study too, and deaf and non-deaf make an effort to communicate with one another. One of our



projects is for the teachers of the non-deaf classes to learn the sign language too.

People from other cities have started coming to see how to begin this kind of work. For the moment, our school is the only one in the state - with 8 million inhabitants and as big as France - where poor deaf people have access to the same culture as everyone else. What is lacking most is still the adequate training of teachers. In our part of Brazil, nothing is provided for the training of teachers of pupils who have mental or hearing handicaps. The nearest place is 2500 kilometres away, which means that in our conditions it is impossible to get training there. In addition, there exists almost no training material in Portuguese for specialised teachers. So at present, the teachers work with their own intuitions and their love for the children, aided by a few visits that some have been able to make to places in the more developed South of the country.

## Brazil: “A Festa de Jesus”

*Taizé brothers have been living in Brazil for over thirty years, sharing in the life of the very poor. In the city where they live now, Alagoinhas, Bahia, there are many handicapped people, especially the deaf. Here is one of the brothers describing their celebration of the Feast of the Transfiguration this year.*

Just like last year, the young people in our neighbourhood prepared for the Feast of the Transfiguration by spending six weeks trying to find out how in our context they could live out one of the parables of the Kingdom of God: Luke 14, 15 - 23. “... Go out quickly into the streets and alleys of the town and bring in here the poor, the crippled, the blind and the lame... to make sure my house is full.”

And that is exactly what they did, for the “Feast of the Jesus”, on 5 August. They went out two by two into the streets of our city, like the seventy-two disciples sent out by Jesus. Beforehand, they had spent a weekend together in silence, thinking about what Jesus had taught his disciples before he sent them out.

1500 handicapped people came, including very old people and people who accompanied the handicapped, from many of the surrounding towns in a radius of 100 to 200 kilometres, sometimes having to overcome considerable difficulties - vehicles, roads, prices - in order to do so. In fact, one part of the

transportation was called off at the last moment.

These were really the poor who came. None of them, for example, had a camera. The contribution requested for covering the costs of the day

was either some fruit or else half a kilo of some kind of food. Everybody brought something, but it was exclusively the food of the poor. Like in another story from the Gospel, at the end of the day there were several baskets of leftovers.



One of the participants composed a “Hymn for the Feast of Jesus”. “Hoje é um dia de graça e de luz, venham todos meus irmaos para a Festa de Jesus.” “Today is a day of grace and light, come all my brothers and take part in this Feast of Jesus.” With its many verses, sung to a melody typical of Bahia, it finally had everybody dancing.

Many people asked to make their confession or to receive the sacrament of anointing the sick. One of our brothers who is a priest and several priest friends spent many hours in the church, which had obviously been far too small for the Mass.

The day was spent like last year: like a parable lived out literally. Several groups presented theatrical sketches on “welcoming and being welcomed”, often very realistic, sometimes very moving. Others, especially the deaf and the blind from our school, presented songs and sketches that were very joyful.

Still others presented their projects in the field of support for the handicapped. In our region practical initiatives are still rare, and there are few places for the handicapped in the state schools and in the workplace.

Children from our neighbourhood sang and played for the older people. One group put on a vigorous and enthusiastic show with instruments made from trash: packing cases and cans, and parts of old cars. Another group danced a samba, with the aid of handles from street sweepers’ brushes.

Continued on page 17



One elderly man led traditional dances in the old style, playing his accordion - the most valuable thing he possessed, and which was probably as old as he was. A young blind man, passionately fond of rhythm, and who, because he has no drum, usually "plays" on public telephone boxes, presented his art on a real drum that we had loaned him.

Another important aspect of the Feast was the fact that it enabled the young people in our neighbourhood to show what they could do, to discover something about Jesus and about his way of living, and also to show that they too are capable of living something for other people. So often they become resigned to the fact that nothing works when you are poor...

On the big day, two hundred children and young people from the neighbourhood turned up to welcome the "VIP guests" of Jesus. Catechists and young people preparing for confirmation, as well as young people who had nothing at all to do with the Church, took responsibility for all the different tasks of the day. The trust that has been built up over the years through taking part in the "hour for children" - the meeting for children we organise every afternoon - played a big part in this.

Like last year, our parking boys rose to the occasion with all their professional competence. They did everything possible to make sure that the cars and buses did not get stuck in the mud that is our street. Before the Feast, the town hall -taking part for the first time - tried to fill the worst potholes with reinforced sand. But the tropical rains came precisely these days and got the upper hand, creating a huge mixture of mud and sand. To get out of the mud, each bus pushed the others, and the parking boys pushed the cars.

By evening, there was another group of adolescents who were very tired indeed. Throughout the day, they had carried all the benches, chairs and tables from one place to another. Because of the torrential rain that fell during the Feast, we had to move everybody six times. The means at our disposal here, in a poor neighbourhood of Alagoinhas, are very limited for welcoming such a crowd.

"When you offer a feast, invite the poor, the crippled, the lame, the blind; then you will be blessed because they have no means to repay you..." Luke 14.13-14. It was this happiness we were able to experience together on the day of the Transfiguration of Christ.

## Designed for the daily needs of the disabled

A powered mobile arm support unit that assists disabled people with muscular weaknesses to perform everyday functions has been developed by a group of engineers at Cambridge University.

The prototype device which can be attached to the back of the wheel chair support the weight of the arm of the user in a sling enabling the arm to move backwards and forward using his or her muscle power.


The sling is attached via a mental linkage to an electronically powered mechanism, which lifts it up and down. The user can control the height with a switch that can be operated by the opposite hand or another part of the body.

The equipment has been tested by more than eighty volunteers at 13 different assessment centres in the UK in a program co-ordinated by the muscular Dystrophy Campaign. The trials have been declared as successful and the equipment as very useful for people with reasonable muscle control but insufficient strength to carry out actions unaided.

Samuel Lesley, Professor Roy Farmer and Dr. Tom Bligh who developed the Mobile Arm Support (MAS) system in Cambridge University's engineering department is collaborating with the UK firm Neater Solutions a specialist designer of products for the disabled to develop a marketable version.

"I am extremely impressed with a unique design of this powered mobile arm support," said Jon Michaelis, managing director of Neater Solutions. "The University of Cambridge has come up with a device that easily outperforms the many that I have tried. I am proud that Cambridge has chosen Neater Solutions to move this product forward. Neater Solutions designs, manufactures and supplies specialist eating and drinking systems worldwide for people who have difficulties in feeding themselves. The Neater Eater System which is probably its best known product is based on modular system ensuring that the equipment include the right features for the user or diner".

It aims at smoothing out tremor and eliminating uncontrolled movement. The electronically powered automated and programmable unit is equipped with foot control option. Other products include the Neater snacker and drinker, mugs, plates and ceramic ware, cutlery and attachments. There are also Neater buttons for easy switching and a special computer mouse. The company continues to design develop and supply a range of complimentary new equipment that give disabled people greater independence, dignity and choice in their lives. -London Press Service; From Kenya times, October 3rd 2001.

Continued on page 18 





# DISABILITY CULTURE DEFINED

*A view of what disability is from a disabled person who is proud of himself inspite of his disability.*

I cannot begin to count the number of times I've been asked this question in the past decade or so. Some people desired a one-sentence response, others a one-paragraph answer and still others just wanted to argue about or mull over the idea. In the past five years or so, there have been hundreds of documents discussing disability culture being distributed. Don't believe me? Well, for the first time in a year or so I just did a couple of searches. Entering the keywords, "disability culture," Yahoo returned 2020 web page matches; Google 2600 matches; and Alta Vista delivered 1272 matches. Why such interest in the idea of a disability culture. From the international perspective the word "disability" has different connotations to diverse cultures, just as the word "culture" does. The definition of disability that may have become the most known is that of someone who has a major life impairment preventing them from participating easily in a major activity, such as walking, seeing, hearing, thinking. But that definition is one of only dozens in the United States alone. World-wide there may be hundreds, if not thousands of definitions of disability and I would venture the same applies to the idea of culture. Any word that has such historical and contemporaneous significance will create controversy and interest. Put two such words together and the interest is magnified. This is what's happened with disability culture. To return to a definition, here's my one paragraph definition, the shortest I can come up with, published in a 1996 issue of MAINSTREAM magazine that I still use:

People with disabilities have forged a group identity. We share a common history of oppression and a common bond of Resilience. We generate art, music, literature, and other expressions of our lives and our culture, infused from our experience of disability. Most importantly, we are proud of ourselves as people with disabilities. We claim our disabilities with pride as part of our identity. We are who we are: we are people with disabilities.

Those of us working the field of disability culture probably all agree on several basic points. First, disability culture is not the same as how different cultures treat different disabilities. Instead disability culture is a set of artefacts, beliefs; expressions created by disabled people themselves to describe our own life experiences. It is not primarily how we are treated, but what we have created. Second, we recognize that

disability culture is not the only culture most of us belong to. We are also members of different nationalities, religions, colours, professional groups, and so on. Disability culture is no more exclusive than any other cultural tag. Third, no matter what the disability or location of the person with the disability we have all encountered oppression because of our disabilities. Fourth, disability culture in the Southwest of the U.S. may be very different than in the Northeast U.S. or Europe or Africa, but all of us have the similarities described in the first three points. Finally, we who have worked, researched, studied and written about disability culture have most often begun in the arena of cross-disability culture, meaning all disabilities and cultures.

We're aware they're may be nuances, or even larger differences between some of us, but we've had to start somewhere. If we consider all the possibilities of all disabilities and all cultures it's probably more accurate to say that there are "cultures of disabilities." Why is any of this important? I believe there are two significant factors. First, how will we or anyone else know how to relate to us if none of us are aware of our cultural background. For example, most disabilities come with some sort of pain and/or fatigue. How will mainstream society ever be able to incorporate us into itself if neither we nor it recognize pain and/or fatigue as part of who we are. Secondly, and maybe even more importantly, for years we have discussed integration like it was our business to fit in with mainstream society. As we become more aware of our own unique gifts some of us have also become more convinced that this is a backward perspective. It is absolutely not our job to fit into mainstream society. Rather it is our destiny to demonstrate to mainstream society that it is to their benefit to figure out that we come attached to our wheelchairs; our ventilators; our canes; our hearing aids; etc. and to receive the benefit of our knowledge and experience mainstream society needs to figure not how we fit in, but how we can be of benefit exactly the way we are. That's disability culture at least from one person's perspective.

*Steven E. Brown, Ph.D.*

*Co-Founder, Institute on Disability Culture*

*From: -*

*Institute on Independent Living Newsletter 12/2001*

*Newsletter Index:*

<http://www.independentliving.org/newsletter/newsltrindex.html>





## EDAN MAIL BAG



### *Greetings to the EDAN Network,*

I am Bill Gaventa, in the USA, and one who had the good fortune to meet with Sam Kabue and Noel Collot this last summer when they were in New York. I am involved in a variety of networks related to the mission of EDAN, including the Religion and Spirituality Division of the AAMR (American Association on Mental Retardation) and co-editor of the Journal of Religion Disability and Health. In the fall, I sent a box of resource and information packets to the World Council of Churches for your fall meeting, but I had missed the right time, and they got there too late. Hopefully, they are being tracked down and sent to you.

With Sam's permission, I am writing you an email to introduce myself, and some of the initiatives on which I am working with others. If you are interested in learning more about the Religion and Spirituality Division of the AAMR, I hope you will go to the AAMR web page, [www.aamr.org](http://www.aamr.org) and go the section on our Division. We have a number of items there, including mission, information, our annual Co-operative Resource Exhibit listing, and other items. Our quarterly newsletter is not online, but is widely seen here as one of the best interfaith resources that tries to keep up with resources, new ideas, etc. In fact, our current newsletter is printing the short history of the EDAN network and the WCC work in this area which Sam sent to me. In a few minutes, in fact, I will send out a preview copy of the newsletter for you.

We do a number of things here at The Boggs Center on linkages with faith communities, including a New Jersey Coalition on Inclusive Ministries. Last year, a joint project with the Brain Injury Association led to a publication for congregations on brain injury. That can be viewed and copied from a PDF file on our web site. That address is at the bottom of my name at the end of this email.

As co-editor of the Journal of Religion, Disability, and Health, I am writing to invite you to consider linking with the Journal in a number of ways.

First, we are always looking for authors and submitted papers. I have plenty of Information


for Authors brochures which I can send you, but I will also attach a file describing the vision and the ways that people can submit.

Second, we are recruiting individuals in different countries who would like to be on the Editorial Advisory Board. Your role is to help promote the journal in your country, including subscriptions, and submissions. Members of the Editorial Advisory Board receive complimentary subscriptions.

Third, I thought I would tell you about some of the projects currently underway with the Journal. Last year, we published a double issue that was a collection of the theological writings of Wolf Wolfensberger. The next issue coming out is one on international perspectives and cultural voices, a collection of papers from the first ever Disability and Spirituality strand at the quadrennial International Association for the Scientific Study of Intellectual Disability, in Seattle, in August of 2000. We have others working on collections of the essays by Stanley Hauerwas on theological and ethical issues, another of Bob Perske's early writings as a chaplain in an institution, and finally, a collection of Mike Miles essays from his work in the East and Mid-east. These issues are all also published as books. The Wolfensberger book is available.

The journal is not very large, in terms of subscription, but Dr. Coulter, my co-editor and I, are trying to build it up gradually, in terms of quality, and the number of subscriptions. If you would like to join us in this, please fill out the Editorial Board form that I am attaching. Also, those who are members of the AAMR can receive a 20% discount on subscriptions.

I am attaching the cover letter I sent with the packets last fall, and some information about the Journal, and other resources. I hope these will be of interest to you. We are very interested in learning from you as well. The detailed account of your October meeting in Switzerland was fascinating. As they say in Nigeria (where I grew up as a missionary kid), I salute you for your work and for the vision that this network has. I look forward to hearing from you.

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# EDAN MAIL BAG

## MEMO FROM BILL GAVENTA -

### Memorandum

To: Representatives of the EDAN Network  
C/o Mr. Samuel Kabue, World Council of Churches

From: Rev. Bill Gaventa  
Coordinator, Community and  
Congregational Supports  
Co-editor, Journal of Religion, Disability, and Health  
Executive Secretary, Religion Division, AAMR

Re: 1. The Journal of Religion, Disability, and Health  
2. Religion and Spirituality Division, AAMR  
3. Other Resources

Date: September 28, 2001

First, greetings to each of you, and best wishes to you for a wonderful meeting. It was my pleasure to meet Sam Kabue and Rev. Noel Collot this summer in New York. In these days after what has happened in New York, I am even more convinced of the importance of the work in which we are all involved.

Second, this is a letter and package of introduction and invitation. I write from the base of my employment at one of the University Centers of Excellence in Developmental Disabilities in the United States, The Boggs Center. But I wear, as you do, a number of hats, as we say in the US, and those include working with the Journal of Religion, Disability, and Health, and serving in a volunteer Executive Secretary role with the Religion and Spirituality Division of the AAMR. This packet has some materials from all of those roles.

### Journal of Religion, Disability, and Health.

I have enclosed a sample copy of the Journal, several brochures for prospective authors, and a flier about the book version of the double issue of the journal issue which you are receiving. My request, first, is that you share these with people in your countries and networks. Second, we are also looking for country representatives to be on the Editorial Advisory Board. In that job, you would try to recruit writers and subscribers to the Journal. If you are interested in doing that for your country, please send me an email or letter and we will start the process. Members of the Editorial Advisory Board do receive a complimentary subscription.

This next year, a double issue of the Journal (Volume V. No. 2 and 3) will feature papers from the first strand on spirituality and disability at the quadrennial conference of the International Association for the Scientific Study of Intellectual Disability in Seattle last year. It includes papers from theologians, ethicists, pastors, and others, representing a variety of religious viewpoints, including Christians, Jews, Muslims, and American Indians. The next meeting of the IASSID is in Montpelier in 2004. We hope to have another such strand of sessions at that conference. Perhaps that would be a venture with which EDAN would like to collaborate. We are convinced that many in scientific, professional, and advocacy networks are very interested in new dialogue with faith communities around issues related to disabilities.


### The AAMR Religion and Spirituality Division

This network of approximately 300 members, part of the much larger AAMR, is an interfaith network with a regular newsletter. I am enclosing a recent copy. I am also enclosing a copy of the Cooperative Resource Exhibit which we do each year, some of the resources we have for sale. Many are excellent out-of-print resources which have been given to us. We would welcome your membership in the AAMR, or, if you wish, you may subscribe simply to the newsletter. While this network is connected to the AAMR, it has members who work with kinds of disabilities. AAMR is also becoming increasingly international.

### The Boggs Center

In New Jersey and nationally, I am involved in a number of projects related to ministries with people with disabilities. One is a Coalition for Inclusive Ministries in New Jersey. The second is a Clinical Pastoral Education for seminarians and clergy. We also have put together a number of resources which may be of interest. I am enclosing one copy of a recent publication on congregational supports for people with brain injury and their families.

Finally, I am enclosing information about a resource book, On the Road to Congregational Inclusion: Dimensions of Faith and Congregational Ministries with People with Developmental Disabilities and their Families. This is a 124 resource bibliography, our attempt to keep up with the varieties of resources that

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## EDAN MAIL BAG



have been published by many faith groups, and other resources that may be of particular interest and use to congregations. I could not send you each a copy, because of printing and postage costs, but we welcome orders if you are interested.

Through the AAMR and the Journal, we look forward to working with you and the EDAN network. Please send me news of new resources from your part of the world, and, again, we would welcome your connections with us through the Journal and the AAMR.

Also, you may or may not know of, or be part of, an

### Dear EDAN

Greetings in the precious name of our Lord Jesus Christ. On the 20th. December, 2001 I sent this e-mail to Revd. Kathy N. Reeves. She responded, asking me if I could get in touch with you. Hence, through my friend Sarah Babirye of the Church of Uganda Planning, Development and Rehabilitation Department, I managed to get your address so that I can share with you my desire to reach persons with disabilities.

My name is Rev. Henry Katumba-Tamale a clergy in the Anglican Church of Uganda. I'm 41 years of age, married to a fellow clergy, and God has blessed us with five children. Our Diocese of Namirembe sent us to the Anglican Church of Kenya in Mombasa Diocese to serve for a period of three years (Jan.2000 - Dec. 2002) as Partners in Mission for the two Dioceses.

Currently I'm the Acting Principal of Bishop Hannington Theological Institute, and my wife is the Administrator of Mombasa Memorial Cathedral. However, while at University I felt that God was calling me to a special Ministry i.e. to reach Persons with Disabilities (PWDs) with the Gospel of Christ. Such people in my country are marginalised so much. Most of them can hardly come to Church because the majority of our Churches are situated on hilltops! There are no ramps to allow PWDs easy access to Church buildings etc! But, the worst thing of all, is the attitude of the clergy and other Christians in general towards the PWDs. I attribute this to the kind of theological training that the clergy receive in our colleges; which thereafter is passed on to the Christians! It is against this background that after my theological education, I sought training before venturing into this ministry. Hence, I've got both a Certificate and Post Graduate Diploma in Community Based Rehabilitation (PGD-CBR), a programme whose major objective is to ensure that PWDs are able to maximise their physical and mental abilities, have access to regular services and

international listserv on spirituality and disability. You can find out more about that list serv by contacting Dr. John Swinton at [j.swinton@abdn.ac.uk](mailto:j.swinton@abdn.ac.uk).

Again, my best wishes to you for a wonderful, productive, and peaceful meeting. I look forward to hearing from you.


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opportunities and achieve full social integration within their communities and societies. As you can see, this training does not cater for the spiritual welfare of the PWDs.

Now that I'm in a theological college, I've used this opportunity to reach very many people in the sense that I've tried to train and or change the attitudes of both staff and students in the above Institute who happen to come from two big Dioceses i.e. the whole of the Coastal Region of Kenya! Again, once in a while I visit some of the neighbouring schools for the disabled children to pray and share with them the Word of God. Recently in August, I was invited by the Young Life-Capernaum Project in San Jose, California-USA to see first-hand how they do their ministry. I had the opportunity to attend a one-week Camp at Woodleaf where kids with disabilities mixed without any difficulty with other High school students, because of the physical environmental adjustments they put in place for such PWDs. Now that in Dec 2002 we will come to the end of our contract in Mombasa, Kenya, my desire is to change the people's attitudes as much as I possibly can, particularly the clergy for, they are the people at the grass-roots; and therefore can reach and change peoples attitudes towards PWDs in their areas of operation. The way forward the Lord has revealed to me is that of teaching in our Uganda Christian University- Mukono. The only problem I have is that I do not have a Masters Degree. Nevertheless, I know that where there is a will, there is a way. I'm confident that God will give me the required education to this effect.

I therefore, kindly request you to pray for me as I continue to serve the Lord in this Special Ministry of PWDs. I wish you God's blessings in this New Year of our Lord 2002.

Henry.

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# EDAN MAIL BAG

*To EDAN*

## **Application to Ecumenical Disability Advocates Network**

Michael Earle the General Secretary of the Conference of Churches in Aotearoa New Zealand suggested emailing you and asking whether there was any financial support from WCC to enable national gatherings on Disability and Spirituality to take place. We are planning such a gathering in Aotearoa New Zealand in the first half of 2003.

Further to my email to help us in our planning what things can EDAN fund?

Some of things we would like some financial assistance would be - co-ordinator's fee and general office expenses. At present we are hoping that theological institutions might help us with payment/travel costs for speakers and community sponsorship will pay for disability support during the conference. We are in the process of putting together funding applications and I will send you this when it is available.

Yours sincerely  
Vicki Terrell

*From EDAN*

Thank you for your quick response to my enquiry. I am glad that you are planning a much larger conference than I thought when I received the first letter. I do know that this would be a big event whose cost will be high. The Ecumenical Disability Advocates Network (EDAN) is very interested in what you are doing. However our funding limits are very small though we would be interested to make a contribution. It is not so much in our interest that our contribution goes to administrative costs. We would be happy to meet the facilitation costs or even better the sponsorship of some participants but as I have said, our assistance is very limited.

*Dear EDAN*

Thank you for your mail, and having sent three hard copies of EDAN newsletter. I received them recently, and I am looking forward to read them carefully.

I also tried to download the e-copy but my computer says it comes in an unknown format. I am really not trained enough to know how it should be formatted. I will try to get informed.

I wish you a blessed New Year.  
Anne- Lise Nerfin

*Dear EDAN:*

Thank you very much for your marvellous magazine EDAN, Disabled Peoples' International (DPI) is very glad in receiving this issue and coincidentally we have some request from disabled children and youth who would like to receive this as well.

Today we receive a letter from Fred Rocky requesting this kind of material, do you think you can send some past and new EDAN issues to him? His mailing address is: P. O. Box 53, Alamase Krobo, Ghana W.A.

Thank you very much,

Mrs. Pola Ruiz

Disabled Peoples' International Headquarters

## **EDAN NEWS**

### **• Change of EDAN E-mail Address:**

We wish to inform our Readers, Partners and Sponsors that our E-mail Address has changed to [edan@africaonline.co.ke](mailto:edan@africaonline.co.ke)

## **EDAN CALENDAR**

- Pan - African conference on the African decade of persons with disabilities meeting- 4th-7th February 2002.
- WCC week of meetings 22nd-26th April 2002.
- Theological Statement draft team meeting in Geneva - 27th - 29th April 2002.
- Christian Indigenous Blind people's meeting in Riobamba, Ecuador- July 2002
- Bossey Seminar in Geneva - 25th- 29th November 2002
- Central Committee Meeting - September 2002





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