

**RETHINKING CARE –  
FROM THE PERSPECTIVE OF DISABLED PEOPLE**

**VOICES**

*When we look at rehabilitation we can say that very little has been done in the field of rehabilitation as a whole. Especially in the developing countries where famine is recurrently happening and where various kinds of disabling diseases exist worsened by the existence of poverty we can say rehabilitation is non-existent*

From Rethinking care-reflections, Ethiopia

*Voices is a collection of selected short papers, testimonials of disabled people, parents, caregivers and rehabilitation professionals from all over the world. Disability and Rehabilitation team of World Health Organization (WHO/DAR) received more than a hundred such testimonials for the Rethinking Care conference. All the papers received by WHO/DAR are available at Rethinking Care web site: [www.rethinkingcare.org](http://www.rethinkingcare.org)*

“Scientists” have been advocating a rational, detached and objective approach to research. Experiences of individuals have been considered as unreliable and subjective, thus unsuitable for understanding an issue. Only relatively recently, disabled persons and their organizations have questioned the validity of such assumptions and have argued for the importance of individual experiences in understanding a reality.

As these testimonials give evidence, disabled people are undoubtedly among the poorest, and the most socially and politically oppressed groups of people in the world. The medical and rehabilitation services, especially in the developing countries also reflect this state and are scarce or non-existent.

These short papers are written and received in English, even if many contributors do not use this language as their mother tongue. No editing has been made.

We take this opportunity to thank all the contributors for sharing their insights, beliefs and experiences on the subject of “Rethinking Care”.

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## FAUSTINA'S STORY

By Abdul Salim Usman, Ghana

Faustina is a lady of 29 years of age. She lives in a place called Adukrom a suburb of Greater Accra region of Ghana. She uses a wheelchair in order to facilitate her movement and without it she has to crawl on the ground.

Her disabilities came as a result of convulsion, is a disease. When she was ten, she was always attack by this disease easily. One day It came and was rushed to hospital for treatment where, she got an injection on the wrong part like me and that resulted her disability.

By that time her mother was pregnant. The mother was having hypertension. So one week four days after her delivery she was attacked by this disease and died leaving the small baby and her.

After the death of her mother the father was taking her to various places for treatment but there was no any sign of improvement. The father later lost hope and stop taking care. It came

to a time that when she goes to her father side the father drives her away. Her father warned her not to come closer to him again for he has no business to do with her again. Due to this problem her grandmother took her to her village. She was staying with the grandmother took her

to her village. She was staying with the grandmother for a long time.

Her grandmother became old to cater for her and she had nothing special doing to cater for herself. So she decided to come into the city to find something to do to make her life bearable. When she came into the town she did not get any work to do because of her disability. She then decided to beg along the street for living.

She said other people have no respect for them at all. Everybody can come to them and insult them without any reason. When she was at the village her colleagues used to insult her. Sometimes if days are doing something they don't want her to take part because of her disability,

all these drove her away from the village. She could not stand all these non-sense.

In the city too sometimes they are drove away by the police to stop begging. Sometime too if there is a conference or a big gathering in the city the police or any other task force drive them away for they don't want the foreign officials who are participating to see them especially begging along the streets.

She told me that they are now trying to organize themselves to form a society. I asked her of the cause for begging and she attributed that to poverty. She said she really want to have something better doing but she has no money. So the best alternative for her is to beg. She went ahead to say that if she could get some one to help her learn a training then, she would be very happy.

She said there should be some form of education to the public that being a disabled is not a crime so they must give them equal respect as they give to the able people and there should be conference to think of them.

## **RETHINKING CARE**

Anonymous from USA

I am a person with a dual disability (brain injury and a psychiatric label). Over the fifteen years of my disability, I have learned what it is like to be isolated, segregated, and discriminated against. I know this not only because of my own experience, but because I have joined in organizations with others who have the same disabilities, and who have had the same experiences. And for the past eight years, I have been the leader of an organization of people from the U.S. and abroad whose goal is to ensure full human, civil, and legal rights for persons with our disabilities. There is much that needs to change so that we can fully participate in society, and much about the care we get---or don't get---needs rethinking. Prior to my disability, I was an intellectual worker with a bright future. After my disability, not only was I unable to perform my previous work, but I have been unable to do any kind of work at all for a wage. And in the U.S., persons with disabilities who cannot work are

expected to live on an entitlement from the government that is well *below* the poverty level. No wonder we want to work so desperately, yet the majority of us cannot. A survey of the members of my organization found that nearly all of us were employed prior to disability; nearly all of us have been unemployed since; and we are unable to access the services that might enable us to become productive once again.

Like many disabled persons, I have no doubt that it is not my disability that keeps me from being re-integrated into society, but it is the attitudes of others towards my disability as they are reflected in policy and practice. And of my two labels, the one which has most hurt me and hindered my chances of returning to work and becoming integrated into society has been my psychiatric label. I sincerely hope the Rethinking Care conference will address the special challenges faced by persons who must live with psychiatric labels.

I have been a pioneer in seeking rehabilitative services for persons disabled by psychiatric treatment. I sought cognitive rehabilitation services for my brain injury, and found that professionals refused to believe that such an injury could have occurred. Persons with psychiatric labels are believed to be liars and malingerers, or are thought to be psychotic and unreliable. Such attitudes are so widespread that it is difficult to find anyone in the society at large who does not share them, including professionals. This is an almost insurmountable barrier to obtaining care.

Instead of receiving care and services, we are accused of faking our symptoms and disabilities. This happens as well with primary medical care. Persons with real medical illnesses are denied treatment because a primary care physician believes our symptoms must be "all in our head". To take an example from my own life, I recently suffered severe chest pains, and was told by my doctor (after an inadequate examination) that nothing was wrong with me physically, I was only depressed. I turned to another doctor, who knew nothing of my psychiatric label, and he was able to correctly diagnose the heart condition from which I suffered. This condition is not currently life-threatening, but what if it had been? A survey conducted by the U.S. National Mental Health Association, a private charity, finds that this experience of discrimination by doctors is common among persons with psychiatric disabilities

## **DISABILITY: A PERSONAL EXPERIENCE AND ACTION**

By Ashok Hans, India

I was young, doing my first job in Calcutta when my mother fell ill. I returned to my home town to look after her. The doctor's verdict was Leukemia and within 21 days of the diagnosis she died. As I struggled with the the gap left behind by her, exactly a year later, a fourteen year old boy learning to drive a car crashed into my motorcycle wounding me and my father sitting behind me. While my father had a head injury he came out of it, whereas I sustained a spinal cord injury and my life changed overnight. I traveled to the south of the country to the Christian Medical College in Vellore for further medical care to treat bedsores and other complications and rehabilitation. There I came in touch with the Director of the unit Dr. Mary Verghese. A spinal injury had brought her to the field of rehabilitaion.

When I came out of rehab. six months later I faced my first challenges to my changed condition. Socio-political and economic discrimination. My initial concern was to look for

economic independence. After knocking at different doors for an opportunity, I found each door shutting one after another and no response but lots of sympathy ignoring my abilities and education.

I finally decided that if I, a middle class educated youth had immense problems with society and fulfilling my ambitions, the spinal injured especially from rural areas, illiterate would find their situation even more difficult. I took up the challenge to demonstrate that, anything was possible. I set out in establishing a centre for people with Spinal Injuries. I knew that the centre should be able to demonstrate provide medical treatment within a system of comprehensive care, so that given an opportunity, any person with disability could compete on equal terms in society. Shanta Memorial Rehabilitation Centre was born with this vision.

I have been very fortunate to get support of organizations, donors, individuals and institutions. The most encouraging being from IMSOP. Their consistent support has guided us through the many years.

The journey in the process of setting up the centre over the last fifteen years has been challenging. Money was not the only problem. Every one faces this in the social sector. There were other problems, most important getting society and the government to accept our ideas and programmes Even WHO felt that Spinal Cord Injury was not their priority area. Except OXFAM no one else was willing to support, a non-medical approach to spinal injury rehabilitation. For a decade a handful of us worked, going from village to village assisting the disabled wherever and in what ever manner we could..

Finally a decade later, the idea of aim of setting up a unit in Bhubaneswar where SCI patients could be brought for post acute medical and rehabilitation care was fulfilled. We faced innumerable challenges especially as we were working for the poorest of the worlds poor. In their journey the patients visited local and state level hospitals. They had made journeys to temples and looked for help from alternative care specialists. When they came to us they were full of pressure sores and recurrent urological complications which are life threatening. They were also penniless, and their carers could not stay in the hospital as they were daily wage earners and if they stayed the rest of their families would starve. The mortality rate was as high as 98.5% and most died within two years of their injury. These young people were the hopes of the families and potential bread earners for their futures.

We decided that, the only way we could meet these challenges was by developing a Multi Disciplinary and a Comprehensive Rehabilitation delivery care system. This included awareness and training on the management on the site of the injury, transportation and most importantly, training of medical and health personnel in acute management so that, they can come in for early physical and socio - economic rehabilitation and medical care. At each level psycho – social counseling was incorporated. Visits to their place of residents was responsible to enable these persons to access not only continuing health care but more importantly assist them to make their homes accessible. It also meant advocacy for rights of disabled and training the disabled for leadership roles to impact the other persons with disabilities that, not only they have are productive value but also they are no different from the next person.

We recognized that medical aspect of rehabilitation in spinal injury was the smallest part. The other components of socio-economic assistance and advocacy were more difficult but as essential as medical care. The most important part of our care system was creation of

awareness. Again an awareness which was comprehensive in character otherwise it did not fulfill rehabilitation goals. Awareness began from the site of accidents to hospital care, which came under the category of medical care. There was also the component of social awareness, which meant going to the villages talking to political leaders, village elders, youth and women to explain what it meant to be disabled, to encourage communities not to isolate a disabled due to myths and superstitions but to enclose him within their care. We also needed to create economic awareness among the banks, corporate houses and governments that assisting the disabled was not a risk but an investment. Finally awareness among policy makers. We assisted in the national efforts of getting the disability bill passed and compulsory enumeration in the general census. These two together are a powerful tool for a show of strength in numbers as a vote bank but, also to ameliorate their rights. This we realized could only be done by networking with NGOs and creating a convergence of actions as a force to support issues and voice concern facing by people with disabilities.

### SOME THOUGHTS

Poverty is both a cause and consequence of disability. Poverty and disability reinforce each other, contributing to increased vulnerability and exclusion. Disability (is) a Human Right issue.

Social exclusion is often the hardest barrier to overcome. Negative stereotypes are commonly attached to disability.

The consequences are particularly severe for women with disabilities who are also subject to social, cultural and economic disadvantages due to gender / discrimination.

Recently however, there have been changes in attitude, emphasising what is often termed a social model of disability. There is increasing recognition that, term disability does not simply express a medical condition but a complex system of social restrictions emanating from discrimination.

Cross – cultural differences in the interpretation of disability show that the lives of people with disabilities are made more difficult not so much by their specific impairment as by the way society interprets and reacts to disability.

The key to ensure the best use of scarce resources is to listen to people with disabilities and to take full account of their views in making decisions as well as tackling negative attitudes in society as a whole.

## **PERSONAL CARE IN AUSTRALIA**

By Christopher Newell, Australia

In the 1970's and 80's many of us with disability were involved in lobbying for adequate personal care services (in the 1970's mostly called attendant care) for people with disabilities, so as to enable us to undertake various life options, including employment and education. In the 1980's we saw a unique piece of legislation, The Home and Community Care Act (HACC). This was Federal legislation which not only affirmed the rights of people with disability, but also attached money to these. HACC programs were, and are, jointly funded between the state and federal governments, with funding to organisations being required to adhere to the principles of the legislation.

Likewise in Tasmania in the 1980's the efforts of a variety of people with disabilities led to the recognition by the then Labor State government of the importance of funding a personal care service for people with disability. That service, which was HACC funded, provided personal care support to enable a variety of people to undertake important everyday functions. I certainly was one of the beneficiaries.

However in the 1990's in Australia we saw the gradual tightening of resources in the area of personal care support for people with disabilities. HACC funding was capped and demand-containment became important for personal care services, especially in light of increasing unmet need within the community. The new managerialism which was impacting upon governments, with attendant neo-classical economics, meant that services were increasingly not meeting the needs of people with disability.

In 2000 we have a desperate situation for people with disability. In order to illustrate this, allow me to tell Robin's story. Robin has approved the use of her story in highlighting the issues.

### **Robin's Story**

Robin Wilkinson, AM, is one of Australia's foremost disability advocates long involved in advocating for the rights of people with disability and making a contribution to the community as a social worker and activist. She is currently president of the self help organisation Tasmanians With Disabilities. Robyn is one of many people with disabilities who now faces a user pays regime with regard to HACC. That regime requires users to pay a certain fee for weekly HACC services. Yet Robyn uses her personal care for such things as getting up, having a bath, having a meal to eat. As she puts it so well: "Why should I have to pay for assistance with the basic things in life, that other people take for granted. Personal care should be for assisting people to undertake those tasks, and not be subject to fees."

Robyn, like many people with disabilities, cannot pay the fees. Recently she was visited by the bailiffs about her unpaid personal care bill. Theoretically, she could end up in jail as a consequence of not paying for her personal care. Such a luxury in life!

### **The Social Issue**

This story is indicative of the situation of so many people with disability in Australia. It is a scandal that knows no name. Yet, contrast the minute cost of personal care with the cost of residential care (such as a nursing home) if we choose to either take up a nursing home bed or

even an acute care bed. Often a lack of affordable and adequate access to personal care will mean that we need to use more expensive acute care.

Robin's story is indicative of a crisis in personal care support in Australia. A crisis which goes back prior to the International Year for Disabled People. 2001 marks 20 years since IYDP. Yet, we are still having to fight the battles to get adequate access to personal care and other support services.

All of this marks a society where we are needlessly handicapped as opposed to having care provided to enable us to make important contributions to society.

Personal care in Australia. The scandal which knows no name.

## **RETHINKING CARE**

By Muriithi Anthony, Kenya

I must say that life as a disabled person on a wheelchair has not been a bed of roses. It really took me sometime to accept my state. At times I had to hide whenever visitors came home because I did not want them to see me. The primary school life was quite difficult. Other than the little food, there were severe punishments such as going without food. My secondary school life was good although initially I almost quit because I felt out of place as the school was not for disabled students. But through friends I made it and that is where I learnt to accept my state. Currently at the university I get a lot support from friends who help me do alot of things.

Despite all these hurdles I will not give up . My driving force is, **DISABILITY IS NOT INABILITY.**

Concerning the facilities here in Kenya , I must say that most of them are not "disabled friendly". For indtance, some of the storeyed buildings do not have lifts. Telephone booths are too high for those on wheelchairs, the same case applies to Automated Teller Machines(ATM) in the banks. Some of the roads are too rough for the wheelchairs to ride on.

About the health services, I suggest that the hospitals should have specialists for the disabled to handle disability cases. This will bring services closer to the disabled people. Medicines, medical equipment for disability cases and aids such as wheelchairs, crutches and hearing aids should be exempted from taxes. This will make them affordable to the disabled.

My hope for this conference is that it is going to provide a forum for the disabled to air their grievances. One thing especially here in Kenya is that there is social stigma concerning the disabled. Some people consider them to be curses. I remember one time I was in town and I met a man who looked at me then said, "I hate this disabled people". Also one day I went to buy a radio and when I asked the shop assistant to help me go up-stairs, he came with a shilling coin to give me. This shows that to some people the disabled are beggars.

The above mentioned experiences, I have aired them on BBC and also Kenya Broadcasting Corporation (KBC), both Television and Radio. I am currently involved in trying to change the image of the disabled in the society.

## MEETING THE CHALLENGES

By Joyce Marasigan Lim, India

Leo Buscaglia, writer and educator, said,

*"To hope is to risk pain. To try is to risk failure. But risk must be taken, because the greatest hazard in life is to risk nothing..."*

Life for most persons with disability is a great challenge. There is a need to cope with, and rise above pressures and expectations society imposes to help reshape society.

With risks, pains, and falls I learned to live a life where I need to depend on others for my mobility, not personal choice but dire necessity. At age two, I had severe poliomyelitis that affected my functions from neck down. My parents told me that during the onset of the polio, I was rushed to the only government hospital that had an iron lung and accepted patients with communicable diseases. I was placed in the iron lung and doctors gave me less than 24 hours to survive. I survived the critical 24-hour period but remained in the iron lung for days. My father had to manually pump air into my lungs during power failures.

After confinement, my life focused on physical therapy and rehabilitation. I was extremely weak, spoke inaudibly, and could not move any fingers. The years of rehabilitation were tedious and painful and I never understood why I needed such while other children just need to play. It did not take too long to gain minimal functions necessary for daily living. I remember getting my first wheelchair at age 5 and joining my older brothers during study time. My mother provided me with the same lessons as my brothers had in school. I found holding a pencil and writing with the aid of a hand brace difficult. Once I told my mother, "I can't write my name". My mother said, "Yes you can". She held my hand and patiently helped me complete tracing my paper. Weeks later I was able to write and read at an advanced level.

When I was about 7 years old, my mother tried to enroll me in a private school where two of my brothers studied. The school was very familiar to me as I often attended programs and joined my mother in fetching my brothers. The principal gave me written and oral exams and was impressed at my performance. I cannot forget her saying, "You're better than a lot of our Grade 1 pupils". But days later, I learned from my parents that I could not study in that school as Mother Superior said, "We don't have time for the handicapped". Being rejected was painful as I knew that religious people like the sisters, nuns, and priests were working and helping people for the love of God. I was accepted without any question in a nearby public school.

Elementary and high school days were tough. During early school days, some classmates did not like to be near me as their parents feared their children may get polio. As I used a wheelchair, some children called me names while others were amused with my chair. In high school, the head teacher always put me in a ground floor classroom where the lower section students were put. Higher sections where I deserved to be were on second or third floors where ventilation was better. When my classroom was the chemistry room, I had to miss classes when others needed to use the lab as it was not easy to take me to the upper floor. Even when I excelled in academic subjects I always had a lower general average as I was always given only a passing mark of 75% in Physical Education as I was exempted from that subject.

For many, high school was the happiest. I enjoyed college better due to equality in providing education to all. You are accepted if you pass qualifying exams and maintain grade requirements. I took a Bachelor of Science in Business Administration, majoring in Marketing. Such was a far cry from what I really wanted. Presence of students with visual, hearing, and physical disabilities impressed me. I was fully accepted and accessibility was provided. I was like any of my classmates. I excelled in college and graduated with honors. Teachers and classmates looked beyond my disability and they encouraged me to be very active in school activities. Before my last school year, I had to discontinue my studies for a year due to multiple surgeries to correct deformities.

After college, I had years of surgeries and rehabilitation to try to make me ambulate. There were a lot of frustrating years when surgeries were not successful and had to be redone. It was heart breaking as I never anticipated surgical failure. Much time was wasted and my memory was affected.

After completion of orthopedic surgeries, I established a small linen business that exposed me to people in the retail industry. I also tried writing. After years of work, I felt a call to serve God in my own way. At first, I thought it best to be engaged in an organization for persons with disabilities. When applying for membership, I heard a social worker telling a mother of a child with disability that the center could not start their educational program due to having no volunteer teachers. I volunteered immediately, thinking my experience in teaching pre-school to my niece and nephews was enough. I was wrong. When I started teaching, I expected to handle only children with physical limitations who could not attend regular classes due to lack of financial resources. Due to insufficient knowledge and experience in handling students with various exceptionalities, I enrolled in Special Education. Only three universities offered the course and only one was willing to put my classrooms on the ground floor. While volunteer teaching and taking my Master's Degree, I stopped working and tried to obtain a scholarship so as not to depend too much from my family on my educational needs. When I was in the university, I made the department aware of the need for ramps to the library. Now, there are ramps in the entrance, library and cafeteria.

Seeking equal employment opportunity is difficult for disabled persons. Some employers, impressed with qualifications, cannot or will not provide what is needed to allow persons to function well in the workplace. Some, capable of working, cannot work due to no accessible transportation to work place. Pitying persons using wheelchairs, crutches, hearing aids, and guiding sticks does not help. We are thankful for existing laws for provisions of lifts, ramps, captions on televisions but what must really be worked upon is attitude towards disability. Were ramps made to make lives of persons better or because one must follow the law? Are employers willing to hire persons with disability because these workers are willing to work with a lower salary just to be able to get a job? Are schools opening their doors to persons with various exceptionalities?

I am happy I am a contributing member of society. As a Special Education teacher, I have contributed in inspiring my students to look beyond their disability and disabilities of other persons. I always believe that living is determined not so much by what life brings us but by the attitude we bring to life. It is not what we look like that is important but who we are.

## **JORGES STORY**

Jorges from Colombia

I was a student at SAN JUAN BAUTISTA DE LA SALLE and everything in my life was quite normal. I had friends that I used to play with, my brothers and sisters studied in different schools in the city, I loved to listen to music and although I was not the brightest in the classroom I was doing very well at school. My parents worked in a laundry of their property and we used to help them during the weekends on tasks such as receiving, marking and delivering clothes, among others.

It was a Saturday, March 29 of 1986. This day was as normal as any other day. I was helping my mother in the laundry while my brothers and sisters were resting at home. At around 2:30 p.m. I turned on a centrifugal machine where we placed the clothes that had been previously washed with a chemical product that cleanses stains and odors. This machine generated an incredible amount of speed because its function was to squeeze out all the chemicals that the clothes had absorbed. In order to avoid getting my hands I was wearing plastic gloves. I started the machine and it began to work immediately. Soon after I went to check how the machine was working.

Even though it happened fifteen years ago I still keep asking myself why I placed my hands on the edge of the machine. It happened so fast that I couldn't comprehend how it really happened. Maybe the memories of all these years have been vanishing little by little and sometimes, as I try to replay all the movements, all the small instants of seconds my eyes close and I feel an absolute silence in my mind. I keep asking what would have happened if I wouldn't have been there or what if I had let my mother check on the machine, or... so many questions and I don't know the answers.

The machine was vibrating. As I was placing my right hand on the edge of the machine suddenly it sucked my upper arm and it pulled it off. I felt an awful hole in my stomach but I didn't have any reasonable thought. My mother looked at me horrified although she was so incredibly brave and tried to remain calm. She turned off the machine and removed the arm to take me to a hospital. Meanwhile I started to realize what was happening; I felt an unbearable pain, but also I realized that I had to be as conscious as possible as I was bleeding. We took a taxi and I was taken to the Red Cross where the doctors only applied intravenous serum. They also gave me an order to be transferred to San Juan de Dios Hospital.

This hospital was for people of limited resources. As you can imagine the conditions in the hospital were not favorable and there were plenty of patients that were seeking medical attention in the emergency room. We stood there for about seven hours without receiving special medical assistance. I was kept under the influence of the intravenous serum. A doctor approached me and told me: "You lost the arm. We can no longer do anything to save it". And then he left. This was a strange situation for my mother and me; we were not used to receive or accept this type of news. I felt hopeless, tired, and impotent and I could only think of my mother. Her eyes looked so swollen and she could not look at my eyes because she knew that I was sad too. I couldn't talk; I couldn't comfort her and tell her that things were going to be fine, though I wasn't completely convinced myself. And then I felt anger towards the doctor because he sounded so cold, so monotonous that his words were sounding in my head over

and over again until it made me sick. We know that doctors are exposed to realities like this everyday and I believed that after doing so for a long time he lost his sensibility and maybe humanity. Maybe I am wrong but I believe in my heart that doctors should be able to approach the patient in such a way that the patient would not feel the solitude and impotence that one feels in distressing moments like this. For now the only thing that was left was to hope.

At around 7:00 p.m. my father arrived to the hospital. He was heartbroken. It was so strange looking at him like that. He was my father, the man who always confronted difficult situations in his life, the man who was raising five children and from whom I never heard a complaint, the man that I could never disappoint because he would never disappoint me. But there he looked so beautifully human. He saw the conditions of the hospital and that we had not been properly attended that he prepared a transfer to another hospital. At 9:30 p.m. we arrived to San Jose Hospital and the conditions of the hospital were completely different. The attention was very good and the nurses and doctors were very helpful and special. I will always be thankful to them in my heart because they took care of me; they attended me and comforted me when I most needed it. I specially remember the best birthday I've ever had. It was the third week that I had spent in the hospital and my whole family and friends were there to celebrate with me thus all the manifestations of affection and support are hard to forget.

After I left the hospital I returned to school and with the unconditional collaboration of my classmates, teachers and directors I was able to graduate as bachelor in 1987. I was feeling emotionally better every day, capable of reaching goals and continuing my life with new visions and perspectives. Yet, there were more challenges and the following one was the rehabilitation process. I was offered the opportunity to live with my uncles in Houston (TX) to start the rehab in an institute that had great facilities and advanced technology, however my visa was denied in the American Embassy. I thought to myself that everything has a reason to be and therefore good things were to come out of this experience and that I would not let myself down. I am sure that if I would had been granted the permission of entrance to the US, I wouldn't had the opportunity to meet Mrs. Janeth and her team in CIREC. It was there where I started my process of rehabilitation and since then I have been connected with the foundation and their people. With their support and valuable help I was able to enter to their program which included physical and psychological aid; this program guided me to recognize values and strengths of my condition and therefore I was able to overcome the difficulties that this situation brought.

Later on I attended University and graduated as a Business Administrator in the Agricultural Industry. Nowadays I am heading a project that includes the organization and creation of an Assembly Company for the processing of stuffed chocolate candies in San Vicente de Chucuri. It is my goal to build this company in this district because there is a significant amount of handicapped people victims of mines and bombs set by the leftist guerillas in the country. I am aware that this is a difficult project to carry on given the unstable economic conditions that Colombia is going through and the field that I chose is having a hard time in employing personnel and developing training programs. In the same way I still believe that the government should commit to clarify laws in order to provide people with limited physical conditions an equal environment to execute their abilities as professionals and also to educate society in the acceptance of and even treatment to people who has some mental or physical disability. I have hope that in the future anyone who suffer from any type of disability would be able to feel supported by the love ones and the society; I hope that they would have the company and understanding of those who haven't been in this situation, to see beyond the

physical condition and be able to accept them, treat them and love them as their brothers. And I hope they will be as lucky as I am.

## **STORY OF MUHAMMED**

By Abdul Salim Usman, Ghana

Muhammed was two years of age when the unfortunate thing happened. He was staying at the northern part of the country called Tamale the Northern Regional capital. One day he was coming from school and was running unfortunately he fell down breaking his left leg. The bone

between the knee and the ankle broke.

His mother took the trouble of sending him to so many herbalist but nothing changed. Two years later his mother sent him to hospital called Agogo after there, to the central hospital in Ashanti Region in Kumasi. But there was no any improvement.

His mother heard of some herbalist who was staying in Togo one of our neighbouring countries for six months but the situation was the same.

After this journey his mother got heart attack and died as a result.

His father was not where to be found in terms of support. In fact I don't know what is really wrong with our fathers, only mothers are more concern of their children welfare. It is rather unfortunate in this way. His grand mother took ver for six years before she also passed away leaving him. After the death of the grandmother he was depending on his brother who was by that time seeking greener pasture in Lybia.

There was an immigration constraints that his brother was facing in that country. One day he was knocked on the neck with a gun by one of the police and he sustained a very serious injury. He decided to come back to Ghana for treatment but he could not survive. Since that time life began to be difficult for him. He had nothing doing so he decided to beg. He was first begging in Kumasi and later came to Accra the capital city of Ghana to beg.

He also mention that if someone is a disabled no respect for the one. Sometimes people make them feel like they are not part of the society or are not human beings at all. He said he is renting a room in one of the houses around and in fact he is not feeling happy at all.

Especially when there is a ceremony or gathering in the house he will not come out from his room that day because one day there was a ceremony in the house. He wanted to joined the crowd to his surprise the landlord asked him violently to leave the place for the ceremony was not meant for disabled. He wanted to leave the house but he was not having any means so he decided to stay but if there is something going on he will never come out and always in the room weeping.

He said begging is a nasty job so if he get something better to do he will stop begging for any body can come to their end and insult them which is very bad for them.

He said sometimes he feel like committing suicide but he later advice himself that being a disabled is not the end. He said yet is not easy to co-operate. One day he was invited to a marriage ceremony. He was there but regretted for going to that ceremony. This was the reason,

all his peer group were completely different from him interns of everything. Some of them have already married bore children, so he could not stay and the best option was to come. So been a disable in Ghana and in Africa as a whole is not easy at all. He said to them government is doing is doing nothing to help.

He said people should know that is it not their own doing that they became disables, and it can happened to anyone. Some of the people also think it is a curse, which should not be the case. So he is appealing to the public to really come to their aid in terms of finance or any project that will help the disable to get something to do in order to come out of problems.

## **MY LIFE STORY**

By Cathy, Philippines

Just call me Cathy,. I am 15 years old. I was born on March 8, 1985. I am second and the younger one of two children.. I could not recall anything about my parents because my mother abandoned me in the hospital immediately after I was born and my father died when I was only one (1) year old. Only my aging paternal grandmother took care of me and I love her very much. It was really painful when the nuns took me away from my grandmother and endorsed me to the Department of Social Welfare and Development to be placed under the care of Nayon Ng Kabataan. I could vividly remember having cried so much, but when my grandmother explained to me the advantages of being taken under the government's care, I began to understand its benefits especially since I wanted very much to go to school. Being poor and crippled, I realized that I would be a loser if I could not finish even just an elementary education. If I could go beyond the elementar y level, that would be better!

Deep inside me, I suffer from many fears and shame borne out of my condition. During my early years at the orphanage, I could hardly establish any friendship with anyone, since I have always been thinking that being crippled, no one would accept me as a friend. Later however, I realized that my fears were wrong and I proved that despite my physical disability, I could befriend others. Nevertheless, I could not fully overcome my unhappy feelings mixed with fears and shame due to my disability.

Even my future dreams and aspirations are affected by my fears. I was happiest when I graduated last year from elementary school. My spirit was dampened however, when the Social Workers encountered difficulties looking for an accessible school site wherein I could pursue high school studies. Today, I am out of school since the nearest municipal school is composed of several buildings of several stories high which I could not get up to. Besides, I can not cross the street because of the volume of vehicles . I am still ashamed and afraid to face people fearing they might tease or laugh at me. Even when people ask me about my future plans and choices of career I tend to feel less hopeful.

However, I had to reconcile my disability to the choices I made. At first I was eager to be

asocial worker, but I told myself that I could not be an effective one because I could not even attend to my own needs and solve my own problems, or walk as much leg work is needed by this profession. Then I wanted to be a teacher but thought that my students might run away from me and being crippled I could not run after them. So again I dismissed the idea. Then I considered being a nurse, but with this disability, I also might not be able to deliver the medicine as this requires walking. In short, my choices had been narrowed down to a final one: Computer management. I really hope to realize this dream and be a self-reliant individual.

For whatever progress and development that I have achieved at Nayon Ng Kabataan, I still fear for my future especially since I know that in the near future I would leave the center and be on my own. I still envy those who are able to go to different places without the aid of a walker. I am continuously struggling day after day to improve myself and to overcome my fears with the hope of being able to finish a college, with the help of God!

## **FROM OBJECT OF CARE TO SUBJECT OF SERVICES**

By Huys Jos Belgium

As I am a person with muscular dystrophy of 45 years old, I have had the occasion of practical experience concerning the Belgian social security and welfare policies in the fields of health care, technical aids, and personal assistance.

### **Health Care**

Medical doctors, physiotherapists, and others so-called 'experts' pretend to know what kind of treatment I need to maintain my remaining functional abilities. In fact, they don't know anything about, but have the money and the power to determine my rehabilitation process

I desperately need a lot of walking (5 km per day) which requires two persons supporting me by walking at both of my sides. If I choose by myself the appropriate (tall, strong) assistants, I have to pay them myself using my own money. On the other hand, by following prescribed medical treatment, paid for by the health insurance, I have to rely on physiotherapists and their therapeutic intervention, being obliged to follow really limited choices and a far less flexible timetable. To be more clear, I could mention my daily morning physical activity which has to be started early in the morning, at 06:45 A.M., because I leave

my home at 08:00 A.M. in order to be on time at my job. Consequently, it is really difficult to find the appropriate physiotherapists so early in the morning

I desperately need a lot of swimming. By following prescribed medical treatment, which is paid for by the health insurance, I am obliged to travel for more than 20 kilometers and to follow an inappropriate rehabilitation timetable that does not fit with the working hours of a person with a fulltime job under the normal schedule of 09:00 to 05:00, since these rehabilitation facilities serve hospitalized patients. On the other hand, as I have decided to perform my swimming after working hours and in a commercial swimming pool, since it is located far closer to my home (10km), and is open during the appropriate hours for a working person, I have to pay by my own personal budget, entrance fees and moreover the salary of the personal assistant who has to undress me, help me to get into the swimming pool etc.

These examples can be multiplied. The health care provisions are not at all consumer-oriented. The people who have the power of decision on the use of the fabulous health care budget decide what is needed for my personal rehabilitation. On the other hand, if I organize the appropriate rehabilitation scheme according to my personal basic needs ( with appropriate assistants, suitable location and timetable) , I have to pay for my rehabilitation out of my personal income.

I got my driving license abroad, because in Belgium there were no adapted cars available for training. If I want to drive a car, I have to pay for the adaptations by myself, because our bureaucrats don't know (or don't want to know) about the technical possibilities (joy-stick steering) that exist abroad and haven't put these devices in the ' nomenclature' (restrictive list of products that can be paid by the public welfare authorities)

I need adapted shoes for my daily mobility. I have got several pairs of orthopedic shoes, that have been paid by the health insurance by more than 1.000 EURO or each pair, but I never could walk more than 10 meters by using these shoes. Therefore I buy my shoes directly from a commercial firm in Germany, and I have them adapted by a shoemaker at my home- town, which costs me 1.000 EURO per year, out of my own budget.

These examples can be multiplied. The lists of technical aids, that are paid by the Public Social Affairs Authorities are not determined by consumer experience but by bureaucratic rules and commercial lobbying. Therefore, if I want to participate at work, leisure, travelling, and have a socially integrated life with the help of technical aids that fit to my needs, I have to pay out of my personal budget.

### Personal Assistants

Politicians, bureaucrats and social workers pretend to know what kind of personal assistance services I need to perform my social integration into society. In fact, they don't know anything about it by they have the money and the power to determine my conditions of living

I am in a constant need of personal assistance for daily living activities such as dressing, eating, bathing, shopping, household chores, etc. If I had lived in a nursing home for severely disabled persons, I would have had permanent attendance at the expense of the public authorities. But as I decided to live my own life in my own apartment and with my own

family, I had to pay all the costs of my personal assistants out of my own budget until 1997. Indeed, after a political and media campaign, which lasted more than 10 years, our association 'Independent Living Vlaanderen' succeeded in setting up an experimental project, which allows 50 persons with disabilities in Flanders, including myself, to organize their own personal assistance.

My personal assistance budget however doesn't allow me to organize my assistance at my job. If I spent my days performing occupational therapy, I would be entitled to welfare benefits and qualified personnel to ensure my entertainment. But as a lawyer, I decided to use my professional capacities and perform productive intellectual labor. Therefore I am penalized by loss of social benefits related to my disability, and I have to pay the costs of my personal assistants at my workplace out of my own budget

These examples can be multiplied. The existing services for assistance for people with disabilities are set up and run by non-disabled people and tend to isolate us in a segregated, non productive life.

### Conclusions

It is about time for revolution. We, people with disabilities, have to claim the decision making power and the financial means that are set aside by the taxpayer for disability policies. We have to gain control of our own lives, our own physical rehabilitation, our own personal assistance. We are the experts, we have to build up our own expertise and know-how. We don't need medical doctors, bureaucrats and social workers to decide what our needs are. We know what our needs are and how they can be fulfilled. We ask services that respond to our needs. We don't want to be the object, but the subject of these services.

## **A LIFE STORY OF A YOUTH WITH DISABILITY**

By Ronnie Awa, Philippines

I am Ronnie Awa, a resident of Calawisan, Lapu-Lapu City, a small island located in Central Visayas, Philippines. Before 1992, I cannot stand tall and talk with people the way I do now.

I was about three years old when my older sister and I were struck by polio. The effects on our legs were crippling making us both physically incapacitated. Since then, for almost 10 years, we used both of our arms and legs to move about, like two roaming chimpanzees in a zoo.

At that time, Norfil Foundation, Inc., an NGO that had been in our village organizing people for credit assistance and other social development activities, introduced their community-based rehabilitation program (CBR) for children and youth. Our obvious condition attracted the attention of one of the leaders of NORFIL. A Village Rehabilitation Worker, together with the CBR social worker came to visit us.

My family is poor. My father, at the time was bedridden because of his asthma. My mother is engaged in laundry work is the sole breadwinner to feed a brood of six. My older sister, despite her condition, helped my mother in running the household e.g. cleaning the house, washing and cooking. I attended school despite its distance from my home.

When my parents were first talked into the possibility of an ortho operation by the CBR staff in 1992, there was strong resistance, mostly coming from my mother. She cannot afford to let Lani (my sister) and I stay away from home for two months (the duration of the operation and time for recuperation) because there will be no one to help my mother mind her livelihood and the house including the care of my sick father and my little brothers and sisters. At the same time, there is the possibility that something might go wrong with the operation that may cause our lives! But I was very determined to go through with the operation. And with my constant pleading, my mother conceded.

My sister and I were operated on March 23, 1992. With the help of NORFIL Foundation, the Cebu Society for Crippled Children was tapped to sponsor for our operation and hospitalization at the Southern Island Hospital. My sister and I stayed in the hospital for almost two months. After another month, on July 8, 1992, the plaster cast was removed. I was so excited when I walked with my crutches! At last, I can now walk in standing position, just like normal children!

I believe that education will help my life better. I was determined to finish my schooling. During my first year in high school, I took an achievement test which accelerated me into 3<sup>rd</sup> year high school. A year after I graduated with honors. Then I enrolled and finished my two-year Associate in Computer Science course at the Asian College of Technology in March 1999 through the scholarship of W.B. Pangan Foundation. I am very grateful for this opportunity!

After graduation, I served as a volunteer to CBR. I was elected as one of the officers of AKAPIN, an association of parents and volunteers organized by NORFIL. Through this organization, families are taught how to cope with members having disability

In mid 1999, during the celebration of the National Disability Prevention and Rehabilitation Week, a job fair was hosted by different industrial companies in Cebu in coordination with the Department of Local Government and National Council for the Welfare of Disabled Persons (NCWDP). My sister and I had the chance to apply. Our application was responded favorably by a non-government organization based in Mandaue City. Now, I am a great help to my family!

I am one of the few lucky persons who was given access by NORFIL to CBR services which are rarely found in distant villages in the Philippines. I hope that many more youth and children with disability will be helped by NORFIL's CBR programs and services. Recently, in Bulacan, NORFIL has initiated the formation of a Municipal Sub-Committees in nine municipalities to widen the outreach of Persons with Disability (PWD) in distant towns and cities of the Philippines. I hope that the support provided by the provincial of Bulacan will also be provided by the Local Government of Cebu. So that the children and youth of the Philippines are given the chance to become assets of the country.

Thank you for all the efforts that the NORFIL people has given me. I deeply appreciate with thanks the presence of NORFIL Community-Based Rehabilitation Program and the W.B. Pangan Foundation in my village.

### **ON RETHINKING CARE: DISABILITY AND POVERTY IN THE PHILIPPINES MY PERSONAL EXPERIENCE**

By Carmen Reyes-Zubiaga, Philippines

I was one of the estimated (by WHO) 80% of persons with disabilities living in a rural areas who were deprived of basic rehabilitation services, education and medical services because of absence of facilities and support from the government. I got polio when I was one year and a half which left my legs paralyzed and deformed due to some complications. I am the sixth among nine children. My father was a carpenter earning just right and sometimes less, for the daily needs of a family of 11. My mother helped by working as a laundrywoman on daytime and a dressmaker at night. And to think of her job as a wife and assistant breadwinner, it was quite impossible for her to find time thinking of how to restore the strength of my limbs. Instead, as most helpless mothers would do, she just accepted my fate. Somehow, she pushed for my education. She enrolled me to a nearby public school and carried me everyday going

there. She even reprimanded my brothers to take turns in bringing me to school because she has to earn more for the growing needs of seven who were all going to school. I was 8 then.

I was 12 when my mother heard of the national orthopedic hospital in the city which could possibly help me to walk even with braces. Through the help of a neighbor, I was admitted there and passed several corrective surgeries. I stayed in that hospital for one year and continued my studies in a special school there. I was discharged with cast from my waist down because of the overcrowding of patients in that hospital. I even experienced sharing my bed to other patients several times and having bed bugs inside my cast. At my young age, I was fascinated by an old dilapidated wooden wheelchair with crooked front wheel which the patients took turns in borrowing just to go around the hospital or used to go to the bathroom. I did my best to be extra nice with the nurses and attendants just to win the chair one afternoon a week. One time, I envied an elderly woman sitting on a nice wheelchair who passed by one day in the hospital ward. How I wish I could have one so I can go around the hospital garden and get some fresh air outside. But I was told, that was too expensive and only rich people could buy that kind of wheelchair from the United States of America.

I went back to my home, even more helpless with my cast. I was again confined in my small dark room, with a small radio as my companion from morning till night. My four year old sister took care of giving me what I need but she needs to play most of the time. Mother has to work and all of my brothers has to do summer job. School was about to open in a month's time but mother told me that I could never go to school with my condition. How I wished I was not discharged from the hospital because it would be possible to continue my schooling if I was there. After the cast was removed, it was even harder because I could not sit or move my legs. I need physical therapy but the hospital was really far. Nobody could help, except myself. I tried and slowly, I was able to sit. The next visit to the hospital was to have a brace fitted on my legs but mother has no money yet because brother has to pay tuition to go to college. It was expensive and no assistance was available. One year passed and there was no visit to the hospital. I heard of a club of American Women. I wrote them and asked for a wheelchair because I wanted to go back to school and finished elementary. They visited me and I was very happy to receive a nice wheelchair. I was able to go back to school and graduate from elementary.

I really love schooling. But because of physical and economic barriers, I had to give up schooling after graduating from elementary. I stayed home doing everything I could do to keep me busy and to help in some way in my family's economic needs. I learned to sew dresses and earned some money from this skill I learned. The thought of going to school was always there within me but I didn't know how. My mother kept on telling my brothers that they have to take care of me till I get old. She thought marriage would be impossible for me and I didn't have to think about it. I was 24 when I decided that I really had to go back to school. I remember a Belgian missionary whom I met 12 years ago in the hospital who was helping disabled people to find a home, to study and to improve their lives. I remember the school that I went to when I was in the hospital. I saved money and one day, I told my father to accompany me to the hospital. The school was still there and growing. I told the Directress that I wanted to come and she encouraged me to do that in coming school year. After six months, I came back bringing all my things and I was ready to go to school. But there was no place for me. It was the greatest disappointment in my life. I looked for Sr. Valeriana Baerts, ICM, the Belgian missionary. Luckily, I found her I told her my story. In tears, I told her what I want and my wish and what I believe I can do. We both cried together, then, found a solution. She sent to me to a newly built dormitory for disabled students and enrolled me to a

nearby high school, a regular school. She thought my braces were so heavy, so she looked for a wheelchair that I can use to go to school. That wheelchair made a remarkable change in me. It gave me a sense of freedom. It was not that easy to enter school. There was a strong resistance from the principal to accept me because she thought I was too old to be in first year high school. I fought in my innocent way with strong desire that I must go back to school on that moment. I won.

After six months in high school, I took the government placement test and from first year high school, I was promoted to first year college. I took AB Mass Communication. I've got scholarship from the university being a senior staff in college paper and on the merits of my grades. After graduation, I worked as Public Relations and Fund Raising Manager for the House With No Steps, a rehabilitation center founded by Sr. Valeriana Baerts with the help of the Belgian government. After six years, I took a Masters Degree in Development Management and worked on Community Based Rehabilitation Program for the House With No Steps. In 1996, I was accepted as UN Volunteer specialist. I was assigned in Cambodia to develop the National Center of Disabled Persons under the Ministry of Social Affairs.

My personal experiences helped me in developing programs relevant to the needs of people with disabilities in the rural areas, especially in addressing their economic problems, advocacy and establishing support systems in their communities. I spearheaded establishing cooperatives and income generating activities managed by people with disabilities and linking them to resources. I founded the Rizal Council of Persons With Disabilities, an umbrella organization of all community based organizations in Rizal which acts as an advocate for people with disabilities at the provincial level. Presently, I am the Executive Director of this organization.

In 1999, after my contract with UNV in Cambodia, a group of former beneficiaries of all the services initiated by Sr. Valeriana Baerts, ICM organized the Sr. Valeriana Baerts Foundation in recognition of her dedication to improve the lives of persons with disabilities and to sustain what she had started for people with disabilities. We are focusing on providing education, both formal and non formal for young people with disabilities to provide them with better employment opportunities and assume leadership in their community organizations. We are working closely with other organizations of people with disabilities to link our beneficiaries to services and other opportunities.

I also spearheaded the organization of Women With Disabilities Leap to Social and Economic Progress, a group which aims to empower Women With Disabilities for economic and social participation. The group received a grant from the Global Fund for Women to fully develop the organization as a cooperative. It is now providing business loans for women and running a cooperative business managed by women with disabilities and providing employment opportunities for them. In developing countries where the gap between the rich and the poor is so wide, people with disabilities are often on the least priorities. Absence of basic rehabilitation facilities prevent people with disabilities in developing their full potentials to participate in daily activities required to live like any other normal human beings. Because of these, people with disabilities are often at the very edge of poverty and deprived of opportunity to participate in economic and social activities. This is going to be a vicious cycle unless, stringent measures are applied as in the case of developed countries where empowerment of people with disabilities became the focus of the strategy. We can see that basic education on human rights created an impact to every individual and it became an igniting factor in organizing and creating people's awareness.

Community based rehabilitation is indeed an effective tool to bring basic services closer to people with disabilities in the rural areas but government agencies should working on disability issues and services should see to it that people with disabilities are involved as partners not as mere beneficiaries. Funding agencies should also look into their policies in channeling of funds and should consider working closely with organizations of pwds in developing community based programs.

As a person with disability myself, my utmost concern is to call the attention of governments who are lumping disability concerns in their general welfare services. This often results to neglect of other concerns relevant to the needs of persons with disabilities.

In most developing countries, challenges of the new millenium is becoming huge than ever, especially for people with disabilities who cannot cope with the fast phase of technology and development. While people with disabilities in developed countries have access to all necessary information through the worldwide web, people with disabilities in underdeveloped areas do not even have pencils nor paper to learn how to read, nor access to schools or basic services. Much even worse is that change of attitude towards people with disabilities is not so significant. Discrimination is still there in the work place, within the education system, everywhere. Integration seems to be only a mouthpiece but to working towards its achievement seems to be a long way.

I am hoping that this seminar will be an eye opener to all governments that always put disability as only one of the social problems. Much more to people with disabilities who are now in positions where they can make significant change on the lives of other people with disabilities. I am also hoping that through this seminar, the Long Term Program of Action for People with disabilities and the Standard Rules on Equalization of Opportunities be reviewed again

## **RETHINKING CARE - REFLECTIONS**

By Shoarega Zewde, Ethiopia

Disability and Disabling factors existed since man's creation.

Mankind has been fighting disabling factors (diseases, famine, and man made problems) according to human civilization and growth of knowledge.

Man has fought disabling factors and disability in four frontiers in prevention, treatment, rehabilitation and giving support services. In the first frontier a lot has been done by the WHO the vaccination of different diseases... small pox, polio, T.B vaccination and etc have helped a lot specially in the developing countries. The fight against venereal diseases, malaria, river blindness are o great importance in fighting disabling factors in the whole world.

Giving health services is more expensive than prevention so lesser job has been performed in our world specially in the developing countries as treatment is given at lower level in developing countries. Currently our world is faced with a series problem of HIV virus very expensive to give treatment and worst of all that it is not possible to cure the infected person.

When we look at rehabilitation we can say that very little has been done in the field of rehabilitation as a whole. Especially in the developing countries where famine is recurrently happening and where various kinds of disabling diseases exist worsened by the existence of poverty we can say rehabilitation is non-existent.

Wars between countries, the planting of mines in agricultural areas cause numerous accidents resulting in more disability and deaths.

Governments do not give priority to rehabilitation. Hence support of disabled persons to a great extent remain on the shoulders of the family. Many disabled persons are left to live at a destitute level in countries like mine.

Governments of our world should be encouraged to cooperate to give priority to the rehabilitation of disabled persons.

Our world is spending quite a lot of money in producing arms for the destruction of mankind. The resources that are being used for the production of warfare and production of mines should be diverted to the production of medicine and rehabilitation appliances.

Rehabilitation should be taken by all countries as a right not as a favour to its society.

In the conference "Rethinking Care" member countries should be asked to allocate certain percentage of their expenses on warfare and defense.

I hope the conference will have a tangible policy change on health, rehabilitation and social services.

## **STORY OF JAYA**

By N. S. Hema India

One day a man accompanied by a nun walked into the office of APD and asked, "Who is in charge of this place?" Do you keep disabled people here?"

APD is a day center, not a residential center, but I asked him why he was inquiring. The man said that there was a young woman who needed shelter and someone to look after her. When I asked if I could meet this young woman, he told me she was waiting outside in the car. He said she couldn't come in as she couldn't walk.

So I went along with the man and the nun to the car and saw a young woman with a pretty face and a big smile. I offered the young woman a wheelchair so that she could come in to

APD, but she herself told me that she didn't need a chair and that she could walk. When the door of the car was opened, and the young woman got out, I saw how short and overweight she was, with badly twisted legs, and heavy shoes.

After she walked with difficulty to the office, I asked her to tell me why she had come. At that she started crying. I let her cry for some time before encouraging her to tell me her story. The young woman apparently came from a family that was well-off. From birth, she had been treated as if she was a curse to the family. She had been kept hidden away in an upstairs room, and many relatives did not even know she existed. She stayed all by herself in this room while her sisters went to school, and she was not allowed to participate in any festivals or family functions.

When the girl turned 12, she revolted and began to question the father, asking why she should be treated so, and saying that she too wanted to go to school too. Her parents did not want to let her leave the house. They didn't want their own relatives to see that they had a disabled daughter. They worried that it would be difficult to arrange marriages for the other children if people came to know there was a disabled child in the family.

One day the girl asked her sister for help, got into an auto, and came to the Stella Maris school in Vyalikaval. The nuns took her into the school and placed her in the 7th standard. She was a bright student and had learned how to read and write from her sisters. The girl began to study regularly at Stella Maris, completed her studies there, joined Mt. Karmel College, and completed a BSc degree in Botany.

All the while, her father was extremely angry and never supported or encouraged her.

After finishing her degree, she boldly suggested to her father that she could help him with the family business. The father became furious at this suggestion and told her never to interfere in his work.

Except for her sisters, the whole family was against her. So, the young woman made an emotionally difficult decision to leave her family's home and try to live on her own. She first went to the home of her brother's friend and told him that she had nowhere to stay and would stay at his home until she found a proper place. This was the man who had brought her to APD.

I told the young woman that I would need some time to try to find a place for her. But she had no other place to go. One week later, I heard that she had gone to a convent where she had been given shelter. Then, a few days after that, my little niece came home from school and told me that she had a new teacher who was very small. It turned out that the young woman had been given shelter by the nuns running my niece's school and was now teaching at this school.

A year or so passed, and the young woman's father passed away. She then moved back home and began running the family business.

I lost touch with her after that, but imagine that she was successful. She seemed quite an enterprising woman.

What marked me the most, though, was the painful story she narrated to me that day. The way the family - a so-called educated family - can reject their own child, thinking that disability is a curse that must be hidden from the community.

## **STORY OF PUSHPA**

By N. S. Hema India

This is the story of a woman with muscular dystrophy. I met her in a temporary job at a government setup. She saw me there and we became good friends. She was constantly crying that though she had been there for 8 years, they had not made her permanent. She was on a daily wage.

Her parents were very supportive.

Then I met her again after a few years in the same place. The situation had changed. She had lost her parents. She had a permanent job in government, and she was in a wheel chair and couldn't walk. After a few years, she desperately came to see me to ask if I could find a hostel for her. I asked her what the problem was. She had quarters given to her by the government, and her brother's family had moved into these quarters with her. She thought it would be good to have someone at home, but actually she was supportive to the family. She was the one who took charge of the family and got the children educated and married through her money or loans she got from government.

Now she was quite fed up. She said, "Look, I'm aging; I have a few more years before I retire." They are constantly asking me to spend money. When I retire, I need to manage my life. To avoid this problem at home, she wanted to leave the house and get into a hostel. She thought that was one way of solving her problem. If she moved into a ladies hostel, the brother's family would manage on its own.

Her younger brother was so demanding. He was also telling her, if you're spending so much money on my elder brother's family, why can't you spend some on my children. So he was planning on moving into the house with his family also. She was so desperate.

When disabled women become strong, the exploitation starts. The families make use of their ability - particularly the money. They will not bother at all about their future, their well being.

## **MY STORY**

By Abdul Salim Usman, Ghana

First of all I would like to introduce myself. I am Abdul Salim Usman of twenty-three years of age. I am living in Offinso a district in the Ashanti Regional Capital of Ghana. I am chocolate in colour and living with three family members, that is my mother who is taking care of us, my younger sister and brother. I am a disabled to be precise and a student who had recently got admission into one of the universities in the country.

Really I have experienced a lot being disabled. Being a disabled in Africa and more especially here in Ghana is not easy compare to those in Europe, though nobody in this universe wish to be one. We the unfortunate ones could not deny what nature gave but we are trying to improve the situation in a way by rehabilitation, learning a training and any other skills to enable us to get a better standard of living.

I became a disabled when I was nine months old. I was well informed that I was sick and was sent to hospital for treatment. In the course of treatment I received an injection on the wrong part of the body which caused my disability, deforming my left leg. Since then life seemed not to be easy. I could not walk till the age of eight. During these days my mother used to send me to so many herbalists for rehabilitation but only few of them were able to help me to walk. Still I was using my hand as support by lifting the leg with my left hand. I easily got tired after a short walk, always falling in those days.

My father stopped taking care of me He refused to send me to school. Whenever I asked him why, he never gave a correct reason for not sending me to school. Life became unbearable between my father and me. But my dear mum and my grandma never lost hope, they took the full responsibility.

My mother called him to take me to school when I was twelve years old. He did so but he was only paying 30 % of the cost involved and the rest, 70 %, Was settled by my mother. He later refused to pay even a percentage, but my mother never gave up knowing very well that he wanted to use a trick to send me out from school, so she was paying it all.

She also knew very well that there were much to be done to improve my situation. She worked very hard together with my grandmother to get more money, only to send me to the orthopaedic hospital for rehabilitation, to enable me to walk without holding my leg.

I am a Muslim. In Islamic Religion the father controls everything. Even if the women are riche they cannot do things on their own without the knowledge of their husbands, it is against the law.

She informed him that she wanted to take me to hospital for rehabilitation and to everybody's and my surprise he refused to grant us the permission to go ahead.

In fact I was not happy at all, things were worsening as I was growing. Cleaning a pair of trousers was not possible, they easily torn apart due to the pressure exerted between my hand and thigh.

When I was walking people were staring at me as if I had committed a crime. Some teased me with my disability by imitating how I walked. Some used to insult me saying that it was due to my bad deeds that I was punished by God and a whole lot of things.

Sometimes I became sad especially when I was with friends there were so many games that they were playing but due to my disability I could not join them.

Some of the ladies tried to influence my mother to stop spending time and money on me for I was not the only child that she had given birth to, but she did not listen to them. After her refusal they insulted her on so many occasions.

On my thigh and palm was another problem. All the time there were blisters on these parts of the body, even to the extent of using sharp blades to get rid of these without any pain, because there were no blood circulation.

Life was so miserable that I wept all the time because of some peoples misdeeds about my situation. I was talking to my father all the time on the issue of my rehabilitation but he was not listening. There was a time that I forced him by telling him clearly that he would be jailed if he refused. I was lucky, he agreed and I was sent to hospital for surgery in 1990. My grandmother was with me at the hospital, taking care of me for eight months. I was lying in bed for six months, I could not sit only lie in bed.

Now, by the grace of Almighty Allah I can walk without any difficulty, Wear a pair of trousers of any type and so on.

Really, life is much better than previously, and if there are some people to say thank you to, apart from Allah the Almighty, then these are my mum and my grandmother.

It was not easy, but they were able to stand up against all these misdeeds of some people and went ahead to rehabilitate me.

I will say I was lucky to have my mother and grandmother supporting me all the time though they are not rich but they are managing. So many people with disabilities be it mental, physical, or any other form are really suffering. Some of them are very poor so that they even cannot have a square meal nor a balanced diet a day. When money for food is hard to get, how should they get money for surgery? You will see some of the people with disabilities on our streets, begging for alms.

Some parents give birth to so many children, due to this they don't get enough time to the ones with disability. Some people feel to shy to let their children with disabilities mingle with other children. When they are having visitors they look then into their rooms in order not to be seen by the visitors. Some of the disabled persons also feel shy to be in public because people will stare and laugh of them. Some people will even go to the extent of saying that their children with disabilities are not true human beings created by God. They go far by consulting fetish priests to get rid of these children claiming they are spirits produced from rivers and seas. I was involved in a case like this where a baby was supposed to be killed because the family claimed it was a water child. What a pity. With our tiny intervention, we were able to stop them, but still the child was sick and died.

Previously the situation of the people with disabilities was bad. But from the last decade things started to improve bit for bit. People have been educated to understand that being disabled does not mean that the person is bad or God is punishing somebody for his bad deeds.

Some of our disabilities come as a result of our own mistakes like the nurse who was giving me the injection on the wrong part.

Some also become disabled through accidents, cancer, poliomyelitis and other diseases.

We have non-governmental organisations for disabled people. I am a member of one of these organisations. I have been with this society for twelve years. Being an active member I know a lot about this and other organisations dealing with people with disabilities. The society trains them to acquire vocational skills like tailoring, dressmaking, carpentry, shoe making and lather works and also send them for operations. The organisation depends on foreign donors to finance the society.

There are so many problems that disabled face. Most of the children with disabilities lack parental care. Some of them are too poor to improve their standard of living.

Talking about the societies, most of the societies don't have adequate funds to finance their projects. Lack of proper administration personally is one issue. Most of the chairmen of their organisations doesn't know how to manage things well especially with the finances and the issues.

Some also have monopolised everything, and they do not like working with other people as a team. They like to decide everything themselves. It is extremely difficult to organise a whole society by one person. Some of the chairmen mishandle the funds given to them for unnecessary purposes or private affairs.

There is a lot to be done to improve the situation of the people with disabilities. There is the need of well trained people who know much about disabled people, having the interest of working with them and also having the knowledge to manage all the things. They should work as a team to exchange ideas.

There should be training centres to train them well. For this you need enough funds and trustworthy people. Really I am much concerned about the people who can run the centres. Some of them are not living up to expectation. More education should be given to other people, to know that disabled people also can do even better work than the leaders, if they are given the chance.

Another problem is to find centres which care for people who have both mentally and physically disabilities, especially children. We have more than three of these children and we have tried a lot, to get special places for them, but we have not yet succeeded. These children can neither talk, nor walk, nor sit and they are taken good care of by their parents. We need special centres that can deal with these situations. One of these children's situation is worse, and the mother has run away from the child. I tried with Monna, Yvonne and Anja to get a place for the child, but no way! The parents should be educated on how to live with their disabled children. A lot of them need personal support and advice.

When I got information about the Rethinking Care Conference I became happy, and it is a very good idea to have something like that lasting. I hope that after this conference a lot of suggestions will come out on how to help disabled people to improve their standard of living in the world.

## **FROM CAMBODIA**

Anonymous from Cambodia

I have got polio since I was 2 years old. My parents were not aware of that I got polio. They thought that one of my leg couldn't move. Because I was injected when I got cold. They were very upset with the doctor. It was difficult to access to the health service because that time was Pol Pot regime. Working hard at a very long distant field was compulsory. My parents and older sisters were forced to work far away from home. I stayed at home with my older sister, one year older than me. We had no food and very poor health.

My first day in classroom was remarkable. The class was at lunch time and many children in one class with different ages- about seventy children. We learnt to read Khmer alphabets. My house was three kilometers from school. I could walk but in only short way at that time. I always go to school with my older sister. She carried me on her back, when I was tired and felt difficult to walk. As I grew up I acknowledge that all members of my family felt pity with me and they always encourage me to learn to walk, so that I can stand on my own feet when I get old. Sometime I felt very disappointed with my disability life, when my classmate laugh at me and imitated me. In general, in Khmer society disabled people seem to be looked down and excluded from other programs in the society. People with disability have been considered as a lower class and live isolated in their community. It is difficult for them to apply for any jobs even they are qualified. They would choose normal people rather than the disable one if both of them are the same of ability. As myself an example, when I had finished the secondary school, I wanted to be a school teacher, but they didn't accept my application form due to disability reason. It made me feel more and more disappointed and hopeless in my life.

## **MY HOME IS NOT MINE**

By Shahidul Haque, Bangladesh

Really it is Shame and unfortunate for the Persons with Disability that in my home no environment is for me. As in my home there is no facility for me to lead my life easily almost in every case I have to depend on others. From bed to bathroom every where I need help. Whereas if there would taken a little thought about my presence then it would help every one in the family. Though I am there physically but I am not in their Planning and decision making process. So whatever is being done there nothing is carrying my comfort rather it is creating day by day a frustration to all in that family including myself. I don't know whether there is any record of the suicidal case of the handicap people to any one most probably not. Because there is also a barrier to commit suicide.

Being a person with disability I am wondering what is my identity in the family and to the state. Do state recognize us if not then why my family and myself will pay tax and abide by the law of the state. Where is my Place, who am I, are we citizen of Bangladesh or not? We are now in dilemma.

As 13 million disabled persons we are there question is whether Government are accepting our tax from us or from my family if so where is the return of my tax benefit? Why we have no facility anywhere in my country. From Home to the graveyard where is that place where we will feel free to take me there to Have a pleasure or peace this we want to know from the nation. Could you any one take the responsibility to let me know so that we can pass the message to all those family who are crying to get relief from this unbearable pain?

It is a matter of great regret if we look into the nature of the physical infrastructures of our Courtney (both in rural and urban area) which are bare necessity for people's daily living, we find those are not accessible and useful to all types of people including people with disability, old aged people and children. Under the following sub heads we will try to visualize the relation between infrastructures design and disability. This will give you an Idea how people with disability are passing their days in the case. Definitely it is neither desirable nor acceptable by any one.

### **CONSTRUCTION OF SCHOOL, COLLEGE AND UNIVERSITY:**

Is there any institute, which is accessible for all types of impaired children? From where they will be educated and will learn to lead their life independently. Unfortunately there is not a single institute till in Bangladesh, which can show that we are trying to ensure the education for all. Is it not violation of the basic HUMAN RIGHTS of the Person with disability?

### **CONSTRUCTION OF OFFICE, HOUSE BUILDING:**

Almost in all of the buildings, both entrance and staircase are not accessible for the people with disabilities especially for the wheel chair users. Even inside the buildings doors of bathroom and kitchen are not wide enough to enter there with a wheel chair.

### **CONSTRUCTION OF HOSPITAL, CLINICS:**

In most of the cases, there is no arrangement of ramp facilities at the entrance of hospitals, clinics, diagnosis centers, and consequently people with disabilities can not enter inside to avail of their treatment whenever it is necessary.

### **CONSTRUCTION OF RECREATION CENTER AND GROUND:**

All people deserve some recreation for the development of their mental faculty. Nevertheless, these centers and grounds are not accessible for all. Such as entrance of 200, park, sitting arrangement in the cinema Hall and The after and designed in such a way that the people with disability, old aged people can not enter inside of those.

### **INACCESSIBLE FOOTPATHS:**

Lacks of simple slopes at both ends of the footpaths are not only inaccessible it is inconvenient for all people especially people with disabilities, old aged people and children.  
**INACCESSIBLE SHOPPING CENTER:**

Due to lack of proper designing (which is again not the result of technical inefficiency but the lack of disability concern) markets, shopping center even kancha bazaar are not accessible for people using wheel chairs, crutches, and old aged people. As a result they are deprived of buying something by their own choice and they have to remain dependent on other non-disabled people.

**INACCESSIBLE TRANSPORTATION SYSTEM:**

Transportation system of our country that suffers from disability concern can be divided into two aspects such as the following:

Inaccessible terminal:

Bus station, platform of railway station, Launch terminal, Ferry Ghat, Boat station, airport is not accessible for all. Such lacking binds the people to remain imprisoned within a particular place.

The stair cases which the passengers used to get in and out from the launch and steamer absolutely inaccessible for the people with disabilities, old age people and children. Even for the non-disabled people it is very difficult and there is a high risk for them to be disabled by accident (if/any).

Transport:

Our public transport even the luxury bases, railway compartment, staircase of airplane are not at all accessible for the people with disabilities, old aged people and children. Scarcity of public transports just aggravates the situation.

**PRODUCTION OF SUPPORTIVE AIDS:**

Unavailability of required supportive aids within the purchasing capacity of people is one of the main barriers to the development of the people with disabilities. Number of supportive aid manufacturing institutes is negligible. Due to lack of patronization quality of the produced goods are not comparable to international market. On the other hand production cost can not be reduced. Despite bare necessity for daily living it is not possible for the low-income groups to afford the supportive aids for ensuring free movement for daily living.

**MOSQUE, CHURCH, TEMPLE, PEGODA AND GRAVEYARD.**

Have ever we thought Person with Disability even cannot visit above-mentioned place?

By their own without help of the others. Will it not give you a pain when Person with disability even cannot exercise their own will to visit this place to get a little mental satisfaction? I feel I need not to say any more on these issue because it is not only inhuman attitude we should feel shy those who claim ourselves as a developmental thinker, Planner and Policy maker. I do believe that if we cannot ensure this then we have no rights to say any thing for the development of the human being. This does not cost money it needs only a pair of good eyes to see the problem of the people and accordingly to take the step to overcome the mentioned problem.

Finally when we see the above-mentioned situation does it requires any more clarification to make understand the people, Family, Civil Society, Decision-Maker and Policy Maker to realize their role to over come from this critical environment. Though Government on behalf of the Nation has signed and committed to the ESCAP to ensure the Equal Rights and Opportunity for the Persons With Disability. Is there any steps we can see from where it can reflects that there is a good will to have or develop a better environment for the vulnerable groups those who are victimized by the state Planner. If not question will be to the state Please tell us how you will realize and will give the attention to the voice of the sufferer so that you take necessary steps to overcome from this painful environment and to build a Safe

and Just Community for all. So that I feel my home is for me and I can enjoy in my home like  
as you

## **MY SON MARTIN,**

By Aloysius K. Bakkidde, Uganda

I and my wife came from a rural set up where I had not seen people with disabilities. I thought people with disabilities were those we saw begging on the streets therefore they were few. When Martin was born with a spina bifida deformity we were still a young couple preparing to raise a small but happy family. We had just started working and we had a lot of hope in the future because of the income we were collectively getting.

The birth itself was difficult because even after birth my wife stayed with a lot of pain for more than a week. The young Martin had to be kept at the hospital for more than one month during which time my wife was expected to report back on duty after the maternity leave. We had no car and my wife worked in a Bank where the schedule of working hours was tight. She had to have a break to rush to hospital to feed the baby.

As a child Martin was no problem. He behaved like all other children except that we had to take him to the Physiotherapist twice or three times a week. Physiotherapy services were only available at the main hospital and therefore we had to go on appointments in most cases using public transport. This was already an indication of a different life from the normal. The economic situation was becoming very bad following a poor political situation.

By 1975 Martin was growing normally but he needed extra care and special needs to cater for double incontinency etc. These were not available on the local market and had to be obtained from neighbouring Kenya. The political environment between the two neighbours was not favourable either such that it was sometimes dangerous to cross the border with such items which the customs or people in charge of the border did not understand.

In 1977 we finally left Uganda to go into exile in Kenya. In Uganda, Martin was already seven years but he could not attend any nursery or primary school.

Generally at that time, people in Uganda had not been sensitised about disability issues. A family with a child like Martin was thought to be harvesting the fruits of their misdeeds in the past. Most families preferred such children to die as quickly as they wished because of the way society treated them, because of the enormous duty of caring and because most people did not think such children would ever be of use in society. Teachers at the normal schools too did not believe people with disabilities make it up to the highest levels of education. We had therefore only negative forces from all sides.

When we went to Kenya, we found the systems a lot better. There were special schools to cater for people like Martin, although most of the staff were more interested in their jobs and not the work they did. The situation was far better though than in Uganda. Martin was able to start on his education and it was during this period that he had three corrective surgical operations on his feet, legs and hips.

As Martin grew up so did the problems mostly regarding special care. Before we left Uganda to go to Kenya, my wife and I were employed by Barclays Bank and a firm of consulting Engineers respectively. One major problem we often experienced was that of maids (house staff). They often came looking for a job but we always presented Martin at the brief interview as the child to look after. Some of them rejected the job and went away immediately

and others worked for only a few hours or days and left the job no matter how much money we offered. They were just not interested. Of the more than 30 people who came to work for us as maids not more than four have been keen on Martin. We however understood the circumstances and have continued to accept the situation as normal.

On education, Martin completed his primary education and was unable to go for secondary education mainly because of unfriendly facilities to children with disabilities. He therefore tried a tailoring course at a government rehabilitation centre after which he tried his luck on producing and selling children's clothes. Unfortunately the market is full of second hand clothes making it impossible for Martin to compete in view of his production rate. There are no ramps to almost all buildings and facilities including markets in the city and towns yet Martin is a wheel chair case. Motorised wheel chairs cannot work in this country, and even under normal circumstances we would not afford it.

The situation in Uganda today has changed tremendously. The present Government has tried for the last fifteen years to uplift the living conditions of the disabled. People with disabilities are fully involved in decision making from the grassroot level to the national level in Parliament where there are four representatives of people with disabilities. At every level of decision making, people with disabilities are fully represented and indeed a Minister of State incharge of the elderly and pwds is a disabled herself. I must say Government has done a lot but the representatives have not yet achieved much. In my view these people cannot work in isolation. There is a lot of sensitisation of the public about disability issues and lobbying to be done. Most people with disabilities come from poor families and therefore this creates wrong impressions.

There are quite a number of N.G.Os (Non Government Organisations) dealing with nearly every sector of civil society but I must say there are few that deal with disability issues. Many cannot survive for long because of lack of adequate funding. Even the few charities that are well organised like the Uganda Society for Disabled Children and Cheshire Homes, are limited and have not been able to cover all districts of the country because of inadequate resources. Funds from donors are dwindling most probably because of their priorities or relocating their activities to other countries. It is necessary to establish long term partnership for sustainability of programmes.

On our side as parents, life has never been easy both at home and outside. We have acted as nurses and social workers or name it and have tried all the time to keep the family together. Martin is double incontinent because he is paralysed from waist down and the implications are many.. As a family we rarely go out to a theatre or for a dinner at a good restaurant in a big hotel because of the facilities which in almost all cases are not user friendly for Martin. We hate the idea of leaving him alone. We therefore opt to stay at home if Martin cannot go with us because of access problems. Sometimes we feel depressed when we arrive at a party or function and some people appear to be offended or would prefer not to have pwds at that function. We have lost friends because they appeared to be close to us without Martin and we gradually withdraw our enthusiasm. We sometimes get the feeling of being isolated. Martin is part of us.

At home Martin is humble and speaks very little. He is healthy and strong. He discusses openly with people who appear to be straight with him. His best friends are the disabled persons like him and will push his wheelchair several kilometres in order to talk to them. He can lose his cool too.

The way forward.

There is a lot of emphasis on integration but in third world countries a lot of facilities are non-existent. It is therefore important to put together the meagre resources together to assist people with disabilities.. Government is committed to integration in schools etc. but some of these children need special care, special schools, special clinics where they can benefit from the services provided. In Uganda. I have heard of very few spina bifida children that have made it to the age of 18 years leave alone to Advanced level education.

The world has put a lot of effort to fight Aids. I would appeal to the world to give more funds to charities that provide a full range of services to people with disabilities. That way appliances, aids, and such items necessary in the lives of pwds will be cheaper. More funds should also be availed to researchers on areas like spina bifida so that the root causes of such disabilities are eliminated.

## **Personal observation and experience that I have been encountering since my boyhood when I have been afflicted with blindness**

Unknown, Bangladesh

Born in a middle class family of a developing country - Bangladesh. Met with an accident at the age of seven while playing ball and injured my left eye. Subsequently, when through treatment and surgery which led to the failure and thus have become blind in both eyes.

Due to the absence of appropriate medical services and lack of adequate trained ophthalmic surgeon, the surgery was found as incorrect. Further, due to the lack of legal coverage, no legal action could be taken against medical malpractice.

After becoming disabled at the age of seven, it was a great difficult time that both my members of the family and myself have experienced. There was practically no opportunity available for appropriate education, leisure and recreation, sports and games, social activity, etc. in accordance to my personal needs and aptitudes.

However, I re-started my academic carrier by entering into a school for the blind. I studied in Braille system with adverse situation both in the educational arena and in the society around me. When I reached to the University level, I found it more difficult to continue my studies as the minimum support and assistance required for visually impaired students were not available. But with the support and help of my class mates and my family members, I managed to carry forward.

My right of employment was denied, inspite of my having requisite qualifications on the ground of disability. It is because that no legal provision exists till now in Bangladesh to ensure right of employment of disabled persons.

Having no opportunity for employment, I considered to initiate NGO activity for promotion of services for the disabled community and also to find a place for me to work. Thus, I am employed for more than two decades in non-government sector in disability development.

Even, now, I do not enjoy equal opportunity for my leisure time and social activities.

In view of my personal account of experience with barriers in different fronts, I certainly believe that the four UN Standard rules: a. Awareness-raising, b. Medical care, c. Rehabilitation and d. Support services are vital in shaping up the policy, attitude, direction and commitment of people responsible in providing policy, plan and services for the disabled persons.

It is the hard fact that the "Shoe-wearer knows where the shoe pinches". Thus, I firmly belief and strongly demand that persons with disabilities must be involved in decision making process concerning issues for the disabled persons themselves.

The World Health Organisation (WHO) itself at the World Health Assembly and its member states in their respective countries along with other agencies must address the disability issue totally with multi-dimensional approach on equal terms with dignity.

The definition of disability perhaps, need to be re-examined/reviewed at the beginning of the new millenium where impairment may be considered as barrier and thus necessary adjustment may allow persons with disability to lead life with independence, participation and empowerment, as the modern technology, knowledge and attitude are driven towards globalisation.

## IDEAL TREATMENT AND THERAPY

By Pierre Mertens – Belgium

The ideal Treatment and Therapy is a realistic community and family based interdisciplinary approach, close to life and with fun for the child; with the maximum participation of the child and his family in the therapy and in the decision making, towards liberation and empowerment of person with a disability and his family.

The worst treatment and therapy is an over reacting, fragmented, institutional, isolated, boring care far from normal daily life, centralised in big buildings with big waiting rooms, without any real participation of the child and his family in the therapy and in the decision making.

Treatment and therapy have the ambitions to cure, to solve or to prevent a problem, to change abnormality into normality.

First of all we have to see whether there is a real problem. When there is no real problem, it is not necessary to start therapy.

When there is a problem that can not be solved or prevented it is not possible to start therapy.

When we wish to speak about therapy it is important first to agree on what is a handicap.

A differentiated terminology on handicap can help us not to do redundant therapy.

These days we are not speaking anymore about "the handicapped" but about people with a disability, emphasising that people with a disability are more than their handicap only.

But is important to differentiate even more this terminology in Impairment, Disability and Handicap.

This classification, adopted by WHO, includes a sociological as well as medical and functional dimensions with impairment and handicap defined as conceptually different.

*"We first of all have a physical problem. We call it an impairment. Of itself, it is not always a big problem. But it can avoid me being able to go to school, to have friends, to get married or to have children. Those are my disabilities. These are the problems that need to be solved.*

*A doctor can't do that for me.*

*This impairment and these disabilities also let other people treat me differently.*

*That is my handicap, or with a better word, my disadvantage.*

*This disadvantage will always remain, no matter how successful a person I am.*

*They don't give me the same chances as other people would get, I don't find a girlfriend, people don't like to talk to me.*

*Against this, I can only fight by myself, I have to empower myself.*

*Therefore, we can say that a good therapy is liberation and empowerment.*

*This means that even with the same objective defined impairment, disability and handicap are different from one individual to an other. It is influenced by familial, social and society conditions. But the largest part will depend on myself!!"*

Recently associations of people with disabilities are correcting this terminology emphasising that the society in its inaccessibility is often the impairment or the disability provoking the handicap for an individual. It is often attitudes that disable. Yes, attitudes by people often disable more than the impairment itself.

An ideal therapy will take these concepts on board. Not every impairment provokes a disability or handicap. Where it doesn't, why should we start therapy ?

To serve the doctors who sometimes think too much in terms of muscles, nerves and spines?

Our medical system has too much the ambition to cure all impairments and adores the goal of normality. What is not normal, has to become normal. But in my opinion not all abnormalities have to be treated. Normality should not be a goal. Normality is often boring: it is watching

bad television shows, cleaning your car every Saturday, is working 40 hours a week... If normality does exist, it has a very bad prognosis. It is impossible to cure. Working with people with disabilities it is important to see the relativity of normality.

When we start to treat all abnormalities of a child with Hydrocephalus and Spina Bifida the child will never leave the hospital. Is this what a human being should expect from life? This overreacting approach does not see the child or adult as a human being with his own ambitions and aspirations.

Some specialists are still the despotic leaders of a specific area. The neurosurgeon for the head, the urologist for the bladder. Concentrating on this small part he does not see the whole picture. All treatment should have the objective to improve the human life, not just to improve the body. We want to be happy people.

Fortunately over the last twenty years in many countries co-ordination and multidisciplinary teams were set up resulting in a better and more appropriate care. It was a difficult reconstruction to bring all the parts of the body, the mind and the soul and the relating specialists together. The result was more than the sum of all parts.

In the picture came the whole human being and his family.

What is the ideal Treatment and Therapy?

It is the question when we want to rethink care. As a father of a child with Hydrocephalus and Spina Bifida (who died by a medical mistake) I am travelling around the world, I am looking at this world through a hole in the back of children. Almost I see the tourist part of a country only on postcards and leaflets in my hotel. What I visit are families and hospitals. This gives me an idea how a nation copes with health care and with children and adults with severe disabilities.

Making a choice through all countries I visited, I think that a good Community Based rehabilitation (CBR) project such as I see in some Developing Countries could be the ideal rehabilitation system if it is combined with the material and financial possibilities of the developed countries.

It would take too long to explain in detail the all CBR approach but what I appreciate in CBR is that therapy is as much as possible part of the daily life. Not isolating children from their friends in the neighbourhood and their family. Ideal therapy is integrated in daily activities as going to school, sitting in the classroom, eating, sleeping etc. The therapist has to leave the big buildings to coach the parents and the children at home and the teacher at school. For children therapy should always be fun.

In CBR Programmes people with disabilities and their families are fully involved in deciding what steps should be taken and are not regarded as passive receivers. The parents are also being trained, and are expected to coach the child.

CBR has many good elements that can be used to rethink treatment and therapy because it is the way that makes a more individual, holistic approach possible.

At least I want to show the relativity of all therapeutic systems. CBR is not a religion, it needs good professionals and management.

In Psychotherapy a lot of research is done to see which therapeutic school has the best results. The conclusion is that the results were not better in one therapeutic school than another. What they found was, that there are good and bad therapists. Then they looked at the skills of the good therapists. This was empathic skills, the skill to clarify, to elucidate.

So, the ideal therapy does not exist. Let's look for good therapists in a close to life approach. It has been said before that the values of a country can be measured according to how they treat their disabled people. I believe that disabled people deserve to live as well integrated as possible in the society and in their families. Unnecessary treatments in hospitals and long stays in specialised centres cannot be a surrogate for that.

Let us care, before we start treating.

## **THOUGHTS, EXPERIENCES AND REFLECTIONS ON RETHINKING ON THE BLINDNESS PROGRAMMES IN BANGLADESH**

By Golam Mustafa, Bangladesh

The problems of blindness in Bangladesh is a tremendous one. Very few initiatives have so far been undertaken to minimise the problem of this large segment of the population of this country. There is no legislation to protect and safeguard the interests of persons with disability in Bangladesh. There is no co-ordinated effort for the prevention and cure of blindness, and education and rehabilitation of persons with disability.

Out of the disabilities, blindness is one of the commonest causes of social dependency with profound human and socio-economic consequences with prevalence rates rising from childhood to old age. Although reliable data on incidence of blindness is not available, it is estimated that 80,000 people become blind and visually impaired each year. Less than 10% of them receive treatment for their vision to be restored and the other 90% are added each year to the total percentage of the blind and visually impaired population. Without strenuous efforts, the prevalence is likely to be doubled by 2020. According to WHO, there are over 1,240,000 people blind and approximately another 4 million are visually impaired.

Cataracts cause 50 percent of visual impairment. Much of the visual impairment where the cause is given as old age mostly results from cataract. Most cataract patients need surgery to regain vision and thereby become able to continue their daily activities.

Its estimated that nearly 4% of all children in Bangladesh develop corneal damage before reaching the age of six years. One million children suffer from eye diseases and 36,000 go blind every year due to vitamin A deficiency. At least 50% of the children with vision impairment die within one year of becoming blind.

Over 80 per cent of all the Blindness could be prevented or cured by awareness generation and surgical intervention.

### **Reflections on Rethinking**

There are only a very limited number of international aid agencies supporting the disability programmes. The capacity of these organisations to run programmes and build up local human resources is limited due to insufficient funding. The reason behind the situation is that the international agencies consider the work for disabilities from a welfare point of view, and not as an issue of development. However, in terms of the capacity of international aid agencies, they are very much capable to provide significant contribution for the capacity building of local and national organisations of the country if aid to the disabled is seen as a vehicle for development rather than welfare.

- The organisations in other countries who have built up resources and expertise in this particular field which could be shared to build up capacities of the organizations working in Bangladesh to initiate services. Moreover, the developed countries who have their own latest technology and expertise which are highly costly and no way affordable by the poor in the region can assist to encourage the local technology to minimise the cost of special services;
- The resourceful international agencies, in collaboration with Bangladeshi GOs/NGOs, may provide the necessary stimulus by running a series of workshops, seminars on the various aspects of low vision care and encourage organisations working in the field of blindness prevention, treatment and rehabilitation and equip them with professional skills, knowledge and resources.

- A regional network can be established to share resources available within the region. This will enable the interested organizations of developing countries to initiate programmes for the disabled aiming to assist persons suffering from their diverse problems

## **MOM HAS HAD ALZHEIMERS DISEASE FOR ABOUT TEN YEARS NOW.**

By unknown

Mom has had Alzheimers disease for about ten years now. She progressed pretty slowly so she was able to stay home for about the first six. I was living with her and became primary caregiver. My two sisters live in neighboring communities and would come one night a week.

As the disease progressed and she could no longer do things like get in the shower and remember what to do, cook for herself, remember to eat, or to stop eating . . . I had to help with those tasks. I was also a full time student in law school at the time, but because I was not married and did not have a family, my siblings decided I had the "flexible schedule" and should be the one to take on these tasks.

I took her to myriad doctor's appointments, monitored her meds, and sought out opportunities in the community for her. I got her enrolled in senior transportation and got her enrolled in lunch program at local senior center where she volunteered for a time as well as ate.

When it became clear that she couldn't be alone during the day I sought out in home care for her, interviewed the providers and set it up. THEY would leave when I got home so I was there all night with her and would get her up and going in the morning. The first woman we hired left us after a few months because she needed benefits. We enrolled mom through Dept. on Aging and got her some home care initially, but when they found out she left the house to go to the senior center for a time every day they discontinued service because she was not "homebound."

After a year or more of struggling with all this, mom was at the point where she would get up at night and try and leave the house, put five outfits on over each other, etc. My sisters decided she needed to go in a nursing home rather than increase their level of assistance. WE could not afford 24/7 care for her, and Medicaid won't pay for that; they will, however pay for her to be warehoused in an institution, fed when they get around to it, having constant urinary tract infections because she doesn't get fluids, and bedsores twice. She has been there for four years and amazingly is still alive. It kills me to leave her there, but to hire someone at home would cost far more than we have and again Medicaid won't pay.

## **PROBLEMS FACING THE DISABLED**

By Jonathan M. Amuah, Ghana

This paper seek to identify some of many problems facing the disabled in the society and what to do as a nation to address them the disabled can be categorised as follows:-the blind, the deaf, the mentally handicapped, the

epileptic, the leper the cripple , persons with speech defects, delicate persons due to malnutrition, tuberculosis, patients etc. negative parental attitude:-

the attitude of some parents towards the disabled children leaves much to be desired. some father go to the extent of divorcing their wives for bringing forth

a disabled child, resulting in a total neglect of the child by both parents. the poor child is compelled by circumstances to beg for alm on the street for a

living. negative attitude of the society:- the attitude of the society towards the disabled is very negative out of ignorance, the disabled are considered as less intelligent, useless, less logical, unable to determine their own life and less realistic. -culturally and politically, the disabled is not allowed to function as a head of a family or head of a clan or as a chief or as a member of or a ministers of state.

-Martifully, many parents are not prepared to endorse the marriage of their sons and daughters to disabled

persons for fear of recycling the disabled race in the family. -religiously, the disabled are not allowed in some

societies to conduct church services. -in the ancient and medieval times and even today, some parts of the world consider the disabled as idiots stupid and useless and offer them as sacrifice to the gods of the land, others are put in pits to die or left at isolated place to tend for themselves. This is unfortunate. inadequate aids or gadget and medical facilities:- those

facilities which must be at the door step of the disabled are not evenly distributed o those in the villages are not benefi The cripple faces the problem

of mobility .unfortunately, tose gadgets are often lacking this making some of them immobile .the immobility hampers has free movement and is therefore compelled by circumstance

beyond his control to depend on others for assistance in various aspects of daily life. -the following services must be provided as a nation to better the lot of the disabled in the society.

1.Ealy medical treatment including postnatal care and periodic assessment of functional development of the disabled child.(m.o.h.).

2.medical Rehabilitation services including corrective surgery and provision of special appliaces (m.o.h.) e.g. wheel-chairs, hearing aid and glasses etc.

3.Counselling,provision of support

services ,recreational facilities and access to public building will all help to ensure the social independence of the disabled person. Conclusion :-there is a growing need for voluntary organisations working for the disabled and the

association whose membership are made up of the disabled persons themselves to establish a common forum for effective co-operation between them for example:-the Ghana association

of the blind, the Ghana national association of the deaf, the Ghana cripples aid society, the Ghana federation of the disabled and

the Ghana society for the blind etc.

## **RETHINKING CARE CONFERENCE**

By Mari-José Schmitt, France

Is this a good title for the planned conference ?

( This question has to be considered as a help for making a step forward in our approach). For a French speaking person "care" has directly to do with health problems and the word health, even if WHO has given a very broad definition, still means for everybody something like " the contrary to illness". Such restricted meaning of care is not only a language problem, but has been over years the usual approach when considering people with disabilities.

Should we rethink care, or, more generally, rethink our place as a citizen next to another citizen, I mean, our sense of a humanity made of equal human beings even if we are not all the same, even if some of us are different and even when this difference is a challenging one.

Of course, care, in the broad sense of the word is needed. But shouldn't it be the normal attitude towards each other? It is up to the society, to each country, to build up the rules as to care for children, for the elderly, for those who need care at one or another time in their life. Care is an obvious need that has to be answered according to the culture and to the wealth of each country.

Care is one of the needs, or better, it is a means for answering the real need which is to be given a place in the society. Citizenship ( not only as tax payer but also as a productive member of the community) has to be aimed at presently in our opinion.

Now, after the UN Rules and on line with the present ICIDH revision process, focus seems to be put on participation. And this is already a second step. Let us imagine a wonderful society where people would be considered to be equally human, equal in rights. This first step having been reached, we now say that all human beings not only have a right to exist, to live in a neighbour house, but that they have a right to participate in the life of the street., we say that they are empowered for so doing. Or , a bit realistically, that they should be empowered...

This positive assertion of participation is challenging people's general trend to exclude those who are different, unable, or " un" something , and the first to be challenged are social services and local authorities.

The welfare society was a very comfortable concept where listed needs could be answered with listed costs. And it was quite easy to make reports on the " cost-effective" side of different services. Luckily enough, integrating of some people with disabilities in regular employment has shown to be cost-effective, at least so long these people were not severely disabled or were not disabled in their working capacities. For people with mental disabilities, such integration process has not always shown to be really cost-effective and in fact it is not when all costs are considered. This was a first difficulty in the current systems. We are afraid to read in different studies such arguments of cost effectiveness used for promoting integration or non-discrimination. Isn't it a pity, in our rich European countries, to take as a fist argument, a supposed lower economic cost? It is a pity and it is wrong because cost-effectiveness in this case has to be considered not only as to the enterprise, but as to the community as a whole. Improving the life for one person, even at a high cost, always shows to be cost effective in long term.

It should be the aim of this "rethinking care" conference to look at participation as a challenge for the coming years. It could be a place where, according to each type of disability, people with disabilities, parents of people with mental disabilities, social workers and others could provide the policymakers with some detailed practical applications of participation and of facilitators that we all have already experienced. We have good practice of facilitators, and it could be useful to share on this topic .

Participation, you know, is a pleasant word and everybody will agree. But, let us sit down and look at its meaning in daily life. First question: are people being educated with the idea that they have a right to participate in all aspects of life? In many European countries there are laws for the protection of people with mental disabilities or mental health problems. Once protected, by law, these people have no more the right to vote. This means that our say is denied in reality, or that we have to change the laws. Are we ready to do so? Second question: are people educated so as to become aware of their possibility to participate? What is done for promoting their desire to participate? In hospitals, in care-centres, at school, in training-centres ( where they sometimes are taught how to achieve tasks that are obsolete on the market), in employment where people with mental disabilities are more tolerated as considered as real participants. In one word: do we believe in participation?

One of the pre-requisites for participation is empowerment. Of course, we all know that. But which are the pre-requisites for empowerment? This conference should help to play hide and seek so as to find the society's ( our) resistance to changes in the last corner where it is hiding so as to be able to say " look, there it is, we will put this resistance aside and from now on, things will be changing" The real question remains in every-day life: are we taking it seriously with opening the doors to a real participation?

We see two main dangers in this new trend towards participation :

1. It could well bring upon a new discrimination, a labelling of those " who obviously cannot participate". Exclusion among the excluded ones. This is a real danger for people with severe mental disabilities. Focusing on participation should not lead to determining those who .... In former times have been said to be useless.
2. It could also be just a new word. Looking backwards, we can see that changes in words do not directly introduce changes in people's daily life nor in legislation. In this sense " participation" could be a dangerous word because it carries some satisfactory ideology. Governments could well consider that having claimed mainstreaming and participation has solved people's problems in daily life.

This is why people involved in disability issues should consider to make practical recommendations to the European governments and bodies on how to implement the right to participate that has been defined as "equalization of opportunities" by the UN Rules and for which the new ICIDH could be a helpful tool.



## DISABLED PEOPLE CARE IN CHILE

By María Soledad Cisternas Reyes, Chile

In Chile, we have an estimated population of 1.500.000 disabled people. Just in the last decade, there was a process of social Claim from the collective, in order to produce a policy about Disablement. An important target of this elaboration was set by N°19284 Law about Social Integration of Disabled People. In that law, three basic principles were studied: Prevention, Rehabilitation, and Balancing of Opportunities; being the last one considered from several points of view, such as education, training, culture, transportation, physical space, as well as tariff franchises to acquire technical aids.

This legislation broke into in January 1994, during the first "Alliance Government" ("Concertación") called Parties Alliance for Democracy (Concertación de Partidos por la Democracia). However on their second period of government, that is to say by the end of 1999. It was formally pronounced a "National Policy for Disablement", together with a course of action which considered the same topics of the legal text.

It called our attention, the late date delivery of this Law to the Nation, even more, when the fact of a Third Government Period of this Alliance was uncertain; this fact can be interpreted by disabled people, a last time announcement that obeys to some other interests but the one we are concerned.

Thus, we reached the year 2000 with a growing need for Disabled People Unions in order to transform the Chilean legal background in this area, as well as formulating the necessary requests to formulate a public policy that starts listening to the proposal consignee, that is to say; the disabled people collective and formulating at once a policy which allows the concrete application of the programmed aspirations declared in official documents. The legislation as well as the Public Policy affirm that prevention and rehabilitation of disabilities are a **right** for disabled people and their family and an obligation of the State.

To this respect it must be signaled that Chile does not perform a strong policy able to hold continuous plans and programs in order to prevent disabilities, nor it assumes the rehabilitation of them. Thus, these aspects

are developed by several private non-profitable organizations supported on volunteer basis. It is also remarkable the great annual campaign carried out by a Foundation that devotes all its efforts to rehabilitation of disabled children up to 18 years old and whose principal income comes from citizenship donations in a 27 hour TV show every year that was able to get a remarkable collecting of five thousand five hundred million of Chilean pesos this year, in contrast with the amount assigned through a General Budget Law which gives FONADIS (Disability National Fund), a state organism, two thousand, three hundred millions pesos to be distributed along 13 regions in our country. This Organism shares its economic resources with all kind of disabled people along the country as well as all working areas such as prevention, rehabilitation and balancing opportunities.

It should be considered that by the next period (2001), this amount will increase to \$2.800.000.000 (pesos), that will help to direct resources to improve existing projects.

Nevertheless, we should consider FONADIS has a Legal Frame which has happened to be limited; anytime, its activity and directions must support technical aids partially or completely to poor people suffering any disablement, based on a catalogue historically limited in what new technology incorporation concerns.

The second course of action area deals with supporting projects not more than ten million pesos shared in

Periods less than 12 months. These projects are not renewable in a following period, not even if they happen to succeed on their execution and interventions. Of course, this can let valuable projects aside, without any hope to get any other financial support for them.

*Moreover, a failing aspect is psychological and psychiatric cares, that are sometimes a valuable support to assume the disability or facing in a better way the difficulties in social integration which has many different problems a disabled person must cope with. In fact, not only there are evident problems in carrying adequate programs able to cope with mood disorders treatment, but also there are inefficient health covering programs, co-payment and subsidies alternatives not only in the Private Health System, but in the Public as well. Psychological and psychiatric subsidies has no relation with subsidies in other branches of medicine.*

The problem can be settled finally, in an urgent need of State support and subsidiary funds, codified in the Constitution, since up to this date, the disabled people care is given to the isolated effort of the disabled person himself, his close family members without any important political will to create an effective prevention, rehabilitation or balancing of opportunities.

This claim does not impede the alternative of the State to not growing disproportionately on its structures, but it must support efficiently non-profit organizations that with so much effort assume the tasks with the virtue of solidary spirit, cooperating in this way in an undeniable obligation of the State.

### **FINAL REFLECTION**

Even though, it is true we must recognize the advances in the Chilean institutionality on what disability concerns; today's challenge is the participation of disabled people as members of the civil society, as leading characters in the diagnosis, elaboration and evaluation of public policies in relevant matters, so as to reach a better approach.

My reflections have been motivated by a personal experience as a disabled myself, that has been

after claims for Scientific Research Policies involved in the prevention concept, particularly if it is considered that genetic pattern of many causes of disabilities which could lead to an eventual hereditary transmission.

On the other hand, I also experienced the need of a psychotherapy to cope with the progressed loss of vision.

Finally, my contribution is focused on my experience as a professional devoted to the area our analysis occupies as well as the direct knowledge of the State affairs on this topic.

## **MY EXPERIENCE/THOUGHTS:**

By Rickhard Uwakwe, Nigeria

Africa has had a wonderful record of care for the disabled: mental, physical or social. A few years back, it was rare to see disabled beggars in African streets; this was made possible to a large extent by the extended family practice system where every body is the others keeper. Today that is no longer the case. Many Nigerian streets are now 'littered' with disabled beggars – Lamé, deaf, blind, mentally retarded, cognitively impaired, elderly etc. We do not have social security provisions or health insurance cover for these disadvantaged groups; although there are some special education centres for the blind, the majority of disabled who are totally neglected constitute undue burden to society, failing to realise their potentials. Use of Braille is rare here. Occasionally some voluntary organisations render some aid to the same disabled who manage to get to the media, for example Rotaract club provided glasses for some blind. Use of hearing aids here is near to non-existent. All mental and behavioral disorders are heavily stigmatised.

Making the sufferers outcasts in society. Nigerian culture demands miracle to remove disabilities, therefore work with the disabled and rehabilitation is very unpopular. There is need for reorientation on the part of our government, society and family. At the moment we do not have any articulate policy on disability and it can be frustrating to those of us in such non-glamorous area. Such policy cannot be universal; needs vary very widely and for those of us in the third world, we need to begin somewhere

## **DISABILITY - THE AFRICAN CONCEPT**

By Chola Kafwabulula, Zambia

By the 1980s there were more than fifty (50) million disabled people in Africa. Sixty (60) percent of them were undernourished which was the major case of disability. Deficiencies in Vitamin A, in particular, lead to blindness. Diseases such as polio were common even though they had been wiped out in Europe. The African did not have access to immunisation. This was partly due to lack of governmental health resources to make vaccines available. In addition, many women were disabled as a result of the practice of women circumcision in many parts of Africa. The practice of removing the clitoris and/or the labia was frequently performed for cultural and religious reasons by village women in unsanitary conditions. Resulting disabilities included chronic pelvic pain and urinary tract infections, mental illness due to the trauma of undergoing the procedure and even mobility impairments.(1)

Generally the disabled people have been the most destitute of Africans. Government planners have tended to emphasize the needs of the majority and thus they have ignored the needs of disabled people and their families. Most disabled people in Africa support themselves by begging in big cities, or charitable institutions supported them.

African attitudes towards persons with disabilities are quite negative. Society in Africa held beliefs and myths that linked disability to sins committed either by disabled persons themselves or by their parents. Families saw disability as something to be ashamed of and this shame could bring about the killing of disabled children or the exile of their parents. In addition, disabled women were in a situation of double jeopardy. African society already accorded women a lower status than men. Thus, disabled women faced discrimination because they were women, and because they were disabled.

Both disabled women and men had few options for employment and meaningful work in the African society. Many disabled people begged in the streets of big cities as religion called on their followers to give to the needy, sick and disabled to build credit towards an after life:

*Dropping coins into the blind beggar's bowl may lead to avoidance of punishment in the afterlife ..... The disabled beggar asks for "justice". Since fate, karma or deity has deprived him, begging becomes his rightful duty and occupation; justice demands that his bowl be filled. If the unseen forces present a poor family with a deformed baby, it is the family's duty to exploit the deformity for financial gains.*

(1) Robin Morgan and Gloria Steinem "The Crime of Genital Mutilation. New York: Holt Rinehart Winstone 1983

THE AFRICAN DECADE OF DISABLED PEOPLE: 1999-2009

The African Decade of Disabled People 2000 to 2009 will be launched on December 3rd in many countries in Africa.

The Pan African Federation of the Disabled (PAFOD) in collaboration with the African structures of the six major international organisations of persons with disabilities will coordinate the Decade activities.

The objectives of the African Decade of the Disabled People will be: Poverty alleviation amongst disabled people and their families; Awareness raising and conscientisation on disability; Combating causes of disability by promoting peace and reducing other causes of disability; Strengthening the African voice of disabled people; Putting disability on the social, economic and political agenda of African governments.

The Decade aims to spearhead the implementation of the United Nations Standard Rules on the Equalisation of Opportunities for people with disabilities, leading to the adoption of a convention on disabled people by OAU member states; the application of UN instruments on the Declaration of Human Rights; Addressing issues pertaining to children, youths and women with disabilities; application of UN Standard Rules as a basis for policy and legislation to protect the interests of disabled people in Africa.

The Organisation of African Unity (OAU) through their specialized agency African Rehabilitation Institute (ARI) have approved the decade.

Under this second Decade of disabled persons, the African continent will focus on the grey areas unaddressed during the United Nations Decade;

1. Proclaims the African Decade of Disabled Persons, 1999-2009 with a view to giving fresh impetus to the implementation of the World Programme of Action concerning Disabled Persons in Africa beyond 1992 and strengthening regional co-operation to resolve issues affecting the achievement of the goals of the World Programme of Action, especially those concerning the full participation and equality of persons with disabilities, as well as those contained in the UN Standard Rules on Equalization of Opportunities for people with disabilities which relates to education, training and employment.
  
2. Urges all member states to review the situation of disabled persons with a view to developing measures that enhance the equality and full participation of disabled persons as well as the empowerment of the disabled people, including the following:-
  - a ) Formulation and implementation of national policies and programmes to promote the participation of persons with disabilities in economic and social development;
  - b ) Establishing and strengthening of national coordinating committees on disability matters, with emphasis on, inter alia, the adequate and effective representation of disabled persons and their organisations, and their roles therein;

- c ) Provisions of assistance, in collaboration with international development agencies and non governmental organisations, in enhancing community-based support services for disabled persons and the extension services to their families;
- d ) Promotion of special efforts to foster positive attitudes towards children and adults with disabilities, and the undertaking of measures to improve their access to rehabilitation, education, training and employment, cultural and sports activities and the physical environment.

3. Urges all concerned specialized agencies and bodies of the United Nations system to undertake an examination of their ongoing programmes and projects in the African continent with a view to integrating disability concerns into their work programmes systematically and supporting national implementation of the OAU declaration.

4. Calls upon non-governmental organisations in the field of social development to utilize their experience and expertise in strengthening the capabilities and activities of organizations of disabled persons.

5. Urges organisations of disabled persons to cooperate with government agencies in strengthening means by which citizens with disabilities may realize their full potential, and to strengthen linkages among disabled persons in developed and developing countries to enhance their self-help capacity.

6. Requests the OAU member states to provide resources in the following:-

- a ) Development and pursuing national, regional and continental programmes of action during the Decade;
- b ) Formulations and implementing technical guidelines and legislation to promote access by disabled persons to buildings, public facilities, transport and communications systems, information, education training, and technical aids as well as empowerment of persons with disabilities.

7. Further requests the Secretary General to report to the Summits of Heads of State and Government biennially until the end of the Decade on the progress made in the implementation of the Decade Programme of Activities and to submit recommendations to the Summit as required, on action to maintain the momentum of the Decade.

8. Urges Governments to consult with disabled people at all times and stages of development in matters that are of concern to them, and also as a measure to use their expertise and experience in providing solutions to their problems.

It is the hope and desire of all Persons with Disabilities in Africa that the various dreams, interests, and aspirations of the disabled shall be fulfilled.

We are no longer "vegetables" of the 1920s and 1930s.

## **AWARENESS RAISING ROLE AND IMPORTANCE IN REHABILITATION PROCESS**

By N Basalat , Palestine

Awareness role is regarded as the backbone of the rehabilitation process. it represents the main component of rehabilitation at different levels, and it reflects the way to communicate with persons with disability in regard to all issues related to their life. Awareness is an essential component of comprehensive rehabilitation process as it paves the road for better involvement of disabled persons and their families in the rehabilitation process of their own.

Awareness among persons with disability of their rights contributes to a large extent to the empowerment process thus enabling them to struggle for their rights. More over it will promote their self-esteem and their self-confidence eventually this will lead for better understanding of their role and responsibility of their own concerns. In addition to that clarity of roles and responsibility will develop the notion of self-confidence and will strength at all levels.

Awareness process involves three aspects:

1)Promoting awareness within rehabilitation process is of basic importance for persons with disability. In the past, rehabilitation used to concentrate only on the clinical medical treatment. However nowadays, we see that rehabilitation process has expanded in order to involve other fields beyond medical treatment. Where as physiotherapy, occupational, vocational and psychological therapy became major components of any rehabilitation plan. Nevertheless the rehabilitation process still in need to be developed more in many aspects. There is by a lack of human resources in some fields of rehabilitation like speech therapy and dealing with complicated disabilities ...etc.

There is also still a need for rehabilitation centers that serve those over 15 years old with mental disability, since the exiting centers don't serve fully this age group. Moreover, the existing centers should be improved.

2) Promoting awareness among the disabled people themselves, so that emphasis should be on building confidence within them, and promoting their ability to adjust with their disability and to rely on themselves rather than on others.

People with disability should also be urged to ask for their rights so that they can live good life. And they should be the initiative in this regard since this will make their rights more legitimate and more reasonable.

3)Promoting community awareness process is regarded as the most difficult task, since it needs great efforts to change the negative attitude of society towards the people with disability whom are regarded as useless and that they need who work and think for them. This negative attitude had accumulated over several generations. The role of awareness process here should concentrate on effecting major shift in the social stigma. And to accumulate social awareness where the main idea recites that the people with disability have the abilities and the skills that can be developed and supported; and this group should be given the opportunity to prove itself.

## END OF CARE

By Shoji Nakanishi, Japan

### 1 Background

The term "Care" is associated with the treatment in the hospital, home help service provided by the government and custody of a baby by the parent. The care is always given with the protection, order and supervision. With determination to live independently in the community, persons with disabilities first must persuade doctors, PTs, OTs, MSWs, nurses, institution careers and the parent.

There is a hierarchy in the medical field. In everywhere in the world, doctor always dominate the medical field. In a rehabilitation center, a doctor's order is also a voice of a god. No one can be free from it. A client is a bottom of the bottom. In my case, I wanted to go back to my university after finishing the rehabilitation training. But the doctor said I must go to a newly established welfare factory as a first model with upper spinal cord injury neither consulting me, nor involving me in the case conference meeting. The other professionals in the center could not resist his decision.

2 IL movement In the society the most prominent professional is a doctor, and among the doctors a medical doctor can get the highest salary and authority. Many parents, therefore, want their children to become medical doctors. Under this circumstance the same kind of tragedy happened to me in the rehabilitation center occurs repeatedly. To resist to this medical discipline, PWD waked up. Ed Roberts created the concept of IL movement. But the medical doctors, PTs, OTs, MSWs and nurses do not yet accept the concept. If they accept, their social status will be lost. Because of the informed consent approach, some doctor change the attitude toward patients gradually. The concept of the informed consent has the same origine. It also tells about the self-determination and independent living.

3 User-oriented service The service that PWDs can get from careers in the hospital and the home-helper of the municipal government in our country had been very bad because they were trained in the medical model. The medically oriented strategy starts at the top level, and bear various kinds of stresses come out on the way. When it is applied at the grassroot, nurses and the home-helpers who have bigger stress and lesser freedom confront with PWDs. In 1986, the first IL center, the Human Care Association was born in Japan. This is the first user-oriented personal assistant service center in the country. The center has three no-limitation rules in providing services; i.e. any kind of service, at any time, and to users with any handicap. Of course, 51% of the board members are PWDs and at the top of the management is also PWD.

4 Doctors and personal assistants as the supporters of PWDs The personal assistant dispatch service is provided by 95 IL centers in Japan. Personal assistants are employed by PWDs under the contract as employee, so that the relationship between them are equal. With equal partnership, they respect each other. The personal assistants are trained in an IL center, not in the medical institutions. Their attitude toward PWDs is totally different from the current home-helpers provided by the municipal government.

5 Future role of WHO Medical professionals must change their view and respect the user-oriented concept. It is medical doctors who should be changed first. Then the rest will follow. Information technology will change the world where no authority can remain. Even the president of USA no more can keep a secret. Professionals were allowed to have authority,

because they could keep their knowledge and skill within themselves. If they are not allowed, then their power will decrease. WHO must help the professionals share their expertise with us. Doctors are not our lord whom we have to obey, but an equal partner who can assist us live independently.

## **BARRIER-FREE ENVIRONMENT FOR MEN AND WOMEN WITH DISABILITIES (THE EXPERIENCE OF DISABLED PERSON)**

By Sushila Paudel, Nepal

The problems of persons with disabilities (PWD) vary in keeping with the circumstances and the country in which they live. (PWD) are always a disadvantageous group be it in a developed country or underdeveloped.

*However, problems are more severe and life of (PWD) is more complex in a country which is rated as underdeveloped. While conservative and orthodox thinking of the society we live in is there to perpetually discourage us, the facilities and our access to us always remain remote. A Himalayan country like Nepal which inhabits nearly 24.6 million people, her development endeavors against her land-locked geography and the natural calamities claiming tolls on human lives and properties, has been really daunting.*

In that struggle-full life for survival even to the ables, persons with disabilities have numerous problems. The society being still superstitious and conservative, many think that disability is a curse hurled on them by the divinity for sins committed in previous life, its always been a fierce struggle on the part of disables for survival and existence.

**Actions Initiated:**

No efforts have been made to better lives of persons with disabilities. However, such efforts fall short to the need of disabled. Efforts like CBR programs, loan disbursements for micro-credit schemes and awareness as well as skill development training to them have been launched by non-governmental organizations as well Governmental organizations.

But, such programs have not been able to bring benefits in real terms to the targeted groups.

### **Problem & prospects:**

The biggest problem that confronts (PWD) at present in Nepal is the problem of free mobility. While disabled are already disadvantaged in compare to the ables, the numerous barriers obstructing their free movement have further forced them to fall behind.

Until now, whatever efforts have been made is directed towards empowering them with skills and providing them with fragmentary loans to start with small income-generating activities. (PWD) have also been provided with office and managerial training. However, the disabled still remain deprived of the real benefits. In other words, they have not been able to exploit their potentialities for the benefits of their own.

The biggest hindrance has been the barriers, which have defaulted their efforts for a better life and better living. The skills and potentialities notwithstanding, the problem in commuting has posed the greatest problems. In the world they live, nothing is virtually made for us. We have been the most discriminated ones because people have been so pre-occupied with their own problems that hardly any one is there to think about us. The buses are not made for us because we can't board on it. The offices are not made for us because we can't wheel-chair ourselves through as the staircases block our ways. The barriers are always there to defunct our capabilities.

### **Prospects:**

The prospects are not that gloomy, however, massive efforts in sensitization and advocacy is needed. Not that the numbers of disabled in the country is thin, however, awareness about the rights and the state's responsibility towards them is hardly realized by disabled. The (PWD) have been so pre-occupied with their problems of subsistence, and psychologically inferiored by prevailing thoughts and concepts of society, that we can't really move our campaign for barrier-free environment forcefully.

Nevertheless, although feeble, a barrier-free movement has begun in the country.

To carry it into a larger scale aiming to sensitize parliamentarians, legal practitioners, human right activists and journalists, greater efforts backed by adequate resources will be needed.

The need is widely felt, however, aggressive lobbying in favor of barrier-free bill in the parliament is just needed.

Efforts mobilized targeting different section of the community is bound to bring a desired result. The need at the moment is to kick the ball rolling for barrier-free movement.

## **REFOCUSING ON THE CHILD WITH DISABILITY**

By Anita Ghai, India

Family is central to the lives of most people. It is not very uncommon to find the notion of family as indicative of a romantic harmony and as a stable unit. The last few years have seen a considerable change in the family structures in India, Despite media's innumerable attempts to portray a joint structure, society is witnessing the slow but sure disintegration of the collectivity. Caught in this changing life cycle are parents, who attach to their children countless dreams, fantasies, illusions, and projections into the future. Children are their second chance, their decisive "life products." the mirror image and extension of their very being. Few would argue that this job of parenting assumes an altogether a different nuance when it comes to a child with disability. Facing the devastating and continuing loss of having an impaired child is among the most painful experiences that a person can confront. After working with parents of the impaired for many years, I have come to believe the life takes on a different meaning for them after the child is born or acquires a disability after birth. Negative reactions, lack of adequate measures for diagnosis lack of facilities for education and rehabilitation, their sorrow knows no end. It is a situation wholly beyond their control and most are completely unprepared for it. The ordeal begins with the very act of diagnosis. Doctors and allied professionals tend to avoid breaking the news, typically offering a cause for disability after the child's birth, giving the news abruptly or failing to give the parents the true picture of the disability. Presumably this is done to reduce the stress of the situation, although each measure may serve only to increase parental feelings of futility and hopelessness. That their insensitivity knows no bounds is revealed by the trauma, which a mother with a cerebral palsy child had to undergo, when she was told that if she were to stop feeding the child, the child would just wither away.

Parents have variously described the experience as one of powerlessness, helplessness, vulnerability, anger, despair and grief. The experience impacts upon every aspect of their lives. All of them pass through a series of emotional states before accepting the situation. Very broadly these stages reflect a cycle of initial shock, denial, anger/sadness, adaptation and readaptation. How the sequence of these reactions is coped, depends on the kind of interpretation parents attach to the child's disability. If fate or destiny is seen as causing the problem, the chances of parents providing the opportunities of rehabilitation become less. However if the challenge is accepted, then the endeavor is to put their hearts and soul into the child's welfare. Conversely the kind of meaning parents attach to the situation is a result of definitions encountered in interactions with others especially significant others, which includes family and friends. As another mother recalled with horror her experience after her mentally handicapped daughter's birth, when her sister in law told her that it was her shrap/curse, which was instrumental in giving the parents such a child. Obviously such reactions cannot be ignored. They have the effect of parents considering the disability in the language of dysfunction and pathology. Very few people understand the burden that the caregiver carries. The public typically cannot recognize or understand the child's symptoms, so the parent is in a state of continual turmoil in order to minimize public discomfort and manage public contacts. For example parents are more likely to inform others and start up conversations in public. As a child grows up fears and vulnerability's keep on adding on to the parental stress. Disability has other consequences such as economic hardship; it is likely they

will be a single income household, one parent remaining at home to care for the child with the disability, or being restricted to part time employment. As one of parents was told by a counselor that *the way to deal with adversity or pain was to "tough it out."* *If you could avoid showing the pain, then you had been brave and stoic and dealt with the problem competently.* I have come to believe that pain has to be worked through. Consequently the advice should relate to enhancing the quality of life of the child in a practical way. To achieve this it is important for helping professional as well as the broader society to see the issue in context of family realities and the demands of every day life with a child with a disability. Positive outcomes for the child and her family are essentially about accessing appropriate advice, supports, and services from a range of experts in rehabilitation fields. A briefing on developmental and social factors outside the field of medical expertise and an interpretative framework for consideration of the special needs of the child and supports required by her family needs to be provided. The society has to acknowledge that, until there is a coordination of efforts between a range of medical, allied health, and developmental services, families will go on facing recurrent stress and pain.

## **HUMAN RIGHTS & DISABILITY**

By Shahidul Haque, Bangladesh

3rd December is the day for the memorization of UN declaration for the empowerment of the Person with Disabilities. This day was declared in 1981 and today is 1998. Long 17 years we have crossed and in this declaration all the member state of the UN bodies signed to ensure the equal right and opportunities of the person with disabilities.

Lets see how far we have been able to do that. My main mission to write this article is to tell you how silently every day and every moment human rights are being violated by us what is neither desirable nor acceptable being a citizen of the country.

In the constitution of Bangladesh Government in Article No.26, 27 & 28 Section clearly stated that all the citizens have the equal rights and opportunities of the state facility. Here it is also important to remind again that this country has got the independence by a liberation movement. To get this liberty we had to fight against Pakistani Army for long 9 months.

During this period we have lost lots of our colleagues and at the same time a large number of young people became disabled.

To protect the life of the disabled freedom fighters Bangladesh Government took some steps for Rehabilitating them like as Muktijoddah Kallyan Trust, Muktijuddha Rest Centre and also allocated some monitory monthly help for the wounded freedom fighters.

UN Decade declared in 1981 for recognition of the disabled persons, 1983-1992. During this period UN bodies formulated policies and programs world wide to be implemented by the all countries. To ensure the implementation of this program a Standard Rule was also developed for a concrete guideline to judge the development in 1993, 20th December. At the end of the

UN Decade when it has been found a little has been occurred in Asia and in South Asia people were not even known about this Decade. The UN-ESCAP decided to declare another Decade only for the Asian Pacific for the disabled in 1993-2002. Internationally 3rd December has been selected to observe and evaluate the progress of the position of the persons with disabilities.

Main theme of the day and Decade declaration was "Full Participation and Equality" of the persons with disabilities.

The provisions of this declaration call for the respect of the right of all human being with full dignity of human beings with or without disabilities. We must aware all that our society can not enjoy full development without proper consideration of all members. Where there is no provision is acceptable for all people, where individuals are excluded and deprived for their right and dignity - that society never can be developed where there is no room for "Human rights for All".

Purpose of my this writing is to indicate some points on how Human rights are being violated every day and every moment for the disabled people in our country.

Declaration of Human Rights

Article 1:

All human being are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

Example of Violation:

We the persons with disabilities are imprisoned in many ways like culturally, socially, attitudinally, which crush our mental strength. Till it is in my mind that in 1983 I appeared for the Cadre Service after successfully overcome the written test and when I faced Viva Board there simply they ignored me by looking at my crutch meaning that the handicap people are not allowed to be in Cadre jobs. There I did not find any scope even to talk to them just to say that due to my disability the people like them are in the chair or in this position.

Article No: 5

No one shall be subjected to torture or to cruel, inhuman or degrading treatment a punishment.

Example of the violation this article:

Rehana aged 28 wheel chair user. She is now an under severe mental punishment due to her disability. She is not allowed to come out from her house. Though she is living in their own house but she lives on 3rd floor. None is in her family to take proper care of her. She can not enjoy social gathering due to lack of proper care or treatment to her. She has lost her father now her brothers are the Guardians of here. When her father was alive then one caretaker was for her. But it is very unfortunate when she has lost her at the same time her brothers did not allow extra caretaker for her. Even she cloud not see her father's death body only for lacking to take the initiate to here from 2nd floor to ground floor. Where is the right reflects it demands a question mark here.

Article 6: Everyone has the right to recognition everywhere as a person before law.

Example of Violation: All most 90% disabled children are being deprived from getting the opportunity to have their education. Due to of their disability from school authority & family both a silent.

Article No:13

Everyone in entitled to all the rights & freedom set forth in this declaration without distinction of any such as race, color , sex, language, religion etc.

Violation of this Article: If any body simply see around the Bangladesh I do believe every one will notice absence accessibility of wheel Chair user in the city, market, recreation center as there is no accessible environment to move easily. As a result they are prisoners in the house.

Example our public building, Shahid Minar and hospital, Private house, even in the transport

means easy where person with disabilities are being discriminate to get right and freedom to bad the normal life.

Article 16 : 1. Men & Women of full age, without any limitation due to race, nationality, religion have the right to carry and to found a family. They are entitled to equal rights as to marriage, during it and its desolation.

2. Marriage shall entitled into only with face and full consent of the intending spouses.

3. The family is the natural & fundamental group unit of society and is entitled to protection by society & state.

Violation of the mentioned Article :

It is a dream to give the respect on this article as till in our country following the feudalism style in maximum place their spouse has no choice. Parents decide their marital partner. There the mentality of the parent of the person with disability is very shaky as it is hard to say that they are also equal in all respect in different way has not been proved so here this right is not at all being respected by the community. Here what is happening that is sale and purchase of the person with disability by the name of the marriage. Example Teacher of a high school he has two daughter those who are hearing impaired for this reason he has to arrange marriage for her daughter to the servant of his family and whether regarding this article

CONCLUSION: Finally if it is ended drawing the attention of the article no: 29 and 30 what has been stated there that Everybody has duties to the community in which alone the free and full development of his /her personality is possible and In the exercise of his/her rights and freedoms. Also everyone shall be subject only to such limitations as are determined by law solely for the purpose of securing and respect for the rights and freedoms of others and of meeting the just requirements of morality of the democratic society.

If we see it in practically what we will say? Is it maintaining or violating all mentioned subject what should not be? Where in article number 30 it has been clearly stated that Nothing in declaration may be interpreted as implying for any state, group or person any right to engage in any activity or to perform any act aimed at the destruction if any of the rights and freedoms what has been stated in the human right declaration. But it is sad that fortunately or unfortunately it is being violated before everyday before my eyes as we are not concern about person with disabilities Nothing is for us in this society everything is for the privileged group. Person with Disability has only the right to see everything silently They can raise their voice strongly that will be count not implemented You have the right to enjoy everything, which is stated in the paper Just you have to wait for a little and that may sooner and later What you can not ask when it will be. Because you are suffering with person with disability.

## **RETHINKING CARE**

By Helen Meekosha, Sydney, Australia

"Care" sits at the point of intersection between social management of disability and the politics of personal autonomy. Care can be construed as violence against the person - for instance in behavioural management of people with intellectual impairments. Care can also be construed as liberation, where the individual can control their care needs while the costs are socially borne.

In order to "rethink" care, we need to understand its historical roots.

It has been a focus for struggle and social conflict over many years, in the relations of dependence, independence and interdependence. Critical dimensions that underlie the political economy and the personal politics of care include:

- the nature of the welfare state and increasingly the role of the market state in the delivery of social services
- definitions of 'care' beyond the individual to a society of compassion where access to public space, transport and services is included within the concept
- conceptions of difference and the capacity of the state system to validate a plurality of life needs, in relation to people with impairments
- the distribution of wealth and income via state provision on the one hand, and the market on the other
- ideologies of individualism and privatisation, in particular conceptions of the individual and society
- political struggles for autonomy and empowerment by excluded groups of disabled people, and their purchase on wider social value systems
- struggles over gender linked social practices, in particular, the role of women as carers, care-needers, and state and private welfare system personnel
- the patterns of provision and exclusion associated with histories of ethnic and racial conflict and difference
- ideologies of social provision, as in 'mutual obligation' and 'social justice'.

An analysis of care from this perspective suggests that at any moment, the pattern of care-provision represents the balance of forces -economic, ideological and communal.

Such policy directions would focus on moving the balance towards the end of individual autonomy within social relationships of recognised interdependence. In order to do this I propose a model of care that embeds diversity as a crucial dimension of care policy, and empowerment of disabled people as the central mechanism for ensuring the recognition of diversity.

## **THINKING CARE-BY CBR NETWORK**

By Indumathi Rao, India

### Disability Statistics

In India no serious attempts have been made to collect data on disability. Even the latest National Sample Survey made in 1991, has very limited application as it did not cover all disabilities and the definition adopted was not broad enough to furnish a true picture of the Disability Scenario in the country. Some states like Karnataka, Haryana, Gujarat and Madhya Pradesh have attempted to have some information on disability. But these attempts did not yield desired results as they did not have the required logistic supports in the form of well trained personnel, administrative back up for a survey of this kind. Only the survey conducted by the Govt. of Karnataka was more systematic and also more comprehensive. But even this survey ultimately proved useless as there was gross under reporting in respect of certain disabilities like hearing disability, mental retardation, low vision, etc. It is learnt that Census Commissioner appointed by Govt. of India has rejected the proposal to include disability census along with the general census in the year 2001. This attitude reflects lack of commitment to the spirit of the UN Standard Rules and total ignorance about the importance of having basic data of disability.

### Prevention of Disability

In the last 3-4 decades no doubt some initiatives have been taken for prevention of disabilities. The Govt. launched some programs in this direction. The immunization program, supply of Vitamin A, the National program for control of blindness, MDT Program, mother and child health program and ICDS are the examples of such preventive action. But prevention of disability is not in sharp focus under any of these

activities.

They are considered more as health programs rather than measures for prevention of disability. Still we will have to admit that a lot of good has really been under these programs. Now action has to be taken to improve quality of the services. The primary health care consolidated the gains of these programs and also improved quality of services. The primary health care services are still in very bad shape in terms of coverage and quality. The importance of basic health service can hardly be exaggerated in countries like India where even today more than 70% people reside in villages. At this point it is imperative to mention that there is no well defined national policy of prevention of disabilities.

As regards early detection and intervention, so far no systematic and serious attempt has been made though they are equally important. A large number of children with disabilities are not identified at all till they become adults. The consequences of this are quite obvious. Lack of early intervention increases the severity of disability on the one hand and on the other hand the costs of rehabilitation become enormous.

Non-identification of early childhood disability will lead to under reporting of persons with disabilities.

### Equalization of Opportunities

A comprehensive legislation called the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995, was passed by the Indian Parliament and the Act came into force from 7th February, 1996. This legislation has given rise to a lot of hope among the persons with disabilities as it contains provisions assuring equal opportunities in all walks of life, including education and employment.

It guarantees non-discrimination and removal of barriers, both physical and psychological and ensures certain affirmative action for the full inclusion of them. The Act contemplates setting up of Coordination Committees with a view to regulate the activities of Govt. departments dealing with the persons with disabilities so that proper direction could be given and concerted efforts are made for the welfare of this section of the society which has been very badly marginalized.

No legislation could do wonders without a strong political will and administrative support to implement the Act in letter and spirit. In past four years after the passing of this legislation not much has been done. There was inordinate delay in constituting coordination committees and appointment of the commissioners. The Rules that are required to enforce the Act were framed after much delay. The administrative action to provide free primary education to the children with disabilities, which is a mandatory provision of the Act, is tardy and directionless. We notice same kind of apathy of part of govt. administration in respect of employment, transport facilities, removal of physical barriers in public buildings, vocational training, etc. Besides the tardy enforcement the Act itself contains glaring mistakes omissions. Though UN Standard Rules are the spirit behind this Act, many important provisions have been very much diluted for no apparent reason. The rehabilitation services are mostly available only in urban areas and could be accessed by a few. In rural places no services are available and no rehab professionals are found. In India even today NGOs are the providers of rehab services. We see most of the NGOs working in urban setting. What is really surprising is that no strategy to the persons living in remote villages and hilly areas and tribal colonies has been devised. By now, all over the world the importance of CBR strategy is being recognized. But the policy of the Govt. of India as reflected in the Act and also in other Govt. orders we notice conspicuous

absence of rural bias and reference to community based rehab strategy. As a result the govt. of India appears to be in the dark in so far as the question of reaching the unreached is concerned. With pain and dismay one must recognize the fact that even the NGO members of the National Coordination Committee have failed to influence the policies of the government in this regard. The reasons for this are anybody's guess.

### EDUCATION

It is heartening to note that the Persons with Disabilities Act, in section 26, provides for free and compulsory education of all children with disabilities up to the age of 18 years in appropriate environment.

The term appropriate environment could mean Inclusive Education in respect of the majority of the disabled children and institutional support of Special Schools only in the case of severely disabled. The U N Standard Rules very specifically stipulates that Inclusive Education through main stream schools should provide education and there should not be any discrimination between the disabled and non-disabled children. The regular school system alone should cater to the educational needs of all children, including the children with special education needs. This basic spirit has been callously overlooked in the Act. This amounts to total neglect of the Children with special needs and also perpetuating age old, but now discarded concept of special education. Further it could be seen that as per this provision of law the authorities of the education department are not responsible for the education of the children with disabilities. In other words, mainstream schools are not accessible to these children. The children with special needs continue to depend on special schools and those in villages will be deprived of education for many more years to come. Needless to state that the Salamanca Declaration, for which India was also a signatory has been very conveniently overlooked.

Education is so vital for human development that its importance can hardly be exaggerated. Now education has been recognized as a fundamental right and it has been asserted by the provision under section 26 of the Act. But the same provision has been violated by the authority of the State. It is true that under the constitution of India have to take initiative and provide education to all including the children with special needs. The international authorities like WHO may have to take this matter with government of India. Otherwise the disabled children, particularly those in villages will be deprived of their right to education.

### EMPLOYMENT

The situation in regard to employment is no different from that of education. Quota measure or the reservation policy is being implemented in haphazard manner, there are no reviews and accountability. The jobs that could be managed by the people with different kinds of disabilities are not identified and timely action is not taken to notify them. The prevailing attitude of apathy and insensitivity continue unabated as most of the bureaucrats and politicians have colossal ignorance about the potentialities of the disabled people and they fail to appreciate their needs. The status of the woman with disabilities is much worse.

### NATIONAL COORDINATION COMMITTEES ON DISABILITY

By now all state governments and the government of India have set up Coordination committees. However, they have failed to make any remarkable impact on policies of the respective governments. It may be argued that four year period is not really long enough to assess the efficacy of the coordination committees. But it is equally true that a majority of

these committees do not meet regularly and deliberate in a very casual manner. The fact that the Government of India constituted a committee to propose amendments to the Act without consulting the Central Coordination Committee goes to show that the committee has failed to assert its existence. Perhaps this statement holds good in respect of state coordination committees also. If this trend continues in the future also the persons with disability will be disillusioned very soon and this new experiment of combining bureaucracy and non-officials in one fold will become a flop show. In order to avoid such a consequence the NGO members should rise to the occasion and exhibit their real commitment to the cause of disability.

### PROSPECTS IN TWENTY FIRST CENTURY

Despite a number of international conventions on disability and policy declarations and the Asian and Pacific Decade of Disabled Persons, the situation remains the same. This may sound very pessimistic and govt. may dispute this statement. Even today hardly 3-4 percent of disabled get rehabilitation services. The vast majority living in rural areas are denied of all services. We hardly notice any policy change to cover rural people. The Community Based Rehabilitation strategy still takes a back seat. Even some NGOs running special schools in posh urban areas feel that their very existence might become irrelevant if community based strategy is accepted. Such wrong notions are partly due to ignorance and partly because of vested interests.

A sound national policy on disability to reach the hitherto unreached disabled people in villages and a firm commitment for INCLUSION will cause a sea change in bleak situation. Community Based Rehabilitation is the only option available for developing countries which has wide coverage and at same time cost effective. Any delay in adopting this strategy would be a very costly mistake. All governments, NGOs, advocacy groups, people with disabilities should realize this and act decisively.

The Agenda papers as presented now contain a large number of platitudes and pious hopes as reported by government sources. But the hard realities are otherwise and bitter to taste. The international conference of this scale and magnitude should not cover up the facts by wishful thinking.

## **CHILDREN WITH DISABILITIES: THE IMPORTANCE OF AN INCLUSIVE CRC APPROACH**

By Els Heijnen. Save the Children, Sweden /Bangladesh

Children with disabilities and how to address their rights and needs, is no priority in society. Still, the World Health Organisation (WHO) estimates that at least one child in ten is born with, or acquires, a serious impairment which, if no due attention is given, could impede the development of the child.

As no reliable national surveys have been carried out in Bangladesh it is difficult to ascertain the precise magnitude of the disability problem. Estimates range from 1.06 % (Bangladesh Bureau of Statistics, 1995) to as high as 14.4 % (ActionAid Bangladesh).

Bangladesh was one of the first countries to ratify the Convention of the Rights of the Child (CRC). CRC covers survival, protection, development and participation rights for all children, irrespective (dis)ability, gender, race, religion or socio-economic background. Many organisations in Bangladesh claim to be working from a CRC perspective, but children with disabilities seem to remain invisible in most of these programmes. Other organisations treat children with disabilities as a 'special' group and plan segregated programmes. 'Special' children are mostly cared for by organisations from a social welfare or a charity perspective. This is not the same as promoting the rights of the child or providing equal opportunities. Even though charity and social welfare may be based on genuine compassion, it is often

limited to kindness, and results in treating children as passive objects. This is particularly true for children with disabilities. In general, children in Bangladesh have little opportunity to have a voice in matters that affect their lives, and the situation for children with disabilities is even worse.

All communities are diverse and consist of different individuals. However, when disability comes up, people tend to view this as 'less able', or 'not able' and 'a social burden' instead of differently able. Children with disabilities are hidden in order to avoid embarrassment. Deprivation often starts at family level and children learn to be submissive, to withdraw from education, recreation and other forms of basic prerequisites for a holistic development. Such negative social attitudes also increase the dangers of (sexual) abuse and exploitation, especially of girl children with disabilities.

Children with disabilities are often considered a separate group because of their 'special' needs. This segregates them from other children in the family, community, and society at large. Approaches are being developed for them, forgetting that they are part of society having the same survival, protection, development and participation rights as other children. The right to education, development, participation, and recreation all fit for 'normal' children. Attention for children with disabilities only seems to emerge when reflecting on CRC Article 23. Training kits, manuals, promotion materials on CRC focus on the rights issue as a general approach which uplifts the rights of all children, but does not make an attempt to include children with disabilities.

Including children with disabilities in educational or other programmes does not automatically address their needs. The needs of children with disabilities however are not "special" - they are the needs of all children for food, shelter, protection, love, stimulation and education. To label children and put them in 'special' categories - children with disabilities, street children, working children - often distracts attention from the ways in which attitudes, policies and institutions exclude or marginalize such groups. All children should be viewed as unique human beings with different learning needs and learning speeds. Furthermore, the right to equality of opportunity, laid down in the UN Declaration of Human Rights, does not mean that everybody must be treated in the same way. In education, equal educational treatment is often the wrong answer. In a classroom, children are not homogenous and should not be treated as if they were. Indeed, the principle of justice requires that they be treated unequally to be able to respond to children's individual needs.

When talking about "Education For All" (EFA) people tend to think and plan for 'normal' children only and do not think about an inclusive approach, which would give equal opportunities to children with and without disabilities. The Compulsory Primary Education Act (Bangladesh 1993) does not even include children with disabilities. Many of the 'problems', which exclude children with disabilities from education, are the result of exclusive planning! Children, who ironically have the greatest need of education, are thus the least likely to receive it. The question may have to be asked whether there is special education, or maybe just EDUCATION, because good teaching, which implies addressing individual needs, is not different for children with or without disabilities - good teaching is good teaching for all children!

Most children with disabilities need individualised education rather than a different kind of education. Schools and classrooms may need to change into more flexible, resourceful and humane systems that not only benefit children with disabilities, but all children. Attitudes and

perceptions of teachers may be more critical than special teaching skills. It may be time to get rid of the prevalent way of thinking that all children must achieve the same things at the same time in the same way.

All children are equal and must be accepted and valued for what they are and what they can contribute. For some children sign language will be their first language, for others mobility will be by wheelchair. Being unable to see or communicate verbally are differences, not failures! Children with disabilities are children first and foremost and while they may require individual learning programmes or different forms of therapy, they also need plenty of opportunities to play, make choices and interact with other people, including peers without disabilities.

Attitudes and perceptions regarding children with disabilities, negative language use and incorrect generalisations need to change. A child with cerebral palsy or with a hearing impairment may be very bright intellectually. A child with an intellectual impairment may have exceptional creative skills. The disability is only one part of the individual characteristics of a child, and that is why they should not be labelled 'the disabled' or the 'mentally retarded'. A person is not a disability, a person may have a disability. A child may have different characteristics such as black hair, a soft voice, brown eyes, and Down syndrome.

An inclusive, child rights approach implies refraining from judgments and generalisations. Individuals and child-rights organisations may be decisive in enabling or disabling a child's optimal development by including or excluding him/her from human development programmes. Initiating a change in attitude and perception in society must start within organisations that work for and with children from a rights perspective. In order to be sure that all children get equal rights, all activities that involve or affect children must be reviewed from a disability perspective. People and organisations must constantly ask the question whether children with disabilities are given the same opportunities and rights as their peers without disabilities

## **SOME THOUGHTS ON CURRENT TRENDS IN REHABILITATION POLICY**

By B. I. Koray, Ghana

The traditional approach to rehabilitation regarded persons with disabilities as objects of sympathy and compassion.

Such persons were considered entitled to care and rehabilitation for religious or moral reasons.

Disability issues were also regarded as welfare matters, which should be accorded separate, special or different treatment.

This type of thinking informed charity projects and the promotion of special institutions such as special schools and workshops.

Another aspect of this traditional approach was that it focused mainly on individual, medical, rehabilitation, that is, to improve the physical or mental condition of the individual in order to enable the individual to take advantage of the opportunities that are available in society.

However, this approach ignored the obstacles that hinder the integration of people with disabilities into society. These include lack of access to mainstream activities, services, information and documentation.

The assumption was that people with disabilities regardless of rehabilitation would never be able to achieve full integration into society.

It became clear that this traditional approach did not fundamentally change the overall situation of people with disabilities.

The situation of people with disabilities began to engage the attention of the international community from the 1970s onwards. The General Assembly of the United Nations adopted the declaration on the Rights of Intellectually Disabled People in 1971, and the declaration on the Rights of Disabled People in 1975.

1981 was observed as the International Year of Disabled Persons under the theme of "Full Participation and Equality".

The most important outcome of the International Year of Disabled Persons was the World Programme of Action concerning Disabled Persons which was adopted by the General Assembly of the United Nations in 1982. Its purpose was to promote effective measures for prevention of disability, rehabilitation and the realization of the goals of full participation of people with disabilities in social life and development, and of equality.

The World Programme of Action formed the basis for the United Nations Decade of Disabled Persons, which spanned the period 1983-1992.

At a meeting of Experts to review the implementation of the World Programme of Action in 1987, a process aimed at developing a guiding philosophy based on the recognition of the rights of people with disabilities was initiated. This process culminated in the adoption by the United Nations General Assembly of the Standard Rules on the equalization of opportunities for persons with disabilities in 1993. The purpose of the Standard Rules which were developed on the bases of the experienced gained during the decade of disabled persons, is to ensure that people with disabilities are citizens of their societies enjoy the same rights and obligations as others.

Another notable international development was the adoption of the Salamanca statement and framework for action on special needs education by the World Conference on special needs education, access and equality at Salamanca, Spain in 1994. The statement which proclaims the fundamental right of every child to education provides that children with special education needs must have access to regular schools which should accommodate them within a child-centered pedagogy capable of meeting these needs.

These international developments indicate a fundamental shift from the traditional charity-based notion of disability issues to a human rights based notion that has occurred over the last two decades. This notion regards disability issues as human rights issues, which are multi-disciplinary and inter-sectorial in character. It emphasis the equalization of opportunities in order to enable persons with disabilities to participate fully in society.

This new thinking is essential for the independence and empowerment of persons with disabilities and their effective participation in their societies. This approach has also been reflected in legislation and policies concerning disability in many countries. It has given rise to Community Based Rehabilitation, which has been developed as part of a global strategy for supporting cost-effective, education and training for persons with disabilities. It is a specific approach within community development aimed at rehabilitation, equalization of opportunities and social integration of all people with disabilities, it should be implemented through the combined efforts of people with disabilities themselves, their families and communities and the appropriate health, education, vocational and welfare services.