

PARTICIPATION

By:

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**By Mr. J.B. Munro
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People with disabilities and their advocate agencies have been encouraging the United Nations General Assembly to adopt a convention on the rights of people with disabilities.

The latest development is that the ad hoc committee, set up at the general assembly of the UN earlier this year, following the resolution from Mexico, will report back to the Secretary General and the General Assembly at the next session prior to Christmas.

I wish to read and underline the statement made at the press conference following the ad hoc committee on rights and dignity of persons with disabilities at the conclusion of the committee's deliberations.

"The world needed to change its current attitudes as well as the environment and economic realities experienced by persons with disabilities, Luis Gallegos Chiriboga (Ecuador) said at a UN Headquarters press conference this afternoon (09/08/02). Mr Gallegos is Chairman of the Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities.

Briefing correspondents on the work of that Committee, which concluded its work today, he said the search for an integrated society, with a sense of community – based on the principle of universal human rights was a fundamental aspiration of humankind. With more than 600 million people with disabilities at birth or during their lives representing 10 per cent of the global population, the world would have to face up to the challenge of this demographic reality.

The experts consider that 30 to 40 per cent of the households of the world have members with disabilities. As the planet ages, the number of people with disabilities increases.' He said. The advancement of the rights of people with disabilities required effective means and

tools to address the inequality and discrimination against them. For that to happen, societies need to change, he added

Mr Gallegos said that integrating disability concerns into a holistic international convention on the rights of persons with disabilities would call for a new approach that would include not only traditional human rights concerns, but also new realism of concerns in human rights and development in a rapidly changing world. Those concerns, ranging from technological and genetics to war and conflict, epidemics and poverty in a globalized world, were generating new and emerging issues on the global agenda.

Asked by a correspondent what comparisons there were between disabled persons in developed and developing countries, Mr Gallegos said disabilities were similar or equal in all countries, the difference being largely one of resources. There was also a cultural element as well as an educational issue of how to deal with people with disabilities.

“What we’re looking for is to integrate disabilities into a worldwide covenant that would protect those rights, but that would also give them opportunities, with new technologies, of integrating into society,” he said. ”

It is the responsibility of policy advisers, policy makers, legislators and influential citizens as well as the numerous civil servants who can exercise so much power in having decisions implemented or lost, that they hear and understand the message from Mr. Gallegos. This goes also for the private sector and civil society along with influential citizens of every country across the globe. The world media needs to be stimulated and prompted into awareness and action. Go positive - forget the negative.

The world bank is beginning to realize the enormity of the challenge. This week’s initiative of the Asian Development Bank is a progressive step and i hope that in addition to this department the whole of ADB will be aware of what is needed. No matter what aspect of

business is being undertaken or encouraged, disability concerns along with aging need to be part of all employment policies and greater encouragement given to support local initiatives.

The combined leadership of world authorities such as the United Nations and its agencies, the World Bank, the Asian Development Bank, foundations and other influencers for good, can surely have placed on the agendas of influential political and governing forums and assemblies, the need to recognise the impact disability has on work, family, community and nations.

Societies across the world continue to regard people who are different by virtue of colour, race, gender, old age, physical and mental or intellectual disability as somehow less than whole - less worthy, less deserving of respect, less capable, and for many - in constant need of protection and paternalistic policies and programmes, to manage their daily lives.

How ridiculous, how stupid, how ignorant can some people be? Just ask a person with disability what they would prefer. Each person born is a unique individual and we should do unto another as we would have done to ourself. We should never agree to policy and principle interpretations or laws which prevents the human spirit from flourishing and yet for far too long there has been the imposition of restriction and curtailment on individuals with disability to blossom and grow as their own person because we see the disability first, rather than the person. The attitudes of prejudice and outrageous ignorance has been a real barrier to individuals with disability getting a chance to reach for their potential so that they can contribute like everyone else.

These barriers must be replaced with respect for the individual regardless of the circumstances and acceptance by each of us to the value to all humankind of individual self determination.

Self determination is no different for a person with disability and a person without any apparent disability. The directors of large corporations, the cabinet ministers, the staff of an

unlisted company, doctors, lawyers, professors – it matters not - for each of us disabled or not - we value our right to self determination.

The principles of self determination should be the same for everyone - the freedom to decide where and with whom we live and to be heard and respected in every aspect of one's life. Disability support should not just be available to those who can afford to pay or are able to barter.

Individual self determination requires changes in cultural assumptions about the nature and meaning of disability, old age, and all those categories or labelling which modern society has been so adept at using to demean or infer a less worthy being.

For people with disabilities to be empowered to participate equally in their communities and economies, there needs to be some significant shifts in policy by such global enterprises as the Asian Development Bank, the world bank, the private corporations, central and local governments. All need to begin encouraging at a faster rate, the need for families and communities to be more supportive of each other and develop locally agreed community values.

We need a mechanism of sharing examples of good practice. The media emphasises bad news with any good stories hardly considered. What an indictment on us all.

Examples of good practice where people with disability are included and not excluded and shared with other communities will encourage better attitudes. Resources for this to happen need to be identified.

We need to encourage new education curricula to incorporate improved attitudes and understandings by pupils towards colleagues they perceive as different.

Every encouragement should be given to the media and other forums for wholesome discussions and creative thinking on how to address perceived differences. A better informed populace would overcome bigotry.

Governments conducting nationwide census should include the identification of households where there is some-one with a disability and then have a follow up regime of implementation so that no one with unmet needs is lost to the system.

Greater resourcing of communicative devices, sign languages etc for those who have lost or may never have the ability to express or articulate their preferences, desires, likes and dislikes. Others too could well benefit from hearing from people never before heard!

Let me draw on two recent experiences i have been involved with over the past year which i feel is an example in a very small way and with very limited resources how changes for the better can happen and individuals given a sense of worth and well being.

One relates to the empowerment of parents and the other identifying people with disability through a programme of community surveys.

Inclusion international, the global NGO of national societies whose members support and advocate for children and adults with intellectual disabilities recently began an initiative called PMAG - parent mobilization action groups.

Inclusion international formerly known as the international league for societies of or for persons with a mental handicap was formed by parents of agencies mainly in the western world who from their experience realized that if you did not rock the boat, lobby and push hard for improvements for educational and work opportunities for their sons and daughters with disability, little or nothing would happen from officialdom.

By forming the league the founders set about to try and influence the un system and encourage the formation of local societies of parents in many countries.

Since World War 2 the number of NGO's has increased hugely and in many instances, they are a real burr under the saddle of officialdom. The partnership between governments and especially the un system with NGOs still needs significant improvement.

For parents of children with severe and profound disability there is strength in linking with a fellow parent and combining to advocate for improvements for their youngsters. What

PMAG recognises is that born of frustration, lack of resource and often impoverished in their goals and organizational skills parents need encouragement, knowledge of what is possible, and friendship. Parents of children with disability seek training and ideas of how best to advocate and influence policy makers and local community leaders on behalf of their child with disability. They also seek to understand better the disability, its causes and how the family can cope better.

Inclusion international's PMAG initiative brings together member societies from developed & developing countries in order to encourage the involvement of more parents to build an effective, efficient and responsive organization. On the one hand the developed country gains from sharing and the developing country parents receive advice and support for them to make things happen.

An interesting and innovative aspect of PMAG is that retired executives from international companies are becoming involved as volunteers with PMAG by giving willingly of their time and experience to help the PMAG programme with backing from their previous employer.

The PMAG objectives are;

To encourage parents of children with intellectual disability to become more involved in their national society at the local level to help strengthen organization effectiveness

To empower parents and volunteers through organizational capacity building to advocate for improved education, health, employment and living arrangements for persons with disability, especially those with an intellectual disability.

To increase public awareness, visibility and community understanding of persons with an intellectual disability

To seek sponsors and funding to assist the development and strengthening of the national organization at all levels

To encourage the adoption and application of the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities, the UN ESCAP Decade of Disabled Persons Agenda for Action 1993 – 2002 and the Fundamental Principles of Inclusion International.

To promote support for disabled people in the activities of governments, the UN system, donors and other stakeholders.

Currently PMAG is functioning in Romania, Kenya, India and Indonesia. In Indonesia, where I am involved, close to 1000 parents, teachers and supporters have attended a series of empowerment training sessions across the country, funded mostly from New Zealand government and NGO sources. Properly managed locally I can see great potential with this encouraging programme. We saw parents develop local solutions such as reaching out to other families and taking their children shopping for the first time and as a result breaking down the barriers of prejudice.

Such Local Solutions Must Be Encouraged By Those In Power.

The other example is from the Pacific Island Nations. In April last year key leaders in the disability field from several Pacific Island Nations met in Fiji to strategise how best to respond to the perceived unmet needs of hundreds of Pacific Islanders with disability. This was a cross-disability exercise. A survey had, the previous year, been undertaken by the Department of Education in Samoa with funding assistance from UNDP and consultancy help from a New Zealand colleague of mine. The survey was aimed to identify all children in Samoa under the age of 15 who had a disability. In all 1200 children were identified with a number of school age who, it was discovered, had never been to school, primarily because of their disability. Many are now regular attendees at their local inclusive school.

Using that survey as a model the Fiji meeting last year asked Inclusion International to coordinate surveys across the Pacific and seek out funding for the project. With funding from the NZ government agency for international development (NZAID) surveys are now underway

in several pacific countries. Local 'surveyors' are identified and trained, a survey management team formed, a data base established and the standard survey form adjusted to meet local conditions and language.

In Samoa for instance, the prime minister put his weight behind the survey plan and involved his department of statistics who are not only inputting the data but were able to also list the households which, in the recent census had stated there was a person with disability in their home.

That survey is close to completion and individual unmet needs are being identified and strategies put in place to positively respond with as much local solutions as possible. It is amazing what can be done locally when the need is identified and the community spirit goes to work. Families, agencies and individuals are feeling good about the process. It is recognised that while some of the unmet needs can be positively responded to locally, there is still much more to be done but cannot, because of the lack of resources. For instance a 12 year old disabled youngster was found – he had never been to school – he could not walk and while a wheelchair was made available for him it was not until the local school came up with the plan for the senior sports team to be rostered to carry junior and his wheelchair to and from school each day.

Poverty is a major problem, affecting many individuals with disability and their family. If you are not able to earn because of your disability you become more dependant. This applies across the world whether in developing or so called developed countries.

The world we live in is a world of abundance. Unequally shared. There is enough food, talents and resources for everyone to live an adequate, safe and enjoyable life. The issue is how the abundance is distributed and accessed and how the extremists of the world in politics, religion and vendettas can come to their senses. Our globe is here to be shared by all. Each nations wealth needs to be better apportioned and each nation must ask "and who is my neighbour"

People with disability suffer the humiliation of dependency and real poverty. They are restricted from determining life for themselves. Self-determination is a god given right which no circumstance of wealth or adversity should be able to erase.

There must be for all people an adequacy of resource to live at a sustainable level. Each country must determine the level for itself. Nations must find ways of sharing better amongst us. The economic influencers such as the Asian Development Bank and kindred souls must broaden their development strategies to encourage individual self-determination, family strengthening and local community development. Each country must be encouraged to address: inequalities of humanity, income adequacy for each person and have appropriate economic policies which encourage inclusion and not exclusion of all of its citizens.

At the individual level we must find more effective ways to strength family life, address the inequalities of society and urge a greater acceptance of those with disability who are people first and warrant our respect as unique individuals who like the rest of us are part of the rich tapestry of life.