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Nassibi Pourazar: Honorary Vice-President of Iranian Society of Disabled Persons (ISDP), Invisible hand leads handicapped

Introduction

The 'invisible hand' is a term for the unseen process of coordination, which ensures consistency of individual plans in a decentralized market economy. Adam Smith (1723–1790) introduced the phrase, and stressed the role that the invisible hand played in attaining a harmony of interests. Smith argued that an individual "who intends only his own gain" is "led by an invisible hand to promote an end which was no part of his intention". The end referred to here is the interest of society. The modern view is that, while the hand undoubtedly operates, it is arthritic. A major limitation of invisible-hand doctrine is that it only works well under conditions of perfect competition, and it is unrealistic to assume such conditions exist in the real world.

Perfect competition is descriptive of a market structure or an industry that is characterized by a large number of buyers and sellers, all engaged in the purchase and sale of homogeneous commodities. It involves all the participants having perfect knowledge of market prices and quantities, with no discrimination in buying or selling, and with perfect mobility of resources. Perfect competition is often used synonymously with pure competition, although there is a technical distinction: pure competition does not require perfect knowledge or perfect resource mobility, and hence does not produce as smooth or rapid an adjustment to equilibrium as perfect competition.

Paradox in economics principles

It is uncertain whether the economics rhetoric principle could combine the conditions of the hypothesis, as stated, to solve the real world's social and economical problems. The hypothesis has two aspects. First, the economist's technical sense and criticisms; second, the handicapped peoples' continuing debate over the merits of the economics mechanism. But even if 19th century conditions could be replicated in the present day, one can only

presume that this would be a temporary victory at best. Soon the historical ball would start rolling once again and, starting from a renewed *laissez-faire* environment, similar social pressures would emerge to push society back onto the road it has already travelled. There are a number of basic reasons (aside from the 'technical' sources of market failure listed in the textbooks) why these social pressures emerge.

(1) Even if everyone were to agree that a competitive market system would provide the best economic environment for society as a whole, no individual, business firm or labour union has a private incentive to uphold market principles in their own sector of the economy. A business firm would prefer to be a monopolist in its particular product or products; union or professional association members would prefer a 'closed shop', and so on. Hence, participants in a market economy are trying to escape from the condition of the marketplace in their own field, and a large part of actual economic history is the record of that struggle. Paradoxically, therefore, state intervention (in the sense of competition policy) may be required simply to enable the market system itself to survive.

(2) A market system is a competitive system not only in the economist's technical sense but also (and more importantly) in the everyday sense of this term. There will be winners and losers, and this is necessary if the system is to provide the incentives, which are its lifeblood.

Those who have lost in the marketplace, however, have no incentive to keep to the rules of the game and have every incentive to attempt to reverse the market's verdict through the economic process. To take just one example, it may be agreed that free trade will maximize welfare for a nation as a whole and for the world as a whole. For participants in an industry, which will lose out to foreign competition, however, it will still be in their interests to resist free trade and advocate protectionism through the economical process. The country as a whole may be worse off and the world as a whole may be worse off, but the industry participants will be better off. Economic theory will not persuade them to the contrary unless some mechanism can be found in which the gains of the winners can somehow be redistributed to compensate the losers.

This is a general principle. In other areas beside trade, there will always be some kind of social contract (and presumably therefore a role for the state) that income should be redistributed such that those who do not do well out of the market process are more or less content to accept its verdict. This is not even a question of altruism or social justice. If the minimally necessary adjustments are not made, those who have lost will simply have an incentive to overthrow the system by political means (if they are not a minority in society). Even if individuals do well out of a market mechanism in terms of income, its results may not be acceptable on other grounds — moral, aesthetic or religious. The current revival of interest in environmental issues is an obvious example of this. Even on the simplest level, it may be true that market forces dictate that the countryside around big cities be swallowed up by ugly urban and suburban sprawl, but no amount of economical theory can force anyone to like it. It is sometimes argued that individuals will not, in a free market, demand as much of certain commodities as 'society' or the 'community' deems that they should consume. Thus, a distinction between the individual's own demand for the product and his or her need is drawn.

The 'need' concept may be justified in terms of the good being a 'merit good', the consumption of which is intrinsically desirable. An alternative argument, and one that is increasingly used, is that need refers to a demand by some individuals for goods to be provided for the consumption of others. Thus, a person's 'need' for state medical care may be said to be determining by the demand, which the rest of the community exercises on his or her behalf. This demand by others arises on his or her behalf. This demand by others arises from altruism. It is clear that it could not be enough for various and emerging society needs. Hence, the most general interpretation is a state in which the government plays a positive role in the promotion of *social welfare*. All activities of government can thus be counted as part of the welfare state in that it is likely to be claimed that they promote social welfare. The term is more specifically used to refer to the provision of education, health care and housing at zero or subsidized prices; the personal social services provided for the old, the handicapped and the children in care, and the cash transfers to particular groups, such as the sick and the unemployed.

For all these reasons, it is unlikely that the free market rhetoric will represent the last word in the continuing debate over the merits of the market mechanism, although they have certainly changed the parameters of that debate from where they stood during the initial years.

Now it is necessary that disabled persons be shown in the context of a historical challenge. First, by the end of the 1940s because of the low level of health and treatment, a normal illness or accident ended in death. Persons with disability seldom lived. Minimum care and services were provided in the traditional family and community context; disabled persons with simple jobs had their own semi-normal lives.

However, after the establishment of WHO in 1948 and the start of the improvement of global health in certain zones, disabled persons were able to live longer. Hence, the population of disabled people increased.

At the beginning of the 1980s a series of international reports stated that 10% of the world's population was disabled. Poverty and malnutrition, war and conflict, ignorance and superstition characterized huge areas of the globe; the numbers were continuing to rise. In view of the economical principle, it was expected that by developing the region the economical problems would be solved for all, as the opportunities of full participation and equality for all people increase. But it did not happen. Also, the opportunities for some people, particularly people with disabilities, decreased day by day. Why? Do economic principles have a real gap? Do economical principles lack elasticity? Are the regions, in terms of action, not doing well?

It is much better to revise the pure competition rules that have already been mentioned. There were large numbers of buyers and sellers engaged in the purchase and sale of homogeneous commodities and having perfect/pure knowledge of market prices and quantities. There was no discrimination in buying or selling, and perfect mobility. There were voluntary exchanges between producers, consumers, workers and owners of the factors of production.

Freedom of choice in consumption — it is so clear that none of these conditions has a real compatibility with a disabled person's situation. For example, the disabled are not great in number and, hence, they are not able to impress the market economy. Engaging in the purchase and sale of commodities or perfect mobility requires non-disabled persons. The consumption of disabled people depends on the type and level of their disability: hence, homogeneous commodities do not cover all their needs. Finally, having perfect/pure knowledge of market prices and quantities requires perfect mobility and well-organized communication, but these are not accessible in developing countries. Moreover, there is a scarcity of resources, and competition in daily life is a challenge. There is no longer an opportunity for the family to provide services for disabled members, particularly in rural areas. Also, it should be remembered that in developing countries the public sector could not play an essential role in a disabled person's life. Generally, it is limited to physiotherapy and rehabilitation. The family provides some primary services (food and clothes, primary medical welfare equipment, primary education, etc.).

Our field study shows that more than 90% of uneducated disabled persons have a scarcity of family revenue (transport, costly expenses, non-accessible pedestrian systems, etc.). Parents pay 96% of the costs for educated disabled persons while the disabled themselves pay 3%. The government supports only 1% of the cost.

Although, income equality is not good in the whole country, the disabled case is worse. For 80% of the population only 30% of the income is available. Although there is considerable inequality in general, for disabled persons the inequality is greater — 80% of disabled people have only 12% of the income (Table 1).

Table 1. Measure of the inequality of income distribution

% Total income	0	20	40	60	80	100
Non-disabled share	0	7	14	21	30	73
Disabled share	0	15	3	3	3	30

Source: Pourazar FN et al. Field study "Socio/economic condition of young persons with disability, Iran". Tehran, in preparation, 2001.

A similar situation has been extended from developed countries to developing countries but with some differences. Hence, in Rehabilitation International's manifesto *Charter for the Third Millennium*, the emphasis is on the subject:

“In developed and developing countries, in the North and South of the world, segregation and marginalisation have placed disabled people on the lowest rung of the social and economic ladder”.

According to our study this situation results from various reasons: First, at the same level of income, persons with disability spend about 30–40% more than non-disabled persons (on inevitable expenses of rehabilitation aid articles, transportation, housing, etc.). Second, in spite of the law to allocate 3% of government jobs to people with disabilities and other criteria, employers prefer to employ non-disabled individuals. The employed disabled are often given a job at a position one or two levels below his or her real ability, especially at graduate level. Hence, their incomes decrease.

Replacing the preferences of needs often solves the paradox of more expenses and less income. Table 2 shows the problem in the lives of disabled persons. Their expenditure is compared with that of non-disabled persons.

Table 2. Comparison of the shares of the total average gross expenditure of disabled persons with average annual rural household gross expenditure, on non-food commodities and services (1999–2000)

Expenditure category	10th decile: Non-disabled	Total average: Disabled
Clothing and footwear	27	26
Housing, water, fuel and power	15	25
Furniture, furnishings, equipment and operation	14	14
Medical care and health services	12	9
Transport and communications	18	23
Education, recreation, entertainment and cultural services	4	1
Miscellaneous personal goods and services	10	2
Total	100	100

To close, I would like to give a definition on economy:

“Economics is a science concerned with those aspects of social behaviour, and those institutions, which are involved in the use of scarce resources to produce and distribute goods and services in the satisfaction of human wants”.

However, it should be remembered that we are so far from what we want that we aim only for our needs. After about half a millennium the disability experience is not sweet. I believe our life involves an inevitable struggle with no chance for a cease-fire or peace. Our existence depends on our cooperative in NGOs. These bodies should have access to decision-makers at the highest level to achieve equalization of opportunities, full participation and sharing. Also, we should believe that economics is not organized for losers. The various groups of people with disabilities in Iran, Asia or anywhere are never considered as sinful, rejected, or deprived of divine gifts. They are the victims of conditions resulting from a significant departure from a long-held perception of people with disability.

Abdul Salim Usman: The needs and challenges of disabled people, Ghana

Over the years, and specifically during the last two decades, the WHO has been working continuously to give the necessary support and rehabilitation to disabled people, but this does not seem to be enough to meet all the needs and challenges of people with physical impairments. There are still some needs and challenges that disabled people face which must be addressed holistically.

It is against this background that I deem it necessary to bring to the attention of this conference some of the needs and challenges faced by disabled people in my society, and how I foresee the future of these people in terms of health care, rehabilitation and support services. In this presentation, I would like to tackle these needs and challenges from social, political, academic and healthcare perspectives. I will limit myself to the confines of my community, which is the Office of Community in the Ashanti region of Ghana.

To begin, disabled people are socially rejected. Many times, and during social gatherings in particular, a disabled person is declared *persona non grata* because most people are of the opinion that an impairment is a result of numerous sins against the supernatural. Because of this, people think they are cursed and, hence, the ensuing social rejection. Disabled people are shunned because people fear they may become disabled themselves if they associate with them. The result is loneliness on the part of the disabled in society. How long should or must the people in society carry this misconception?

Politically, disabled people have no chance and even where there are opportunities they are very limited. There was one case where a disabled individual was a candidate for the position of an assemblyman in our area but he lost the election to a non-disabled opponent. The reason people gave for his defeat was that he was physically disabled, so could not lead them. This has discouraged other disabled people with political aspirations.

In families, parents usually tend to favour children who are not disabled rather those who are disabled. This creates a major psychological problem for the disabled child.

Academically, it is only a few disabled individuals who are able to make it to the top owing to various obstacles in their way.

In terms of health, disabled people are not given the necessary assistance for rehabilitation, as the cost involved is considered too great for society to bear. There are NGOs that have set up rehabilitation and training centres for disabled people. One organization in my community is the Office of Rehabilitation and Training Centre for disabled people, run by Mr S.T. Barirnah Antwi. However, due to financial constraints the Centre is not running as well as it should.

Yet in spite of these challenges, the WHO has proposed the *Rethinking Care Initiative* to help promote and enhance the lives of the disabled people. Its aim is to achieve the full social inclusion of disabled people in their own communities, based on equal opportunities and human rights.

But is the future of this programme bright? For me, *rethinking care* will yield positive results by virtue of its focus on health care, social services for rehabilitation, support services for disabled people with the view to creating possibilities for independence, participation and empowerment in different settings in the community and institutions. When this is achieved disabled persons could live very well and fulfil their goals in life without too much difficulty.

Anika Rahman Lipy: Associate Coordinator, Centre for Disability and Development, Bangladesh

I was born in 1966 with spina bifida. Unfortunately, the doctors in our country could not diagnose my problem at that time. When it was detected, I was 1 year and 3 months old. Surgeons from a medical college diagnosed my condition and advised my parents to remove the lump immediately. By that time I already had irreversible damage to my legs. The local hospital did not agree to do the surgery because of the risk. My father had to take me to Karachi for the said operation. I was operated on but they could not recover the damage that had already been caused. The surgeon declared that I would not be able to walk like other children. But my parents were hopeful. They sent me to Denmark with the help of the TDH in 1972 when I was 6 years old. I stayed there for nine months and returned home with below-knee callipers and two elbow crutches.

As days went by I grew and the callipers and crutches became too small for me. My parents looked for a replacement but could not find any organization or person who could make these. When I was 12 years old I developed severe back pain from the deformities, which were beginning to develop, and also a bladder and chest infection. We could find medicines for the infections but could not find any physiotherapist or occupational therapist who could help to prevent most of these secondary problems.

Through my working experience I found that in Bangladesh there is no qualified occupational therapist and only three qualified physiotherapists. The only orthopaedic hospital provides prosthetics, which in most cases are unusable because of the pain and discomfort, and most people stop using them.

After the final diagnosis most parents find themselves in a very difficult situation, as they do not know where to go for help, or who provides which service. In most cases the available services (which are very few anyway) are expensive. On the other hand, most parents want to 'cure' their disabled children rather than helping them to develop. For example, most parents will spend money on treatment but not for the education of the child or for an assistive device, which could make the child able to participate in the community.

In most cases of cerebral palsy and intellectual disability, children receive the wrong treatment from the medical practitioners. The medicines given can make the condition worse than expected. In Bangladesh mortality rates among disabled children are much higher because the 'care' needed to survive is simply not present. Families do not know how to care for these children, there is no one to teach them these skills in the community, and no centre providing the care.

The People's Republic of Bangladesh was born on 25 March 1971. Its population is estimated at about 124 million. The percentage of disabled in the population is unknown (one estimate is 5–10%) Before 1980 very few NGOs were working with or for disabled persons and those who were working were mostly service delivery organizations.

GO has special schools for children with hearing, speech and visual disabilities in seven divisional headquarters. There are 64 integrated schools for blind children, 38 of which have residential facilities (10 seats). There is one vocational training centre and sheltered workshop for persons with physical disability, and one specialized hospital for orthopaedic problems.

In general, disabled people were outside the ongoing development activities of the NGOs and GO. It is estimated that the existing organizations can provide care to 10 000 disabled people a year.

There are 27 000 NGOs working for community development, the components of which are:

- education (adult literacy/NFPE)
- health/MCH (prevention/nutrition)
- family planning
- environment (arsenic/forestation)
- agriculture (fisheries/poultry/homestead gardening)
- women's empowerment/child and human rights

In 1991 a National Forum of Organizations Working with the Disabled (NFOWD) was formed with 22 members. By the year 2000 the membership had increased to 113.

The Government has formed the National Disability Foundation and National Coordination Committee. It also enacted the

Disability Welfare Act 2001 on 4 April 2001. A National Day for the Disabled Person has been declared as the first Wednesday in April.

The Centre for Disability and Development (CDD) emerged in 1996 with the mission of ensuring equal opportunity and full participation of disabled persons by providing human resource development services to development organizations with strategic guidelines for systematic inclusion of disabled persons in mainstream development activities. The CDD provides the following training courses:

- Disability Awareness for Managers (DAM)
- Community Development Workers for rehabilitation services (CDW)
- Social Communication (SC)

To date:

- 111 Community Development Organizations (CDOs) have received training from the CDD
- 152 have received DAM training
- 214 have received CDW training
- 147 have received SC training
- It is estimated that around 900 disabled children have been integrated into school
- It is estimated that around 6000 disabled persons have received primary rehabilitation therapy
- It is estimated that around 4500 disabled persons have been integrated into development activities

This information has been provided from only 54 responding CDOs.

Alice B. Nganwa: Ministry of Health, Needs and challenges of users and service providers, Uganda

Introduction

This paper is based on experience in Uganda, a landlocked country in East Africa that straddles the equator.

Uganda like most of sub-Saharan Africa has its share of peace, war, a vibrant mixture of cultures and a mixed economy with the very rich and the very poor. Eighty-nine per cent of the population is rural and 46% live below the poverty line.

History of care

Since time immemorial, the care of older persons and persons with disabilities has been the responsibility of the family and community. Since older persons were rare, the precious care of older persons was approached from their needs. The approach to the care of persons with disabilities often depended on the disability. Some disabilities were respectable enough while others carried a high stigma and therefore less care was given.

With the advent of conventional medicine, a shift in thinking occurred. I will not dwell on the reasons, but the community shifted the responsibility of care to the state. The state and charity organizations institutionalized care and provided professionals and modern places in which to provide care.

The care provided by the state was a drop in the ocean of the total needs and this resulted in a greater burden to the family as the community directed the family to the state for care. In addition, the care provided by the state and other organizations could only reach very few people and it was culturally very foreign. The state also provided care on the terms of the service provider and not from the perspective of persons with disabilities (PWDs) or older persons.

Perspective of users

Two studies and a workshop (1–3) were conducted with the purpose of enquiring into the various health needs of disabled

people. PWDs and parents of PWDs were among the researchers and facilitators respectively. The key issues that arose are listed below.

Negative attitude

The negative attitude of health workers is the biggest factor that affects access and quality of services.

The PWD is thought to be a beggar. The PWDs or the parents do not know ... it is the health worker who knows. The health workers talk over the head of the PDW as if he/she is part of the furniture. The health workers mock the women with disabilities (WWDs) for becoming pregnant.

In larger hospitals, a child or adult with disabilities is sometimes referred automatically to a special clinic for various chronic conditions even if he has come in with another simpler ailment such as cough or malaria.

The attitude of traditional health care providers was reported to be different. They accept, listen to and respect the PWD. As a result many WWDs opt to deliver in the home of a traditional birth attendant (TBA) even if the hospital is near.

Lack of information

This was the second most common problem. Health workers do not provide information or advice. If advice is given it is inappropriate. The more educated PWDs and parents of PWDs often find out later that the health worker actually does not know what to do about their condition.

Physical inaccessibility to facilities

Health institutions are often far away, have steps, and dirty latrines, etc. A WWD said, "*at the TBA's you deliver your baby on a mattress on the floor but in the hospital you need to rely on somebody else to lift you up*".

Communication

Difficulties in communication are not limited to the deaf. The intimidating atmosphere and impatience of health workers make communication difficult.

Lack of rehabilitation facilities and assistive devices

Surprisingly, this issue did not feature as an important concern of users of the services. However, when it was mentioned, the main concern was that assistive devices are expensive. Some PWDs complained that they were not given a choice or adequate information as to which assistive device to use.

Perspective of service providers

Inadequate training

From the two studies, front-line health workers (nurses and clinical officers) confessed that they did not know how to care for PWDs. Some confessed to fearing them. This was traced back to basic training where there was no exposure to PWDs. Rotation through neurological and orthopaedic departments or special clinics for chronic diseases is brief and disease/treatment oriented. The needs of the organ/impairment are addressed but not the needs of a person.

Ignorance of needs of PWDs

Health workers were very sympathetic on learning of the suffering they cause PWDs and parents. The health workers would like a feedback mechanism to inform them of the needs and feelings of their clients. However, they wished this could be done outside the hospital or through suggestion boxes. PWDs, on the other hand, found it difficult to provide feedback to health workers because they feared victimization and being misunderstood. Instead, the PWDs responded by with drawing.

Long lines of patients, not enough time

Health workers are not able to provide proper care because of the heavy demand on their time. This is worse in public facilities. In a

private clinic, the pressure is less and the stakes high — therefore, the health worker's response is more accommodative to the needs of PWDs.

Few rehabilitation workers

Training schools for rehabilitation workers are small and do not attract students. As a result there are very few rehabilitation health workers.

Narrow rehabilitation

The rehabilitation profession is narrow, with little (or no) opportunity for professional advancement. Very few rehabilitation professionals have positions of authority in government institutions, yet the government is the main employer of rehabilitation staff. For example, a nurse may open a drug shop in the country and be successful, but a private physiotherapy unit in a small town or rural area will collapse.

Disability and chronic illness are not emergencies

This results in low prioritization of these services, low funding and inadequate care. As long as governments only look at the quality of life and not quality resources, the services for disability will continue to be low.

Recommendations

Both users and providers recommended modifying the basic training of health workers to include a comprehensive approach to rehabilitation. The PWDs and parents strongly recommended that they should be among the teachers of health workers' institutions, "*Otherwise how do they know about us?*"

Health workers also recommended more exposure to PWDs during basic and in-service training. They recommended both a clinical setting and a non-clinical setting, e.g. homes, schools, and seminars, for this exposure.

Both groups, users and providers, made amorphous recommendation for prioritizing disability issues.

Both groups recommended extensive awareness-raising, as often as possible to be done by PWDs.

PWDs recommended that they should be involved in managing health units and health services as a whole.

PWDs and parents requested rehabilitation services that are closer to the community.

Parents recommended special homes or units where severely disabled children can be looked after for three months or during the day to give the carer time to recover — but the PWDs were strongly against this.

Conclusions

Care can be rethought. It can be re-oriented and approached from actual and not perceived needs. This requires the service provider to surrender control. It also means the user must take on more responsibility.

I believe the current situation can be improved with increased dialogue. For this to happen, the users of the services must leave their shell and establish a dialogue. It is surprising how the 'monster-providers' are willing to listen and learn.

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Pen Mony: National Coordinating Body for Disability and Rehabilitation, Cambodia

The following text is derived from notes taken by one of the Conference Rapporteurs: Colin Barnes. The Chart is reproduced from an overhead projection used by Mr Mony during his presentation.

Cambodia is one of the poorest nations in the world. Disabled people in Cambodia experience several problems.

Economic problems

The disabled need food to eat. They need vocational training, grants, loans, and credit.

Physical problems

They need mobility, physical rehabilitation and assistive devices.

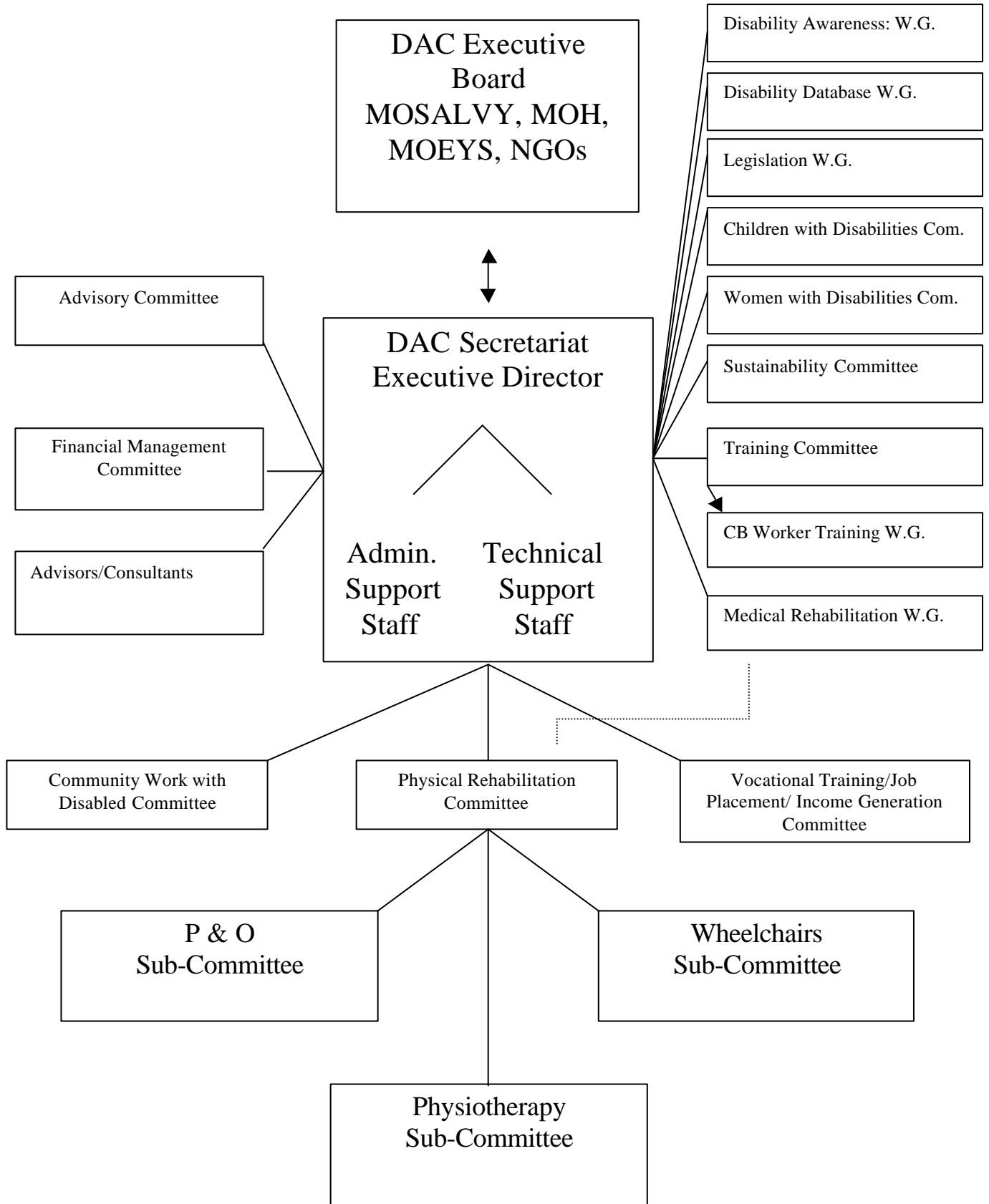
Emotional problems

They need counselling in the community. They need encouragement and emotional support. They need mainstreaming, i.e., awareness-raising.

Social problems

Many disabled people are illiterate through no fault of their own. Many become beggars. They encounter discrimination and environmental barriers. Disabled people need advocacy.

Organization chart of the DAC as national coordinating body for disability and rehabilitation



Vic Finkelstein: Visiting Senior Research Fellow, Centre for Disability Studies, University of Leeds, United Kingdom, Rethinking care in a society providing equal opportunities for all

Three years ago I was asked to prepare a paper for the WHO on *rethinking care*. The background to this was the acceptance that:

“whilst in principle provision of community care has become an internationally accepted goal, problems in implementation have persistently undermined realisation of this aim”.

In writing this paper I tried to encourage deeper thought about problems in providing ‘care’. The paper was prepared for delegates to consider before attending a conference where they could share *new* ideas and make *new* suggestions for future developments. Three years on, and days before this conference became a reality, I still did not know whether my paper was actually seen by those attending the meeting. For me, this is yet another example of the chronic failure to seriously rethink care. How can anyone face up to the continuing problem in providing ‘care’ in the community when so little time is spent on questioning *all* the basic assumptions that people make about what is, after all, a *failed* approach to services?

This conference is about *rethinking* ‘care’. To me ‘rethinking’ means the conference is not about the same long-standing issues: begging for more state intervention with more money for more carers with abilities, more occupational therapists with abilities, more social workers with abilities, more nurses with abilities, more administrators with abilities, or more training for people with abilities. In other words, it is not even about more money for people with abilities to ‘care’ for us while precious little of this ‘*more money and training*’ actually comes into disabled people’s hands. Surely, we have heard enough about the need for more rehabilitation services, or more community-based rehabilitation when the original idea failed to solve *all* our problems so many years ago? As I see it *rethinking care* means starting again, but this time seeing problems faced by disabled people in the community through the eyes of disabled people themselves. There should be no assumptions handed down by people with abilities about what disabled people *need* to do. If we are going to *rethink care* then we must remember that *all* the established professions

and services that are active today were invented *by* people with abilities *for* disabled people.

I *am not* suggesting that because the existing services were set up by people with abilities they must have got it all wrong! I *am* saying that people with abilities confuse two quite separate issues concerning disabled people's needs — the social provision of 'care' services and the social provision of 'support' systems. We must stop confusing these two different approaches to the services. After all, *everyone*, not just disabled people need access to 'care' services *and* 'support' systems from time to time. When it concerns themselves, people with abilities are quite clear about the difference between these two ways of obtaining assistance in society.

Children and people who are ill need a range of 'care' interventions provided by workers in the medical, para-medical and social services. Before disabled people reach adulthood or when the disabled or older people are ill they also need good quality 'care' services. Nobody has ever suggested a social approach to disability issues (providing services according to the social model of disability) means that the disabled do not also want good quality medical services — just like everyone else.

As I understand it, the aim of good medical and para-medical 'care' is to restore the patient or client into their communities fit and as well as possible. In this sense *all* medical and associated practices should be rehabilitative. In my opinion the invention of 'rehabilitation' by service providers with abilities in response to the 'care' needs of disabled people is a serious mistake. I see it as a symptom of a global fault in the practice and provision of medicine, and the way in which people with abilities have created 'health' services. I believe 'rehabilitation' should be discussed and understood within the universal 'care' structures of society. Keeping the concept of 'rehabilitation' within medical services, where it belongs, means that the experiences learnt from working with disabled people could teach people with abilities how good medical practice should be run. It is no accident that 'community-based rehabilitation' (CBR — not to be confused with 'industrial rehabilitation centres') is not found in the major industrial economies, but has been exported from them to the majority world

by people with abilities. Is this because CBR is not good enough for the developed world but acceptable for the developing world?

In my view, discussion about 'medical care' and 'rehabilitation support services' should *only* be raised in conferences about the general, or universal, medical (or health) services used by all people. They are not specifically disability issues. As I see it, discussing these two subjects in isolation of the general problems faced by the national medical and para-medical services means that disabled people will not have the opportunity to help people with abilities overcome the problems of the present national health and medical services. As long as the national medical services remain confused no one, not just disabled people, will receive the 'care' they may need from time to time. As long as the national medical services remain confused, disabled people will find it difficult to concentrate discussions on community support systems that we do need and that are absent. Healthy living requires appropriate good quality support services in the community. People with abilities understand this very well for themselves.

People with abilities have created far greater community support systems and spent proportionately more money on these systems than they have spent on disabled people. They do not view these provisions as part of social 'care'. Let us take mobility aids (or 'assistive devices' as they are sometimes called) as an example. Buses and trains are 'assistive devices', and roads and railways are special pathways for these mobility aids. They are not provided as part of a community 'care' service but are part of the support system that people with abilities have created for themselves. They are equivalents of wheelchairs and ramps. It may be that people need wheelchairs from time to time when they are ill or after an accident, but such an 'assistive device' is very different to the wheelchair which is used by a disabled person. In fact, such a mobility aid should not be called a wheelchair at all because it is not a 'chair on wheels' but much more like a shoe used by an ambulant person. Shoes, it should be remembered, are nothing more than pieces of the floor or carpet, which are attached to the feet. Let us face it, the human foot is a rather pathetic mobility device! But shoes used by people with abilities are not provided by the rehabilitation services. It is the confused 'care' *culture* promoted by people with abilities that prevents the understanding of the two very different types of wheelchair. Perhaps we need a

new word for a disabled person's wheelchair. This is bound to develop as disability culture really advances.

The emergence of a disability culture is not only changing the way disabled people are thinking about themselves (and personal artefacts like wheelchairs) but also creating *enormous* significance for *rethinking care*. Despite the importance of disability culture in *rethinking care* it is not even on the agenda in this conference! We are still thinking about the changing lifestyles of disabled people as though this was covered by the narrower concept of 'awareness-raising'. This is because the culture of 'care' prevents people from rethinking the whole social approach to disability — we seem to be embedded in the problems handed down to us by the concepts of 'disability' and disability-related services created by people with abilities. Yesterday, we were obliged to discuss the "*current status, identifying constraints in the following areas: medical care, rehabilitation support services and awareness-raising*" without any formal opportunity to discuss the real constraint on *rethinking care* — that is, the culture of 'care'.

I hope that in the time still available to us here we are able to discuss the kind of 'support services' that are appropriate for disabled people. I see such a service approach developing within, what I will call, an 'aspirational culture'; i.e. services that are essentially concerned with supporting disabled people to realize their personal aspirations. This is a 'recipient requested' service, i.e. the service user requests assistance to meet his or her *own* aspirations and goals. It contrasts with the 'care' services which are 'deliverer determined', i.e. the service provider assesses the needs of the disabled person and then decides which services can be provided.

In my view, the real challenge in *rethinking care* is for service users, providers and policy-makers to identify appropriate skills found in the training and qualifications of the existing caring professions. These skills can then be joined together with the unknown and neglected skills needed for a new community-based 'recipient requested' support profession and service. Successful integration into the community as a respected citizen demands access to support systems, which can assist in achieving *unpredictable* aspirations. 'Unpredictability' in deciding the important factors for one's own lifestyle can be regarded as an

essential component of being human. This is a right and necessitates a different approach to identifying an individual's objectives from that of the needs assessment procedures prescribed in the culture of care. Being a citizen is an active exercise in identifying and realizing one's own comprehensive ambitions.

From my viewpoint a new community-based professional should:

- have a good working knowledge of environmental and architectural design as well as some engineering concerns;
- be familiar with ergonomics;
- be able to work with and teach people how to identify their aspirations;
- be able to communicate home management skills including personal goal setting and how to achieve service rights;
- be able to argue and campaign for general citizenship rights;
- be able to participate forcefully in committees concerned with social support systems such as transportation;
- be able to fund and run facilities providing disability-related services such as wheelchair provision and servicing, etc.

In other words, we should discuss the elements that might be needed to create a new profession, which is designed by disabled people and replaces the existing 'care' professions.

More than 20 years ago in the United Kingdom we tried to find ways of working with the existing 'care' professions so that they would be more aware of, and responsive to, the kind of services we wanted. We were not successful. All that seemed to be wanted from us was collaboration so that the 'care' culture could be more credible in the community. I think we have long passed this stage and I can see little point in disabled people assisting these ailing 'care' professions. Disabled people have set up Centres for Integrated, or Independent, Living (CILs). People who I believe will become the basis for a new community-based support profession are staffing these centres. I believe *rethinking care* should mean paying greater attention to what is needed for an effective support system. This has been the focus in my paper for the conference.

Dr Dena Hassouneh-Phillips: Assistant Professor, Oregon Health Sciences University, United States of America

I am honoured to be here and to have the opportunity to introduce a nursing perspective into this discussion of *rethinking care*. I would like to begin by returning to the issue of attitudes, which was so powerfully described to us at the beginning of the conference.

Part of my faculty role at Oregon Health Sciences University is the instruction of Nurse Practitioner (NP) students. Last week in a clinical seminar for NP students that was focused on the subject of end of life decision-making, a faculty colleague presented the story of one of her former patients as a teaching case. This was the story of a man with progressively worsening multiple sclerosis (MS) who was clear that, should he experience a life-threatening event, he wanted all possible measures taken to preserve his life. Unfortunately, his health care providers viewed this man's wishes as misguided and unwise. Eventually he was coerced into changing his stance by his physician who threatened to abandon him — in effect to fire him as a patient, if he would not agree to the placement of a 'do not resuscitate' order in his medical record. This story is alarming, but the absence of any critical response on the part of my students was perhaps even more alarming to me. My students were however graduate students, all of whom were registered nurses with many years of clinical practice behind them. There seemed to be an accepted assumption among the student group that this man with progressively worsening MS must have such a poor quality of life that, should a life-threatening event occur, efforts to sustain his life would not be worthwhile, and instead would be counterproductive.

Such attitudes stem from views that persons with disabilities are tragic and dependent individuals whose lives are somehow less valuable than the lives of non-disabled persons. Unfortunately, these attitudes are commonplace among health care providers and are accepted as truth rather than as perception. All too often it is these attitudes that shape our practice.

We can see the influence of negative attitudes in all areas of health care delivery. I would like to focus today on two areas, which exemplify this problem.

The first area is preventative health care. We have heard here today some concern that there is too much emphasis placed on preventative health care at the expense of other important areas such as long-term care. I believe that the bulk of efforts in preventative health care have been targeted at non-disabled persons, and that persons with disabilities, as a whole, have not received the preventative health care they need. In the words of well-known disability research, "to talk about wellness in the context of disability is to break the stranglehold the medical model has had on disability interventions for far too long." Too often, the attention of health care providers is focused entirely on a person's disability and, as a result, consideration and discussion of preventative health care and health maintenance activities never occur. By changing our attitudes, nurses can begin to view persons with disabilities as whole people who are survivors of disabling conditions rather than as victims. We can work toward ensuring that persons with disabilities have access to the same standard of preventative health care that exists for all persons in our local areas. This standard of care varies across countries and regions, and may range from annual health maintenance exams that include screening for cervical, breast, prostate and colon cancer, and the prevention of heart disease, to a focus on sanitation, adequate nutrition and immunizations. Irrespective of the standard of care, nursing must advocate a change in attitudes, a change that will facilitate equal access to preventative health care for persons with disabilities wherever they may live.

The second area is reproductive health care where the harsh effects of stereotyping and discrimination can also be seen. There is an unfortunate stereotype that women with disabilities are asexual, or conversely, overly sexual. We have also heard here at this conference about common views among health care providers that women with disabilities should not become mothers. These stereotyped attitudes have been carried over into the medical and nursing school curricula, leaving health care providers ill-equipped to counsel women with disabilities when they make decisions about contraception, pregnancy, prevention of osteoporosis, and hormone replacement therapy. Education of health care providers in the area of reproductive health care must include appropriate and accurate information about women with disabilities. We must recognize that women with disabilities have the same need for reproductive health care as all other women. This recognition must

first emerge, and then additional considerations of potential influences of disability on reproductive choices can follow. Thus, standard women's health care measures such as universal screening for violence and abuse, pelvic and breast examinations, discussion of birth control options, and sexually transmitted disease could be consistently provided to women with disabilities wherever these services are available.

Preventative and reproductive health care represents only the tip of the iceberg when considering the profound influence that systematic marginalization of persons with disabilities in society has had on health care delivery and the quality of health care services received by persons with disabilities. We all know that the detrimental effects of discrimination go much further. Certainly, the man in the story that I shared with you earlier knows this to be true. Thus, given the pervasive nature of stereotyping of and discrimination against persons with disabilities, the question arises: What can be done to facilitate change?

I believe that education of health care providers will be a key factor in addressing the problem. This education should include awareness-raising among nurses that focuses on assumptions and stereotypes about persons with disabilities. It should also include developing and implementing basic and continuing education curricula in partnership with persons with disabilities. Finally, it should include recruitment of persons with disabilities into the ranks of nursing and other health care professions. Persons with disabilities are the true experts with regard to the care that they need and we in nursing can only benefit from this expert knowledge. These measures should result in highly relevant content, the experience of working with persons with disabilities as colleagues, and a view that genuinely supports self-directed care.

It is my hope that this conference will serve as a wake-up call for my colleagues in nursing, a call that will engender critical reflection, soul searching, and the will to change. It is time for nursing to renew its commitment to social justice and to work in partnership with all marginalized populations to ensure that health care services are accessible and equitable. These services should be delivered in ways that preserve the human dignity of all users in all health care settings. Thank you very much for your attention.

Mary O'Hagan: World Network of Users and Survivors of Psychiatry, New Zealand

I was asked to speak today on the experience of 'care' from the perspective of people with psychiatric disabilities. I have decided not to do this because it is covered in my paper, which you will find on page 28 of *Rethinking Care from Different Perspectives*.^a

I am here today to represent the World Network of Users and Survivors of Psychiatry. I have experience of using psychiatric services and for the last 15 years I have worked in various advocacy and advisory roles in my own country, New Zealand, and at the international level.

The experience of people with psychiatric disabilities in 'care' mirrors the experience of other disabled people. We share most issues in common. However, people with psychiatric disabilities experience:

- more stigma, discrimination and social exclusion than most other disability groups;
- more state-imposed forced treatment and detention than other disability groups.

Before I begin I would like to share the sense of discomfort that I feel at this conference and at all global conferences where people from low-income and high-income countries share experiences and ideas. I suspect that historians of the future will say that the most terrible inequality of our current historical era was the enormous gap in wealth between low-income and high-income countries, though I fully acknowledge the terrible inequalities that occur within countries.

I have a limited grasp of global economics but it seems to me that people in high-income countries, including many disabled people, obtain their relative wealth through maintenance of the poverty of people in low-income countries, including disabled people in these countries. We cannot really resolve this issue today and we should not let the enormity of it immobilize us, but I think it is crucial that those of us from high-income countries openly and honestly acknowledge it.

^a See: WHO. *Rethinking Care from Different Perspectives*, Geneva, World Health Organization, 2001. Also available on <http://www.leeds.ac.uk/disability-studies/archiveuk/index.html>

Today, we have been asked to think about solutions — about ‘care’ in the New World. A man called Ibsen from Norway once said, “The person who is right, is the person who is in league with the future”.

When it concerns the future of ‘care’ I have no doubts that disabled people are far more in league with the future than service providers, bureaucrats, politicians and the general public. Now I want to share with you a simple illustration of the future of care according to disabled people.

We, disabled people, say that the purpose of ‘care’ is to enable us to live as well as we ourselves define it, and not as others define it.

If we think of the *rethinking care* logo as the seat of a stool where disabled people can sit and live well, the seat cannot hang in space — it has to be supported by legs and firm, stable ground.

However, please note the well-disguised comfortable cushion with the rethinking care logo.

The first leg of the stool represents powerful disabled persons, whether they are powerful as individuals or as a part of the disability movement.

The second leg of the stool represents communities that include us.

The third leg of the stool is where ‘care’, according to the first four Standard Rules, happens — in services led by disabled people.

If you shorten or weaken any of these three legs you will take away the ability of disabled people to live well on their own terms. That is why services must focus not just on their own leg, but the other two legs as well. This illustration clearly shows how we need to ‘rethink’ and ‘redo’ care:

RETHINKING CARE

Disabled Persons

Living Well

Powerful Disabled Persons

Disabled-led Services

Inclusive Communities

Human Rights

- 1) Disabled people must lead services. They need not always deliver the services but they must be planned, evaluated and improved by the disabled as individuals and as a collective. All disabled people who use services must be able to say “this service enabled me to live better”.
- 2) Services, as part of the new paradigm of care, must actively enable disabled people to find and use their power, both as individuals and as a movement. Otherwise, the services will not enable the disabled to live better.
- 3) Services, as part of the new paradigm of care, must open doors and not shut out the disabled from their communities, as in the past and present.
- 4) The new paradigm of care must stand firmly on the fertile ground of human rights, not as they have in the past on the stony ground of charity, coercion and containment.

When those who provide ‘care’ meet these four conditions, disabled people will be able to sit safely and securely on the stool of ‘living well’.

There are many people at this conference who are ‘in league’ with the future of ‘care’. We have a rare opportunity to give our vision for the future of ‘care’ to the WHO. I am concerned that, so far, we are not seizing this opportunity as well as we could.

Let us, in the time left, give the WHO a vision of the future of care that is simple, clear, bold and based firmly on our experiences as disabled people.

The following papers were submitted for presentation on Tuesday 24 April but were not presented due to the extra time allocated to the *Rethinking Care* workshops

Professor Alan J. Sinclair: Diabetes Research Unit Centre for Health Services Studies, University of Warwick, United Kingdom; International Diabetes Federation, A summary statement

Introduction and background

At the International Diabetes Federation (IDF) we recognize that diabetes mellitus may impose a significant burden on individuals with respect to disability and handicap, and that this burden often extends to family members and carers. The extent of diabetes-related disabilities in most societies has not been quantified although we know that for older subjects above 70 years of age, about one-third of people with diabetes have a significant mobility disorder or restriction of daily activities. We appreciate that in many societies, the provision of suitable care for people with disabilities may be minimal and inaccessible, irrespective of the cause, and the IDF welcomes this opportunity to participate in a conference designed specifically to take account of the disabled person's perspective.

I have summarized the scale of the problem into a series of bullet-point items, which includes special features of disability in diabetes, recent initiatives in this area, and concludes with a description of how the IDF can promote an improvement in care.

Scale of the problem

- High prevalence of Type 2 diabetes mellitus associated with a marked age-related increase in prevalence
- Rising prevalence of Type 1 diabetes mellitus
- Significant burden of unrecognized disability and handicap
- No rehabilitation available for those with diabetes in nursing (care) homes

- High socio-economic impact of this chronic disease on the individual, family, and society
- Special features of disability in patients with diabetes mellitus
- Preponderance of major vascular complications leading to pain, immobility, foot ulceration and amputation
- The impact of micro-vascular complications — visual loss and blindness, renal failure and neuropathy
- Special disabling states such as cognitive impairment and dementia
- Major behavioural and socio-economic impact of the diagnosis of diabetes — social function, employment, lifestyle modification, insurance, etc.
- Major requirement for carer involvement in the management of diabetes-related disabilities
- No current framework for the management of diabetes-related disabilities in European and other national health services; lack of recognition of the importance of disability in diabetes mellitus; overemphasis on the management of micro- and macro-vascular complications

Current initiatives in the approach to disability and handicap in diabetes mellitus:

- Evidence of progress in the area of managing disability — management of diabetic foot disease with significantly improved outcomes
- Greater cooperation between ophthalmologists and diabetologists in the management of visual loss secondary to diabetic eye disease
- The development of the Frailty in Diabetes model (Sinclair AJ, 2000) which encompasses disability and places a greater emphasis on functional status and maintenance of well-being, and recognition that interventions based on both the vascular

and rehabilitation models complement the metabolic approach to restructuring diabetes care

- Encouragement of empowerment approaches and self-management for people with diabetes, especially in younger patients

Needs and challenges of the IDF in relation to rethinking care:

- Recognition of the impact of diabetes in creating disabling states
- Development of rehabilitation programmes for patients with diabetes mellitus that are user-focused and allow people to receive services and care that they desire and need
- Promotion of educational and training programmes to assist both patients and carers in minimizing disability
- Greater need for interdisciplinary collaboration to promote rehabilitation in diabetes mellitus to enhance the quality of care provided
- Greater emphasis on diabetes in ageing individuals in relation to multiple pathology, frailty, and the presence of high levels of disability and associated handicap
- Greater emphasis on community-based programmes and approaches to care for those with disabilities with improved access to services and greater accountability for those who deliver this care

We accept that rehabilitative approaches to managing diabetes-related disabilities are not well developed at present although diabetes care is fundamentally a multidisciplinary model of care.

The Culture of Care clearly needs to adapt and change appropriately. The IDF wishes to work closely with the WHO in this extremely important area and hopes to be able to raise many of the issues discussed at the Global Conference at its meetings and by dissemination of information to its members. This is a responsibility we accept in line with the UN Standard Rules that were discussed at the conference.

Franca Smarrelli: Chairperson, World Stroke Association, Australia, Global needs and challenges for stroke

Stroke is ranked sixth as a cause of healthy years of life lost in *The Global Burden of Disease* study (1). The study also estimates that stroke will be ranked fourth by the year 2020. Globally, stroke caused 5.5 million deaths in 1999. Moreover, there were one million severely disabled stroke survivors, and about 50 million disability-adjusted life years lost due to stroke (2).

Despite the magnitude of this international burden, stroke remains an area of slow development and low investment. It urgently needs a greater focus at the international level, as well as having separate approaches to the problem in developing countries and developed countries.

Stroke in developed countries

Stroke organizations in many developed countries share the same issues with regard to research and evaluation, health policy, acute care services, rehabilitation and community care provision. Research shows that there are now interventions that can reduce, in some cases quite dramatically, mortality and morbidity from stroke.

Continued development of these initiatives, and their application, are needed in many countries.

Addressing each phase along the continuum of care and ensuring seamless linkages between these phases is vital in the provision of stroke care. These phases are:

- 1) Prevention: stroke is a preventable disease. It is caused by several modifiable risk factors including hypertension, smoking, and physical inactivity. Preventing these risk factors through population and targeted approaches will greatly reduce the burden of stroke.
- 2) Acute care: involves education of the public and health care professionals on the warning signs and symptoms of stroke and the need for immediate action if these occur. The organization of stroke care in this phase is also a very important

consideration. The use of stroke units and stroke teams has been shown to reduce delays for evaluation, provide specialist care, improve continuity of care, and improved patient outcomes. The use of best practice guidelines is also a very important component in this stage.

- 3) Rehabilitation: evidence suggests that an early start to rehabilitation has definite advantages. Having a multidisciplinary rehabilitation team is also very important.
- 4) Community care: well-developed and coordinated community services are crucial for the person with disability following stroke.

Stroke in developing countries

The Global Burden of Disease study (1) reveals that developing countries account for two-thirds of stroke deaths, and projections to the year 2020 suggest an accelerating epidemic. There is, however, very little evidence available on the prevention, incidence, management and outcomes of stroke in developing countries. Anecdotal evidence suggests that stroke awareness in these developing countries is poor. A physician from Africa reported recently:

“Stroke is unfortunately a very common problem in our country as a complication of hypertension. The reason is mainly the cost of treatment which is a little bit expensive for the great majority of patients; but also because in African culture in general, chronic disease is not easily accepted. Traditional healers we call ‘Guerisseurs’ used to say that if the disease is not controlled within two or three weeks, probably it’s because a taboo has not been respected, and the patient will have to do some sacrifices. Unfortunately, it is in that situation that stroke occurs, because a correct treatment of hypertension is not implemented.”

The needs for stroke in developing countries are enormous. Along with the lack of data on stroke, we know that the life expectancy of developing populations is increasing, resulting in a dramatic increase in the incidence of stroke, and the prevalence of other noncommunicable diseases such as cardiovascular disease and diabetes. These increases are compounded by the fact that these

populations are also faced with lifestyle changes propelled by urbanization, industrialization, and globalization. Poor nutrition is reflected in increasing blood pressures, body mass index, and cholesterol and diabetes levels.

Tobacco consumption is increasing, as transnational trade becomes a focus for tobacco companies. Risk factors of stroke are increasing more than ever before.

The WHO, together with the National Stroke Foundation of Australia, sponsored the *Asia Pacific Consensus Forum of Stroke Management* in October 1997. The conference saw the development of the *Melbourne Declaration (3)*, which included a consensus statement on stroke in developing countries. The goals were:

- 1) To increase awareness of stroke among health planners and government in developing countries.
- 2) To establish priorities in terms of resource allocation for stroke services. These should include stroke prevention as the most important priority, in particular detection and management of hypertension, prevention of smoking, and other lifestyle issues such as diet.
- 3) To develop effective training programmes for professional caregivers.
- 4) To develop effective public awareness and education programmes for stroke prevention, rehabilitation and treatment.
- 5) To collect accurate data on stroke.
- 6) To develop ways of transferring rehabilitation knowledge and skills to family members and other community workers as endorsed by the WHO 'Community Disability Services' initiative.

The way forward

Owing to the enormity of the problem of stroke worldwide, there is a need to establish high quality programmes in acute care, rehabilitation, community care, and prevention.

The World Stroke Association, which holds its inaugural meeting in Portugal in May, looks forward to working with the WHO and other stakeholders in progressing frameworks for stroke in developed and developing countries, and in turn reducing the global burden of stroke.

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Elaine Johansson, Parent from Inclusion International, Sweden

Of utmost importance to me is that all people, with or without disabilities, are equal and that they have the right to influence their own lives. I believe it is important to fight for a society that stands for these values. Communication, such as expressing feelings, is a basic need of us all. We create such possibilities. We believe that all people can communicate and want to do so. When asked if all people have a language a female scientist in Sweden once said, "Yes, the wish to give signals and receive signals is just as primitive as the need of food and air".

It is important to start where we can. I work in an activity centre for persons with severe and profound intellectual disabilities in Gothenburg, Sweden. The people I meet have not only many difficulties but also many possibilities. It is there that we must start. It is not useful to consider what a person cannot do — that person has a right to develop his or her own abilities. All people can succeed. It is up to us to create the conditions such that everyone is given the opportunity to do so.

Many people with intellectual disabilities are in need of help in their daily lives, and therefore it is so important to give them every opportunity to influence their own lives, to manage what they can, and to decide as much as possible for themselves. For example, it may be to choose what food to eat or what activities to follow. This will increase their independence.

People with intellectual disabilities have difficulties in abstract thinking. The level of intellectual disability relates to what and how much is understood of one's own environment. The reality must be specific and more understandable. At an early level personal experience facilitates understanding. At an early level it is often difficult to assess how a person thinks and perceives. When someone cannot talk and explain, how can we really know what is needed? There are ways to learn more from persons with intellectual disabilities if one is humble and open-minded. To understand intellectual disability it is useful to know how young children develop. All human beings follow the same basic development, but for some it takes longer to learn.

There are differing ways of looking at talent or ability. People with intellectual disabilities are only disabled on the intellectual level. They may have a musical, social or emotional talent, for example.

Many children and adults with intellectual disabilities cannot tell us themselves that their vision is poor and perhaps they do not even understand that this is the problem. It is easy for parents and staff to misinterpret difficulties caused by poor vision as yet another aspect of the intellectual disability. Eyesight is perhaps man's most important means of receiving information. People should not have to live with poor eyesight just because they cannot explain that their vision is blurred, especially when spectacles could easily correct the defect and when there are objective methods of examining eyes.

Before meeting a person with intellectual disabilities it is best to have information on his or her eyesight, hearing and other senses. Even this is not enough. You should discover the person's interests because that is what the person will do gladly and often. Activities that are not perceived as interesting are not done at all.

We can legislate on the right to relief and support, the right to a home and daily activity, but we can never legislate on the right to *love*. In fact, love is of utmost importance for persons with intellectual disabilities and their parents, and indeed for us all. If we were forced to surrender all except one thing, then surely we would choose the persons closest to us — our family. The lack of close relations and of love and the ensuing isolation of intellectually disabled persons are tragedies for both the persons themselves and their families. The challenge in the future is to encourage society to welcome persons with intellectual disabilities and to facilitate their opportunities for friendship.

In recent decades Inclusion International has worked for and given support to persons with mild intellectual disabilities in order for them to participate and to become more independent. Now it is time for persons with severe and profound intellectual disabilities to be visible. The fight against negative attitudes towards persons with disabilities must be intensified and we must put persons with the most severe and profound disabilities on the agenda.

Dr William J. Peek: President Elect, International Society of Physical Medicine and Rehabilitation (ISPRM), Netherlands

The International Society of Physical Medicine and Rehabilitation is the worldwide organization of doctors and other health care professionals working in the field of physical and rehabilitation medicine. The Society was formed in November 1999 as the result of the merger of two international organizations on physical and rehabilitation medicine: the International Rehabilitation Medicine Association (IRMA) and the International Federation of Physical Medicine and Rehabilitation (IFPM&R). Both organizations have coexisted for more than 40 years: the IRMA as the association of individual doctors working in the field of physical and rehabilitation medicine; the IFPM&R as the international federation of national societies of specialists in PM&R. A few years ago they decided to combine their mission and goals, and to merge and integrate into one organization.

The ISPRM has individual members as well as national society members. Active members are doctors working in the field of rehabilitation medicine and their national societies; associate members are other health care professionals working in that field and their national societies.

The mission is:

- To be the pre-eminent scientific and educational international society for practitioners in the fields of physical and rehabilitation medicine.
- To help improve the quality of life of people with impairments and disabilities.
- To provide a mechanism to facilitate the input of rehabilitation medicine to international organizations with special emphasis on those dedicated to the field of rehabilitation.

Important goals are:

- To influence rehabilitation policies and activities of international organizations that are interested in the analysis of functional capacity and the improvement of the individual quality of life.
- To encourage and support the development of physical and rehabilitation medicine as a comprehensive medical speciality.
- To encourage a wide interest of physical and rehabilitation medicine in all physicians.
- To help national professional organizations to influence national and local governments on issues related to the field of physical and rehabilitation medicine.

For more information about ISPRM please look at the web site www.isprm.org

Needs and challenges in *Rethinking Care* for the ISPRM:

(1) *Need*: Involvement of the 'patient' in the rehabilitation medicine process. Rehabilitation medicine cure and care aims at preventing or minimizing disabilities in the activities of daily living, the social aptitudes, psychic aptitudes and communication. If long-lasting or permanent disabilities cannot be prevented and will result in handicaps it is aimed at the maximal re-integration of the disabled person into his or her normal lifestyle. Throughout this process the 'patient' and his or her next of kin must be very actively involved.

Thus, one could say that rethinking care ought to be an intrinsic part of rehabilitation medicine cure and care. It ought to be, but in many cases it still is not. It is different in different countries but, even in the countries where this concept of rehabilitation medicine is accepted and practised, there are differences in how psychiatrists and their interdisciplinary rehabilitation teams accept the active role of the 'patient'.

The challenge for the ISPRM is to contribute to making this concept an intrinsic part of rehabilitation medicine practice all over the world.

(2) *Need*: Participation of persons with disabilities in health care and social services. One of the items in the mission of the ISPRM is to help improve the quality of life of people with impairments and disabilities.

A way of accomplishing this goal has been mentioned: cooperating and maintaining close liaison with other international societies having the common objective of improving the quality of life of people with impairments and disabilities.

The challenge for the ISPRM is to make this a reality and thus to help achieve full social inclusion of persons with disabilities in their communities, based on equal opportunities and equal human rights, all over the world.

María Soledad Cisternas Reyes: Lawyer, graduated at Pontificia Universidad Católica of Chile with a Political Science Master's Degree, membership of Legal Investigation Center; Public Interest Actions Programmes from the Law School at Universidad Diego Portales, Chile

1. Equality juridical programme versus discrimination — disability area/juridical programme on disability

Introduction

The transition from the concept of the benefactor state with strong assistance but low citizenship participation, towards a subsidiary role of the state, has brought about structural transformation in the way some social topics are treated. One such topic is 'disability'. In many developing countries neo-liberalism has generated progress in terms of technological advances and an 'improvement' to the quality of life of the population. The combination of the rhetoric of egalitarianism and economic growth has invigorated disabled people. Their role in society may now include involvement in developing public policies as well as decision-making in their own lives. The problem of 'invisibility' is a reality for many disabled persons and it is stronger with reference to disabled women.

The challenges for disabled persons are countless and extend to all aspects of social life, i.e. access to education, training, labour, communication, information, culture, physical space, sport and entertainment, as well as justice, decision-making, processes of participation, etc. The elaboration of '*Weltanschauung*' would mean giving real content to the Equality Principle, with respect to every human being, and the development of these concepts through a policy of true equality of opportunities and social integration. From this general overview, it is necessary to discuss several strategies and perspectives relevant to a holistic approach to disability.

Description

Firstly, to strengthen the Equality Principle within the context of the struggle for a meaningful democratic society, a juridical programme has been designed as an indispensable strategy to achieve those goals. It is believed that any initiative on this subject

cannot come from the state. Yet it is an essential contribution to the organization of the nationhood. This programme was developed in 2000 in the law school at Diego Portales University. It is part of a global project called *Public Interest Actions*. It has two independent but related components: Diagnosis and Intervention.

Diagnosis

Disabled people have different experiences to non-disabled people and this produces social divisions. Disabled people need social integration. They face discrimination and there are many needing help – about 1 400 000, according to the WHO. The development of National and International Juridical Codes has brought all these issues into the open. Victimized people have nowhere to go when they need to know about their rights and when they need legal counselling. In some cases they need legal defence because they have been discriminated against owing to their disability.

There is free legal counselling, but the high specialization of these matters brings about an inappropriate way of focusing some of the questioning. The effect has been underestimated. In some specific controversial cases the affected person is left after questioning with the feeling of defencelessness, which increases uncertainty and desolation.

The characteristics and needs of disabled people are so complex, and exacerbated by poverty, that they are unable to access private juridical consultants. Hence they encounter difficulties receiving appropriate advice and support. In legal terms, the 48th article of the '19284 Law Code 1994' about the social integration of disabled people in Chile is quite clear. It prescribes:

“Without detriment of the existing administrative and penal standards, every person who as a result of an arbitrary or illegal act or omission suffers discrimination or threat in the practice of the rights and benefits by himself or anyone of his name, to the judge of a correspondent Municipal Court according to his address who must take measures to guarantee and re-establish his affected right.” (*Translated from the original*)

However, this text has been in use for six years and there has been no ruling judgement registered concerning discrimination or

the denial of rights (the law prescribes that a ruling judgement be registered in the National Disability Register).

This demonstrates that the spirit of the law has not been fulfilled. The aim was to make people respect the basic principles for the complete integration of disabled people and to give them access to legal redress in defence of their rights through judicial tribunals.

There have been no appeals for habeas corpus or precautionary actions over constitutional rights in these cases. The problem is serious because the Chilean social system is sheltering injustice on human rights violations, on infringements of rights that hardly ever come before tribunals or courts, but which actually occur every day.

Intervention

Intervention is directed at fortifying the Equality Principle of every individual. It has been protected judicially by the Political Constitution of the Republic of Chile since 1980; also by its laws and the International Juridical Code as well as by the inalienable right to psychical integrity, honour and private life inviolability which are sometimes affected in these cases.

This situation has been criticized many times for the apparent lack of standards and its failure to build on the principle of Equality of Human Beings. The juridical programme holds that it is possible to perform important actions within the context of the constitutional, legal and regulated material available.

The legal programme has been conceived with the intention of making the law more accessible to citizens. At the same time it is intended that the disability issue creates a link with the academic world. This would further the development of a more analytical approach and would also add a new dimension to the political debates on disability issues.

This programme was not designed to simply lay the foundations of 'assistance', but it is also an action-based project founded on scientific analysis. Thus, individual cases may be well supported and have an important symbolic significance at the general level. Furthermore, the programme has an interdisciplinary perspective

involving the law with political science, sociology, psychology, and social communication. It may also initiate the possibility of other social sciences.

The programme involves an alliance between the university that sponsors the juridical programme and various state organizations. It produces materials such as diptychs, triptychs, posters and information for disabled users. Participant organizations include the Social Organizations Division of the General Secretary of Government, Social Services Division of the Social Security Institute, Women's National Service, and National Disability Fund. In addition, the programme will contribute to fortifying the associations of disabled people every time a case of discrimination is verified. Finally, the insertion of the programme into the heart of the law faculty of a prestigious Chilean university will allow law students to be educated in interdisciplinary and intersectorial juridical subjects connected with 'disability'. This will provide a future resource of professionals with expertise in disability issues.

There are two immediate goals of this proposal that will contribute to a cultural evaluation of the Chilean State.

(a) Promotion of individual and collective rights of disabled people:

The first goal is to provide information about rights to vulnerable groups and to the community in general. Activities include the production of printed material, audio tape recordings, radio and TV spots, training courses, and lectures and seminars directed at judges, social leaders associated with disabled people, teachers, students, public and private authorities.

(b) Counselling and specific juridical defence in cases of disability discrimination:

There is a general lack of knowledge about disability discrimination in Chile. The juridical programme will confront this issue as its second plan of action.

For people to participate in specialized discussions it is necessary to provide a procedure accessible to those who suffer discrimination. Most people declare themselves to be tolerant and against any kind of discrimination. However, discrimination happens and the victims do not know where to go. Sometimes their cases have been rejected owing to the lack of juridical

procedure that would lead to justice. On the other hand, it would be good to give people their inalienable rights without considering a specific procedure that the victim must follow. Discrimination occurs because people are able to get away with it and the victims are not well informed.

The project proposes to measure the changes in attitude by means of scientific research. Relevant cases include the casuistry of two processes of discrimination concerning disability, presented to the Chilean tribunals by the lawyer:

- Denial by a TV station that a disabled artist was not allowed to participate in one of its shows because of low ratings.
- Onerous restrictions applied to blind passengers by LAN Chile SA. *(The sentence of the Supreme Court supported the Airline, but the case was taken up by the Interamerican Commission of Human Rights where it was actually carried through.)*

2. Human rights and disability

In relation to the Equality Principle and disability, I consider a juridical doctrine indispensable to secure disabled people's human rights. These rights are based on the fact that disabled people are human beings and that disability is not a voluntary option in life. I will now give a summarized enumeration of these rights.

(a) Right for free access to technological aids (preventive and rehabilitating technology):

Under Chilean law, 'technical aid' support or the total or partial subsidy for its acquisition is conditioned to the fact that the beneficiary must be a person in poor economical conditions. In addition, the catalogues show that a very limited technology is in use. The legislator does not distinguish disabled people on the basis of their economical situation.

However, it may be argued that problems arise because of the way the state organizes its resources. The legislator must consider that disability is usually accompanied by poverty. This is due to reduced labour opportunities, expensive treatments and transportation costs. These costs are exceedingly onerous when compared with those of the rest of the population.

Technology has enabled the production and development of sophisticated aids that allow an individual to compensate for his or her lack of functional abilities and to improve the limits of communication. Most disabled people have no access to them because of their high cost.

Since the Chilean middle class does not qualify as 'poor people', they can neither apply for such subsidies nor afford them independently. Even the exemption tariff provided by law for computerized equipment does not help.

(b) Right for scientific investigation:

With respect to prevention good health is legally protected. A disabled person has a legitimate right to the scientific investigation of the causes of impairment and to appropriate treatment. In an ideal world, we would try to make impairment less common. This is very important for genetic illnesses as chromosome information is transmitted to the offspring. This causes some disabled people to avoid having families so as to avoid transmitting their conditions to future generations. This in turn causes stigma that affects their private lives and psychology. In this way disabled people are 'biologically and mentally castrated'.

The right to scientific investigation encourages the National Health System to follow the latest medical advances of developed countries. It obliges them to encourage disabled people to participate in experimental therapies. These have an important impact on scientific advances and are an ethical obligation to future generations. Obviously, in the application of this right, it is assumed that experimental treatments should be harmless for the individual's health.

(c) Right for rehabilitation:

It is important to clarify here that I am considering psychological rehabilitation which is often more important than physical rehabilitation. This important aspect of disabled people's lives is not widely treated in developing countries.

The mourning process a disabled person sometimes undergoes includes depression, anguish and severe mood disorders. These may lead to incompetence. Nevertheless, the legislators do not attach much importance to this fact. This allows health systems,

especially the private ones, to establish in their codes and regulations restrictions on access to psychological and psychiatric consultations and therapies. Another consequence of these restrictions is that the subsidies for treatments and consultations are lower in comparison to others.

Raising these issues within the context of “Disabled People’s Human Rights” could increase the likelihood of their resolution.