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## Disabled People and the Community

Dr. Louis Minster  
Lecturer - University

**Disabled people have the same fundamental rights as their fellow citizens of the same age; first and foremost, to enjoy a decent life as normal and full as possible.**

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The world is organized around an assumption that everyone has a range of fundamental abilities. It is short from that assumption to the perception of people with disabilities as being fundamentally different. It is a short step again to the provision of services and patterns of life which confirm that difference.

We are societies which pride ourselves on our efficiency, productivity and material progress; we haven't much time to waste on those of our members who fall short of the competence we demand.

We all know that physical perfection exists only on the advertising posters; but we keep on buying the wares they offer. We slap on cosmetics against the reality of physical imperfection and decay. We turn to this food fad and that, to build ourselves against weakness. We jog away the reality that by the time we are seventy, we can expect to be categorized as severely or appreciably disabled.

We resist the thought, above all, that in the imperfect bodies and minds of those already so categorized, we are seeing a mirror image of ourselves. We put away the thought and we put away the people.

Educating people about disability has been variously described as a 'huge task' a 'mammoth undertaking', and the 'uniting of two nations enough to deter anyone from trying. Nobody doubts the need, yet few have attempted to discover the wherewithal.

'There is a glass wall separating the able and the disabled.' So wrote Christy Brown, the Irish author, handicapped from birth, who penned his autobiography with his left foot. And such walls are every bit as daunting and difficult to cross as the brick ones which once surrounded cripples' institutes, epileptic colonies and mental sub-normality hospitals. The difference today is that disabled people can see what they are missing. Although many live in the community, few are part of it.

Community education about disability is a huge and important task. Its aim is the complete acceptance and integration of disabled people into every facet of daily life - equal opportunities in education; the same chance of participation in recreational and social activities and similar freedoms to travel - and all this not within a selective, segregated and parallel system, no matter how excellent, but shared with the non-handicapped community.

Disabled people - as the very name implies - are misfits. A wide range of special services have sprung up to cater for them. Admittedly this is a great advance on the days when people with handicaps were neglected or shut away. But our systems are far from perfect; they have colluded with society in labelling and segregating disabled people.

But first we need to look at the terms 'community' and 'disability'.

### **The Disabled**

'People think we're all the same - but we're not all the same, we're not all the same.' Strong words spoken by a Dublin lady who is mentally handicapped when she was interviewed for a television programme. She could have been speaking for all disabled people. Some would stress the difference between various forms of disability - deafness, epilepsy and mental handicap. Others will emphasize the degree of impairment and may even use terms like defect, disability and handicap to mean different things. At other times, the difference between acquired disabilities and those present from birth may be stressed: "Some people are born handicapped, some have handicap thrust upon them and there are even some who achieve handicap by their own efforts" (P.Phelan giving evidence to the Snowden Committee.)

### **The Meaning Of Disability**

What do we mean when we say that someone is disabled?

First there is anatomical, physiological or psychological abnormality or loss. Thus we think of the disabled as people who have lost a limb or part of the nervous system through surgery or in an accident, become blind or deaf or paralysed, or are physically damaged or abnormal in some particular, usually observable, respect.

Secondly, there are chronic clinical conditions altering or interrupting normal physiological or psychological processes, such as arthritis, epilepsy, schizophrenia and manic depression. These two concepts of loss or abnormality and of chronic disease tend in fact to merge.

A third meaning is functional limitation of ordinary activity, whether that activity is carried on alone or with others. The simplest example is incapacity for self-care and management, in the sense of being unable or finding it difficult to walk about, negotiate stairs, wash and dress.

### **The Distorted, Disfigured, Disturbed Or Dependent**

These are features of disability. It says nothing of matters such as pain, shyness, awkwardness, and abnormality which are known to us all. We have met some of them in our illnesses; we may carry some of them with us in our everyday lives and most of us can expect to encounter them in old age if we are not thrust face to face with them by ill-luck and misfortune in youth or middle age.

### **Communities**

The term 'community' is usually understood to cover both the physical location and the common activity of a group of people. The definition of a community, however, or even of a neighbourhood, is increasingly difficult as Society becomes more mobile and people belong to 'communities' of common interest, influenced by their work, education or social activities, as well as they live. Thus, although traditionally the idea of a community has rested upon the geographical locality - and this remains an important aspect of many communities - today different members of a family may belong to different community of interest as well as to the local neighbourhood.

A community is more than a collection of people, houses or streets. Rather it evolves out of personal relationships and is sustained by them. Two concepts in the above definition capture this theme- 'mutual aid' and 'communities of interest'. By defining communities in terms of friendships we bring a new dimension to the expression 'community care'. This implies that there exists not one, but many communities who could care.

### **Integration**

Most people look upon integration as being a question of technical problems. They believe that integration will be initiated automatically if only we give the disabled technical aids, adapted flats and remove the obstacles confronting him when taking

his place in society.

When basic social services are discussed the starting point is very often technical aids and arrangements. In this token way we cater for a large section of the disabled. Special lavatories for the disabled were sited within restaurants whose entrance arrangements virtually excluded the possibility of the disabled ever actually arriving at their tables let alone using the toilet facilities. Specially constructed ramps led the way into pedestrian precincts from which there was no effective exit. Such practical demonstrations are useful reminders of the half-hearted manner in which we attempt to accommodate the disabled amongst us. But they tell very little of the full story. As long as disablement means little more than the difficulties of getting around in a wheelchair, then the solutions appear simple. All these questions and all these measures are of considerable importance and no one would deny any of them. I would ask you to consider though that integration is a psychological process and that most disabled people need psychological help as well as technical aids. Many attempts of integration have failed when this fundamental fact was forgotten.

All psychological and sociological investigations show the impossibilities of improving the individual resources of a person if he lacks stimulating contacts with other human beings. One of the most important things for the disabled is to receive full support so that he can live as normal a life as possible in the community and in co-operation with others.

Of importance to the disabled himself is his readiness to demonstrate that he has abilities.

The disabled should not look upon his situation as a static one. He must also give more interest to his abilities than to his disabilities. He may be a man with other abilities than those of the non-disabled, but he is not without abilities.

It follows then that the social and psychological situation of the disabled will be a better one if those who meet him do not fix their interest on his disabilities but on his abilities.

### **A Programme Of Action**

What can be done to overcome these setbacks and the enormous social and economic barriers which confront people with disabilities?

Is it possible to move from a system based on segregation, discretion and precarious minimum rights to one based on distributional justice?

It is clear that permissive legislation is not enough. Rights must be clearly established by law and the necessary resources committed to achieve them. But that law must also have the support of public opinion and particularly of those people it is intended to serve.

There can be little scope for administrative or professional discretion if rights are to be firmly established. Emphasis must be placed on universal entitlements rather than on selective ones which carry stigma. Most importantly, people with disabilities themselves must be centrally involved in every stage of the planning and administration of benefits and services.

### **Integration**

Most of the money spent on medical treatment and medical rehabilitation will be of little value if we forget our duty to bring the disabled person back to a social life and give him the possibility of living such a life.

Integration must start at the pre-school stage and go on through and after schooling. Housing must be available to integrate the disabled into the community and of equal importance is to find ways of integration during working hours and in leisure time activities.

### **Education**

In education labels are again attached to young people with disabilities and many of them are segregated from their non-disabled peers and taught in special schools. The point is not that children with disabilities do not have special educational needs, which many undoubtedly do, but that the exclusion entailed by special schooling reflects and supports their segregation in society as a whole.

Children with disabilities in special schools are deprived of the education of each other's company. For children with mental handicaps, this segregation is even more acute because they may be excluded from all aspects of social life by being placed in institutions. The contradiction that separate provisions poses for children with disabilities and their families has been summarized forcefully by someone who said:-  
...how can parents treat a handicapped child "like a normal child" when they see him excluded from schooling with ordinary children and from services used by other children? Instead he is made the responsibility of agencies bearing the explicit aim of giving him special treatment because he is different.

The time has come to state unequivocally that large hospitals and institutions do not provide a favourable environment for a mentally handicapped or physically disabled child to grow up in...I can think of no more important aim than to try to ensure that

all children who do not need specialist health care have the chance to grow up and develop to the best of their potential in their own homes or in small homes in the community.

## **Housing**

If we wish to give the disabled the chance of a social life, the most important thing is to give them a home of their own and not a room or a bed in an institution.

The psychological effect of getting a home of their own and living in the same apartment as non-disabled people can never be underestimated. I must point out, however, that many of these severely disabled persons encounter many difficulties during their first six to twelve months in this new environment. For the first time many of them have to take full responsibility for their own lives, plan their time, order their purchases, clean their clothes, and so on.

## **Employment**

The problems confronting the disabled who has to go out and find a job are considerable.

One of them is the habitual attitude to work itself. Most people must work for their livelihood. For many disabled this is not the situation. They have their pensions or are taken care of in institutions. Two other things are more important for them. At work they meet other people and learn to know them. The work itself - as well as the money they earn for it - contributes to their self-reliance and self esteem. From these two aspects the sheltered workshop is not as good as the open market. A real integration in the working situation is of equal importance to integration in education, housing and leisure time activities. It is my belief that the sheltered workshops are often the easiest way to avoid solving the problems of the disabled and at the same time afford us the impression that we are doing something for them.

A gradual reconstruction of the attitudes and values of society is required which can proceed only in relation to the reduction or elimination of many forms of social prejudice and superiority.

## **Social Services**

The fourth component of this plan of action on disability is the provision of a wide range of social services which would enable people with disabilities to live in the community. Many people with disabilities require specially constructed or adapted premises in order to live independently or inter-dependently and a programme of specially built housing for them and their families is an essential aspect of any

community care policy. Personal social service support in the form of home helps, meals on wheels, social work assistants, foster parents, aids and adoptions are again often crucial in keeping people with disabilities out of institutions.

The basic social service must give the disabled a real chance of living a social life. This can only be done when the community is prepared to accept the disabled as a person with the same requirements and demands as other people; the same right to his own home with the necessary personal help and the possibilities of communicating with other people. The community and its doctors, social assistants, politicians and other such persons must give the disabled a possibility of choosing his own way and taking responsibility for this choice.

### **Leisure**

Finally, many disabled have an abundance of leisure hours but few opportunities of doing anything during them. From a psychological point of view it is very important for them to share leisure activities with other people. Interest in and practice of sports or different cultural activities are specially useful. It is, however, necessary to train the disabled for such activities. In rehabilitation it is therefore important to afford the disabled this kind of stimulation at the same time as we give him training and exercises for the reduced abilities he may have in muscles or joints.

### **Conclusion**

For too long we have given the public information about disability but we have done little to increase their knowledge of disabled people. There are ways of increasing knowledge and understanding about disability.

These methods have been used to bring together peoples of differing religion, race and social class. They have proved effective, too, in helping to integrate disabled with non-disabled people and they have worked for us in our efforts to introduce mentally handicapped adults to their attitudes; but they will change if they experience a need to change - through meeting disabled people, listening to them talk about themselves, finding out more of the aspects which most interest them, and discussing their reactions and feelings with others.

Such approaches require more time, commitment and personal contacts than do talks, information leaflets and mass media campaigns. They must be carefully planned and tailored to meet the needs of that target audience and they must be used regularly and systematically so that everyone in the community has a chance to participate. In sum, the same methodical approaches we use in the education and training of disabled people have to be applied to the even greater challenge of educating the public.

But whose responsibility is it to bring about change? To educate the public. The people most obviously affected by negative attitudes and who stand most to gain from community education are disabled people themselves. As more of them shrug off the mantle of helplessness and live full and varied lives within the community, they will challenge the public's presumptions. The frustrations and depressions in doing this are many.

Increasingly people with physical or mental handicaps are beginning to speak for themselves. They need to complain and assert themselves, even more for our sake than their own.

Given the traditions and patterns of services for disabled people in western countries, one group more than others must take on the responsibility for community education - the parents. They are ideal mediators between the two communities - living in one and working amongst the other. Yet so often the bridges are left unbuilt.

Most of the advances in the care and education of disabled people have sprung from the initiatives of these wise people. I expect that many of them will want to be at the forefront in community education and we trust this seminar will give them support and encouragement.

Introduction can lead to friendships, friendships to sharing, and sharing to change. During the past century our services for disabled people have changed as they have evolved. The evolution must continue. Educating the community may help in the end to bring about the extinction of a species - *Homo sapiens handicapus*.

## **Normal**

What we state as our criteria for the normal has changed from time to time and from place; and it is changing now. There is nothing to say that the package that makes up the package of "normal" is immutable. Concepts of abilities and inabilities can change.

We can and do change it, either to draw its boundaries more closely, and exclude more and more people as 'abnormal' or to widen those boundaries increasingly to include them. We are all in this together. When we choose matters critically to people with disabilities, for their experience is the product not simply of their individual bodies, hearts and heads but of the situations they find themselves. In the past, it is they who have carried the responsibility for fitting into 'normal' social patterns. There has been little thought that these patterns should adapt to encompass them. Today, the inability of certain people to do certain 'normal' things is still seen as their handicap, a consequence of their disability. The first official aim of the International Year of Disabled People in 1981 was 'helping disabled people in their physical and psychological adjustment to society'. The real question to this is a different one. How



far is society willing to adjust its patterns and expectations to include its members who have disabilities, and to remove handicaps that are now imposed on their inevitable limitations?

The answer to these matters concern us all. Not just because one day those of us who do not reckon to have a disability might join those who already do. It matters because it will say a great deal about the tolerance that our societies have for any human differences, any human weaknesses, any human failure to meet their increasingly complex demands. And in saying that, it will say something about our understanding of the essential thread of experience that binds us all into a common humanity, whatever our individual quota of ability and inability.

People with disabilities do not require patronage but action. Collectively they have an enormous potential which our society cannot afford to ignore or reject.

If we reject that common experience, it is, in the end, a part of ourselves that we are rejecting. If we accept it, we could all find ourselves a little nearer wholeness.