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PHYSICAL DISABILITY - A PROGRAMME FOR ACTION

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PHYSICAL DISABILITY - A PROGRAMME FOR ACTION

29TH NOVEMBER, 1989

Choice, consultation, information, participation, recognition and autonomy comprised the guidelines issued by the Living Options Working Party in 1985 for community services for people with disabilities. "Inadequate" and "inappropriate" were the most commonly used terms to describe the level of services for and the perceptions of physically disabled people in the community in 1988, at a one day conference organised by the King's Fund to discuss the practical implications of the two most recently published reports on the community services for people with physical disability: Last On The List (Virginia Beardshaw, King's Fund); and Living Options Lottery (Barrie Fiedler, Prince of Wales' Advisory Group on Disability).

During the course of morning presentations given by the authors and comments by a representative panel of those involved in the provision of services for physically disabled people, the conference heard how the disparity lay in insufficient resources, poorly trained professionals, a lack of coordination within and among state and voluntary care organisations, and, above all, a long-standing inability to take into account the wishes and experience of those on the receiving end of services for disabled people themselves. Open discussion of the authors' findings engendered lively debate, and all the issues raised during the morning were taken into a series of five, mixed workshops to try and establish how change might be effected.

The Current Picture

Virginia Beardshaw identified three main groups of people with disabilities:

(i) those requiring practical help;

(ii) those with a specialist disability;

(iii) and those whose general welfare was disability related.

But she was quick to emphasise that the definition of disability depended on a range of social and environmental factors. Latest figures published by the OPCS show that there are just under a million people with a physical disability in England and Wales who are aged between 16 and 64, but it is estimated that there are some 4 million "with a significant degree of physical impairment".

Funding

Over a million people with a disability require specialist help with mobility and day to day practicalities, but as one of the four main community care groups, they receive only 4% of total expenditure compared with 22% for people with learning difficulties, 20% for those with mental health problems, and 54% for elderly people. There is currently a shortage of 150,000 adaptive housing units in the rented sector; and despite the fact that stroke is one of the commonest causes of disability, many health authorities do not have a stroke unit.

Funding is also subject to inflexible administration: an example cited by Barrie Fiedler was that of Mrs. B., aged 25, with polio, and a wheelchair user, who had limited use of her arms. She had had to give up the use of her car because there was no one to transfer her to and from her wheelchair. She lives independently in council accommodation with five hours' homecare a week. Without a car she is housebound and had to refuse a recent job offer as a result of having no transport. But had she accepted employment, her homecare would have been withdrawn.

When there is funding, it is often inappropriately directed: Virginia Beardshaw found that up to 50% of aids and equipment were wholly unsuitable for the user with disability and thus were never used. Because there is no clear funding structure, those requiring financial aid often do not know how to go about obtaining it.

Service Provision

"Services for disabled people are a low priority everywhere", commented Barrie Fiedler. The findings of the 1986 Living Options Research Project seem to bear this out: less than a quarter of the main statutory service providers claimed to be offering a service for people with disabilities. During the course of her research, Barrie Fiedler found that some voluntary care organisations were afraid to go public for fear of being deluged with demands that they would be unable to meet. During the course of the open discussion, it was generally felt that most service providers have very little idea of what constitutes a good service. All too often, reliance is placed on the expectation that a relative or spouse will provide the necessary care; housing may be provided but may be adapted only for the user with a disability and therefore unsuitable for an able-bodied carer; some of the most basic services such as medical and dental care fail to provide wheelchair access. As Virginia Beardshaw put it, "Services are inexpert; very little is properly assessed and audited. If a service is poorly evaluated there is little investment, if there is little investment it is poorly evaluated.

Training and Communications

(1) Training

Poor evaluation has it roots in a lack of awareness, which, in turn, has its roots in the poor training of those professionals involved in the care and administration of people with disabilities. Too few specialise in disability and too many lack the appropriate expertise and general knowledge of this field, with the result that entrenched and outdated attitudes are allowed to persist. Consequently, people with disabilities find themselves on the receiving end of the medical model of care which:

- Focuses too much attention on the physical condition of a person with a disability
- Offers institutionalised care in preference to integration within the community and the possibility of having an autonomous life-style
- Encourages disabled people to learn to adapt to a restricted life-style rather than encouraging them to identify their needs
- Assumes that "professionals know best", which denies an active role for the users of the service, whose participation is not recognised as valid.

The issue of training was a vexed one. The panel discussions revealed the fear that training might simply cause professionals to "reprofessionalise" and thus continue to ignore the voice of disabled people, or that valuable and limited resources might be diverted away from disabled people. None the less a distinct role for professionals and the benefits of advocacy were acknowledged. The Case Management Project (CHOICE) is in the process of drawing up guidelines for case management.

(2) Communications

Inadequate training among professionals is compounded by poor communications. This is particularly evident between specialist and GP services; and the relationship between health and social services is known to be poor. All too often this results in a lack of continuity of care.

The fact that many disabled people of working age have lower than average incomes has contributed to the assumption that they have no voice of their own. This perception is often reflected in the language used to describe disabled people, a hotly debated issue at the conference. It was felt that language can disempower and disenfranchise, and the use of such terms as "handicapped" promotes the notion that disabled people are either responsible for their disability, or are to be pitied because of it, a perception which is popularised in the media. Whether disabled people should be referred to as "users" or "consumers" refuted the popular assumption that disabled people are powerless.

As the gap between the needs of and provisions for disabled people continues to widen, organisations for and run by people with disability continue to grow in strength and number, encouraged by the number of reports highlighting the lack of adequate services, particularly the Griffiths Report, on which the government has yet to act. Groups, however, are short of money, and Richard Wood (BCDOP) reported during the panel commentary that despite this government having signed the UN charter of rights, committed to the funding of disabled organisations in the community, only £4,500 had been given to actual user groups.

The Way Forward

Various points for change emerged from the morning sessions and the five afternoon workshops, the most unanimous of which was the need for programmes to be evolved with joint consultation between professionals and disabled people.

Barrie Fiedler set out the following points for change:

(i) Even those with the most severe disability can and want to live independently, and this must be encouraged and provided for.

(ii) Consistent national standards need to be set and maintained.

(iii) Secure funding must be provided.

(iv) There must be consumer consultation.

(v) There must be sufficient, appropriately designed housing and equipment.

Members of the panel offered the following:

Christine Murphy (NE Regional Thames Health Authority) stated that services for disabled people need to be made a priority, and to do that additional resources must be made available and pressure maintained nationally and locally.

John Fraser (Service Development Officer, North Tyneside) pointed out that there was an absence of reliable and factual local policy data, which if collated and published, could help to compete with other consumers of dwindling community care resources. He reminded the conference how elderly people and those with a mental health problem fell within the joint planning system, but that disabled people did not, and he emphasised the importance of the need for disabled people to organise themselves to raise their profile.

Debbie Ounsted (Habinteg Housing Association) reflected that the new Housing Bill will inhibit any possible increase in the quality, quantity and choice of housing available to disabled people, but that good provision reduces the level of support care services.

Penny Banks (CHOICE) emphasised the need for a single entry point into the system of care, which, at present, is complex and confusing, and to this end, the importance of maintaining case management, because this is the point at which users' views are heard and their needs monitored.

Richard Wood (BCDOP) urged greater commitment of government resources to the funding of grass roots organisations of disabled people.

Nancy Robertson (Chairperson, Living Options Working Party) wondered whether a united voice for disabled people was possible or even desirable given the spectrum of disability, but that efforts should be made to find a way of working in a united manner.

The workshops were divided into five action groups with the following remits:

A: Why involve users?

B: How do we involve users?

C: Once the user group has been identified, what mechanisms do you need to develop?

D: What are the implications for professionals of user involvement?

E: What are the implications of user involvement for the multi-professional?

Group A concluded that the involvement of users ensured the delivery of a better service with more economic use of resources and positive attitudes to coping with long-term disease. There was a note of caution, however, that user involvement could be perceived by authorities as an end in itself and not as a means to an end.

Group B emphasised the importance of being aware of groups of disabled people in the area and the importance of knowing them as people. It was suggested that better use of local media could also be made and that information databanks could be established. Group B also felt that professionals could act as facilitators, developing groups themselves, or going out to groups rather than the other way around, and that training shouldn't be the exclusive province of able-bodied people.

Group C concluded that education to raise awareness about the needs of disabled people was a must, and that national groups should be established from local groups to campaign for more personal control and development of local policies.

Group D felt that the implications of user involvement were greater partnership, empowerment of disabled people and control of the allocation of resources; that greater awareness of disability issues across the board would result. It was concluded that there were many different ways of helping staff to change their attitudes and that there were different levels at which these could be introduced. For example, more information could be disseminated in locations where there is already interaction between user and professional, such as hospitals.

Group E felt that bringing in users would challenge fundamental and deeply held beliefs, but that policies might change in unexpected ways. Procedures, practices, and documentation, in addition to the way in which information is collected and disseminated, would all have to change radically. Perhaps, it was suggested, professionals might encourage users to become political when they couldn't access resources themselves.

Conclusions

Examples of good practice were cited at the conference and found during the course of Barrie Fiedler's research, but clearly, disabled people are still a low priority. Sweden spends 10 times more per head of the population on disabled people than the UK, but more effective use of resources is clearly feasible, provided that consultation with disabled people is taken seriously. There has been a strong disability movement since 1981 and disabled people have a string of damning reports to add strength to their convictions. It is precisely because of that, intimated Dr Michael Oliver, Chairman of the conference, that it is important to seize the opportunity to concert and coordinate the efforts of all those working in the field of physical disability: "....It is important that we don't miss our opportunity. The historial moment is now".

Caroline M White
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TUESDAY 29TH NOVEMBER, 1988

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