

9. Care of Disabled People

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The British Council of Organisations of Disabled People (BCODP) has followed with interest the formulation of central government policy for disabled people as now outlined in the White Paper *Caring for People* (Department of Health, 1989). BCODP member organisations made a substantial contribution to both the Audit Commission report, *Making a Reality of Community Care* (Audit Commission, 1986), and the Griffiths report (Griffiths, 1988), both of which are precursors of the current proposals. In this respect, BCODP was the only representative national voice of disabled people to give evidence on how disabled people themselves viewed 'care in the community'. Despite the vociferous call for a more holistic and realistic view to be taken of the needs of disabled people and a more proactive pursuit of the real solutions to our problems, the government's proposals amount to 'more of the same' as far as we are concerned. Significantly, the White Paper ignored the call from disabled people for self-empowerment, and concentrated instead on the re-hashing of existing inappropriate services and devising new roles for yet another new breed of professionals who will have more control over our lives than we have ourselves.

The fundamental problem with these proposals stems from the notion that disabled people want care. Disabled people have never demanded or asked for care! We have sought independent living which means being able to achieve maximum independence and control over our own lives. The concept of care seems to many disabled people a tool through which others are able to dominate and manage our lives. The truth is that this view of disabled people as 'sick people' or people in need of 'care and protection' is the view most often held by governments and the professionals, and it is the view that dominates services, policies and strategies which other people have imposed on us. So strong is this medical model of disability that many disabled people have also come to believe that they must let others manage their lives since they are not competent to do so themselves. Thus, disabled people's lives are often dominated by professionals and services which de-skill us and turn us into passive recipients of care.

The evidence for this is overwhelming. Disabled children 'enjoy' a special school education system which has little or nothing to do with education. The decision to place a child in a special school is almost always

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medical grounds.

Disabled people 'enjoy' a special employment service which classifies and labels people according to 'their percentage of disability'. Other people need training, we need 'rehabilitation'. The latest word from the Employment Department is that they are going to train their front-line staff to 'recognise people with disabilities'!

The benefits system is a system that sees you as 'sick' or 'fit'. Disabled people fall into the first category. The phrase 'are you severely disabled or sick?' often appears in benefits literature. Disabled people find the medical assessment for a social need (mobility allowance) degrading, whilst the assessment for attendance allowance is a clear example of an 'at-risk' benefit. We see nothing in the present system which promotes independent living. Even the introduction of the Independent Living Fund has removed disabled people from benefits by right to the status of begging for charity.

Social Services Departments often fail to deliver 'social services'. Their service delivery is based on crisis intervention to alleviate risk where 'normal' care arrangements have broken down. We are not competent to make basic decisions about which technical aids are appropriate (a professional has to assess us and buy for us), whether we can have 'care' services (we have no control over who comes through our door or what they do when they get there), or how our social needs can be met (we often go to day centres in 'ambulances'). Their simplistic view of disabled people as eternal children is almost an abuse of our lives.

The control goes on, even in the most unexpected areas. The right to travel by air will (with some airlines) depend on your GP declaring that you are 'fit to travel'. What does 'fit' mean when one question on the medical profile asks 'does your patient smell?'?

In nearly every area of a disabled person's life the medical view of us dominates. Yet this view has led to services described in recent reports (Beardshaw, 1988; Fiedler, 1988) as 'fragmented' and 'unco-ordinated' and, as far as many disabled people are concerned, irrelevant to our real needs.

The problem is two-fold. First, services are delivered by policy-makers, planners, professionals and carers based on observations of disabled people's lives. The 'I know what they need' syndrome rules. Second, disabled people (that is, people who suffer the effects of imposed services and policies every day of their lives) have never been asked what their real needs are. No wonder that existing services and policies fail to meet our needs. This brings us back full circle to the point that BCODP has informed the consultative process about the real needs of disabled people, but once again the planners and professionals have chosen to ignore

our voice. By doing so they will continue to waste billions of pounds per year on irrelevant, retrograde services which do little or nothing to promote our full integration into society.

Let us state what disabled people do want by first stating what we don't want.

WE DON'T WANT CARE!!!!

To lead full and equal lives in the community, disabled people need:

a)

Full access in every sense of the word. Not just access to the environment but full and equal access to education (including higher education), training, employment and information.

b)

Transport systems which we can use on main routes on demand.

c)

A programme for accessible housing to ensure that disabled people have full mobility within and between communities.

d)

Access to the real technical aids which we need to assist us to achieve independence.

e)

Personal support services which are directly under our own control, or that of a chosen advocate.

f)

The right to choose where and how to live.

g)

The right to real equal opportunities and not just 'everything being equal' equal opportunities.

It will be seen from these statements that people in the disability movement (world-wide) have a fundamentally different view of both the causes and the solutions of disability. Our emphasis is on breaking down the barriers which prevent disabled people from living as equal citizens in the community. We believe that these social barriers are the true cause of disability and that the solution to the independence of disabled people lies in using their direct experience to inform social policy which would be designed to remove these barriers.

For each and every disabled person the words 'choice' and 'control' are of paramount importance. These are the words, not care, which should underpin all policies and strategies which impinge on our lives.

Our final need is for disability to be seen as a civil rights issue. The Americans have finally acknowledged the discrimination and oppression of disabled people in the United States. Disabled people in the UK are striving to obtain anti-discrimination legislation to ensure that our right to live in the community, as full and equal citizens, is protected in law.

References

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