

COMMENT
ON THE
REPORT OF THE AUDIT COMMISSION
“MAKING A REALITY OF COMMUNITY CARE”
BRITISH COUNCIL OF ORGANISATIONS OF DISABLED PEOPLE
AUGUST, 1987

1. Basis of this comment

1.1 The British Council of Organisations of Disabled People (BCDOP) is made up of 37 organisations of people who are themselves disabled. It is a fairly recent re-grouping of some existing national organisation which now provides a focal point for all groups controlled by disabled people to 'come together' and add to a national voice of our own. It includes organisations of people who are blind and deaf as well as mobility impaired. It has received a small grant from central government for the past two years; it is a member of the Disabled People's International (DPI); and is, in that capacity, recognised by the United Nations as the official voice of disabled people in Britain.

1.2 We are aware that disabled people are enmeshed in the same highly inter-dependent social structure as are people who, at this point in their lives, are non-disabled. However, we recognise that in addition, many of our members are physically dependent on others for very basic personal needs. Sometimes this dependency is socially constructed and thus artificial. For example, because the rudiments of sign language are not taught in schools, the simplest communication between the deaf and hearing world is often totally dependent on special interpreters.

Because of the dominance of the printed work, access to information vital to independence can be denied to blind people. Because of poor housing design or lack of appropriate technical aids, many other psychically impaired people are forced to call on family members or statutory services for personal assistance.

1.3 Our daily experience of disability thus teaches us that our dependence on others differs according to the environment we are in.

The context in which our need for personal assistance arises is therefore a crucial aspect of any concept work such as ‘community care’. Again, we are aware that other factors affect the level of need for support, e.g. Age or intellectual impairment. The basis of this comment is, as a consequence of the above points:

- (a) grounded in direct experience
- (b) in context of the interaction between disabled people and their environment, an
- (c) at present predominantly concerned with physical disablement, including sensory impairment, with efforts being continually made to include and respond to mental handicap and mental illness.

1.4 We realise that the Commission’s Report is concerned with all so-called “client groups”, with a view of arriving at a widely embracing scheme for “community care”. Our situation however, is that of being a distinct social group with quite specific needs which are related to our experiences are shared with other groups in the same way that we hold things in common with wider society. However, we believe it is necessary in the interests of clarity - and ultimately economy - if we confine this comment to our own situation, without making assumptions about the situation of others.

2. Introduction

2.1 Inasmuch as the report is centrally concerned with ‘global’ strategic issues it clearly cannot deal in a detailed way with putting “community care” into practice.

We take this to be consistent with the statement in the Report to the effect that the Commission is itself aware that the extent to which “community care” can be directed from the centre is inherently limited. WE note and acknowledge this recognition by the commission of the limitations of its own role in developing policy.

2.2 However, this recognition can only be seen in a positive light, if the consequences are fairly and squarely faced, and in this we think the Commission has failed. Existing policies do conflict and often appear irrational to disabled people who have to live by them. In the opinion of BCODP, this confusion cannot but be so because existing policies and practices have been based in incomplete and inadequate information. This has come about because of the long, historical exclusion of disabled people from mainstream social life in general, and from policy development in particular. Public policy in this field has been dominated by non-disabled perception of our problems which can only yield a limited view of their solutions. The information which is derived from direct experience has been systematically limited or excluded from the decision making process. Attempts to correct this have been desultory both on paper and in practice (e.g. S.15 of the Chronically Sick and Disabled Persons Act 1970).

2.3 Worldwide, disabled people are rejecting this irrational approach to the formulation of policy and service planning. When the Commission says that the purpose of their Report is to convince interested parties that “community care” is far from being a reality this is hardly news to the thousands of disabled people still living out their lives in institutions or living on a knife-edge in the community. We know the services and facilities are not there. We know we are not there when they are planned.

We know that, had the design, delivery and control of services been based on a solid commitment to utilise information derived from the experiential as well as the observational perspective on disability, we would not be in the chaotic situation we are in today.

2.4 The Audit Commission's Report is thus fundamentally flawed in as much as it has failed to identify the root cause of the problems facing physically disabled people. In terms of "community care", that cause is the exclusion of experiential information from policy and planning. This comment is in part designed to correct the omission, by making available some collective insights from the BCODP membership.

3. Defining "Community Care"

3.1 By definition, the Report says "community care" involved looking after people. It proposes also that it involves a wide spectrum of "care" ranging from minimal domicillary support on the one hand to long stay hospital on the other. We take issue with these points.

3.2 In the first place the need to be "looked after" may well adequately describe the way potential physically disabled candidates for "community care" are perceived by people who are not disabled. This viewpoint has a long history, and a correspondingly successful application in practice - which has led to large numbers of us becoming passive recipients of a wide range of professional and other interventions.

But, however good passivity and the creation of dependency may be for the careers of service providers, it is bad news for disabled people and the public purse. It is a viewpoint which meets with strong resistance in our organisation.

3.3 In the second place, it is remarkable how the Commission has slipped from the otherwise rigorous examination of many of the issues surrounding “community care” by simply repeating the familiar idea that there will always be some people who will need institutional forms of care. It is the experience of physically disabled people that, for any among the residents or patients in long-stay institutions, it would be possible to find someone more severely physically impaired and dependent living in the community. This happens through a variety of methods - but it merely involves shifting support from the institutional setting to a house in the community. This fact has often been noted, even by those with vested interests in this field - but it has never curtailed the expansionist appetite of the residential care lobby. Indeed, as the Report clearly shows, one adventitious change to the Supplementary Benefit (Board and Lodging Regulations) is seized on immediately by this interest group and turned to their advantage. We think that the development of support in the community for physically disabled people should not be based on unsubstantiated statements and we are critical of the Commission for offering an opportunity to the vested interests in institutional care to use their Report as a means of maintaining or extending their influence at the expense of appropriate support *in the community*.

3.4 Whilst BCODP appreciates that it is quite consistent for a concept such as “community care” to be stretched by existing controllers of disability policy to include segregated facilities of all kinds, this is an approach which we would find necessary to reject. For us, lumping everything which has been provided to us - or foisted on us - under a single ‘spectrum of care’ distorts and obfuscates the issues at stake.

The requirement for disabled people in Britain is for changes which will enable us to participate in everyday life in ordinary community settings. It is a struggle for integration, involvement and the taking up of responsibilities as well as rights. The technology exists to make this possible today and, like the Commission, we believe the resources to make this happen also exist - expect, of course, that they have been for years and still are, inappropriately applied.

3.5 For physically disabled people then, appropriate community support should replace concepts such as “community care” by making a clear break with the wasteful bad practices of the past. Presumably, the reasoning behind lumping all existing services under one banner is that, in the minds of the Commission, they are all linked by the word “care”. In our view a more acceptable link would be the word “community”. Whilst the meaning of this word does attract debate, it is less likely to perpetuate the policy distortions the Commission has noted in its Report. The recent mushroom growth of segregated residential institutions can emerge quite easily under a spectrum of services which has “care” as its banner. But to focus on the word “community” would help re-instate the core idea which lies in the backgrounds to the development of this policy. Furthermore, to cluster future service developments round this idea would lead to a careful examination of the aims and goals of existing services, and this is long overdue.

It is a major weakness of the Report that it gives the impression that what is most needed is for someone to recognise existing facilities rather more effectively than they have been in the past.

3.6 It is interesting that the Commission, in linking the concept of “community care” to the idea that we need “looking after”, is itself adopting the “medical model” of disability which it rightly identifies as an expensive service orientation.

The proper focus, in our view, should not be towards us, as individuals, but towards the community itself. It should not be about the creation of yet more dependency on new or re-jigged services, but about removing the causes of our unnecessary dependence. It should not be about expensive forms of segregation, but about a commitment to social integration - to *the full participation and equality* - which was the aim of the International Year of Disabled People, now 6 years ago.

4. Medical and Social Models of Disability

4.1 As we have pointed out, one of the major causes of the waste of resources inherent in many of the services which have been built up on the needs of disabled people, lies with the almost exclusive control of those resources by non-disabled people whose perceptions are limited by lack of experience, and whose (medical) model of disability is based on the idea that it is an individual tragedy or misfortune. Whilst we do not accept such an individual pathology to be a proper basis for the development of appropriate community support, we do accept that the medical model can and should occupy a more clearly defined relationship to the services for social integration which we need to be involved in developing in the future.

4.2 For clarity of service planning in the field of disability, we think it essential to re-define disability in social terms rather than an individual tragedy. BCO DP, and its international counterpart DPI, already base their activities on a social model of disability and its consequences are already being developed in centres for independent or integrated living (CIL's). CIL's in Britain are presently struggling with insufficient resources to get established and to get on with key aspects of the job of developing "community care",

and we would suggest that they are a strategically essential organisational component of any attempt to overcome bureaucratic barriers and institutional inertia, which are part and parcel of the task of re-directing existing resources.

4.3 Much of our challenge to the Commission's suggestion of a "spectrum" of care approach to developing CIL's in context of the social welfare infrastructure here in Britain. An essential practical requirement of re-directing resources is a clear aim for service development drawn from a clear focus on the nature of the actual problems physically disabled people face. The Commission's "spectrum of care" approach is the very antithesis of clarity, and in our view will lead to an ineffectual reshuffle of service interests with no, or little change.

4.4 From this position, we are content with the proposition that locally accountable, community based responsibility for expenditure should rest with local authorities.

This is because physical disability arises in any given local community which should be the focus of its resolution. There is also amply room within local authority structures for further devolution of accountability and control, as well as for new partnership arrangement between authorities and voluntary organisations. We recognise that a shift of responsibility where required from the NHS to local authorities is in effect a de-medicalisation of disability and is thus to be welcomed but, in the absence of a re-definition of disability itself the medical model will continue to dominate service developments based on Social Services Departments.

5. Community support in context

5.1 “Looking after” physically disabled people is emphatically not, we have argued, what appropriate community support should be about - although it is quite consistent with the welfare paternalism which is the essence of “community care”. Providing disabled people with access to personal assistance to deal with function they are unable to carry out independently is however what is desperately needed. However, personal assistance must be set in context of other interlocking needs if public money is to be used widely. Without such a context, “care” because an end in itself and a euphemism for containment and social control.

5.2 For many disabled people, the degree of dependence on help from other human beings depends on whether they have appropriate technical aids and equipment - which in turn can be determined by the design of housing. Dependency on their people can be increased by lack of accessible transport and by barriers in the built environment.

Lack of information in an appropriate form about such things can further exacerbate this situation. Prolonged enforced dependency can also create psychological problems which may then need specialised counselling to overcome. These are the factors which, either singly or in some combination, prevent or restrict the ability of disabled people to develop their independence or to take part in normal social activities. Taken, together, they provide a framework for an integrated approach to service provision. One logical progression towards independent, integrated living for a given individual, which is being developed by one CIL, takes the following form:

Information
Counselling
Housing
Technical Aids

Personal Assistance

Transport

Access

For physically disabled people, “community care” would be a meaningful concept only insofar as it was able to respond effectively to these tightly interlocking factors. As things are, we are seeking appropriate community support which will focus resources on these fundamental needs. Targeting resources in this sense is essential to being about the long-term structural changes which will, in turn, remove much unnecessary, repetitive and wasteful individual casework.

5.3 Some CIL’s and other grassroots organisations of disabled people which follow that pattern, are working to spearhead a holistic approach to dealing with these fundamental needs.

Working in context in this way throws a new light on what we see to be a moribund concept of “community care”. It shifts the notion of “care” away from reactive containment towards proactive ennoblement. We think it is essential, for physically disabled people, their families and the community at large for public spending to be given this positive emphasis. The Commission’s report is, we think, singularly weak in this respect. To move existing resources in this now, positive direction will require considerable leverage. It is not enough to point out that present management structures do not promote an integrated approach to operational planning or to exhort that local agencies must work together. What is required for this to happen in practice is for the establishment within authorities of a clear focal point for supports for independent, integrated living. This is the way we see “community care” developing for physically disabled people.

5.4 It will not be enough to insert into the existing disparate structures a new tier of “managers” with the task of getting people to work together to plan and deliver “community care”. To take this approach is to completely misunderstand why we have reached a point in the historical development of services where today much expenditure is wasteful and irrelevant in the field of physical disability. It is a failure to recognise the futility of attempting to “administer away” the needs of disabled people. The central requirement is for disabled people themselves to become active agents of social change. The kind of help we need is that which supports our own self-help and capacity, and a truly positive interpretation of “community care” is one which supports, encourages and facilitates disabled people themselves as co-participants in the design, delivery and control of services.

5.5 The ideal fulcrum for structural change is not some new managerial function inside existing bureaucracies: such a move will simply contain change within the same administrative ethos which produced the passive dependency of disabled people in the first place. The Commission’s Report will almost certainly tempt a “new bureaucracy for old” approach with various administrative models for managing or manipulating services. What is required is a medium for change which taps into the experiences of disabled people and uses that as a resource.

A century and a half of increasing dependency on an increasing variety of services cannot be managed out of existence. In our view, the ideal vehicles for developing the right kind of “community care” are centres for independent/integrated living.

5.6 We know that, for many of our members, personal assistance will remain the most vital element of their support system - although the contextual factors we have mentioned will still have varying degrees of prominence in the lives of them or their helpers. However, given the essential task of targeting resources more precisely on need - an particularly the requirement to replace short-term need by long-term structural change - we think it is vital to move away rapidly from a position of pumping money along separate conduits of “care”. Today’s task is a holistic one, we need to commit ourselves firmly to it, and CIL’s offer a realistic and practical way forward.

6. Accountability

6.1 Another facet of the drive to establish a form of “community care” which does not reinforce existing patterns of waste and dependency is the need to consider more appropriate forms of accountability. Whilst it is likely that the dominant direction of accountability will remain towards those having ultimate responsibility for decisions on spending, and whilst we accept that the present fragmentation of responsibility between different agencies calls for rationalisation, we think it should not be an entirely one-way process. The normal constitutional arrangements which have conferred authority on bodies such as the NHS or local authorities have led to the consolidation of insular intra-authority oligarchies who decide disabled people’s needs for them; who develop local strategies for service development in private; who decide how, when and to what extent “needs” should be met: and who monitor their own performance according to their own criteria.

For productive outcomes, accountability should have more than one direction. Mechanism which could take formal account of the collective interests of disabled people themselves in service provision, need to be properly established.

For the most part our interests have been looked after by others acting in our behalf, and the inadequacies of this arrangement are all too apparent. Although some authorities, through Equal Opportunity departments are slowly beginning to evolve new structures, there is a long way to go before disabled people have a formal input into say, the design, delivery and control of arrangements which are supposed to serve our needs.

6.2 The Report is, again, lacking in recognition of this basic requirement.

It is fundamental to disabled people's own case for appropriate community support that is continuously responsive to their fundamental needs in relation to independent integrated living. Also, in the same way that non-disabled people expect services to reflect changing expectations, so should this be the case for disabled people. Establishing suitable mechanisms for securing the participation in services of people with direct experience of disability should therefore be part of any strategy for change. There are interesting examples of mutual accountability which we know of which have evolved in recent years. One CIL is based on a management structure which secures equal representation from disabled people together with non-disabled representatives drawn from health and local authorities – and its staffing policy also provides for disabled and non-disabled people to work together. Others are being planned along the same lines.

6.3 This approach shows that new participative forms of organisation, which provide for continuous adjustment and the potential for change, can evolve within local authority structures.

Such forms, we believe, point the way to services which will enable a better quality of life and be more cost effective. But there has to be a parallel commitment to stimulating more organisations of disabled people, which ensure that disabled participants or representatives can themselves be accountable to their peer groups.

7. Finance

7.1 Most of the descriptions proved in the Report concur with our own experience of developing appropriate community support, and many of our members suffer from the glaring anomalies and contradictions which exist in present arrangements. Our view is that the basic principles which need to be observed in any rationalisation of the financing of community support are:

“It should promote community support in context of a wider framework of interlocking fundamental needs such as those set out at para 5.2”

“It should aim to secure and support the maximum possible independence, social integration and control by the disabled person over their own situation”

7.2 Financing the personal assistance element of community support should not depend on disabled people having to pass through the Supplementary Benefit gateway in order to gain access to sufficient funds. Many disabled people live each day at an extreme level of dependency either on technology or human help or both, and this vulnerability should not be exacerbated by uncertainties in funding arrangements or by means testing. Because of the substantial preventive aspect of personal assistance services (which in our view should be available for social, as well as domestic and personal requirements) the NHSD should transfer funding for this purpose

(which should not be dependent on hospital closures) to local authorities. In turn, and as we have said, authorities should promote the delivery of such a service in context of other needs; in a way which satisfies the question of accountability both to elected members and representative disabled people; and in a way which draws on the experience of disabled people as a resource. AS we have mentioned, BCODP would like to see this develop in CIL's.

7.3 The development of comprehensive and flexible systems of personal assistance is, because of its crucial role in the lives of our most severely dependent members, a priority area for action. We are aware from experience, that there are areas of inefficiency and waste not referred to in the Commission's Report, for example, many disabled people are quite capable of recruiting, training and organising their own personal assistants - and should not be put in the position of inflating administrative costs by being obliged to use the services of domicillary services managers or their equivalents. What is required here are mechanisms for placing the necessary resources into the hands of disabled individuals, linked with appropriate arrangements for accountability. All other arrangements for their provision of personal assistance to physically disabled people should provide for control to be exercised by disabled people within the process. The Commission's recommendation for better training for staff should be re-thought in the light of the need for providing disabled people, where necessary, with the skills to train and manage their helpers. Much personal assistance is of too fundamental and intimate a nature to be determined for a disabled person out of impersonal health or social services bureaucracies.

7.4 We are aware that the fragmented nature of funding sources for personal assistance - some benefits being administered centrally and other costs being met locally - can cause conflicts which are rarely to the advantage of disabled people.

This local authorities who do not make a charge for domiciliary services are continually under threat of losing out under block grant penalties. Such threats produce limited budgets, limited domiciliary help hours and inadequate levels of service delivery. Those authorities who do make charges fail to recognise that, in clawing back Attendance Allowances, they exploit already stressed family members (often female), by perpetuating their position as a poorly paid or unpaid source of labour. Either way, in our view, the present arrangements are as incredibly inadequate as they are short sighted: there can be no justification for perpetuating a system which, at the end of the day, produces any unnecessary pressure for family breakdown or expensive institutional provision.

8. Conclusion

8.1 The Commission's Report is helpful in highlighting many issues of concern to physically disabled people. From our point of view it also contains weaknesses which we have gone some way towards identifying in this comment. Inasmuch as the Report will lead to more detailed discussion, quite possibly with profound consequences for the future of many severely disabled people, it is essential that representative disabled people are fully included in any such deliberations.