

## **RE-THINKING CARE IN A SOCIETY PROVIDING EQUAL OPPORTUNITIES FOR ALL**

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### **Introduction**

This paper is concerned with 'community care'. I have not, however, set out to analyse the legal and structural components of 'community care'. Nor have I examined how well or how poorly community care policies are implemented. The paper does not look at or present research on this topic. I do not refer to and depend upon data from surveys or literature reviews. I have not taken my starting point from critical reviews or theoretical publications on community care, although, I would maintain, the content of this discussion is informed by such readings. Most importantly, it is not a purpose of this paper to set out and argue for a detailed solution or approach to community care. I offer no simple formula for addressing what is increasingly acknowledged as an international problem in implementing an appropriate level of care services in the community for those who may need such assistance.

Having said what this paper is not about I need to make clear what is intended. I have been asked by the World Health Organisation to prepare a discussion document that raises questions, stimulates critical thought, challenges assumptions and encourages informed deliberation about the nature and provision of 'community care'. The background to this invitation is a central acknowledgement: *whilst in principle provision of community care has become an internationally accepted goal, problems in implementation have persistently undermined realisation of this aim.*

In addressing this issue I should emphasise that my argument has been shaped by two prevailing influences in my own development: Firstly, I have been concerned and actively involved with a wide range of disability issues for over forty years. During this period I have participated in the establishment of 'disability studies' as an academic subject at university level. I have taught a very broad range of lay and professional workers in the field as well as students simply interested in the subject as part of their own personal development. I have carried out research concerned with service delivery and policy development, actively engaged with other disabled people in setting up and maintaining organisations of disabled people, and written and presented papers which challenge hitherto unquestioned assumptions about the nature of disability and concerns of disabled people. I do not claim that this extensive 'disability' experience, when focused on community care, is a qualification for determining the access needs of all groups who may use the 'caring' services. I do believe, however, that the social experience of disabled people is singular, and that this uniqueness can provide extraordinary insight into the transformation of 'care' as this migrated from the community into institutional settings and then back again.

Secondly, my understanding and analysis of community care from the experience of the disability field has been formed within the confines of British policy and provision. This has

had a rather patchy (often described as a 'piecemeal') history since the 1960s and I make no claims about this being a good starting point for the development of an international consensus on what community care should or should not be about. As long as community care is viewed in economic, managerial, professional and technical terms the cultural component of service provision and service utilisation tends to be neglected and this, in its own right, will undermine the best of policies. In this respect different national traditions need to be addressed in specific detail whatever global proposals are made for the incorporation of cultural issues in the development of community care. The British experience should be viewed as just one of the cultural range of approaches that are currently addressing the subject of 'care in the community'.

### **Where to start?**

In general, problems in the delivery of community care service are most frequently attributed to insufficient funding, inadequate planning and preparation time prior to implementing the service, and the absence of staff training or the training provided is inappropriate for the interdisciplinary teamwork that is required for an effective service. Since the emergence of community care proposals in the 1960s these concerns have been intensively raised and discussed. Solutions, however, have on the whole maintained an attachment to the doctrine of delivering 'care' to client groups according to assessed needs. In other words solutions, from the technical {such as seeking to improve the management of services, improve the assessment of needs to ensure resources are not wasted, etc.}, to the more radical {such as shifting from a medical model of community care to a social model of neighbourhood care) have not doubted the veracity of providing resources for services to those who are deemed to have special needs. In this respect there are two general presumptions made about community care which are rarely questioned: firstly, that community care services can assist 'people in need' to attain a greater degree of independence than otherwise might be possible for them if left entirely to their own resources, and secondly, that community care services can address the special needs of 'vulnerable groups'. I believe that reliance on these assumptions is one of the reasons why problems in community care are difficult to resolve.

In many respects, it seems to me, the absence of doubts about the value of community care corresponds with the absence of incisive questions about the legitimacy of addressing assumed independence needs of vulnerable groups. In any natural science a 30 year history of problems with a particular approach would certainly raise questions about the veracity of that approach. This seems to be a good starting principle for an examination into the problems of implementing community care services. With this in mind a return to the beginning of the lengthy historical process which eventually resulted in the current promotion of community care policies seems to be a sensible starting point. Three stages are raised in my mind when community care is looked at in this way:

Firstly, with 'disability' as the working example, prior to the development of residential, institutional and professional approaches to services for disabled people whatever help or interventions were on offer were provided in the community. Disabled people, their supportive family and friends had to be self-reliant. In these circumstances there would have been two concerns that had to be dealt with - 'caring' for those deemed unable to manage and 'supporting' those who can manage with assistance. Thus, in its origins, interventions directed

at ameliorating the home conditions of disabled people involved an undifferentiated mixture of 'care' and 'support' provided by 'lay' helpers.

Secondly, following the population migration from the rural to urban areas as industrialisation developed and families faced new stresses their ability to provide care and support became increasingly difficult to sustain. Disabled people then became more reliant upon help from outside the family if beggary was to be avoided. This would apply to those most severely impaired and rather more dependent upon care than support. In time, then, as social affluence came with industrial development non-family interventions provided by the state targeted on the more urgent need for the provision of care. In these circumstances interventions became progressively professionalised around the perceived needs of those most liable to be displaced from the family. Care, then came to characterise and define the health and welfare approach to interventions directed at disabled people.

Thirdly, as the welfare state fragmented and its ability to provide care for a growing population of disabled people became more problematic pressure increased for interventions to be provided in the community. But during its lengthy incubation in exile from the community 'care' had become the dominant approach to intervention in the lives of disabled people. Thus on returning interventions back into the community it has taken the form of care in the community. Each of these stages can be considered in more detail.

### **Independent Self-Reliance**

*In the absence of State health and welfare provision* the advent of a child born with a defect, or the appearance of an impairment due to illness or accident later in life, would present a family with additional concerns alongside the 'normal' pursuit of food, clothing and shelter. Most immediately this would entail the survival of the person with the impairment and consequently the need to solicit medical intervention. The intention of inviting such an intervention, into the home environment, would be to enable the removal of any physical impediment which threatened the person's endurance. The emphasis would have been on 'cure'. Once this immediate danger had been removed further medical expertise could be canvassed for advice and possible additional attention on the physical defect because of its known long-term life-threatening implications. The emphasis in these circumstances would remain focused on the removal of the defect, or at least reducing its severity. That is, the most immediate family judgements in the home would be driven by the need to find a cure for the presenting impairment and this would surely be followed by decisions about moving as much as possible in that direction.

Thinking about impairment and developing an awareness about its implications during the earliest active stage of intervention, then, would be agitated by goals directed at obtaining a cure. 'Impairment', 'cure' and 'medical treatment' in this context constitute a tight *primary configuration of relationships* which are firmly attached to disabled people at a very basic level. Once the threat to survival has receded and the impairment attained a relative level of stability the functional autonomy of the individual is bound to become the family's secondary concern. However, the individual would now have a medical intrigue stamped onto their external, and hence, social identity. This identity, having been laid-down during the primary concern with curing the impairment, carries with it an automatic comparison with images of an idealised 'normality'. Henceforth the ability to complete 'normal' day-to-day activities of social

life would be bound to trigger interpretations within this medical milieu. In this event the person with an abiding 'medical condition' (an Impairment) would be surveyed for the impact of their impairment on their ability to function in what are a secondary *configuration of relationships* in three scenarios: being able to function 'normally'; functioning with 'support'; or having a lasting dependency upon the provision of 'care'.

(a) In the first scenario little social significance would be attached to the permanent medical condition. The loss of a finger, for example, might have no implications for independent assimilation into existing social relationships and facilities that are within the attainable circulation patterns of the individual. Curing this medical condition would not then become an important family priority. The impairment would be seen more as an '*abnormal*' curiosity than as a condition which demands medical attention.

(b) In the second scenario the individual with an impairment may be able to function relatively autonomously within the existing environment (even though it has been created only by, and for, able-bodied people) provided an appropriate level of support is at hand. Asking a family member to make a cup of tea or requesting assistance to go to the toilet, for example, could be regarded as providing the kind of support in the home that would enable autonomy to be retained. The critical issue in the provision of 'support' is that the individual with the impairment asserts his or her own aspirations by deciding the goals to be attained while others help to accomplish these aims. This enables a level of autonomy to be achieved rather than independence or inclusion in an able-bodied world. In this scenario social significance would be attributed to the 'medical' impairment because others are called upon to provide assistance.

Although the magnitude of support requested would be covertly influenced by the accessibility of an environment designed for able-bodied living, it is *dependency upon others* that would be overtly 'suffered' by the supporting non-disabled members of the family. Consequently non-disabled people could easily come to regard social 'dependency' to be dormant behind every significant impairment. It is in this sense that every disabled person capable of managing their own lives with assistance could be considered 'vulnerable'. Any subsequent request by the family to external resources for additional help, then, would be attributed to the severity of the impairment and taken as evidence of disabled people's vulnerability and intrinsic social dependency.

The absence of reliable support outside the family setting would make the external able-bodied world largely inaccessible. In the period prior to State intervention perhaps the only active route that a person with a severe impairment could follow in gaining support to enable autonomy outside the home was by working hard at beggary. This would not negate the association of disabled people with 'vulnerability', however, because the disabled beggar would simply have changed status from being vulnerable as a disabled person to being vulnerable as a beggar. Indeed, in the public arena 'beggar' and 'cripple' would be almost synonymous terms (undoubtedly a major reason behind the modern erroneous presumption about the etymology of the word 'handicap'). Whatever else, the disabled beggar would not have entered the 'normal' world where autonomy is achieved through employment or marriage.

(c) In the third scenario the help that is offered is 'deliverer determined' rather than 'recipient requested'. It is in this respect that any universal acceptance of the right to autonomy (the right

of individuals to determine the choices in their own lifestyle) can become profoundly undermined in relation to people with impairments. Family members may unthinkingly assume that they must be the decision-makers for their impaired relatives because the level of impairment predicates a level of support that simply cannot be provided in the home. When this happens 'support' starts to be replaced by 'care'. There are several reasons why this transformation may occur:

i) **Time:** The amount of time needed in order to support a person with an impairment may encroach too much on the helpers available time. For example, the female helper (invariably the wife or a daughter) could have a full programme of household duties involving cleaning, shopping and cooking. These activities have to be scheduled in relation to all members of the family. If the person with an impairment requests assistance at a time when the helper is about to leave for the market the helper may refuse because the sought-after purchase at the market may not be available at a later shopping time. A decision has to be made. If the request for assistance takes priority then this can have an impact on all members of the family who will forgo access to the intended market purchase (the menu for a meal may have to be changed). Certainly, the pressure would be on the helper to provide the assistance as swiftly as possible *and in a manner that suits the deliverer of help* rather than follow a slower course of action requested by the person with an impairment.

In circumstances where the absence of support at a requested time can exacerbate the home environment for all family members (eg. incontinence) the deliverer of help may insist on an action not requested by the person with an impairment (eg. place the disabled person on a toilet before leaving for the market). It is easy to see how limitations on available family time can lead to the imposition of practices on the person with an impairment (ie. others make decisions for that person) so that possibilities of family 'support' become eroded and increasingly replaced with 'care' regimes. Here is another example: the person with cerebral palsy who eats slowly and spills food at meal times may be fed by others rather than allowed to organise their own pace of eating because otherwise meal-times become too invasive in the family's time-table and after-meal cleaning becomes too time-demanding.

ii) **Finance:** The financial status of the family will also affect the pace of transformation from 'support' to 'care' within a family. Financial resources to purchase or have made appropriate aids or equipment, such as an individually designed spoon so that the person with cerebral palsy can feed her or himself more efficiently (in terms of the families needs!), could influence *if, when* and *how* the person with an impairment is to be cared for by being fed. The state of technological development in society, of course, will provide the permissible context for this development. Improvement in community sanitation and medical expertise could result in more people with severe impairments surviving in families that are less able to support them without a concomitant improvement in, and access to, appropriate aids and equipment. The extent of the hiatus between the presence of increasing impairment and new technology. enabling autonomy would, I believe, have a significant impact on any emergent demand for the social provision of 'care'. Conversely, the more affluent family may buy-in workers to care for their disabled members, rather than purchase any aids or equipment that would facilitate autonomy.

iii) **Attitudes:** Another consideration in how far a family, or individual helpers in the family, are prepared to go in providing 'support' before 'care' becomes the behavioural alternative, is

the perceived *attractiveness* of the task to be carried out with the disabled person. Helping a disabled person dress, brush their teeth or bath may be regarded as unpleasant tasks and carried out to a minimum standard and as infrequently as possible. If over a period of time it is the helper who makes most of the decisions about when and how these tasks are to be carried out then what started as supporting the desires of the disabled person may turn into 'caring for' that individual.

Obviously those who are engaged in helping disabled people may hold any combination of attitudes towards the help that they feel obliged to provide. These attitudes will be seen in the perfunctory or elaborate way that helping support and/or care are actually provided. Being seen in public pushing a person in a wheelchair, for example, may be regarded by the non-disabled person as a particularly unpleasant, embarrassing or shameful experience. In these circumstances the prospective helper may select more secluded environments to take the person in a wheelchair or try and get other members of the family to carry out the disliked task. In such circumstances it is the helper who starts to become the 'majority shareholder' in the decision-making process and the degree of support offered is eroded by extending the bias towards care.

The thesis presented in this section is that prior to the development of substantial state intervention in the lives of disabled people families provided an unrecognised composite of support and care. It is my contention that these two forms of help were undifferentiated in the minds and actions of those providing assistance and that in the short and long term bustle of family life there would be moments as well as periods of time when either of support or care would predominate. It seems to me, however, that when the care form of assistance assumes supremacy over a period of time in the family setting and the fluid movement of help between support and care becomes more difficult to sustain, then having the disabled person taken into care may reluctantly be seen as the only option.

### **Collective Institutional Intervention**

The care approach to intervention, then, would appear to have started its journey towards an independent, distinctive and formal career only when informal assistance, comprising an undifferentiated mix of support and care, began to break apart. Before 'care' could be repackaged as a service delivered by health and welfare professionals, however, it not only had to be separated from family 'support' but the latter form of assistance had to become culturally subjugated. My contention here is that in the face of limited time, insufficient finances and changing attitudes families found it increasingly difficult to provide an appropriate level of support. This resulted in a pressing demand for publicly available care services. Using such a service, of course, would immediately reduce the burden that non-disabled people might feel in assisting disabled members of the family. This would reinforce its attraction as a universal form of assistance. As a result the importance of developing and providing disabled people with support was devalued and the demand for care services began to dominate both professional and public presumptions of what is an appropriate form of assistance for disabled people.

Disabled people too would seek access to care services when the prevailing experience of the support provided in the home is perceived as 'deliverer determined'. This is because the provision of 'objective' efficient care might be considered less stressful than being dependent

upon the intrusion of others when assistance is reluctantly provided or coloured by strong emotional and personal ties (eg. in dominating, over-protective or possessive families).

Disabled people placed into the diverse range of institutions providing a variety of care would be joining other population groups who have been removed from the community -such as the homeless and beggars, those taken from their homes because of illness, or when abuse in the family is reported. Staff working with these groups in the medley of institutional settings isolated from the community, then, would have their experience of disability coloured by those most dependent upon assistance and most vulnerable to abuse. In this context it is easy to see how disability could then come to be equated with dependency and vulnerability.

The grand historical trend then, I would argue, was for 'support' to be disowned and replaced by 'care'. Consequently, 'support' as a form of assistance for disabled people never acquired formal recognition and never became the property of any specific group of researchers or service providers. With the support approach receding into the background 'care' entered the public health and welfare domain as the most conspicuous and indispensable component of services for disabled people alongside that of medical intervention. The bipolar 'cure' or 'care' approach to disability, and all imputed 'vulnerable' groups, then, became the warp and weft for the fabric making up the national health and welfare service.

It should be noted, however, that support in the family certainly never completely disappeared, although this form of assistance was probably increasingly interpreted in terms of 'caring for the disabled'. I shall argue later that in the 1970s the 'support' form of help, in the guise of 'independent living', began to re-emerge as the newly formed organisations of disabled people developed their own, and spontaneous, alternative to 'care'.

The distillation of 'care' out of the community into the hands of specialist service providers was undoubtedly a long, complex and inexact process which began in the mid-nineteenth century. Its development followed fluctuations in the national economy, commercial demands for access to workers, changes in the fortune of political parties and the ability of parents and disabled people themselves to exercise pressure on governments for change. Given this diversity it is only practical in this paper to indicate the possible key elements which now appear to constitute the essence of professionalised 'care'.

As already mentioned, the disabled recipients of care are in the first instance a very select group of people. These will be the people who have been identified as unable to cope with the 'normal' activities of daily life because of the severity of their physical or mental impairments. While in some cases it might be readily agreed that individuals are taken into care because *their families* cannot manage, on the whole the cause of the difficulty would be attributed to the problem of accommodating a *person with an impairment* in a particular household. This provides us with two fundamental components in the construction of 'care' as a definable service: firstly, that disability creates, causes or is a problem; and secondly, that although this problem belongs to or is a part of each individual disabled person, its resolution requires the active intervention of (non-disabled) others.

The most basic way of dealing with the problem *created by disability* (as discussed here) is custodial - taking the disabled person into care. Once within an institutional sanctuary those providing assistance could then concentrate on ensuring that the elementary conditions for

sustaining life were delivered. Caring for the 'unfortunate' in a residential institutional setting has been extensively analysed. However, this has tended to focus on the nature of the institution's caring regime and its impact on the inmates. The converse, that is the impact of assumptions about 'disability' on the evolution of institutional care, has been neglected simply because the validity of *caring for the disabled* has not been questioned. Thus, in the isolation of the institution, the difficulties faced by disabled people could be addressed *as if these were quite independent of any relationship to the real physical and social world* and the construction of care in this setting could incorporate unchallenged notions of disabled people as incapable of autonomous social functioning. My contention here is that care, as a systematic approach to intervention in the lives of disabled people, developed in isolation from the community and that this isolation was an essential ingredient for the foundation of the modern caring professions and the knowledge base underpinning care policies.

Within the secluded environment of the residential institution, hospital or rehabilitation centre (as these developed over time) disabled people and other dependent population groups placed in these localities are a captive community where the *culture of care* can mature with little of the uncertainties that accompany 'recipient requested' support interventions. Managing the institution and managing patients or residents requires a level of planning that can only become effective with the identification of a number of matters that *must* be dealt with. These matters are wide-ranging and include such concerns as when, and what, materials should be purchased for running and maintaining the estate, at what times should staff be employed, how should the budget be determined, etc. Similar management issues would have to be resolved in maintaining the welfare of the inmates of the institution (the residents or patients), such as when, and what, food is appropriate for their consumption, at what times should they be allowed or assisted to or from different parts of the building, how should resources required by the institution's users be calculated and budgeted, etc.

Solutions to these compelling administrative problems require well-defined itemised inventories. Leaving aside management issues related to the building and its maintenance the question for staff working directly with patients or residents is what is the best administrative means for constructing an inventory of those matters related to the welfare of the residents so that the appropriate resources can be made available? In my opinion, during the lengthy period in which the 'care' approach to interventions matured in isolation from direct contact with the community, the identification of *needs* was to become the pre-eminent tool in composing an inventory of an individual's problems requiring physical and human resources. The task of the *expert carer* (as the work of staff in these places of care were transformed into professions) was to carry out the needs assessment and then administer to the resource provision (sanctioned by legislation).

In this section I have argued that a 'culture of care' evolved when the support and care forms of assistance were separated, the 'care' component was isolated from the community and then transformed into a professional service. The key features of this culture may be summarised as:

- care and support forms of assistance are separated
- care becomes a specialism during its incubation and while isolated from the community; support declines in significance
- problems in social functioning are attributed to personal defects (impairments)

- impairment is thought to result in disabled people becoming dependent on designated service providers (the care professions) who are socially responsible for dealing with vulnerable groups
- the identification of needs becomes a central focus for determining the allocation of resources
- 'medical', 'administrative' and 'individual' models of disability add variation to the final shape of the culture of care (with the medical profession exercising overall hegemony)
- the culture of care is deliverer determined (ie. no service users contributed to its development or the formulation of the service details which it encompasses, standards are set by the care professions for themselves by themselves)
- in the culture of care the real client is not the recipient of the assistance because funding for the service does not originate with the users.

### **Regulated Community Care**

A builder or designer can always conceive of ways to improve a house. The only constraint on removing a wall, altering a room, adding a floor or extending the garden are the financial resources and amount of time available to make the changes. It is in the nature of being a good professional to constantly seek creative ways of applying one's expertise. This has certainly been true of the caring professions. Working with a captive and dependent group of people with the objective of bettering their health and welfare is an open invitation for the dissection of patients or clients into a plethora of problem areas where one's skills can be applied and improved. With the analysis and assessment of each problem area comes an infinite expansion in the development and regulation of professional expertise and resource requirements. The creation of large custodial and remedial institutions (especially the asylums, and later hospitals for the 'mentally ill', 'mentally handicapped' and 'chronic sick') provided an ideal environment for collecting together 'vulnerable' groups of people where formalised approaches to intervention had the maximum opportunity for the caring culture to germinate.

While this growth originated in large custodial institutions it was the creation of a National Health Service that sanctioned the massive professionalisation of care. With this came a new breed of worker, nurtured in the culture of care, and dedicated to remedying the health and welfare problems of their patients (later according to the fashions of the time also referred to as clients and service users, etc.). The growing number of 'practitioners' in the caring services precipitated a demand for more efficient therapy, training and courses focused on vulnerable groups, and finally qualifications and career structures with higher salary scales. As the expertise of each class of carer became more identifiable, and professionalised, *faith* in the singular importance of 'care' turned into *fact*. The transformation of occupational therapy from its beginnings as a way of filling the time of convalescent (and chronically ill) patients to a planned schedule of functional activities specifically designed to achieve physical and mental goals exemplifies the motive logic of the 'care' culture. No one questioned whether a profession, which models the correct way of doing things for others, should legitimately originate from deliverer determined practice involving taking care of people who are removed from the community. Nevertheless, the demand for occupational therapists seems endless, particularly with the advent of community care policies. In the context of 'care' there is a logic in the growth of the professions alongside a persistent shortfall in the numbers of practitioners.

Considered from the perspective of disabled people the institutionalisation of 'care' has been a mixed blessing. As the boundary between support and care crystallised care workers were able to focus attention on the identification of physical and mental deficits where aids, environmental adaptations and equipment can assist individuals achieve greater approximation to 'normal' functioning. However, with each improvement in independent functioning disabled people gained opportunities to formulate and exercise their own judgements about forms of assistance appropriate for themselves and who ought to have the right to determine the nature and structure of the helping service. The expanding professionalisation of care services creates its own ambiguities in the minds of the 'users'. Experts who broaden one's experience and vision of what is possible are valued while at the same time the intrusive attention of these workers inevitably raises anxiety about their continuing influence over one's lifestyle. The institutionalisation of care not only concentrates attention on the individual's deficits, or problems, but in so doing identifies and reinforces the boundary which separates disabled people's right to specialised help from that of the 'normal' citizenship right to public utilities. In the 'care' culture disabled people's rights are detached from basic human rights; such as the right to choose, the right to privacy and, most important for an active citizenship, the right to have a defining influence on the nature and structure of the supportive services that one is entitled to use. In the 'culture of care' it is a self-evident fact that disabled people are *vulnerable, special and dependent*; others therefore make the decisions.

In my view a fundamental internal defect in the collective institutional provision of 'care' eventually made its continuing expansion isolated from the community unsustainable. In the long run this defect appears to have resulted in the following irresolute problems:

- 'care' generates a bottomless demand for resources managed by an increasing population of service providers targeting on finer and finer subdivisions of people's bodies and lives;
- people who are in various forms of care isolated from the community where interventions are aimed at maximising functional 'normality' and then return to their own homes are often confronted by disabling environments that the development of personal skills cannot resolve;
- in the late 1960s there was a sudden and rapid growth in dissatisfaction with the cumulative experience of incessant 'assessments' which nevertheless still left gaps in provision and at the same time left administrative control over disabled people's citizenship rights intact;
- the growth in provision of 'care' services had little effect on disabled people's access to mainstream national institutions and public utilities;
- despite any commitment to independence goals growing provision of 'care' was often experienced as increasing passive dependency upon experts.

With increasing government, public and user awareness of the unresolvable problems resulting from the provision of care in isolation from the community the case for a shift to community based services became overwhelming. That these problems may have arisen as a consequence of separating 'care' from 'support' and then institutionalising the former while stifling the latter did not feature in the debate about developing a more effective national approach to the provision of services for 'vulnerable' groups. The caring ethic and attendant culture, then,

began to migrate back into the community where it clashed, collaborated or merged with existing social and welfare service suppositions.

During its exile from the home environment of users (the so-called vulnerable groups, especially disabled and older people) the philosophy of 'care' had become the property of very influential professions. They were in a particularly advantageous position to discuss, research and promote their approach to intervention because there was no real alternative to the care culture. As far as disabled people were concerned one either cured or cared for this problem group. With the introduction of community care legislation, as the health and welfare services began to fragment under the stress of maturing unworkable policies, the caring professions faced no rivals in securing cultural domination over the new community based services.

The implementation of community care policies, however, immediately ran into three main intractable problems:

- The recipients of the new community based approach to services were often already familiar with the power of deliverer determined 'care' in defining what are appropriate physical and mental standards and consequently wary of even greater control over their lifestyles in the community.
- Whatever the rhetoric an important reason for shifting services into the community was the State's need to limit or even reduce the ever expanding costs of 'care'. Since the crises in institutionalised care was already exacerbated by shortages' in staffing and resources, maintaining or cutting funding could only increase the problem of implementing care in the community. As a result the development of community care almost immediately triggered complaints about inadequate funding and personnel. With 'care' at its heart community care was not proving to be any cheaper than the system it was meant to replace. Indeed, with staff leaving because of poor pay and working conditions the ability to attract and maintain adequate numbers of carers now seems even less viable. Taking 'vulnerable' people into custodial care is once again threatening to return (especially in relation to 'mental illness').
- In the 1960s and '70s the fragmenting health and welfare services strengthened people's wish for an improved supportive service which could provide assistance in realising lifestyle aspirations, rather than having one's needs cared for. This galvanised disabled people into advocating and eventually setting up their own support systems. These have generally been located in the offices of voluntary organisations or Centres for Integrated Living (also referred to as Centres for Independent Living). Not only do these services represent the embryonic return of 'support' in the community but also a return to the original tension between the care and support components of help. With full backing from the State, experts, families under stress, the vastly expanding numbers of unpaid carers and the prevailing culture of care, community care is asserting its hegemony over all services in the community. However, disabled people are now championing their citizenship rights in strong self-help organisations which are much clearer about the kind of assistance and mainstream utilities that are wanted. 'Care', as currently conceived, appears to be universally disliked by service users. This tension is certain to increase, making the new community service, with its skewed emphasis on 'care', unworkable.

To these problems we can add an entirely new set of challenges to the concept of community care. Amongst the most obvious are:

- The drive for efficiency, which was integral to moving 'care' back into the community, has generated a whole new battery of needs assessments. These are far more elaborate and intensive, creating a new round of tension between deliverer determined and recipient requested notions of appropriate resource allocation. Successful living in the community as an integrated citizen demands access to support systems which can assist in the attainment of unpredictable aspirations. Indeed, 'unpredictability' in deciding what is important for one's own lifestyle can be regarded as an essential component of being human. This is a right (even if substantially absent for very many people) that is expected in the mainstream community and necessitates a different approach to reckoning an individual's objectives from that of the needs assessment procedures prescribed in the culture of care.
- Providing assistance when entering the home of a 'client' is not at all the same as delivering a service to a person isolated from the community " Within one's own home, no matter how one construes what is wanted or needed, the recipient of help has some idiosyncratic control over the identification of barriers to be addressed. While the carer, or the professional assessment, may identify a healthy or correct way of carrying out a task or arranging the home environment a disabled person in her or his own home, for example, may have different inclinations which will take precedence. Entering a client's home with prescriptions about the 'right' response to different types of impairment (guided by the medical model of disability) may well be experienced by the service users as oppressive.
- The power exercised by the caring professions in determining what is appropriate for 'vulnerable' people that is maintained by the boundary between special and mainstream services is not unchallenged in the community .Disabled people in the self-help organisations that they have created see themselves as part of a diverse society where 'special' and 'mainstream' services and utilities are not mediated by 'carers'. The growing demand for 'rights not charity' exemplifies a simmering conflict with the hegemony of 'care'.
- Being a citizen is an active exercise in identifying and realising one's comprehensive ambitions. Whatever the intention a holistic approach to community care, which is driven by idealised normal functioning, cannot actually facilitate such self-control because it is an exercise in patching together the historical division of disabled people's lives into professional concerns. The resulting boundary between different caring professions inhibits the active role that disabled people can play in defining and participating in assistive networks.
- The emergence of a 'disability culture' has set the stage for an alternative, and I believe we might say, holistic drama in which care in a society providing equal opportunities for all can be subjected to a thorough re-examination. Na"ive presumptions which underline the late 1990s growth in courses, training and qualifications in a one-sided approach to community care are bound to attract increasing hostility from service users as they explore the importance of 'support' in their own political campaigns for civil rights; academic courses and research; auditory, visual and performing arts; and self-help services.

In many respects the appearance of these endemic and new problems are not surprising. They are exactly what can be expected when 'support' is excised from the provision of assistance within mainstream society. In other words the return of 'care' into the community has

highlighted the one-sided nature of professional assistance that was created when a boundary was erected between the original mix of care and support provided in the home's of disabled people and the provision of segregated care delivered by specialists. 'Care' cannot be mainstreamed (return into the community) without resurrecting the return and provision of 'support'.

Faced with this problem professional carers have tried to fill the gap in service provision (the missing support) by increasingly engaging disabled people (and other 'vulnerable' groups) in the process of refining community care. In the first place there have been a number of determined consultative exercises in which disabled people were invited to make presentations at professional conferences and in professional journals. This has been followed by professional/user collaboration in research projects; such as the correspondence in views between providers and recipients on the effectiveness of service delivery. More recently, collaboration has led to 'consumer' participation in the training of caring professions (such as social work). The latter appears to be concerned with improving quality control in training and service delivery. However, in all these exercises the agenda is being set by the caring service providers; that is, the collaborative exercise is deliverer determined. 'Care', as a concept in practical intervention for specific 'vulnerable' social groups, is not questioned. Consequently, whatever the intention, the function of engaging users in service appraisal ends up being an exercise in providing legitimacy to a impoverished community care programme. The recipients of 'care' are now being asked to lend 'support' to both lay and professional carers! Perhaps in this context it is no accident that one of the rapidly growing areas of concern is the need for support networks to assist carers.

I believe the lesson emerging is that assisting disabled people (and other specific groups) in the community can only become viable when the concept of 'aspirational support' is addressed -that is, how to construct services which are in essence concerned with supporting disabled people realise their personal aspirations. This, it seems to me, requires an honest admission that community care cannot succeed because a key aspiration of care receivers is not to be a vassal of carers. This is more than not just wanting or needing 'care' but recognising that care and support {; need to be reconciled, repackaged and then *offered* to an informed citizenry who perceive the new form of social assistance as just one of the many mainstream utilities at service to the public. I am arguing, here, that the fundamental defect in the culture of care is that the conceiving boundary between care and support eventually gave birth to a boundary between providers and users.

### **Aspirational Support**

Of course, the majority of disabled people, like most other 'vulnerable' groups, remain in the community where families provide an imperfect mixture of support and care. As I have suggested before, this is almost inevitably perceived within the framework of the dominant culture of care as involving a struggle to care for one's dependent family members. However changing circumstances, including the real gains facilitated by carers and economic affluence, as discussed earlier, provided an opportunity in the late 1960s for some disabled people to gain access to mainstream society and the social debates of the *time*. This afforded both the stimulation and opportunity for the *creation* of a new breed of self-help organisation which advocate full integration into mainstream society. Instead of accepting the prevailing view that their impoverished social circumstances is the product of personal physical and mental

impairments their situation is now being attributed to disabling barriers created by a world designed for able-bodied living. Criticism of the medical model in other areas (such as health and midwifery) was applied to disability and the social model of disability was adopted as the framework for developing recipient requested support services.

The key feature of this development is that it is the aspirations of disabled people that is guiding the identification of disabling barriers that need to be removed, the resources that are required and the services that need to be put in place. In practice there is no separation between the political campaign for civil rights legislation and making resources available in a support system to assist people identify and realise - their lifestyle goals in a barrier-free society. This enables interventions to perceive individual idiosyncrasies within holistic concerns. 'Disability studies' and 'emancipatory research' are two areas wholly created by disabled people where the new paradigm is being developed.

Care in the community, however, with its deliverer determined orientation is still being pursued as if there has been no fundamental shift in the balance of evidence which demonstrates the unworkability of this one-sided approach to community based services. Indeed, where the community care philosophy has complete ascendancy, such as in academic institutions, disability studies is being absorbed into the care paradigm. Of course this effectively suppresses the emergent emphasis on the provision of support that disabled people are bound to champion. I have not the slightest doubt that in these circumstances service users will ultimately attack the academic veracity of the community care qualifications that are awarded.

On the ground, in the community, the fragmenting health and welfare services have opened a slot where disabled people have managed to start their own services guided by the social model of disability and, although perhaps often not recognised as such, where they are developing and implementing interventions based on the principle of 'support'. These are often referred to under the heading 'independent living', and the facilities as 'Centres for Independent Living' (CILs). This can be rather confusing because the term 'independence' is well-established in the language of 'care' and perhaps reflects the extent to which the culture of care has been absorbed into the consciousness of prevailing service users. The term 'integration' is also used to highlight disabled people's aspiration to integrate into mainstream society with the concomitant goal of integrating their own service ideas with enabling community based services. CILs, in this case, refers to 'Centres for Integrated Living'.

These developments are still at a very early stage and under considerable threat from economic constraints and a still strident advocacy of community care by non-disabled service providers. In essence, while community care remains an esoteric service independent of mainstream provision, organisations of disabled people have invested considerable and growing attention on mainstreaming their needs alongside society's diverse population groups and many faceted cultures. An important constituent of this development has been the creation of a disability culture challenging the hegemony of the caring culture. In my view the unfolding social model of disability not only needs to rediscover the importance of the long suppressed 'support' component of assistance located in the community but champion its rightful place, at the very least, as an equal contributor to the formation and transformation of the next generation of service interventions.

While, in many respects 'care' can be interpreted as irresolute support it would be incorrect, in my opinion, to regard the availability of care as having no relevance to disabled people, whatever their age. The real challenge in developing appropriate mainstream community services based upon equal opportunities for all, is winning over service users, providers and policy makers to the notion of disentangling appropriate skills located in the training and qualifications of the current caring professions together with the hitherto unknown and neglected skills that may be informed by a support paradigm and repackaging these into new community based professions. This model of provision has been called 'resource consultancy'. The new community worker (Resource Consultant) would need to be conversant with care and support skills which are at the service of aspirant citizens who face social and physical barriers in achieving their personal goals. This lifestyle orientation would be geared towards assisting people attain their personal goals and aspirations. The focus of any identification or assessment procedure would not be on the origin and meaning of an individual's deficits but making resources available for future goals. This could not be guided by any stereotype which sees disabled people in terms of pre-ordained dependent lifestyles.

Unravelling the care and support components of community based assistance and repackaging the exposed skills more appropriately according to the perspectives of the principal resource users could generate more profound opportunities for users to contribute truly innovative approaches to the services that they use. This could create a mutually healthy learning relationship between disabled people and service consultants.