

What future for care?

Viewpoint
Informing debate

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Care is a contentious policy concept. Numbers of people needing care are rising. Radical change is planned for care policy to increase choice and control through 'personalisation'. A new conceptual framework is now needed to take forward policy and practice for the twenty-first century if people's rights and needs are to be met.

Key points

- Attitudes to care are complex and contradictory. The priority, status and funding given to both paid and unpaid care and carers are limited and widely seen as inadequate.
- Service users see the low value that is attached to care as resulting in a lack of adequate, appropriate, reliable and good quality services and support.
- There have been increasing pressures towards the 'commodification' of care, and for it to be reduced to a set of standardised procedures and services.
- The 'apparent ordinariness' of care is deceptive and can often hide sophisticated, highly skilled and much valued approaches to personal and social support which address difference and are committed to social justice.
- Care can serve both to reinforce and to challenge inequalities and discrimination.
- Two ideas have developed – the feminist ethic of care and disabled people's philosophy of independent living, which offer competing policy approaches to care for the future.
- Major changes are planned for social care policy and practice, based on the idea of 'personalisation'. This aims to match support to the rights and needs of the individual rather than slotting them into existing services, and places an emphasis on 'choice and control' for the service user.
- Mainstream public policy is as much creating as addressing support needs that require to be met.
- While the demand for support is increasing, the supply of both formal and informal support is subject to increasing pressures.
- The term 'care', a relatively recent arrival to public policy, has exceeded its sell-by date. It is undermined by its association with inequality and discrimination. A new language and conceptual framework is now required if people are to have the support more and more of us need to live our lives fully and on equal terms.

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Where are we now?

What is this life, if full of care,
We have no time to stand and stare?

(W.H. Davies)

Care is at a time of fundamental change. Social, cultural, economic and demographic pressures all highlight the need to re-examine it. Service users have developed an influential discourse which challenges it. Government is committed to reforming it. There is no agreement about the form it should take, the conceptual basis on which it should rest or how it is to be funded. Service users' experience of care, as they report it, is at best mixed, at worst poor.

Who wants care?

While modern policy has been framed in terms of care, little attention seems to have been paid to what people might feel about the idea. The reality seems to be that while care might be regarded by many of us as a good idea in principle and something that some people might need at some time, few of us identify with it for ourselves and actually want to be 'cared for' in this sense. There is a strong reluctance to see ourselves or to be in this position, because it implies dependence. Care is a concept that is primarily associated with children. Models for adult caring have tended to be borrowed from childcare and grow out of the unequal relationships associated with looking after children. This has been the basis for many people's assumptions and understanding of such care.

The emergence of care

Care has emerged as a key concept in welfare and public policy, of similar significance to family, community, poverty and renewal/regeneration. Care wasn't much used as a term under the Poor Law and originally terms like social services and assistance were more often used in the creation of the welfare state. If anything, the use and importance of 'care' has grown rather than diminished in recent years. It has now become the descriptor of a discrete area of policy – social care. Following the creation of the welfare state, the talk was more of personal social services and social work. This terminology has now been significantly replaced by one based on care, for example social care, community care, primary care and care in the community. A set of new key organisations has also been developed framed in these terms, including the Social Care Institute for Excellence, the General Social Care Council, Skills for Care and the Care Quality Commission. A sub-set of roles and tasks has been developed framed in terms of care, including care management, care planning, care package, extra care housing and care worker.

At the same time, care is a key concept in ordinary understanding. The term is commonly used in colloquial conversation. In this sense, 'care' is something that matters to most of us. Significantly, it is also a word with multiple meanings and this is perhaps at the heart of the issues it raises. Care has at least three key meanings which are relevant to this discussion. More complex still, these meanings can be interrelated:

- feel concern or interest;
- look after; and
- feel affection or regard.

We may care for someone in the sense of loving or having feelings for them and care for them in terms of looking after them. This second meaning of caring has mainly been understood in relation to children and child care and this has undoubtedly influenced understandings of it in relation to adults. Because we as human beings feel love and empathy for others, we have concerns for them, which mean we will want them to be looked after and may be both ready and expected to take on that role ourselves. Thus the two meanings of care may be juxtaposed and indeed can become opposed, in both formal or informal roles.

The downgrading of care

Care in public policy is now most associated with social care. But it has also long been linked with medicine and health, particularly when much of their role was caring rather than curative. Thus our founding image of nursing is of Florence Nightingale as ‘the lady with the lamp’, offering care and compassion. However, the history of health care can be seen as one increasingly moving towards the prioritisation of scientific and technical expertise. The evolution of professionals can similarly be seen as heading towards becoming a technical expert.

In both health and social care, caring ‘tasks’ have increasingly been hived off to workers operating in lower status ancillary roles. This has been happening in both nursing and social work, with professionals increasingly divorced from the hands-on contact of undertaking routine care tasks with service users. While social workers do not have a comparable scientific competence to that associated with nurses and doctors, being reframed as care managers has had similar effects. The holistic role of the professional can be seen to be under challenge as they are expected, and in some cases come to expect, no longer to take on ordinary caring tasks. Given the importance of the relationship with practitioners highlighted by service users, the overall effect may be problematic.

Complex and contradictory attitudes to care

Attitudes to care are complex and contradictory. The prime minister recently hailed informal carers as heroes. Yet the levels of benefit that informal carers receive are among the lowest. The terms and conditions of care workers are comparable to those of supermarket shelf stackers. Many of the groups who need support in our society are groups who it might be expected would be seen as ‘deserving’, for example, older people, people with learning difficulties and disabled people. Yet the under-funding of care services for them is widely recognised as a chronic and long-standing problem.

The low status of care

Social care is a policy about which there is little public awareness or understanding. It has long commanded limited political priority and inadequate funding. While the NHS continues to be a universal service, predominantly free at the point of delivery, social care

remains a residual service, means tested and operating with locally inconsistent and narrowing eligibility criteria. Service users repeatedly highlight the inadequacy, unreliability and poor quality of much social care provision.

The low status of care workers

Judging by their poor levels of pay, conditions of work and levels of training, a low value is placed on care workers. This is reflected in high turnover rates and problems with recruitment and retention. It is a workforce where women, immigrant and black and minority ethnic workers are over-represented. It is also an ageing workforce. While service users praise positive practitioners, existing conditions do not offer a basis for ensuring a reliable, good-quality workforce. It is difficult not to see connections between the treatment of the workforce and poor practice. People with learning difficulties, for example, repeatedly highlight problems of poor practice and bullying from care staff (Taylor *et al.*, 2007). Problems of abuse and neglect regularly emerge in social care settings, particularly in residential institutions.

Making care mechanical

In both domiciliary and residential settings, care has come to be conceived as a range of basic tasks to support people’s daily living in terms of daily maintenance, for example getting them up and putting them to bed, dressing them, feeding them, helping them with toileting. This may also include social maintenance in terms of cleaning and shopping. Care is increasingly organised as a set of mechanical tasks. The range of these tasks has tended over time to be restricted and sometimes divorced from their human associations. The skill and experience required to undertake these often intimate and potentially invasive tasks in a sensitive, respectful and positive manner tend to be overlooked. The emphasis has been on outcomes rather than process and the opportunities they offer for communication, social contact and relationship building have been underplayed. Service users frequently talk of the succession of ‘strangers’ who come into their house to provide ‘care’, that they may never get to know or have more than perfunctory association with (Beresford *et al.*, 2005; Branfield *et al.*, 2006). Initial contact and assessment for eligibility for support is now in some cases carried out through call centres with unqualified staff using standardised scripts.

The commodification of care

These developments have been associated with and reinforced by the increasing commodification of care. People have increasingly been required to pay for their care, either through the state system or as 'self-funders'. Since the community care reforms of the early 1990s, care providers have increasingly come from the private sector, with large multinational companies playing an increasingly important role in the supply of both residential and domiciliary services. They have so far shown themselves most capable of providing standardised services, based on economies of care, rather than matching the individual needs of service users.

The creation of the 'informal carer'

Youth is full of pleasance, age is full of care.
(William Shakespeare)

The terminology of 'care' is a relatively recent arrival to public policy. The term and concept of 'informal carer' is even more recent and can be traced to the mid-1970s. Its emergence seems to relate to four key different but interrelated developments of lasting importance for the practice and conceptualisation of care:

- political and economic change;
- the move to community care;
- feminist discussion of the role of women; and
- the scale and hardship of unpaid familial 'caring' in society.

Political and economic change

Political and economic change were the context for the discovery of the 'informal carer'. Major international economic recession was the trigger for new restrictions on public expenditure, as well as encouraging the development of globalisation and a political shift to the right. The new political right was hostile to state intervention and expenditure and strongly supportive of the market and individual responsibility. It disliked welfare interventions, which it saw as encouraging dependence and undermining wealth creation.

The move to community care

These broader changes coincided with the running down of expensive institutional services for service user groups, including people with learning difficulties, mental health service users and disabled people and a shift to a philosophy of community care. This was to mean people supported to live locally, participating alongside other members of the community. At a time of restricted public expenditure and political devaluing of state intervention, this became an opportunity to talk about care by the community. This was presented in terms of building on and supporting the informal and voluntary care provided by kin, neighbours and in communities. There was increasing ideological interest in shifting responsibility for people to take more care of themselves and each other, both through making their own financial arrangements for formal services and through increased reliance on unpaid 'informal care'.

Feminist discussion of the role of women

The feminist critique, initiated by Janet Finch and Dulcie Groves (1983), highlighted that such informal care mainly meant care by women within the family, imposing an unequal burden on them to take on caring responsibilities, without real choice and with deleterious consequences for their autonomy, health, social relationships, income levels and social security.

The scale and hardship of unpaid familial 'caring' in society

Interest in carers was given force by the very large numbers of people, particularly women, who were providing such support, in some cases for many hours a week over long periods, frequently with minimal formal help or recognition. At this time national and local carers' organisations and groups grew in numbers and visibility.

Legitimising the issue

Much of the support people have has historically long been provided by those close to them rather than through formal provision. New to the discussion of care that developed in the 1970s was that now this was stressed as a reality that needed to be recognised and supported, rather than an issue that the state should intervene in to change, for example through the making of more formal provision. The emerging rhetoric was of 'caring for the carers' to enable them to maintain their caring responsibilities. Thus the maintenance of informal caring was assumed in the planning and provision of broader health and welfare policy, and indeed some critics argued that it came to be premised on increasing responsibilities for informal care. Research however shows that providing services for older and disabled people is the most effective way of supporting carers (Glendinning and Arksey, 2008, p223).

Definition of the informal carer

An informal carer is generally defined as someone who looks after another person – a relative, neighbour or friend, but predominantly a relative – who has an impairment, mental health problem, or (chronic or life-limiting) illness. Most caring follows from a relationship and is based on feelings of love, commitment and responsibility. The term has come to be associated with people who act as carers in an informal or unpaid capacity, although it has also been attached to paid workers. Six million people are identified as carers. The 2001 census recorded that more than one fifth of carers were caring for 50 or more hours a week. One and a half million were aged 60 and over; 350,000 were aged 75 and over (Glendinning and Arksey, 2008, p220). Informal carers are the main source of help for older people in all developed societies.

The problem of carer policy

In 2008, Caroline Glendinning and Hilary Arksey identified four approaches to carer policy in health and social care. These are:

- carer as resource: treating carers instrumentally as a resource to be used, supporting their well-being to maintain care-giving;
- carers as co-workers: recognising their interests, but still primarily to maintain their functioning;
- carers as co-clients: where carers' well-being and needs are recognised in their own right and services provided to support them; and
- the superseded carer: where services are provided to support service users, enabling carers to achieve independence.

They conclude that current policies are primarily based on the 'carer as resource' model and suggest that 'until the conceptual model underpinning it shifts, it is likely that carers will continue to experience negative outcomes in their health, employment and finances' (Glendinning and Arksey, 2008). The 2008 Carers' Strategy, introduced as part of the Government's radical review of social care, does not represent a shift from this approach. While carers' organisations repeatedly seek to present informal caring in terms of the savings it makes to government (calculated in 2007 at £87 billion – more than the annual spend on the NHS), this has so far failed to secure major investment for informal care (Glendinning and Arksey, 2008, p219).

Formalising the informal; arguing against the formal

If I'd known I was going to live this long, I'd have taken better care of myself.

(Eubie Blake, American ragtime pianist, on reaching 100)

Two apparently contradictory developments in care can be identified over the last 30 years. They relate to the increased emphasis placed on unpaid care and the questioning of paid care. Both, however, can be seen to be about the *restructuring* of care.

Policy interest in unpaid care from the late 1970s was presented in terms of fostering self-help and mutual aid, enabling people to look after each other in local communities. This was highlighted as the traditional, natural and often preferred way of people looking after each other. However, it can also be seen as an extension of state intervention, seeking to formalise and organise people's roles and relationships, restructuring them in terms of 'informal care'. Part of the role of care management was seen as managing informal care. New paid roles, like care organisers, were created to encourage and focus 'local caring networks'. This was often done in unhelpful and damaging ways, colonising people's networks as a resource to be harnessed and controlled by formal social services, operating under increasing funding constraints. Both patch and community social work were conceived in the early 1980s on this basis. A range of methods were adopted, from 'supporting carers', to initiating mutual aid and self-help groups and formal volunteering. There was a particular reaction against this from black and minority ethnic communities, who felt that their informal networks were being both misinterpreted and appropriated.

At the same time, ideological arguments developed that paid care was a measure of the failure of people to care for each other (despite the evidence of large-scale informal caring). The normalisation movement, for example, saw paid workers as part of the problem for service users and emphasised the importance instead of voluntarism and developing informal relationships with 'valued people'. Organisations like the Natural Death Movement argued against the involvement of professionals in death and dying, seeing support from people's loved ones as preferable. Such reactions against paid care workers, including social workers, fed into broader ideological reactions against professionals. They took little account of the degree to which societal change limits the availability of informal care, the potential benefits of paid support, people's own personal preferences or, indeed, the division of labour and dominance of employment in western societies and economies. In relation to death and dying, for example,

people with life-limiting conditions highlight the value of the support they receive from social workers and make clear that either they didn't have anyone else to turn to, or they would often be unable or unwilling to seek such support from those close to them (Beresford *et al.*, 2007).

Self-care

Another concept of care has also recently emerged. This is the idea of self-care, which has come from the state health system. It is seen by government as one of the building blocks for its idea of a patient-centred health service, with a role to play both in keeping people healthy and for people with long-term conditions. Methods identified to take self-care forward include the expert patient programme, where patients get a better idea of managing their own long-term conditions, and self-care skills training and self-care support networks. Self-care is conceived of as both an opportunity and a resource, 'deploying the biggest collaborative resource available to the NHS and social care – patients and the public' (Department of Health, 2008).

It can thus be seen as another state-led attempt to harness people's care, in this case self-care, to its own agenda. It is framed in terms of empowering patients to take more control over their lives. But again it focuses primarily on people's individual responsibility for taking care of their health, without necessarily taking adequate account of broader social, class, economic and other factors that may impact upon them and their health and well-being. Bearing in mind that the constant message from modern research has been that health inequalities are closely related to social and economic inequalities, this can be seen as both a limited response and a very partial understanding of self-care. This is self-care based on the perceptions and concerns of government, rather than one generated by patients and service users themselves.

The particular contribution of professional support

Rose Barton makes an important point in relation to caring when she comments that 'the apparent ordinariness of caring is deceptive' (Davis, 2000, p43). This comment applies to both informal and formal care. A study of service users' views of specialist palliative care social work highlights both how much they value it and its unique and complex contribution to their support. Important aspects they emphasise are:

- the focus of the social worker on the individual, their social circumstances and the interrelation of the two;
- the ability to address psychological, material, spiritual and other needs;
- social work's commitment to social rather than individual or medicalised models;
- the nature of the relationship with the social worker: bounded, yet flexible;
- the importance of human qualities of warmth, empathy and respect;
- the ability to listen, provide reliable information, be non-judgemental;
- the provision of advocacy, advice and support;
- their use of a range of approaches, including individual, family, group and community work approaches; and
- an anti-discriminatory approach, valuing diversity and supporting equality.

Significantly, however, social work, while a profession that has pioneered anti-oppressive working, continues to be devalued. Its professional commitment to supporting people's self-determination and autonomy has been undermined by it being subjected to increasing control as 'care management' (Dustin, 2007).

Learning from other approaches

Western analysts interested in re-evaluating care have also looked to different approaches developed in other cultures and societies, notably in the majority world. There, models have developed based on extended family, kinship, faith, village and tribe, with support, however, generally provided by women. In some countries such patterns of support has been disrupted by AIDS. Globalisation associated with accelerated economic development, coupled with restrictions on public expenditure, has also had major effects, challenging traditional support arrangements while restricting the provision of public alternatives. Two key expressions of such globalisation can be identified:

- Major socio-economic change and increasing urbanisation, impacting on traditional ways of living, networks and ways of providing support.
- The export of western approaches to support (including medicalised provision, residential institutions, community based rehabilitation (CBR) and professional social work).

Valuable insights are likely to be offered through the emergence of new forms and structures of 'care' in the wake of the collision between old and new social and economic structures.

Care and difference

Addressing issues of difference, in terms of age, gender, sexuality, disability, ethnicity, culture, belief and so on, has particular importance in care. This is because care is often involved with people:

- with difficult lives or at very difficult times in their lives;
- in intimate aspects of their lives, emotions and bodies;
- in relation to key family, child, partner and sexual relationships;
- who may have different understandings of gender roles, disability, age, sexuality and spirituality;
- with widely varying traditions, customs and beliefs;
- from a wide range of communities;
- where rights and entitlements may be affected; and
- where issues of difference may have a central bearing on what is and is not helpful and appropriate.

Care also needs to reach groups facing particular exclusions and barriers. These include people:

- who communicate differently;
- within the prison and criminal justice system;
- who are travellers or homeless;
- with multiple impairments;
- in residential services; and
- in rural environments.

Social care has the potential to reach these groups and address these issues through its development of anti-oppressive (AOP) and anti-discriminatory practice (ADP). However the downgrading of care and the low levels of training among many face-to-face workers can be expected to create problems in addressing such diversity.

Particular issues for care are raised in relation to ethnicity and nationality. These relate to:

- broader inequalities of opportunity, disadvantage, exclusions and discrimination experienced by BME groups and communities;
- the use of care and welfare systems to police immigration;
- particular health issues and incidence of impairments within different BME communities and migrant groups;
- additional barriers, isolation and restricted access to support experienced by refugees and asylum seekers;
- the persistence of racism in the care system; and
- the unfamiliarity of BME groups with and/or their reluctance to use care services.

We know that:

- some service users are disadvantaged and face serious discrimination and risk in the psychiatric system;
- BME communities are less likely to access valued care services, like palliative care and counselling services in the mental health system, while more likely to be subjected to the controlling aspects of provision, for example within the care system for young people and sectioning in the psychiatric system;
- people with learning difficulties from BME communities experience racism and bullying in the service system both from staff and other service users; and
- crude and inaccurate assumptions continue to be made about the nature and availability of support through extended family networks in BME communities by the social care system.

Other issues for care are now also being highlighted. These include:

- the emergence of Islamophobia;
- the isolation of migrant groups and their vulnerability to abuse;
- the need to move beyond understandings of people's complex identities in terms of 'multiple disadvantage' to 'simultaneous oppression';
- tensions in meeting the need for choice in terms of providing separate services for particular minority ethnic communities and making all services inclusive to everyone;
- changing understandings of ethnic identity as groups mix in society; and
- the importance of supporting and adequately funding local BME community and service-user controlled organisations.

New ideas for moving forward

To say we do not care is to say in the most literal sense that 'we choose death'.

(Barbara Ward, writer and educator)

Two key new discussions have emerged relating to care in recent years. Both are aimed at having a transformative effect. The first is based on a feminist ethic of care and seems to have been developed mainly by feminist academics. The second, the development of the social model of disability and philosophy of independent living, originated with and has been developed by disabled people and other service users.

The feminist ethic of care

This critique of care starts from the changing nature of the family and networks of relationships, resulting in diverse living arrangements. It has addressed the care of both children and adults. It challenges both the view that consumerism has fostered a narrow selfish individualism and the emergence of 'self-actualising' men and women less restricted by obligation and duty. It argues that while the family has changed significantly, there has been no diminution of commitment to caring, but rather a change in the shape of commitment and how it is being expressed and realised.

As Fiona Williams highlighted from the five year *Care, Values and Future of Welfare* project (CAVA) funded by the ESRC:

People are less dependent on blood or marriage ties; their commitments extend across different households linked by dissolved marriages, reconstituted families, non-resident partners and transnational kin. There may be more blurring of kin, ex-kin, sexual partners [including same-sex partners] and friends in people's networks, but little of this indicates a loss of commitment itself. When faced with dilemmas they generally negotiate 'the proper thing to do' in and through their commitment to others.

(Williams, 2004, p7)

This critique also foregrounds the effects of other broader social changes. More mothers are in employment, the UK is an ageing society, more people live on their own and global migration can mean that family commitments may cross continents (*op. cit.* p6).

Williams and her colleagues concluded that in these circumstances people ask themselves 'How can I best manage this?' and proceed on the basis of a set of practical ethics. These include:

- being attentive to others' situations;
- accommodating one's own needs to those of others;
- adapting to others' changing identities;
- being non-judgemental and open to making and receiving reparation;
- acknowledging the fairness, respect, care, communication and trust valued by children.

Advocates of the feminist ethic of care argue from the evidence that policy-makers underestimate the importance people place on care and commitment in their lives. They take the view that 'care' is 'usually absent from official discourses of citizenship, participation and civil renewal' (Barnes, 2007, p59). Instead they advance an ethic of care that promotes it 'as a political value as well as one that concerns inter-dependencies between people in their private lives (*op. cit.* p62). They call for the valuing of care and the balancing of the work ethic with the care ethic as a more effective basis for policy development. They emphasise the importance of providing time and support for such care and challenging the complex inequalities in care that currently exist.

Some commentators also argue for a much broader understanding of care and caring, for example taking it to include:

Everything we do to maintain, continue and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, ourselves and our environment.

(*op. cit.* p62)

Barnes argues for a wide range of public policies to be based on the feminist ethic of care, including civil renewal and social cohesion as well as social inclusion and public engagement. She argues that 'the relational aspects of care and the significance of care contributing to social justice are given scant attention in this context, seeking to challenge the restriction of the concept of care to the private sphere'.

Potential problems

The feminist ethic of care carries strong personal and rhetorical appeal. It connects the personal with the political and, based on evidence, reflects the diverse reality of people's current experience and values at the heart of their lives. What is more difficult to envisage is a government signing up to its potentially radical policy and financial implications. The lessons from the recognition of informal care as a political and policy issue from the 1970s are not encouraging. As advocates of the feminist ethic acknowledge, much current caring activity is taken for granted, made invisible and not valued. Despite the development of highly visible campaigns and increasingly skilled and established national carers' organisations, as has been seen, over a period of a generation, there has been a relative failure to secure positive policies for informal carers.

It is also difficult to see how such a policy approach would avoid being used in a reactionary way. Social policies identified with broad values seem the most vulnerable to subversion. How would the feminist ethic of care overcome the risk that people's commitment to care based on a sense of reciprocity, altruism and commitment, did not continue to be used to pressure them to take on and maintain large and unsustainable responsibilities caring for others? Framed still in the ambiguous language of care, how would it offer new more effective ways of ensuring that people's commitments to and for each other were not used by the state to reinforce requirements for them to 'care for' others, willingly or unwillingly, with or without adequate support, reinforcing traditional inequalities?

Independent living

The second development central to an understanding of caring has its origins in the emergence of organisations and movements of service users, particularly the disabled people's movement.

Service users' questioning of care

These movements have tended to be critical of the concept of care. Some feminists have interpreted their approach in terms of their devaluing of 'care' and a narrow prioritising of individual autonomy. Barnes, for example, talks of the "downplaying" of care in favour of independence, rights and empowerment' (Barnes, 2007, p71). These movements, however, have developed an important and different critique of care, linked with a much broader set of values, theories, ways of working and goals. It will be helpful to examine these more carefully to make sense of their contribution. While the development of ideas in these movements has been continuous and is far from monolithic, there have been some key consistent strands in thinking. The disabled people's movement has challenged traditional

concepts of care, but in search of a more egalitarian idea and practice. This has been linked with a move to more social understandings and more inclusive forms of collective action which have called into question traditional distinctions between self-help, mutual aid and campaigning.

Care and disabled people

As Jenny Morris, the disabled feminist and researcher has said, for many disabled people, the term 'care' assumes dependence and has meant others taking charge of and controlling service users, restricting their autonomy. For her, whether it refers to people giving paid or unpaid help:

It does not mean to 'care about' someone, in the sense of loving them. Rather it means to 'care for' someone, in the sense of taking responsibility, taking charge of them ... We need to reclaim the words 'care' and 'caring' to mean 'love' to mean 'caring about' someone rather than 'caring for', with its custodial overtones.

(Morris, 1993, p150, 174).

It is not the ideas and values of mutuality, commitment and affection that such service users reject in 'care', but what in practice has been the inherent inequality underpinning it. They see this as true of both paid and informal caring. A key reason why many disabled people continue to argue against the registration of their personal assistants is that they do not want them and their role reframed in traditional terms of 'care'. They are also critical of the way in which historically the views of those looking after them rather than their own views have been prioritised.

It has often been suggested that disabled people and service user movements have been polarised against informal carers. They argue instead that it is the social construction of informal carers of which they are critical, because of the way in which it reframes relationships between parent and child, partners and siblings in unequal terms of carer/cared for. Reliance on family members for support limits the autonomy of both the service user and the carer. It may diminish personal relationships, rather than being a positive expression of them. Writers like Jenny Morris also make clear the reciprocity that exists within relationships between disabled people and family members and highlight how many disabled people also have caring responsibilities, both as parents and with other adults. They make clear the way in which the care system can both reinforce the over-protectiveness of family members and create barriers in the way of them advocating for the independence of service users.

Negative and unequal imagery of care

The imagery associated with care has also emphasised inequality: the dependence, perhaps pathos of the recipient and the authority and often altruism and kindness of the care-giver. Charities have long relied on this approach in fundraising, reinforcing stereotypes of service users' vulnerability and incapacity (Hevey, 1992).

Alternative understandings

The disabled people's movement sought to uncouple caring responsibilities from loving relationships, in order to improve the support people received, to safeguard their relationships and to achieve greater equality. They developed two different interrelated ideas, which have gained broader support from service users more generally. These provide the basis for an alternative concept to 'care'. They are first the social model of disability and second, the philosophy of independent living. Both are concerned with humanising social policy (Priestley, 1999; Oliver, 1996). Both seek to make it more responsive to service users and to the role of society in relation to them. They are concerned with equalising the relationship between the service user and the support they receive. This is conceived of as a process of 'co-production', rather than one of dependence.

Social model approaches

The social model of disability draws a distinction between an individual's perceived *impairment* – physical, sensory or intellectual – and *disability*, meaning the negative societal reaction to such impairment. Developing discussion has explored the interactions between impairment and disability and the barriers disabled people experience from society, including attitudinal, physical and communication barriers. Such 'barrier based' approaches to understanding are now being related to a widening range of social care service users.

The philosophy of independent living

The philosophy of independent living follows from the social model of disability. It is based on:

- ensuring people the support that they need under their control to be able to live their lives as fully as they can, on as equal terms as possible with non-disabled people; and
- equalising their access to mainstream policy and services, like housing, health, education, employment.

The philosophy of independent living turns traditional notions of independence on their head. It is not pre-occupied with the individual or narrow ideas of personal autonomy. It does not mean 'standing on your own two feet' or managing on your own. Instead of seeing the service user as having a defect or deficiency requiring care, it highlights the need to ensure them the support

that they need to live their lives. This support is not expected to come from family members required to be informal carers. It rejects the concept of care and replaces it with the idea of support. The Government's 2008 Independent Living Strategy signs up to these values.

The disabled people's and service user movements thus frame their objectives in terms of rights, not needs, requiring support and change, rather than care and welfare. They are concerned with the achievement of both their civil and human rights, collective as well as individual rights. To achieve these goals and values, service user movements have developed new approaches to collective working. These place an emphasis on self-organisation – developing their own 'user controlled' organisations – as well as on participation and people 'speaking for themselves'. But they also take account of people's feelings and needs for support in the process. To make this possible they have increasingly highlighted:

- inclusion; and
- empowerment.

Inclusion

Many service users face significant barriers to participation, for example they may communicate differently, have learning difficulties, be unable to go out, live in residential services, have pain, limited strength or energy and need personal assistance. Service users have placed an emphasis on ensuring access, which can include physical, communication and cultural access, to enable broad-based involvement in their activities. They have developed imaginative ways of working together, making innovative use of electronic communication, performance, music, DVD and other forms of involvement to achieve this.

Empowerment

Service user organisations make clear that they see working together in their own organisations not only as an effective way of making broader social and political change, but also crucial for increasing service users' confidence, self-esteem, skills and experience. Collective working thus plays a key part in capacity-building, as well as in making wider change. The idea of empowerment is valued by these movements because it unifies the need for individual and social change; for personal and political development (Charlton, 2000). This is reflected in the wide range of groups and organisations developed by service users, which challenge traditional distinctions between self-help, mutual aid and campaigning. There is particular recognition and support for people's emotional needs and feelings.

Potential problems

The philosophy of independent living and the social model approach it is based on are powerful and persuasive, particularly for service users. They often talk about first hearing about them as being 'like a light bulb being switched on', altering their consciousness. These ideas challenge feelings of guilt and dependence which traditional discourses of care encouraged. They have begun to be embodied in public policy internationally. But they also face their own difficulties.

The idea of independent living continues to be confusing to some service users, particularly older people, some of whom interpret it in individualising terms. Some members of BME communities prefer a 'holistic' approach, rather than one based on independent living. Some also do not find the division of people into 'service users' and 'carers' helpful and are critical of both conceptions.

We are also learning that it is one thing for policymakers to adopt the language of independent living, but it may be another for the practices to be implemented. Funding limits and narrowing eligibility criteria, rather than criteria of independent living, still largely determine what if any support people receive. There is still far from adequate or secure funding provided for service users' organisations, despite increasing government commitments to it. Finally, what has been developed as a democratising and liberating approach to supporting service users through them being in control of their own 'package of support' has tended to be reconceived by policy-makers in consumerist terms as the equivalent of them being an individual customer simply purchasing a service. This has seriously limited the gains achieved so far by these radical new ways of thinking.

The move to personalisation and self-directed support

I wish I could care what you do or where you go
but I can't ... My dear, I don't give a damn.

(Rhett Butler, in *Gone With The Wind*
by Margaret Mitchell)

Major changes in 'care' are now planned for the UK. These have been framed in terms of 'personalisation' and are part of a broader personalisation agenda that is meant to transform public services, customising them to each individual citizen. In social care this development was initially presented as synonymous with a move to 'self-directed support', which was to be achieved mainly through 'individual budgets'. These represent a development of the direct payments pioneered by disabled people as part of the independent living movement. Here the aim is for service users to determine and control the support that they need to live independently. Qualifying service users receive a sum of money to spend as they wish on their support. More recently, personalisation in social care has been discussed in broader terms to denote a move to more person-centred approaches to support across all services and support arrangements, including residential, day and traditional domiciliary services. The rhetoric is that personalisation will offer service users greater 'choice and control'.

Personalisation, however, has mainly been discussed as a new approach to providing *support*, rather than *care*. It is offered as a fundamental departure from a traditional menu of care-based responses, to a much wider range of possible means of offering support. These may be:

- mainstream provision, rather than dedicated social care services;
- conventional medicalised provision (for example, for mental health service users) or complementary therapies; and
- user-controlled support services.

The emphasis is on people being able to work out imaginative and effective ways of meeting their needs, regardless of what these are. In addition to personal assistance to help with daily living tasks, this can include money to pursue recreation and hobbies, to gain skills, to undertake education courses, to have breaks and holidays, to visit friends and strengthen circles of support, to have company or help from a trusted person out of hours, to access a user-controlled crisis centre, to pay for a pet, counselling or peer therapy.

Pressure for change

A number of major issues are emerging for the future of social care. These highlight the increasing demand for support, as well as barriers to meeting this.

The rising demand for support

As yet the rising demand for support has mainly been expressed in terms of the growing numbers and proportions of older and very old people. This is seen as both reducing available resources for public expenditure and imposing increased costs. It is also associated with significant rises in numbers of people affected by Alzheimer's and other impairments associated with old age.

However, a number of other factors are also increasing the numbers and proportions of people with support needs. These are particularly associated with improvements in medical and health care. Conditions that might once have been acute or terminal are now increasingly requiring longer term support. This relates to:

- increased survival of early term babies with impairments;
- greater life expectancies of disabled people with both inherited and acquired impairments;
- increased length of survival for people with cancer and other previously life-threatening illnesses and conditions;
- increased survival rates from road traffic and other accidents after major trauma, including head injury; and
- service people acquiring major trauma and impairments from military action.

Meeting rising demand

The NHS is a universal service, still significantly free at the point of delivery. However, at present social care, which has the major responsibility for providing such long-term support, is a residual service which largely has to be paid for. Whether this inconsistency can continue is open to question, especially with needs changing and the desire for the integration of health and social care. Social care has not received comparable investment in funding to the NHS. The major shift in demand identified above will require further reallocation of funding and resources to long-term support. This will need to be reflected in the scale of funding for social care. The funding of social care is currently being reviewed. As yet, however, there is little indication that governments are prepared to move in this direction. This raises big questions about:

- how to meet the rising demand for long-term care;
- how to secure political commitment to address this with adequate funding; and
- how to move beyond the current dominance of medical models in health care to more social understandings.

Informal care

Since the late 1970s, policy-makers have placed increasing emphasis on informal carers to meet the need for support. However the approach to carer policy they have adopted, 'the carer as resource', is unlikely to continue to be tenable in the longer term. There is not expected to be the necessary supply of informal care. Changes in family and household make-up, geographic, social and economic change, are all likely to have an adverse impact.

- As adult children are more likely to live away from elderly parents, distance will create barriers to informal care.
- Demographic change is likely to mean that people expected to care will themselves be increasingly old and frail.
- Disabled and older people may expect greater choice and control over their support (Glendinning and Arksey, 2008, p224).

For policy-makers, there are now also competing priorities between care-giving and employment. We are now beginning to hear carers described by policy-makers as socially excluded, because of their relatively low levels of employment. This may result in increasing pressure on them to join the labour market.

Social care reform

The current commitment in the UK to radically reform social care highlights both recognition of the need to re-examine care and the desire to do so. An interesting aspect of government commitment to personalisation is the degree to which it is based on and encourages the reframing of 'care' in terms of support. It has also highlighted that such support is not something that one person does to or for another, but that it can and should be a process of 'co-production', which service users shape, influence, inform and ultimately may control.

Addressing support across policy

There is increasing recognition by government that dedicated social care policy alone is not enough to meet people's support needs. All public policy should as far as possible be geared to take account of support needs. This relates to a new term emerging in local government: 'place-shaping' – 'the creative use of powers and influence to promote the general well-being of a community and its citizens'. However, at present addressing people's support needs in mainstream policy across both private and state sectors is far from happening. If this is to change, then policy-makers will need to acknowledge that currently public policy may be creating rather than removing barriers. Thus, for example, the closure of local amenities like post offices, inadequate pavement maintenance, the centralisation of shopping, increasing reliance on car driving, the inadequacy and continuing lack of access of some public transport, reduced funding for lifelong learning, the weakening of rural and in some cases urban communities, the undermining of personal safety in public space and housing and employment policies, are all issues that must be addressed if this is to be possible. We need to develop routine needs assessments in relation to social care service users when developing policies in such areas, if people are to be fully included in the mainstream without unnecessarily having to have additional help from specialist services.

Rethinking care

Efforts to rethink care need to extend to rethinking both policy and practice and the conceptual framework upon which it is based. Service user movements have argued determinedly for a generation that the concept of care as applied to them is inherently unequal and controlling, framing them as dependent. They have had some success in getting their philosophy, based on equality, support and independence, written into anti-discrimination, direct payments and independent living legislation. More recently the advocates of a feminist ethic of care argue for the values of care to be acknowledged and adopted by public policy more generally. Those concerned with social care need to subject its underpinning ideas to rigorous review. In doing so, it will be helpful to be aware that social care is a term that the public neither seems to be aware of, nor warms to.

Questions for the future

The large-scale move to personalisation in the UK raises major questions. Every reform has its own problems and possibilities. But the questions for personalisation are perhaps questions for the future of social care and 'care' more generally and ones which have an international relevance too. They include:

- Will there be sufficient funding to ensure that all those who need support will be able to access the particular support that they want to live more independently and with choice and control in line with the goals of personalisation?
- Will an adequate infrastructure of support, including information, advice, advocacy and technical and administrative help, be established for all who wish to, to operate individual budgets and other self-directed support schemes regardless of impairment and other issues of difference?
- How will effective co-production with service users be ensured in taking forward social care reform?
- Will a meaningful network of local user-controlled organisations be established with adequate and secure funding?
- On what basis can service users and carers best form alliances to secure the rights and needs of both?
- Will better pay, conditions and training be established for the face-to-face workforce to improve recruitment and retention and reduce turnover and provide a reliable and high-quality workforce?
- What help and resources will be offered to bring about culture change in the workforce to embrace this new approach to support?
- What is the most equitable way of paying for support? Should it be a matter of individual or collective responsibility, paid for out of general taxation, like the NHS, or out of people's pockets through insurance, charges or 'co-funding'?
- How will the market for personalised support be significantly shaped by the demands of service users, rather than just by the commercial imperatives of the large multi-national private sector organisations which now play an increasingly significant role in the supply of social care services? How can commissioning policy help in ensuring quality and equity?
- Increasing reliance on the commercial sector to provide support services highlights the importance of effective regulation. How can this be developed to ensure that it reflects the concerns and priorities of service users and operates effectively?
- What would make possible greater public understanding and support for social care?
- How far is it feasible in a mixed economy to address people's support needs in mainstream public policy?

New ideas to meet new demands

Current proposals for policy reform represent a new departure for social care in the UK. Less recognised, yet perhaps more significant, we seem to be at a watershed in care's formulation and conceptualisation. The concept of 'care' no longer provides a viable or virtuous basis for public policy. It doesn't command resources or priority. Few people seem to relate to it for themselves. Many see care as inextricably associated with dependence, control and inequality. Few of us want to see ourselves as, or be seen as, dependent. Care in practice is also being increasingly downgraded through being commodified and made mechanical.

While people have a notion of what a nurse does and there is a heritage of support for care in this context, it has not crossed into social care. Although an apparently warm and familiar word, care has not helped people to recognise or relate to social care policy or practice. A new language and conceptual framework are now clearly needed. We need to find new ways to describe and explain how people look after each other, both informally and through paid work, which are sensitive to the differences between caring for people and being cared for by them. These need to challenge conventional understandings which have served to exploit people's care for each other and in so doing to distort and subvert the love and sense of mutuality that underpin it.

The term 'care' is a relatively recent arrival on the public policy scene and ditching it now certainly need not signify rejection of the positive values and ethos that can underpin it. Instead rethinking terminology has the potential of re-affirming such values. The philosophy of independent living developed by the disabled people's movement has made significant progress as a basis for social policy. But at the same time it continues to create confusion and antagonism because it is wrongly associated with individualism and 'standing on your own two feet'. Two other terms, however, with the same inspiration, command much more understanding and are already beginning to be built into policy and practice. These are 'support' and 'assistance'. Both are readily comprehensible. Both have positive mainstream meanings. Business people as well as disabled people have personal assistants (PAs)! Here are terms which may provide the basis for reconceiving social care in more transparent and more effective ways. Whatever the judgement now, what's needed next is a truly public debate about what frameworks are likely to help all of us secure the personal and social support that improvements in our societies mean more and more of us are likely to need.

About this Viewpoint

The context of this *Viewpoint* is the major reforms of social care and social care funding being pursued by government. It draws both on mainstream research findings and those developed by service user movements and researchers. The author has a long-standing involvement in social care as a writer, researcher, educator and service user.

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