Chapter 4 (In ‘Help’, Tom Shakespeare (2000) Venture Press, pp. 63-84)

HELPFUL

Building on the theme of colonialism, this book has explored the impact on those who receive help, the role of helpers, and the process of helping itself. What options are there for understanding and delivering assistance which empowers rather than disables? Abandoning the philosophy of paternalism, dependency and stigma, and replacing it with a discourse of rights, equality and social justice, is the vital first step. But values and principles have to be combined with systems and policies in order to be realised in practice. The first half of this chapter explores the independent living model developed by the disability movement, raises questions about the relevance of the model for those who do not have physical impairments, and considers other limitations. The second half considers other practical and theoretical contributions which may usefully supplement the independent living idea, especially the feminist ethic of care. I will propose that the most effective way forward would combine elements of this new approach to social policy with the innovations of the disabled people's movement. The question of values is as important as the question of rights: both parts of the equation will be needed in order to achieve positive outcomes for those who are excluded and disempowered.

Independent/integrated living

The disabled people's movement has expressed extreme dissatisfaction with the existing provision of care services. For example, Richard Wood, director of the British Council of Disabled People, has written:

'Disabled people have never demanded or asked for care! We have sought independent living which means being able to achieve maximum independence and control over our own lives. The concept of care seems to many disabled people a tool through which others are able to dominate and manage our lives. ' (Wood, 1991, 199)

Independent living is based on a distinction between physical and social dependency. Within the traditional model, ‘independent living skills' are about being able to dress oneself or make a cup of tea. Yet this stress on 'doing it for yourself' is unnecessary, and may lead to the prioritisation of unproductive activity. People with impairments can be independent if they are able to employ others to provide the assistance which they need in order to achieve their goals. This means having the money to pay other people to perform personal services, be this driving the car, lifting in and out of bed or wheelchair, making meals or giving toileting and cleaning assistance.

The four key assumptions of independent living are that all human life is of value; anyone, whatever their impairment, is capable of exerting choices; people who are disabled by society's response to their impairment have the right to assert control over their lives; and that disabled people have the right to participate fully in society (d' Aboville, 1995). As Jenny Morris writes, *'Independent living is about both human and civil rights. If disabled people do not have, control over the very basic activities of daily living then they cannot hope event to begin to participate in society on an equal basis'* (1993, 162).

No disabled person wants to be institutionalised, or to be dependent on family members or volunteers in order to survive. Sian Vasey writes:

'Before getting a care package and relatively flexible personal assistance I would say my life was a panicky wilderness of stifling dependencies and inappropriate support systems comprising district nurses, Community Service Volunteers, family and friends, and so on, in which survival was my main goal. ' (1996, 86)

Her experiences lead her to conclude that '. ..*disabled people cannot rely on friends and volunteers for the help they need -we must be able to pay for it and be in control of our day-to-day lives and independent of those around us'* (1996, 87). Disabled people want social independence. This equals autonomy and control over one's own life. In the words of Richard Wood: *'For each and every disabled person the words "choice" and "control" are of paramount importance. These are the words, not care, which should underpin all policies and strategies which impinge on our lives'* (Wood, 1991,202).

The removal of social and environmental barriers and the provision of direct payments and personal assistance schemes is the way to achieve this outcome, not the perpetuation of dependency through traditional welfare services.

The origins of the British independent living model lie in the Independent Living Fund, a public charity intended by the government to provide £5 million for a small number of disabled people to live in the community, but which was eventually wound up in 1992 with a budget of £97 million, supporting 18,000 people. The advent of community care and the eventual legalisation of direct payments to individuals in 1995 have led to a partial shift towards this vision of independent living, in which disabled people are given money directly in order to pay personal assistants (PAs) a proper wage for performing empowering roles in their lives (Morris, 1993). By 1997, there were over 60 personal assistance or independent/integrated living schemes in the United Kingdom.

When people are given the choice as to who they want to help them, they do not recruit professionally trained staff. Jenny Morris's research (1993) found that people with real control over employing their PAs preferred to recruit people with little or no qualifications or experiences. People like nurses and former carers had set ideas about how to do things, and were not prepared to listen to the disabled person's experiences or preferences. In some American states, including Colorado, the Medicaid scheme funds attendant services, the US term for personal assistants. But these services have to be delivered by state certified nursing assistants who have received 80 hours of training. Activists such as Laura Hershey (1998) resent this limitation:

'Ever since I moved out of my parents' home, I have hired, trained and supervised my own attendants, based on my own needs and preferences. I negotiated schedules and duties with them, and taught them to do things in the ways that worked best for me. Occasionally, a new attendant would try to presume that her method of transferring me into my wheelchair - based on the instruction she had received in some training program - was better than my tried-and-true method. But I could almost always get them to learn the very valuable lesson that just like everyone else, people with disabilities are individuals who have different personalities, different techniques, and different needs. '

She makes the point that people who use services provided by agencies do not have control over their lives, and have to depend on the organisational timetable. In her experience, there is usually no need for training:

'After all, this isn't brain surgery we're talking about. Most attendant services are essentially non-medical maintenance tasks -dressing, bathing, toileting -which most consumers can self-direct. Does a non- disabled person need special training to dress, bathe and feed herself? Of course not. And a person doing this for someone else does not need special training either. She or he only needs to listen to the directions being given ***by the person receiving the service****.'* emphasis original (Hershey, 1998)

While lifting safely is obviously an important issue, in general the skills needed are straightforward: sensitivity, dependability, intelligence and a good sense of humour. While personal assistants may not need particular training, it is important to note that disabled people may need support in becoming employers. Issues such as recruitment, management and budgeting are not beyond disabled people, but there is often a need for back-up, which is why many Centres for Integrated Living run support services or peer group networks.

Extending the model

Independent living is a new approach to meeting personal support needs which is radically different from traditional care. For this reason, only a small minority of social services clients are currently using personal assistance schemes. There is a low awareness and a lack of information about the direct payments model, which means it is slow to spread beyond a core constituency of disability movement activists. Sometimes, there has been opposition due to ideological differences or vested interests. Some Labour local authorities were slow to implement direct payments, seeing it as a form of privatisation and a threat to democratic control of welfare services. Because independent living involves a transfer of power from professionals to individual disabled people and their supporters, there has been resistance from those workers who may lose status or control and trade union hostility. Yet many enthusiasts argue that not just the vast majority of disabled people, but also other constituencies such as people with learning difficulties, older people, and people with HIV/AIDS, should be able to benefit from the increased autonomy which personal assistance schemes deliver.

UK legislation currently debars people over 65 from receiving direct payments from such schemes. Clearly, one motivation for this restriction was cost. But there is also a perception that older people will be unwilling or unable to have their care needs met via employing their own personal assistants. Current services make the assumption that independence is only for those under 65. For example, Disability Living Allowance is provided for younger disabled people while those over 65 get Attendance Allowance, implying a dependency model. Yet Arber and Ginn (1991) found that older people prefer to stay in their own home and be cared for by someone who does not live there. If they had no spouse, their preference was for formal carers, so that they could be self-sufficient.

Colin Barnes (1997), at the British Council of Disabled People (BCODP) Research Unit, University of Leeds, has explored the response of older people to independent living via a series of focus groups. His study found that on the whole, older people are unfamiliar with the direct payments model, and although critical of local services, are unenthusiastic about employing personal assistants. Partly this arises from their suspicion that any changes to provision might mean a reduction in local services and confusion about what personal assistants mean. Also, some did not want strangers doing personal care and did not want to become employers. Yet older people with experience of personal assistance schemes were more positive: they felt that the administration was no problem at all; they were enthusiastic about the potential of direct payments, particularly for those who lived alone, or in rural areas where services were scarce; they also felt the benefit of not being reliant on family and friends, in terms of exerting control over their life, and being able to avoid helpers who were not congenial. Many wanted to be able to pay relatives or friends and neighbours on a casual basis. None of the participants in the study felt that older people should be excluded from access to direct payments. They wanted direct payments to be an option, not a substitute for services. The research also suggested the need for national and local registers of paid helpers, and for peer support networks.

As with older people, people with learning difficulties can potentially use the personal assistance model. Yet few know about the possibility of direct payments, and implementation has been slow (Holman, 1999) In general, research shows that community-based services for people with learning difficulties are cheaper, and can enable people to develop their capacities and improve their quality of life I(Ryan, .1998). While disabled people and older people may require physical help, perhaps emotional support is the priority for those who are physically capable but intellectually or emotionally restricted. Independent living would have the benefits of avoiding the dependency on relatives discussed earlier.

Modifications to the personal assistance model enable it to be used by people with significant intellectual limitations. The legal framework of a trust is a way of meeting employment responsibilities, for example. Service brokerage was first used in British Columbia in Canada in 1976, as an alternative to institutional care, although it is still rarely used in Britain. With the help of service brokers, people with learning difficulties were enabled to take control of the process of identifying their needs and finding ways to meet them. Packages of individual funding enabled the service user to control the money for their personal support. Service brokers can assist people with learning difficulties to use direct payments, particularly in cases where people have high support needs, while reducing the possible risks of exploitation.

For people with mental health issues, the difficulty may be that when symptoms are not a problem, personal assistance is unnecessary, but in episodes of illness, the individual might not be prepared to use the support of others. However, avoiding the care of families may be important when relatives may be implicated in causing the emotional distress. Equally, many people with mental health problems have very unhappy experiences of psychiatry professionals. Yet retaining some measure of control remains a possibility, even in the case of mental illness. For example, people can prepare crisis cards which express their preferences in the event of problems occurring. These may detail who is to be contacted, actions to be taken, drugs to be avoided, different mechanism enables service users to maintain control of circumstances, based on the same philosophy of choice and empowerment.

The limits to independent living

In the understandable enthusiasm for personal assistance, there is a danger of seeing it as a panacea and overlooking potential drawbacks and problems. Three limitations are explored here: the financial, the political and the practical. While some research suggests that independent living is actually cheaper than traditional services, there is still no definitive answer. While it is undoubtedly more expensive to live in residential accommodation, it may well be that providing effective and high quality personal assistance demands higher payouts by local authorities than the existing pattern of rather inadequate homecare and nursing support.

The danger is that cheap personal assistance schemes rely on the exploitation of the people who are employed to facilitate independence. The reservation that some commentators express about direct payments for independent living is that it marks a return to the era of personal service. Victorian novels unquestioningly assume the provision of servants. There is a history of working-class women and black women servicing middle-class and white households. Hilary Graham (1991) points out that in 1861, 55 per cent of the women in London who were employed worked in personal service. As late as the 1930s, one million women were in service in Britain.

It could be argued that the individual, privatised relationships promoted by the independent living movement risk emulating this tradition. Legally, personal assistants employed to work in the home are classed as 'domestic servants' and as such are excluded from the limits on working hours. Because of high levels of unemployment, people may be driven to accept pay and conditions which are inadequate. While the majority of disabled people pay wages rather higher than the national minimum wage, there is certainly a potential for exploitation as the model is extended. Certainly, most people employed in this way, even if paid well, do not have job security or pension rights. In most personal assistance relationships which I have personally observed, there is an equality of status and mutual respect. However, anecdotes circulate about personal assistants being treated badly in particular cases, and this is undoubtedly a danger of the largely hidden process of personal help. As Ann Brechin argues, good help should be rewarding for both parties (Brechin, 1998, 178). It would be deeply unfortunate if the liberation of disabled people from dependency contributed to the exploitation of another disempowered section of the population.

However, the late twentieth century has seen a massive expansion of the service sector in Britain and other western countries. As women have entered the workforce, pressure on time has led to a reliance on others to provide domestic services such as cleaning and childcare. Inevitably, in some cases this involves exploitation and a return to the servant ethos. But it does not have to. As Andre Gorz and others have suggested, the tendency of modem capitalism is for productive jobs to be eliminated by continuing automation and efficiencies of scale. If structural unemployment is a growing problem in modem societies, then employing more people in personal support services is a way of redistributing money from those with jobs to those on the periphery of the economy. Perhaps many young people would accept decently paid work as personal assistants for a period before, after or during tertiary education.

A final problem relates to the practicalities of relying on someone else to deliver personal care. For example, Sian Vasey's account of using personal assistance shows that, even when funding is available, it is still laborious to organise an effective care package. Even with a rota of people to help in the morning, the evening and through the day, it is clear that full freedom and autonomy is almost impossible. Particularly, Vasey mentions problems with holidays, and a feeling that it would be difficult for her to move house to another area. Other disabled people have found that, having secured direct payments, accessible accommodation and suitable assistants, they are then effectively trapped, unable to move to another job or another town without losing the support which enables them to live independently. Obviously these difficulties apply to other forms of residential and community care. But in the absence of back-up, they may be particularly difficult for personal assistance users.

For anyone who relies on someone else for intimate physical tasks, there is an element of inextricable difficulty in receiving care, as Kate Cooney has written:

'Your carer has to run parts of your body for you. If you insist it is run exactly the way you would have run it, you will be ridiculously demanding. But it still hurts to let go and it's still hard, getting used to the new, circumscribed you - should ask for that or shouldn't I?' (Cooney, 1991)

Many may prefer to have help, especially intimate help, to be given by a loving relative, because of the possibility of trust or lack of embarrassment. Others prefer the more impersonal support of strangers. Yet here there may be a problem of confidentiality. In many cities, the same personal assistants often end up working for different disabled people from a small community, and it may be difficult to maintain privacy and prevent gossip. Yet, the experience of Sian Vasey and many others is that personal assistance, despite continuing limitations, is vastly preferable to their previous lifestyle. Not all disabled people or elderly people will want to take advantage of the independent living model. But it should be a choice which is available to everyone.

Low-intensity support

Personal assistance is not the only alternative model of support available. For those who do not need a full package of personal assistance, or who are not happy with the responsibility of managing their own care package, other options can ensure continued and secure life in the community, and a high degree of control by service users. Also, many older people and disabled people do not qualify for full social services assistance due to resource constraints and targeting, but they may need some assistance.

New approaches to support avoid empowering professionals at the cost of the people they help. They also avoid the traditional dilemma, that services are available on an all-or-nothing basis: rather than waiting till a crisis occurs, and then providing a residential place, these new forms of support are designed to prevent problems occurring and to maximise the coping capacity of the service user. Low-intensity support can prevent matters deteriorating, and can enable people to live independently in their own homes. This might mean local support workers, telephone helplines (important for out of hours), and mutual support among networks of people, involving skill-sharing and social support. The voluntary sector has played a strong role in such developments.

The KeyRing agency in North London is one model of this new service philosophy, which has been designed to meet the needs of people with learning difficulties who require some support. Part-time workers spend 10 -12 hours a week with members of a small network, and in return get free accommodation and other financial support. This is an economical way of maximising independence and avoiding either institutionalisation or isolation. A network for ten people with learning difficulties can be run for the cost of a single place in residential care.

The Yorkshire-based Home-Link scheme is a housing support service for people with mental health problems. It provides a combination of housing, often in proximity to other service users, together with individual support from Home-Link workers. The helpers are intentionally not mental health professionals, and the help they provide is not professional but practical and social. This might involve help with budgeting and paperwork, or with household maintenance and decorating, or basic companionship and reassurance. Each person might receive up to half a dozen hours of help per month, but everyone also benefits from mutual support, because other mental health survivors are housed nearby, and social activities can be easily arranged. The benefits of this type of scheme are that it supports vulnerable people, reduces levels of anxiety, strengthens their ability to be independent, and reduces isolation: over half of the Home-Link users had experienced an improvement to their mental health. The scheme also eases friction with neighbours and the wider community, frees up the time of professionals, leads to improvement in housing management and reduces dependency.

Another model, developed particularly for people with learning difficulties, builds on the familiar philosophy of advocacy. A 'circle of support' is a group who get together to help an individual with learning difficulties, and get to know the person well, so that they can provide help and advocacy. By recruiting other members of the community, the individual can move beyond dependence on professional help or their immediate family. Helen Sanderson explains the principle:

'The family or other people who care about the individual form a circle of support simply by inviting people to join them to focus on the person's future and collaborate to reach her or his goals and dreams. Meetings are held whenever the family or individual needs them, for example, monthly or quarterly. A circle of support is a practical expression of an inclusive community.' (Sanderson, 1995, 247)

Community members may make commitments to support people with learning difficulties in different ways: John O'Brien and Connie Lyle O'Brien (1995) list the functions of anchor, allies, assistance, association and agendas, meeting needs ranging from physical support to social contact and political campaigning. These models promote new types of relationship, based on equality and mutual aid, which are important building blocks in restoring a sense of community for everyone.

A range of other developments echo some aspects of the schemes discussed. For example, some housing associations are now offering floating support as an alternative to sheltered housing. This offers social contact, advice and other assistance in a flexible format. Elsewhere, people have organised befriending schemes with volunteers. This parallels the way that the HIV/AIDS community have developed the concept of buddies, defined by Dennis Altman as *'people who would act towards strangers, as ethically they would act towards friends'* (Altman, 1994, 38). (The same concept of the 'universal stranger' was central to Titmuss's discussion of *The Gift Relationship.)* It may be preferable for many adults, whether older people, or people with learning difficulties, mental health problems or HIV / AIDS, to have someone to provide companionship and support who is not an immediate family member. All these types of assistance are based around a model of help, not care, and they seek to empower the user, not the helper or professional. Many centre on the promotion of social inclusion. These low-cost support schemes can be complementary to main- stream services, and can greatly reduce the need for residential care, with all the cost and isolation which that involves.

Low-intensity support has implications for the kinds of community in which we live, and also for the role and priorities of professionals. This last point may connect with the emphasis in the disabled people's movement for barrier removal, rather than individually-based therapy, treatment or casework. The disabled activist and writer Vic Finkelstein has argued that we need to replace medicalised ideas about care with the notion of support: *'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'* (1998, 4). He calls for a new type of community worker or resource consultant, who would provide support to enable people to overcome social and physical barriers to achieve their personal goals.

'The real challenge in developing appropriate mainstream community services based on 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. ' (Finkelstein, 1998, 14)

The suggestion is that new forms of support, and new forms of helper, may be not only an alternative to independent living but also complementary to it. They represent another option for those seeking integrated, community-based living which maximises the autonomy and quality of life of formerly marginalised individuals.

Feminist ethic of care

Two alternative theoretical models for reforming care are available. One is based on the independent living principles which have been developed by the disabled people's movement. The second is the feminist ethic of care. Both share some criticisms of actually existing care, but offer significantly different strategies for developing new approaches. Disabled writers promote the civil rights of disabled people, and suggest that independence can be achieved via personal assistance schemes. Feminist writers favour replacing the discourse of rights with the discourse of care, and deconstructing the notion of independence itself. Yet neither perspective has engaged with the other, despite the opportunities this might offer for a more holistic programme of reform. It is my argument that such a dialectic is the way forward. I will suggest that the contribution of the feminist ethic is of particular benefit on the issues of independence and of values.

The feminist ethic of care originated partly in the work of Carol Gilligan, and particularly from her study *In A Different Voice,* which criticised the traditional models of moral development advanced by psychologists such as Lawrence Kohlberg and suggested that women were not morally underdeveloped, but had a different approach to morality. Jean Tronto (1993) summarises three major distinctions between what has been called the 'ethic of rights', and the feminist ethic of care'. The ethic of care is based on relationships and responsibilities, while the ethic of rights is based on rights and rules. The former emerges from concrete circumstances, rather than formal and abstract situations. Finally, the ethic of care depends on activity, while the ethic of rights depends on principles. Drawing on these differences, feminist philosophers have argued that public discourse needs to draw on the neglected ethic of care, as a balance to the dominant ethic of rights, and they have elaborated the implications of this approach for welfare.

From a disability studies perspective, one could develop some critiques of this approach. For example, there is a tendency in some of this literature to idealise the caring role, and to develop an almost essentialist idea of women as carers (for example in Noddings, 1984). Yet users of care services may well have reason to reject this for reasons outlined earlier: they may feel taken over, spoken for, undermined, disempowered or even neglected and abused by carers. Moreover, the literature on the feminist ethic of care perhaps fails to grasp a key problem, in the challenge to the ethic of rights, which is variously described as patriarchal in essence or in values (Larrabee, 1993), and which dominates within the public sphere. Abstract universals such as equality and justice are criticised, and a feminist ethic based on relationships and responsibilities is offered as an alternative. This may be a step forward in the public sphere, yet in the private sphere where much caring takes place, a disability rights perspective might argue that the fundamental need is for the application of the ethic of rights to the social relationship of care. So, for example, disabled people have promoted the slogan ‘rights not charity', demanding personal assistance as of right, instead of dependency on care or kindness. As Anita Silvers argues, *'far from vanquishing patriarchal systems, substituting the ethics of caring for the ethics of equality threatens an even more oppressive paternalism'* (1995,40).

However, more recent writers from the feminist ethic of care position move away from the opposition of care and rights, and also show more understanding of the problems of disempowerment. For example, Sevenhuijsen and others have criticised what she calls ‘the shadow side of virtue' (Sevenhuijsen 1998, 12), meaning the conflict, aggression and ambivalence which is also sometimes present in caring:

'Even if care is to a certain extent generated by dependency and attentiveness, the concrete motives in social practices of care cannot always be derived from the urge to protect dependent people from vulnerability. Caring for others can also stem from less noble motives, such as the urge to meddle or to control others.' (Sevenhuijsen, 1998,20)

Marilyn Friedman (1993) argues that justice and caring are mutually compatible: close relationships create special vulnerability to harm and abuse, she claims, and justice is relevant to rectification in this case. In her work, and that of others (Tronto, 1993); there has been some progress towards dissolving the false dichotomy of care versus justice. Certainly, one would want to support the argument that care can bring benefits to democratic citizenship, as long as it was also accepted that justice and equality may bring benefits to caring relationships and the private sphere: this, after all, has been a central part of the feminist project.

Whereas disabled people campaign for independence, feminist ethic philosophers promote the notion of interdependence, seeing liberal ideals of autonomy and independence as being irredeemably bound up with a masculine view of people as separate subjects. For example, Sevenhuijsen criticises autonomy and independence as a goal, and the whole idea of ‘atomistic individualism':

'The ideal of abstract autonomy in fact overlooks what is it that makes care an element of the human condition, i.e. the recognition that all people are vulnerable, dependent and finite, and that we all have to find ways of dealing with this in our daily existence and in the values which guide our individual and collective behaviour: ' (Sevenhuijsen, 1998, 28)

Because women have historically been the care providers, it is suggested that they are less likely to promote an unrealistic view of independence. They realise that a large proportion of people -babies and children, pregnant women, older people, and sick and disabled people -will rely on others in various ways and at various stages. That is to say, over a life cycle, people will variously both receive and provide care: *'Dependence on care should not be seen as something which can suddenly overtake us,' rather it should be seen as an integral part of human existence'* (Sevenhuijsen, 1998, 147). Here there is a revisioning of the idea of human nature to include dependence on others as a core concept.

Moreoever, there is an argument in the feminist ethic literature that it is the denial of this basic interdependence which contributes to the devaluing of people who receive care. Joan Tronto highlights the social construction of dependency which undermines and objectifies ‘helpless' people:

'Because neediness is conceived as a threat to autonomy, those who have more needs than us appear to be less autonomous, and hence less powerful and less capable. The result is that one way in which we socially construct those who need care is to think of them as pitiful because they require help.' (Tronto, 1993, 120)

Selma Sevenhuijsen argues along similar lines:

'In the ideal of the atomistic individual, the moral subject is primarily expected to pursue autonomy and independence. In this way, vulnerability and dependency easily become separated from the ideal self and localized in, or projected onto others: weak or "needy" people. ' (1998,57)

The replacement of independence with interdependence challenges the disability movement approach. Disabled people might reply to the feminist ethic writers that while deconstructing independence sounds good in theory, in practice they would prefer schemes which offer them the choice and control which others already take for granted. As Silvers argues, *'social policy that reconciles equality with difference can advance historically subordinated groups but that displacing equality in favor of positional ethics merely reprises the repression of those already marginalized.'* (1995,31)

Rather than challenging the goal of independence, disabled people want to be empowered to become independent. The crucial move is not just to recognise that everyone has needs, but to break the link between physical and social dependency. While feminist ethic philosophers may see women's dependency as socially constructed, they often retain an essentialist model when it comes to disability, seeing it as arising from particular physical limitations. They fail to deconstruct care. The independent living model argues that independence consists in being able to make choices and exert control over one's life. It does not mean being able to perform particular physical acts. Direct payments and independent living schemes are very direct ways of ensuring that people gain far more independence, and are not disempowered by inappropriate or demeaning care: in contrast, the ethic of care stress on interdependence seems rather idealistic.

Yet the feminist ethic of care is also a valuable correlative to the independent living model. There can be too much stress on independence and autonomy within disability rights discourse. There is a contradiction between the collectivism of the disability' movement and the individualism of the proposed solution to care. In America, this tension is less obvious, because the society is based on individual rights and the free market. Yet Gareth Williams (1984) has identified the dangers of promoting solutions which reify normative ideas of independence, rather than recognising the mutual interests and interdependency of human beings. There is also the problem that there will always be disabled people who are not liberated through barrier removal and personal assistance: some impairments are so significant that work, for example, will always be impossible, as Paul Abberley has argued (1996). Having the individual achievement of independence as the sole value and key goal is to reprise the exclusion of this section, of the disabled community.

As feminist ethic philosophers point out, the notion of independence is inherited from a liberal tradition which has historically marginalised those who are not male, not adult, and not physically able. Within liberal individualism, people are regarded as fundamentally the same, they are abstracted from their context, they are seen as separate and bounded by their bodies. The people who count are the people who are independent:

'In their need, dependent people are therefore seen to constrain others in their own pursuit of individual freedom. As a result, only those who are without need, or without obligation to those with need, are able to achieve full independence and therefore personhood.' (Hockey and James, 1993, 110)

Many liberal thinkers, for example Rousseau and Adam Smith, have suggested that people who are dependent lose their ability to exercise autonomy and make judgements; some contemporary bioethicists would agree.

The notion of independence, therefore, is problematic. As Jenny Morris argues,

'In Western industrial societies, this term has commonly been associated with the ability to do things for oneself, to be self-supporting, self-reliant. When physical impairment means that there are things that someone cannot do for themselves, daily living tasks with which they need help, the assumption is that this person is "dependent ". And in Western culture, to be dependent is to be subordinate, to be subject to the control of others. ' (1993, 22ff.)

For this reason, the disability movement response has been to highlight the social environments which render people with impairments disabled, and to call for systems of personal assistance which enable people to live independently. Yet perhaps it would be more effective to challenge the overall liberal tradition of independence and individualism, rather than to claim access to the notion for a particular excluded population.

This is not to argue against barrier removal or personal assistance. Such innovations are essential to create a 'level playing field', in which interdependency can be based on equality and social justice rather than exclusion. Other innovations might include more extensive day care, the recognition of children's rights, and prohibition of discrimination on the grounds of gender, race, disability and sexuality. We might then recognise that we are all dependent on each other, and that disabled people's limitations are not qualitatively different from those of other human beings.

Challenging independence goes against the grain of contemporary social theory. The work of thinkers such as Anthony Giddens and Ulrich Beck argues for the inevitable rise of individualisation, in which concepts such as choice, freedom and negotiation replace the traditional collective rules and shared values, in a world where more and more people live alone. In this account, independence is vital to living: *'In an individualized society each of us must learn, on pain of remaining at a permanent disadvantage, to conceive of him/herself as the central pivot around which life revolves'* (Beck and Beck- Gernsheim, 1995,40).

Yet perhaps this approach both overstates the degree of change and is complacent about the dangers of unrestrained individualism. After all, many people who live alone also belong to networks, for example lesbian and gay communities, or communities of protest, or youth subcultures. The family is not so much in decline, as in development to a more varied and pluralist set of possibilities (Smart and Neale, 1999). In the modem world, we are more than ever interdependent, despite our assumptions and attitudes. One disabled person suggested to me that the teenager is an effective metaphor for the illusion of independence which now predominates: *'the typical arrogant healthy teenager who thinks he is independent but relies on a whole network of support to carry out his lifestyle. .. shirts ironed, meals cooked, bills and domestic responsibilities sorted, his toilet cleaned. ..and he sees this as independence?'* And of course, it is no coincidence that the image is of a male.

Should we not see the aids and enabling environment which people with impairments require as part of their way of relating to the world as part of their extended self? If a beaver cannot be understood without a dam, then in the same way a person with paraplegia cannot be imagined separately from their wheel-chair. Every human requires some form of clothing and footwear to survive, even or especially in the artificial environments in which we now live. Cars seem a vital part of our species' way of life, even if they threaten to destroy the whole ecosytem on which we rely. Many people require mobile phones and pacemakers and insulin injections and everyone requires mass transit systems and the postal service and food distribution. We should not "distinguish between those externalities which we all take for granted but without which we cannot operate and the experience of people with impairment who rely on particular aids to conduct their lives.

The feminist ethic approach to independence, alongside the demand for barrier, removal and personal assistance, comprises a broader strategy for empowering disabled people. It recognises that dependency is not an exclusive attribute of older people or people with impairments, but is part of being a member of the species: *'While not all people need others' assistance at all times, it is part of the human condition that our autonomy occurs only after a long period of dependence, and that in many regards, we remain dependent upon others throughout our lives'* (Tronto, 1993, 162). Sally French argues that while we are all dependent on each other, disabled people's limitations are often seen as qualitatively different. Despite the way that self-care skills are emphasised for disabled people, everyone in the workplace, for example, requires assistance and support: *'The crucial difference is that able-bodied people* 's *problems are regarded as normal and acceptable, and thus they can ask assistance of each other without feeling guilty or inferior'* (1993,46). Yet our ways of speaking obscure the relations of help and exchange which are going on every day: *'When it is said of people that they can take care of themselves, what is meant is that such persons can make sure that others will take of them, that can return every favour with a counter-favour which its considered its equivalent* (De Swann, 1990, 27).

We need to challenge the philosophy of independence, narrowly understood, and replace it with a demand for negotiated autonomy, based on the inevitable interdependence of modern societies, and including an understanding of the frailty of the human condition: *'In the redefining of childhood, old age and disability lie the seeds of an expanded adulthood, one which admits and indeed values vulnerability as an essential prerequisite for human growth and development'* (Hockey and James, 1993, 183).

It is necessary to recognise the virtue in necessity, because effective helping is a way of giving satisfaction to the one who helps, as well as the one who is helped:

'In striving to realize their objectives, human beings are for ever dependent on one another,' everyone depends on other people and almost everyone is needed by some others. That is what conveys to people their significance for their fellow human beings and that is where they find the fulfilment of their existence.' (De Swann, 1990,21)

Disabled people, in an enabling society, can also have access to this fulfilment, as parents, carers, workers, partners, activists, artists and members of the community, or simply as people who receive the love, help and support of others.

In the end, values

While the first half of this chapter centred on the independent living agenda, the second half has begun to explore broader questions about the values which should inform society and welfare systems. Drawing on the idea of feminist ethic philosophers and some of the practical models for low-intensity support has led to an argument for community and mutuality as a vital component in reforming the ways in which help is both understood and delivered. However, while challenging the individualism of contemporary society and the failure to recognise interdependency, I am not advocating communitarianism. The con- temporary British trend towards teaching civic values within a new form of Christian socialism fills me with concern. When Alisdair MacIntyre writes that ‘modern nation-states which masquerade as embodiments of community are always to be resisted' (MacIntyre, 1994, 303), then I am in whole-hearted agreement. For, as he goes on to argue,

'The modern nation-state, in whatever guise, is a dangerous and unmanageable institution, presenting itself on the one hand as a bureaucratic supplier of goods and services, which is always about to, but never actually does, give its clients value for money, and on the other as a respository of sacred values, which from time to time invites one to lay down one's life on its behalf' (MacIntyre, 1994,303)

With MacIntyre (1987), it is localised forms of community, embodying the practice of the Aristotelian virtues and agreement on what constitutes the good, which I would see as a tenuous but desirable solution to some of the problems of contemporary social policy.

To take this, approach is to place welfare reform in the wider context of community development, which includes empowerment of those on the margins through unemployment or poverty, or through living in isolated rural areas or run-down outlying estates. New models of economic and community development build mutuality through schemes such as Local Economic Trading Systems (LETS), structures which enable members to help each other but do not impose a relationship on any two people. These types of network break down need into smaller units, and enable people to make small contributions which are nevertheless valuable. Help is not a matter of all or nothing, in terms of either giving or receiving. In this way, feelings of responsibility or obligation do not build up. It is when people get stuck in the role of helper or helped that dependency develops, in the process known as identity spread: people become fixed in their role, which goes on to dominate other aspects of their personality. LETS can avoid this, and also the scope for people to feel virtuous or for recipients to feel grateful.

Experienced community workers Tony Gibson and Andy Gibson have suggested to me that empowering community work, in the end, often comes down to beliefs and values. Do you believe people are capable of understanding, or acting autonomously, taking control of their lives? If you do not, then you will not be able to work for change. There is a very narrow line between respect and valuing and control. Helpers can have all the right words and the right theory, but wrong practice. They may aim to respect but end up controlling. People need a lot of confidence in order not to take control. It takes strength of character to relax and let go, distinguishing between things getting out of hand and things getting out of your hand. For the Gibsons, it comes down to a basic faith in other people's capacity: a gut feeling, or built-in spirit level. While this understanding can be suppressed or distorted or overlaid, it remains a knowledge which can be trusted about what is 'right'.

In the attack on traditional welfare, and particularly the role of charity and of helpers, there is a danger of writing out the role of values and compassion in the provision of help. Perhaps this reflects the cynical spirit of the age, in the same way that the call for independence apes the wide fetishisation of individualism. Yet there is a need to resist cynicism, and concentrate on the values which might offer the possibility of a 'solution to those problems which have been outlined in this book. Rights are only half the story. Community is a fragile concept, continually undermined both by the values of the market and by the disabling impacts of particularism and disempowering treatments. But that does not mean that it should not be an ideal which is more explicitly a part of social movement politics.

Postmodemism leads some to suggest that ethics no longer operate, and that there are no foundations for morality, only competing value systems. Yet Zygmunt Bauman has demonstrated that the fundamental imperatives still have resonance and validity in the contempory world. He suggests that post-modern politics should be guided by liberty, difference and solidarity (1997, 207). In the same vein, but working within a feminist tradition, Fiona Williams has set out seven principles of welfare for the new millennium: interdependence, care, intimacy, bodily integrity, identity, transnational welfare and voice. For Joan Tronto, the feminist ethic of care has four elements: attentive- ness, responsibility, competence and responsiveness.

These approaches to politics and particularly to welfare, allow for the diversity of welfare subjects and avoid fetishising independence or normality. Particularly, they replace a paternalistic approach, based on the standpoint of the helper, with an approach which recognises the autonomy of the person who is helped:

'Responsiveness suggests a different way to understand the needs of others rather than to put our selves in their position. Instead it suggests that we consider the other 's *position as that other expresses it.* ' (Tronto, 1993, 136)

Putting yourself in someone else's shoes can be a good thing, but only if it is based on *their* testimony -not your projection of what it is like. This approach means recognising the way that helping can harm: *'The moral precept of responsiveness requires that we remain alert to the possibilities for abuse that arise with vulnerability'* (Tronto, 1993, 135). It also necessitates making communication and dialogue a central part of the strategy for help and empowerment.

Refounding welfare in ethical commitment enables a solution based on justice *and* compassion, rights *and* care. Undoubtedly, the first step in any reform must be the removal of the gross obstacles to the inclusion and equality of mariginalised people: for example, with civil rights statutes, personal assistance schemes, and accessible housing and public environments. This establish a ‘level playing field', in which there was more balance between disabled people and non-disabled people, and dependency was minimised. Yet at this stage, the values of interdependence and the feminist ethic contribute an important dimension to social life. The independent living combination of direct payments and personal assistance cannot solve all the problems. Moreover, the model will never be appropriate for everyone. Many people want to be able to receive care from family and friends, or do not want the stress of employing their own workers, or may not be capable of the negotiation and responsibility which this involves. Disabled people and others still often depend on good will and mutual aid, as all people do. The danger comes when disabled people have no choice and no alternative, and are reliant on unresponsive services or demeaning charity which render them marginalised and dependent. Yet empowered disabled people will achieve a better quality of life in a community in which each recognises their responsibility to the other, rather than a world made up of competing and selfish individuals seeking to maximise their own advantage.

Zygmunt Bauman argues that commitment to the other is a central part of post-modem ethics. Selma Sevenhuijsen promotes the idea of ‘caring solidarity':

'The feminist ethic of care points to forms of solidarity in which there is room for difference, and in which we find out what people in particular situations need in order for them to live with dignity. People must be able to count on solidarity because vulnerability and dependency, as we know, are apart of human existence we need each others disinterested support at expected and unexpected moments. ' (Sevenhuijsen, 1998, 147)

This notion of caring solidarity may perhaps offer some promise in trying to break down the dichotomy between disabled and non-disabled people, recognising that everyone is variously dependent, that disabled people are themselves often carers, and that society is based on interdependence. It would be overly utopian to expect that solidarity or community could dissolve otherness entirely. A more realistic aim would involve diverse individuals working together, able to continually renegotiate their otherness in a condition of reciprocity.

The problem of individualism is a particularly western legacy. In Africa, for example, a different tradition assumes not separateness, but community. Rather than the Kantian *'I think therefore I am'*, John Mbiti has substituted '*I am because we are, and since we are, therefore I am'* (Battle, 1996, 105). This concept is called 'Ubuntu', and suggests not just that people should be treated as ends, rather than as means to an end, but that people are ends in themselves only through the discovery of who they are in others. Ubuntu theology opposes the western tendency to see individual worth in terms of material success -you are what you produce. It stresses that everyone is a 'God carrier', and that to treat. others badly is to spit in the face of God, just as the Quaker tradition exhorts us to ‘look for that of God in everyone' .

'God has created us all to be different in order that we can realise our need of one another: There is an African idiom: "A person is a person through other persons ". *I learn to be a human being through association with other human beings.* ' *(Battle,* 1996, 96)

This theology explains the role of people like Desmond Tutu in seeking reconciliation with the white minority after the disastrous experience of apartheid. Having argued in this book that imperialism begins at home, perhaps it is appropriate to end with a liberating concept from the continent which has borne the historical brunt of colonialism.