

Supplementary Report No 1.

## **Mapping User-Led Organisations**

**User – Led Services and Centres for  
Independent / Integrated/ Inclusive Living:  
A Literature Review Prepared for the  
Department of Health**

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## **Summary**

This report considers academic and 'grey' (not published for general circulation) literature from January 2001 to June 2006 concerning the development of Centres for Independent/ Inclusive/ Integrated Living (CILs) and selected service user-led organisations.

Three key areas are highlighted:

### ***(1) The Development of CILs and User-Led Organisations***

- CILs were developed by the disabled people's movement in the 1970s and 1980s as a means of organising support for independent living.
- Peer support is a vital component in supporting the take-up of direct payments by applicants.
- The legal and administrative framework for community care services presents problems for CILs and service users.
- Government policy over the last decade has supported the aim of independent living, but with a particular emphasis on contracting arrangements for direct payments.
- Access to direct payments has been patchy, both geographically and in terms of service user groups.
- There is a clear trend of an increasing demand for personalised, self-directed services.

### ***2. CILs and User Groups***

- The first CILs were pioneered by people with physical impairments and support services largely reflect their needs.

- People with learning difficulties, black and ethnic minority groups, mental health service users, older people and carers are under-represented among users of direct payments.
- There is evidence that some CILs offer relevant and accessible support for these groups of service users, but overall, there is considerable room for improvement.
- Work has been done to identify other mechanisms for payments that would support the needs of specific user groups.

### ***3. Issues Facing CILs and User-Led Organisations***

- CILs face acute difficulties in accessing sufficient funding, thus making longer-term planning very difficult.
- A lot of funding remains tied up in traditional, non-personalised services.
- Contracting favours larger organisations that offer economies of scale.
- Service users are rarely involved in setting specifications for services or designing outcome measures.
- Service users' roles and responsibilities in community capacity building are not recognised.
- There is competition for what limited funding exists between user-led organisations.
- Support for user-led organisations from local authorities is too often ambivalent, and sometimes hostile.
- There is a need for new organisations that provide peer support for independent living.
- Long-term under-investment by national and local governments has produced a severe shortfall in the capacity of CILs and other user-led organisations to meet the growing demand for independent living support services.

## Introduction

This literature review discusses the position of Centres for Independent/ Integrated/ Inclusive Living (CILs) and user-led organisations in England.

Direct payments and other mechanisms for placing funding under the control of service users to organise their own particular support needs are seen as the key means of effecting independent living. The work of CILs is not limited to personalised funding. Independent living is a broader frame of reference, and this raises certain difficult questions about funding and contracting for user-led organisations.

There is a very long history of self-help groups that are concerned solely with impairment specific concerns and medical rehabilitation. Other groups are primarily concerned with political campaigning and lobbying. While these activities are often an important source of support, such organisations are outside the remit of this discussion. The focus here is on user-led service providers specifically concerned with supporting independent living.

Disabled people have led the drive for direct payments and legislation that supports independent living. They have produced or influenced a considerable literature and this review reflects these activities. There are other important initiatives that seek to push forward change in local authority services, such as 'In Control' (<http://www.in-control.org.uk>), but these are not reviewed in any detail. While this work is important, the focus here is on CILs and user-controlled services.

This report is in three sections. Following clarification of the definitions used, and the recent development of CILs, the discussion centres on their relationships with other service user groups and their perception of other current issues they face.

## Definitions

According to the Prime Minister's Strategy, CILs are:

'grassroots organisations run and controlled by disabled people....Their aims are to assist disabled people take control over their lives and achieve full participation in society.....For most CILs their main activity, and source of income, is running support schemes to enable disabled people to use direct payments. Such schemes may involve:

- Advice and information;
- Advocacy and peer support;
- Assistance with recruiting and employing Personal Assistants(PAs);
- A payroll service;
- A register of PAs; and
- training of PAs.

CILs also:

- Run projects encouraging take-up of direct payments among marginalised groups;
- Provide disability equality training;
- Carry out consumer audits of services' (PMSU, 2005, pp 70-71).

In addition, the following definitions, provided by Jenny Morris, are used in this review:

*"Independent living* means having choice and control over whatever is required in order to go about your daily life.

*"Inclusive living"* means being fully included in society.

*Service user* means people who need support and/or equipment in order to go about their daily lives and who use services that are provided as part of the welfare state.

*User-led organisations* are those where the people who the organisation represents or provides a service to, have a

majority on the Management Committee or Board, and where there is clear accountability to members and/or service users.

*Centres for Independent/Inclusive Living* are grassroots organisations run and controlled by disabled people. Their aims are that disabled people should have control over their lives and achieve full participation in society. They work towards these aims by representing disabled people's views locally and nationally, and by providing services which promote independent living." (Morris, 2006, pp 1-2)

While there are variations on the definition of Independent living, all involve three elements: first, an assertion that disabled people should have the same choice and control as non-disabled people; second, that assistance received should be controlled by disabled people; and third, a challenge to the traditional meaning of 'independent' as doing things without assistance. Here 'independent' means making decisions and having support to put them into effect (Morris, 2004).

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The term 'service user' is not universally welcomed or accepted (Heffernan, 2006). In this Report, we follow *Shaping Our Lives*, a national organisation that works for user involvement in decision-making processes, that:

".... sees 'service user' as an active and positive term ... It is important that 'service user' should always be based on self-identification" (*Shaping Our Lives*, 2006, unpagd).

Many health, social care and charitable organisations describe themselves as led by the needs of their users, but in most instances service users do not make executive decisions, such as exercising control over policy or resources. Hence, in this Report, the term 'user-led services' refers to organisations of service users, that is, organisations effectively controlled by them (Barnes & Mercer, 2006). Nevertheless, it is recognised that some organisations for service users are employing more disabled people as staff and paying more attention to the importance of user involvement although not (yet) a user-led service.

User involvement spans varying levels (Arnstein, 1969), but in practice it has mostly afforded a relatively low level of participation

to service users. Thus, it has not led to organisational change in favour of service users to any significant degree (Hasler, 2003; Carr, 2004; Hodge, 2005). User-led services may be seen as the highest level of citizen participation in civic life and democratic processes (Arnstein, 1969), particularly where initiatives are adequately funded and users have relative autonomy in managing their budget.

However, many organisations of disabled people take a pragmatic stance and employ some non-disabled people (Barnes & Mercer, 2006). There has been much debate about percentages: the number of service users that should be involved for an organisation to be defined as user-led. The disabled people's movement has taken a strong position on this; for example, membership of the UK's Disabled Peoples' Council (formerly the British Council of Disabled People (BCODP) is only open to disabled people (BCODP, 2006). Mental health service user organisations are more likely to have overlapping links with service providers (Beresford, 2006b), while people with learning difficulties employ non-disabled support assistants, who may be party to much organisational business (People First, 2006a, 2006b). It should be noted that CILs are not impairment-specific and that they are open to all disabled people. In practice, restrictions on funding and staff availability have meant that the predominant group of users is people with physical impairments (Luckhurst, 2005; Barnes & Mercer, 2006).



# The Development of CILs and User-Led Services

## *Peer Support*

There is a long history of self-help groups that provide assistance for living with impairment and disability. User-led organisations providing support more specifically with Independent Living can trace their more recent history from the 1970s and 1980s ( see Glasby & Littlechild, 2002, and Barnes & Mercer, 2006 for a detailed discussion). An early group, Derbyshire Centre for Independent Living, formulated seven needs of disabled people as central to their operations: information, counselling and peer support, housing, technical aids and equipment, personal assistance, transport and access to the built environment (Davis & Mullender, 1993). Hampshire and Southampton CILs, have added inclusive education and training, adequate income, equal opportunities for employment, advocacy and appropriate and accessible health care provision to this list (Morris, 2004). Research indicates that CIL-type organisations have aspired to provide the full range of these services, but lack adequate and appropriate resources (Barnes & Mercer, 2006).

Research has consistently shown that user-led organisations are central to the development of independent living. For example, direct payments are more widespread where CILs exist and particularly so where local authorities support these initiatives. The Joseph Rowntree Foundation states that 'services cannot enable people to achieve their aims and aspirations without the full involvement of service users' (2005: 11). Pointing to research carried out in the north of England (Hasler & Stewart, 2004), they note that direct payments have been more successful in areas where local user-led organisations are available to support new applicants (Priestley et al., 2006).

The Department of Health has recognised this issue and taken a leading role by putting in place the Direct Payments Development Fund (2003 – 2006), through which voluntary organisations were able to bid to provide support organisations for service users (NCIL, 2006a).

Peer support is a central tenet of independent living. Paperwork and operating a payroll system can put many service users off managing direct payments and support and guidance makes this process easier and therefore more possible for many (Bewley & McCulloch, 2004; NCIL, 2006a). This mentoring and support should be separate from local authority provision in order to avoid a conflict of interest. NCIL (2006a) notes that an informal process: the sharing of personal experiences was key to the success of peer support in the Development Fund projects they evaluated. Although dealing with bureaucracy was often a difficult issue for service users, employing personal assistants also involves a more complex management of the boundary between work, home life and social relationships and the juggling of competing priorities (Vasey, 2000; Woodin, 2006). The boundaries of local authority departments do not fit easily with this because using personal assistance involves managing support across the whole sphere of life, including the negotiation of such things as transport, education, work, and home life. Furthermore, direct payments represent just one aspect of Independent living more generally.

CILs work in a context where there are still many pressures operating against Independent living (Morris, 2004). An Independent Living Bill to put in place a legal framework for supporting the work carried out by CILs and other user-led service organisations is currently under consideration (Ellis, 2006; NCIL, 2006a).

## ***Social Policy***

Supporting Independent living through devolving control of personal assistance and resources for personal care to service users is a key Government priority. The White Paper '*Our Health, Our Care, Our Say*' (Department of Health, 2006b) sets out plans to increase provision of payments and to amalgamate diverse funding streams into more flexible individual budgets. Personalisation of services through funding arrangements is now a consistent strategy ( Department of Health, 2005b; Prime Minister's Strategy Unit, 2005; Brindle, 2006).

Securing agreement to fund direct payments was a lengthy and contested process (Glasby & Littlechild, 2002) with the 1996 Community Care (Direct Payments) Act representing a major

turning point. Since this time developments have been swifter, with payments extended to older people - initially excluded due to concerns about overwhelming demand - children aged 16-17 and carers (Department of Health, 2000a, 2000b). Offering direct payments to applicants receiving Community Care assessments became mandatory through the 2001 Health and Social Care Act and restrictions placed on who might be employed as personal assistants and how payments may be managed have been loosened (Department of Health, 2003). Direct payments and individual budgets have become a key performance indicator affecting star ratings for local authorities, who are urged to work more collaboratively with service user groups (Clark, 2003).

There are a variety of reasons for developments but prolonged lobbying by service users for choice and control over assistance has been effective. The Prime Minister's Strategy Unit states that:

'by 2025 disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as vital members of society' (2005: 6)

User involvement and the development of social capital in local communities is also an important Government concern. Encouraging citizen participation in public life may reverse the trend towards lower voter turnout in elections as well as build stronger communities. Involvement in community life is seen as a right, and as having the potential to overcome alienation and exclusion and improve the effectiveness of services and resources (Chahan, 2003; Jochum et al., 2005). It follows therefore that direct payments and individualised budgets have the potential to be an effective means of effecting greater independence and participation.

With regard to achieving a better use of resources, the active participation of older people is strongly emphasised, on the basis that this may reduce dependence and future costs (Audit Commission / BGOP, 2004). The financial costs involved in providing traditional services to an ageing population are considered problematic (Ladyman, 2004a, 2004b; Department of Work and Pensions, 2005). Studies show direct payments to be an effective use of resources and worth investment, especially when

considered in relation to the life course of service users (Zarb, 2003; Duffy, 2005; Poll et al., 2006).

The Government has made a commitment to developing the spread of user-led organisations, with Centres for Independent Living seen as a blueprint for local developments:

‘By 2010, each locality (defined as that area covered by a Council with social services responsibilities) should have a user-led organisation, modelled on existing CILs.’ (Prime Minister's Strategy Unit, 2005: 91)

User-led organisations are judged to be well placed to deliver support based on the requirements of service users, qualified through direct experience, rather than services that are moulded to fit the preferences of service providers (Ladyman, 2004a).

### ***Direct Payments and Local Authorities***

Direct payment developments on the ground have been uneven (Pearson et al., 2005) resulting in something of a ‘postcode lottery’ (Morris, 2004; CSCI, 2005; NCIL, 2006a). As has been described above, user-led services are hampered by the context in which they are being developed and therefore it may not be surprising that developments are distributed unevenly across the country. Access to payments and support for Independent living is dependent on where people live and services cannot be moved from one area to another.

The numbers receiving direct payments have risen more rapidly in recent years, for some groups at least. The Commission for Social Care Inspection (2005) reports that in March 2005 28,000 people were receiving direct payments, an increase of 27% in 6 months. These numbers are still very low however in comparison with early expectations.

While the number of recipients has risen across all user groups, the numbers of older people have increased more slowly: from 4,365 in September 2004 to 5,493 in March 2005 (CSCI, 2005). This represents a 26% increase compared with a 130% increase for the previous 12 months. This is despite findings that receiving direct payments is a positive experience for many older people,

most particularly when combined with the availability of support services (Clark et al., 2004). For other adult groups the rate of increase remained steady: therefore the take-up rate for older people is slowing down comparatively.

The opposition of many local authority staff has been widely documented (Clark & Spafford, 2002; Davidson & Luckhurst, 2002; Barnes, 2004; Spandler & Vick, 2005). In particular the 'willing and able' clause in the 1996 Community Care (Direct Payments) Act has been widely used as justification for the exclusion of whole groups on the basis of their impairment, particularly mental health service users (Newbigging & Lowe, 2005) and people with learning difficulties (Williams & Holman, 2006). Clark and Spafford (2002) found that care managers experienced initial difficulties extending payments to older people due to time constraints, concerns about how to offer payments, again including worries about the 'willing and able' criteria. Reluctance by mental health service staff has been particularly marked (Spandler & Vick, 2005), and Holman (2002) notes that the belief that professional staff should provide services has often formed a barrier to access for people with learning difficulties.

Direct payments have been discussed here because they have been seen as the most important means of achieving Independent living. However they are not synonymous. While note has been made above of the common perspective between service users and Government, there are also important differences in outlook. Government policies have emphasised choice and consumerism but user-led organisations are more likely to argue for a democratic and participative agenda (Barnes & Mercer, 2006). Therefore the objectives of CILs are wider: they go beyond services that are part of health and social care responsibilities, to take in broader concerns with social arrangements.

## CILs and User Groups

Centres for Independent/ Integrated/ Inclusive Living (CILs) were formed in the UK by disabled people with the central ethos of retention of control over how they are run and to what purpose. However they have not generally involved a wider constituency of service users, and concern about this has been expressed by several authors (Breakthrough UK, 2005; Morris, 2006). Studies refer to the experiences of different service user groups in relation to CILs. It should also be borne in mind that many services users would identify themselves as belonging to more than one group: the categories are of course not discrete.

### *People With Learning Difficulties*

People with learning difficulties have not been readily included in local CILs (Bewley & McCulloch, 2004; Breakthrough UK, 2005; Morris, 2006). Bewley and McCulloch were only able to find one example of direct payments support provided to people with learning difficulties by an organisation that was run by people with learning difficulties. Further, they found only two support organisations in which disabled people were involved that included people with learning difficulties in running the organisation. Morris (2006) offers the explanation that historically people with physical impairments have been treated as if they also had learning difficulties and many have wanted to distance themselves from the stigma of this.

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Some CIL staff consulted by Bewley and McCulloch (2004) were afraid of not knowing how to behave towards or communicate with people with learning difficulties and some said that people with learning difficulties had different needs from their own. On the other hand, those organisations that did assist people with learning difficulties said that they did not need different advice, but might need information presented in more accessible ways, showing that exclusion is not across the board. Barnes and Mercer (2006) provide evidence that many organisations do provide information in a variety of accessible formats.

Another issue concerns the role of non-disabled people in supporting People First and other self-advocacy organisations

(Johnson, 2006; Morris, 2006). Morris notes that many disabled people consider that non-disabled people have too much influence over self advocacy groups, but she states that it should also be borne in mind that increasingly the role is to support rather than to direct (People First, 2006a, 2006b). Similar considerations apply to family members: Morris (2006) notes that many have taken an important role in campaigning for the rights of people with learning difficulties. However many disabled people have rejected any involvement by family members in their organisations and this issue therefore represents an important difference in perspective (see also below).

Finally, studies point to the barriers to independent living that have been erected by local authorities for people with learning difficulties and urge CILs not to do the same (Bewley & McCulloch, 2004; Barnes & Mercer, 2006).

### ***Black and Minority Ethnic Service Users***

All services, including CILs, have not been effective at including black and minority ethnic service users (Hussain et al., 2002; Vernon, 2002). There is a tendency in the literature to generalise and treat non-white groups as if they were all the same, when there are obviously important differences between ethnic groups. Singh (2003) reports on support organisations for 4 grassroots development projects for black and minority ethnic disabled people. History and cultural expression were important for three of the projects and all succeeded most where they responded to participants' experiences of multiple exclusion. Nevertheless, the conclusion of all authors is that Black and Minority Ethnic (BME) groups have been substantially left out of service provision, and there are indications that this is also the case for Independent living and direct payments.

Stuart (2006) suggests that BME applicants face several additional significant barriers. These include: confusion over the term 'independent living' (where independent living is interpreted to mean living on your own without help), lack of information and advocacy support, discriminatory assessment procedures, difficulties recruiting personal assistants who have the required cultural, linguistic and religious backgrounds, and a failure to use

direct payments in innovative ways. Finally, language and communication remains the most significant barrier.

These concerns have also been reported by Warwickshire Council of Disabled People (Evans & Banton, 2001). Recommendations for increasing involvement of BME groups included: employing a black worker, training on 'race' and ethnicity, consultation and working with black disabled people (and their families if this is wanted by the disabled person) and joint working between organisations of disabled people and black organisations.

Stuart (2006) predicts that while local authorities with high minority ethnic populations are likely to be reasonably responsive, other areas may be less so. He maintains that CILs / user-led organisations will be able to support BME direct payment users with exercising increasing choice and control, to move from direct services to direct payments, be able to explain rights, act as advocates and act as a training and information resource. Conversely, he argues that their commitment to independent living might put off BME service users, and that 'race' equality training will be needed on a regular basis.

### ***Mental Health Service Users***

Mental Health service users face particular problems accessing direct payments (Newbigging & Lowe, 2005; Spandler & Vick, 2006). Some are barred from receiving direct payments but the majority are not and local authorities have been urged to remedy this situation (Department of Health, 2006a).

As mentioned above, there are important variations in the experiences of different BME groups. For example, psychiatric services are particularly problematic for 'Black' people and they are disproportionately represented in mental health services and experience poorer outcomes than their white counterparts (Keating et al., 2002). In this respect, 'Black-led' organisations are often considered to be the only source of culturally appropriate practice (Keating, 2002). The widespread practice of describing all 'visible' (i.e. non-white) groups as an entity can obscure important differences that have a bearing on what support for independent living means.



## **Older People**

The changing demographic profile of the population is the cause of much current discussion, and there are concerns that the increasing numbers [of](#) older people in the future should be supported to live as independently as possible (Audit Commission / BGOP, 2004). Certainly, older people use health and social services more than other groups and policy authors stress the need to re-think the way that older people are seen – from dependency and frailty to independence and ‘successful ageing’ (Wistow et al., 2003).

There is evidence that older people face discrimination in most areas of life, including care and support (Grattan et al., 2002) and this is reflected also in their access to direct payments.

Older people value independence, often seen in terms of *interdependence* with other people (Audit Commission / BGOP, 2004). Priorities are having good social relationships, help and support, living in places that are neighbourly, safe and with good transport links, having hobbies and personal interests, enough money to meet basic needs and having control over life (Gabriel & Bowling, 2004). With regard to these priorities, Priestley and Rabiee (2002) considered the possibilities for commonalities between disabled peoples’ organisations and groups led by older people. While they found substantial areas of agreement, especially with regard to housing, mobility, social isolation, employment and welfare benefits, the two groups often expressed the same concerns in different language. The main difference found by the authors concerned culture and identity: older people and disabled people tended to think of themselves as unlike the other group. They conclude that it probably makes more sense for each to pursue the outcomes they seek independently of one another. This being said, there are clear areas of overlap between the interests of the two parties.

## **Carers**

While there are a range of definitions in existence (see Roulstone et al., 2006) the term ‘carer’ is generally used to denote a person

who provides assistance with daily living activities to another person, on a regular and unpaid basis.

Carers have gained more official recognition in recent years (e.g. Department of Health, 2005a, 2006b). The Carers and Disabled Children Act (2000) and associated guidance extended direct payments to carers aged 16 and over, carers with parental responsibility for disabled children and young disabled people. In 2003 the rules governing payments to family members were relaxed, permitting family members to be more easily employed as personal assistants. However there is still concern from carers' groups that it is difficult for them to secure support in their own right (MacGregor & Hill, 2003; Watson, 2006).

Morris' (2006) question, 'Are carers service users?' reflects the differences of opinion between disabled people's and carers' organisations. There is a long history of disagreement between the two parties, concerning the distribution of resources and different points of view about Community Care policies (Parker & Clarke, 2002). Debates have been acrimonious at both local and national levels although there is some evidence that Independent Living measures are bringing the two parties closer together and differences of opinion are often less marked at local than at national level.

As has been discussed above, relationships are less problematic between carers and people with learning difficulties and black and minority ethnic service users. Mencap has taken a lead on developing individual budgets, for example (Poll et al., 2006). Many disabled people, particularly women are also carers, for young children, older and disabled people.

## ***Discussion***

People with physical impairments lobbied for direct payments and legislation was originally drawn up with this group in mind (Glasby & Littlechild, 2002). Because of this, the formal stipulations associated with payment arrangements have not always been best suited to other user groups. The 'willing and able' requirement allowed whole groups of service users to be excluded from consideration by local authorities, particularly mental health service users and people with learning difficulties. More recently, the

acknowledgement that people might have support to be 'willing and able', combined with sustained lobbying, has opened up opportunities for payments to be made in a variety of different ways and the criteria have become more flexible.

Luckhurst (2005) has reviewed a range of alternative means of giving people access to financial payments, which might more closely match what is needed for more people to receive payments. Independent living trusts (groups set up to receive money on people's behalf and act as the employer) are reported as being taken up by more people with learning difficulties and third party payments (money paid to another individual who helps with managing the process) by older people. These were alternatives where local authorities had assessed applicants as not being 'willing and able' to manage direct payments. Although other arrangements, including brokerage (independent advisors acting on behalf of people receiving payments) and user-controlled personal assistance agencies (supplying assistants) were investigated, these schemes were not widely taken up.

Williams (2006) notes that direct payments is just one of a number of drivers towards more choice and control for people with learning difficulties. These include person-centred planning (Emerson et al., 2005) and support to use individualised budgets. Poll et al. (2006) report on the results of pilot projects in 6 areas of the UK, where people with learning difficulties gained access to funds (following an assessment) that they were free to spend as they wished. They report positive outcomes in terms of service users' control over life events, and their increased satisfaction with arrangements. As part of these pilots, different support arrangements were put in place in each of the areas: family support without independent brokers, choice of a new broker, choice from trained brokers, direct support from CIL staff and assistance from a broker employed and supported by a CIL. The authors note that a diversity of arrangements is likely to be preferable, and point out the slow progress with regard to changing services and argue that new organisations need to be created.

The Joseph Rowntree Foundation (2005) suggests that CILs will need to specifically employ people from other groups in order to successfully provide support. Morris (2006) also advocates developing a network of user-led organisations as a way of

extending support to other groups and encouraging further involvement.

## **Issues Facing Service User Groups**

The creation of more user-led services to support the uptake of individual budgets is likely to pose considerable questions for organisations of disabled people (Barnes & Mercer, 2006). This section will review a range of work that casts light on the current situation with regard to capacity and scope of organisations to support an expanding number of likely applicants for direct payments and other forms of individualised funding.

### ***Funding***

CILs face acute funding problems. Many organisations rely on grants that are time-limited and financial insecurity is resulting in the closure of organisations (Breakthrough UK, 2005; Barnes & Mercer, 2006). Reliance on funding from local authorities and voluntary organisations may limit the range of services that can be offered due to stipulated restrictions on activity. Although some user-led organisations supplement income through other work such as conducting training, local authority funding may be reduced as a result, because some authorities argue that this shows that funding is not needed. As a result, many user-led organisations exist on a shoestring budget and have difficulties recruiting and retaining skilled staff, relying instead on volunteers (Barnes & Mercer, 2006). The practice of setting 'cost ceilings' on the amount of support provided to service users, combined with the still widespread practice of block contracting with service providers militate against support for independent living (NCIL, 2006a).

### ***Contracting***

Closely allied to the issue of funding for user-led organisations is the question of how contracts for service provision are allocated. Stephen Ladyman (2004b) has made the point that local expertise should address local needs, but several studies show that this consideration is unlikely to be the primary consideration when contracts are allocated. Services that were developed by disabled

people, such as support for independent living, are now being put out to tender and local user-led organisations often do not gain the contracts because larger companies and charities are in a position to offer lower unit costs (Morris, 2006). Large organisations often have departments dedicated to applying for funds, while smaller, user-led organisations often exist hand to mouth (Beresford, 2006a). The tendering process is a particular issue for organisations of people with learning difficulties who may require more time and need documents in accessible formats (Morris, 2006), but the lack of resources affects all user-led organisations.

Furthermore, contractors often show a preference for larger, known providers (Barnes et al., 2003). This, together with the fact that much funding remains tied up in traditional services (Morris, 2004), contributes to the difficulties in securing contracts. Larger organisations are more likely to provide a wider range of services, at least some of which are concerned with providing lucrative congregate services. In contrast, user-led organisations are concerned with innovative support for work that is not yet well funded. Contracts typically do not provide core funding for independent living support. They are more likely to stipulate support for using direct payments, which is not necessarily what service users need. Contractors are often concerned with processes rather than outcomes (Harris et al., 2005; d'Aboville, 2006).

While in some areas local authorities have contracted with user-led organisations (Morris, 2006), they rarely involve service users when setting the specification for services or in designing the outcome measures (Collins & O'Neil, 2005). A notable exception to this is an instance where the Joseph Rowntree Foundation funded a project in Wiltshire that enabled service users to design and carry out a Best Value review of direct payments (Evans & Carmichael, 2002). Crucial to this successful venture was the support and encouragement of local authority senior managers. There is evidently scope for further development of consultation and peer support as key aspects of service specifications, especially in relation to black and ethnic minority communities, who experience unequal access to support (Joseph Rowntree Foundation, 2005).

Problems with the ways that contracts are awarded were noted in the Government White Paper 'Improving the Life Chances of

Disabled People' (Prime Minister's Strategy Unit, 2005). Notable recommendations included the stipulation that user-controlled organisations would provide: information and advice, advocacy and peer support, assistance with self-assessment, support in using individual budgets, support with recruiting and employing personal assistants, disability equality training and consumer audits of local services.

With this in mind, the Association of Directors of Social Service and the National Centre for Independent Living have issued a joint protocol recommending to local authorities that they support the development of user-led support organisations (ADSS / NCIL, 2006). Noting that 7 out of 10 of the top performing local authorities on direct payments contract with user – led organisations, they point out that star ratings will be affected as direct payments is now a key performance indicator. It is acknowledged that in some areas support for the development of new organisations will be needed, as well as assistance to develop competence and inclusivity. Finally, they recommend that assistance in the form of services should be separate from advocacy, which service users may need in order to represent their interests with regard to Social Services Primary Care Trusts and other organisations.

As Gillinson et. al. (2005) point out, there is a major gap between the top and the bottom in that the mechanisms and layers between ministers at the top and CILs at the bottom (both being largely in agreement with regard to independent living) are disrupted by conflicts with the middle (local authorities). The authors attribute such conflict and confusion as due at least in part to the fragmentation of services between different departments, with the message being poorly understood across segmented disability services. Despite this, as Rummery (2006) has noted, closer collaboration between different departments, such as health and social care, does not automatically lead to improved experiences for service users. In fact it may lead to a reduction in available resources as finance and attention is diverted to internal adjustments to the system, at least in the short term.

Working in partnership has sometimes caused concern to CILs, who may have worries about being taken over by other organisations (Barnes & Mercer, 2006). However the existence of a user-led support organisation is not in itself sufficient (Robson et

al., 2003; d'Aboville, 2006). Contracting authorities and user-led organisations need to work together.

### ***Competition Between User-Led Organisations***

The Government strategy of increasing choice through stimulating a competitive quasi-market presents certain problems for user-led organisations. As Barnes and Mercer (2006) note, user-led organisations are competing against one another at both local and national levels in efforts to secure contracts. This competition can cause difficulties between organisations (Morris, 2006) and undermines the strength of fragile organisations. While this picture holds for all organisations, it can inhibit the growth of innovative solutions to social problems at grass roots level as commissioning officers specify tenders for work with which they are already familiar (CSCI, 2006).

### ***Capacity Building: Service Users***

A closely allied issue concerns recognition of service users as contributors to local communities and policy. As the Joseph Rowntree Foundation (2005) points out, most service users have important roles and responsibilities as part of everyday life. Many, particularly women, are informal carers for children and other family members and many have important community and friendship networks, making a significant contribution to the local economy. Not least, service users contribute substantially by providing employment to others. These roles are rarely acknowledged in local and national social policy (Joseph Rowntree Foundation, 2005).

In the context of the present discussion, the role of service users in campaigning for direct payments, acknowledged to be one of the most relevant and successful developments in recent years (Prime Minister's Strategy Unit, 2005), and the lead taken by the disabled people's movement in developing support for new users has been rarely mentioned. It is also a matter of some concern to service users that innovative ideas have been appropriated by established service providers, sometimes without due acknowledgement of their origins and the role of service user organisations in early developments (Morris, 2006).

In 2001 there were around 5,500 BME voluntary and community organisations in England and Wales (McLeod et al., 2001). While many were well-established: over half with annual income of between £50,000 and £250,000, and 60% had been in existence for 10 years or more, they also reported problems of securing core funding and lack of official recognition. The difficulties reported above by CILs are also mirrored here. Despite playing an important role in capacity-building, civic engagement and social inclusion, this was not recognised. Instead, funders tended to concentrate on their role in service provision (Chouhan & Lusane, 2004).

### ***Information and Referral***

Breakthrough (2005) argues that many disabled people receive direct payments without being given any assistance from the local authority to develop the skills and knowledge needed for success. Thereby, they argue, recipients may effectively be set up to fail.

Many service users are not routinely informed about the existence of user-led organisations where they exist. This is particularly true for mental health service users (Davidson & Luckhurst, 2002; Spandler & Vick, 2006). In the same way that finding out about direct payments has presented applicants with difficulties, so finding out about sources of assistance and support may also be a matter of chance. At present there is no necessity for local authority staff to inform applicants about such sources of assistance. Above I have discussed some of the contextual problems facing CILs and other user-led organisations. The discussion has shown that organisations are working in difficult circumstances and this is reflected in their weak position with regard to established service providers. The following section will turn to a discussion of some of the issues concerning the internal organisation and capacity of local user-led organisations.

### ***Capacity Building: CILs***

The literature concerning CILs and user-led services shows that there are clear advantages to peer support for Independent Living Assistance, especially for those who have recently acquired an



impairment, is highly valued by service users. The ability of CILs to provide assistance across often fragmented areas of traditional service provision and help with new responsibilities has been shown to be an important source of support.

Most CILs are in very difficult financial straits. Funding is invariably short-term: two thirds of organisations contacted by Barnes and Mercer (2006) had less than 2 years of guaranteed income, making planning for the future very difficult. Many user-led organisations rely on volunteers and have difficulties with the retention of experienced staff.

Funding and organisation are both affected by the fragmentation of Social Care services. Most organisations secure money through local authorities, which have different funding streams for different service user groups. This makes the inclusion of 'hard to reach' groups more complex. While there is evidence that CILs are seeking to reach out to more excluded groups, a difficulty may arise if the only way for an applicant to gain assistance from a CIL is through a local authority assessment. Fox and Kim (2004) note that some impairments may not be 'officially' recognised and in these instances securing assistance can be very difficult. Without diagnosis, advice may be difficult to secure. While local authority resources remain concentrated on those perceived as having the most need for assistance, it will be important that CILs are able to afford to assist people to retain their independence as well as to gain it.

Training, and the time and resources to do it, will be needed if more CILs are to develop. There is evident expertise available from established CILs and other user-led organisations, but particular attention will need to be paid to ensuring that unrepresented groups receive the assistance they need. In expanding provision of CILs, it is important not to inadvertently undermine existing work through overload, but to develop capacity in a way that works for each local area and so that provision is made for further the involvement and participation of service users beyond the immediate present.

## Methodology

This report considers academic and 'grey' (not published for general circulation) literature from January 2001 to June 2006 concerning the development of Centres for Independent/ Inclusive/ Integrated Living (CILs) and selected service user-led organisations.

### Web Sites Consulted

Action for Advocacy: <http://www.actionforadvocacy.org.uk>  
Age Concern: <http://www.aclondon.org.uk>  
Asian People's Disability Alliance: <http://www.apda.org.uk>  
Audit Commission: <http://www.audit-commission.gov.uk>  
Better Government for Older People: <http://www.bgop.org.uk>  
British Council of Disabled People: <http://www.bcodp.org.uk>  
British Institute of Learning Disabilities: <http://www.bild.org.uk>  
Care Services Improvement Partnership: <http://www.cisp.org.uk>  
Carers UK: <http://www.carersuk.org>  
Centre for Policy on Ageing: <http://www.dwp.gov.uk>  
Commission for Race Equality: <http://www.cre.gov.uk>  
Commission for Social Care Inspection: <http://www.csci.org.uk>  
Contact a Family: <http://www.cafamily.org.uk>  
Department of Health: <http://www.dh.gov.uk>  
Disabled Parents' Network:  
<http://www.disabledparentsnetwork.org.uk>  
Disability Rights Commission: <http://www.officefordisability.gov.uk>  
Equalities National Council: <http://www.encweb.org.uk/>  
Folk.Us: <http://www.projects.ex.ac.uk/folk.us/>  
Foundation for People with Learning Disabilities:  
<http://www.learningdisabilities.org.uk>  
Hampshire Direct Payments: <http://www.hants.gov.uk/direct-payments>  
Help the Aged: <http://www.helptheaged.org.uk>  
In Control: <http://www.in-control.org.uk>  
Independent Living Institute: <http://www.independentliving.org>  
Institute for Public Policy Research: <http://www.ippr.org.uk>  
Involve: <http://www.conres.co.uk>  
Joseph Rowntree Foundation: <http://www.jrf.org.uk>  
Kings Fund: <http://www.kingsfund.org.uk>

Mencap: <http://www.mencap.org.uk>  
Mind: <http://www.mind.org.uk>  
National Centre for Independent Living: <http://www.ncil.org.uk>  
National Council for Voluntary Organisations: <http://www.ncvo-vol.org.uk>  
National Forum of People with Learning Difficulties:  
<http://www.nationalforum.org.uk>  
National Institute for Mental Health in England:  
<http://www.nimhe.org.uk>  
Norah Fry Research Centre: <http://bris.ac.uk/NorahFry>  
Office for Disability Issues: <http://www.officefordisability.gov.uk>  
People First: <http://www.peoplefirstltd.com>  
Policy Studies Institute: <http://www.psi.org.uk>  
Research in Practice for Adults: <http://www.ripfa.org.uk>  
SCOPE: <http://www.scope.org.uk>  
Shaping Our Lives: <http://www.shapingourlives.org.uk>  
Skills for Care: <http://www.skillsforcare.org.uk>  
Social Exclusion Unit: <http://www.socialexclusionunit.gov.uk>  
Spinal Injuries Association: <http://www.spinal.co.uk>  
UNISON: <http://www.unison.org.uk>  
Values Into Action: <http://www.viauk.org.uk>  
Valuing People: <http://www.valuingpeople.gov.uk>

### Search Terms Used

The following terms were used as a means of locating relevant information, according to the frame of reference of the database:

CIL

Centre(s) for Independent Living / Centre(s) for Integrated Living /

Centre(s) for Inclusive Living

Independent Living

User-led service(s) / organisation(s)

User- controlled service(s) / organisation(s)

### Databases Searched

AgeInfo

ASSIA

CINAHL

Disability Archive, University of Leeds

Ingenta  
Social Care Online  
Web of Knowledge

A search of appropriate sections of Leeds University Library was carried out, to locate relevant sources of literature.

## Bibliography

- ADSS / NCIL. (2006). *Joint Protocol Between National Centre for Independent Living (N.C.I.L.) and Association of Directors of Social Services (A.D.S.S.) for the Provision of Centres for Independent Living (CILs) and User Led Support Services*. Retrieved 14th October, 2006, from [www.adss.org.uk/publications/guidance/ncilprotocol.pdf](http://www.adss.org.uk/publications/guidance/ncilprotocol.pdf)
- Arnstein, S. (1969). A Ladder of Citizen Participation. *Journal of the American Institute of Planners*, 35(4), 216-224.
- Audit Commission / BGOP. (2004). *Older People - Independence and Well-Being: the challenge for public services*. London: Audit Commission.
- Barnes, C. (2004, 22nd November). *Independent Living, Politics and Implications*. Paper presented at the Social Care Institute for Excellence (SCIE) National Conference on Independent Living, Kensington Tara Hotel, London.
- Barnes, C., & Mercer, G. (2006). *Independent Futures: creating user-led disability services in a disabling society*. Bristol: The Policy Press.
- Barnes, C., Mercer, G., & Din, I. (2003). *Research Review on User Involvement in Promoting Change and Enhancing the Quality of Social 'Care' Services for Disabled People*. London: SCIE.
- BCODP. (2006). *Who Are We*. Retrieved 12th September, 2006, from [www.bcodp.org.uk](http://www.bcodp.org.uk)
- Beresford, P. (2006a, 15th February). Fifth Element will Help to Form the Future. *The Guardian*.
- Beresford, P. (2006a, 18th-20th September). *The Survivor Movement: past present and future*. Paper presented at the DSA Conference: Disability Studies: research and learning, Lancaster.
- Bewley, C., & McCulloch, L. (2004). *Helping Ourselves: direct payments and the development of peer support*. London: Values into Action.
- Breakthrough UK. (2005). *Response to Government Consultation on: Office for Disability Issues*
- Brindle, D. (2006, 18th October). If Health Can Have It, Why Can't We? *The Guardian*, p. 10.
- Carr, S. (2004). *Has Service User Participation Made a Difference to Social Care Services?* London: Social Care Institute for Excellence.

Chahan, G. (2003). *Searching for Solid Foundations: community involvement and urban policy*. London: Office of the Deputy Prime Minister.

Chouhan, K., & Lusane, C. (2004). *Black Voluntary and Community Sector Funding: its impact on civic engagement and capacity building*. York: Joseph Rowntree Foundation.

Clark, H., Gough, H., & MacFarlane, A. (2004). *Its Pays Dividends: direct payments and older people*. Abingdon: The Policy Press.

Clark, H., & Spafford, J. (2002). Adapting to the Culture of User Control? *Social Work Education*, 21(2), 247-257.

Clark, J. (2003). *Independence Matters: an overview of the performance of social care services for physically and sensory disabled people*. London: Department of Health.

Collins, S., & O'Neil, A. (2005). *Response to the Department of Health Green Paper 'Independence, Well-Being and Choice: our vision for the future of social care for adults in England'*. York: Joseph Rowntree Foundation.

CSCI. (2005). *Social Care Performance 2004-5*. London: Commission for Social Care Inspection.

CSCI. (2006). *Relentless Optimism: creative commissioning for personalised care*. London: Commission for Social Care Inspection.

d'Aboville, E. (2006). Implementing Direct Payments: a support organisation perspective. In J. Leece & J. Bornat (Eds.), *Developments in direct Payments*. Bristol: The Policy Press.

Davidson, D., & Luckhurst, L. (2002). *Making Choices, Taking Control: direct payments and mental health service users / survivors*. York: Joseph Rowntree Foundation.

Davis, K., & Mullender, A. (1993). *Ten Turbulent Years: a review of the work of the Derbyshire Coalition of Disabled People*. Nottingham: The Centre for Social Action.

Department of Health. (2000a). *Carers and Disabled Children Act*. London: Department of Health.

Department of Health. (2000b). *Community Care (Direct Payments) Act 1996: policy and practice guidance* (2nd ed.). London: Department of Health.

Department of Health. (2003). *Community Care, Services for Carers and Children's Services (Direct Payments) Guidance England*. London: Department of Health.

Department of Health. (2005a). *Carers and Disabled Children Act 2000 and Carers (Equal Opportunities) Act 2004 Combined draft policy guidance*. London: Department of Health.

Department of Health. (2005b). *Independence, Well-being and Choice: our vision for the future (Green Paper)*. London: The Stationery Office.

Department of Health. (2006a). *Direct Payments to People with Mental Health Problems: a guide to action*. London: Department of Health.

Department of Health. (2006b). *Our Health, Our Care, Our Say: a new direction for community services*. London: Department of Health.

Department of Work and Pensions. (2005). *Opportunity Age: meeting the challenges of ageing in the 21st century*. London: The Stationery Office.

Duffy, S. (2005). Individual Budgets: transforming the allocation of resources for care. *Journal of Integrated Care*, 13(1).

Ellis, C. (2006, 19th July). *The Independent Living Bill*, Speech at NCIL 2nd National Conference, Birmingham.

Emerson, E., Routledge, M., Sanderson, H., McIntosh, B., Swift, P., Joyce, T., Oakes, P., Towers, C., Romeo, R., & Knapp, H. (2005). *The Impact of Person Centred Planning*. Retrieved 20th July, 2006, from [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)

Evans, C., & Carmichael, A. (2002). *Users' Best Value: a guide to user involvement good practice in Best Value Reviews*. York: Joseph Rowntree Foundation.

Evans, R., & Banton, M. (2001). *Learning From Experience: involving black disabled people in shaping services*. Leamington Spa: Council of Disabled People.

Fox, M. H., & Kim, K. (2004). Understanding Emerging Disabilities. *Disability and Society*, 19(4), 323-337.

Gabriel, Z., & Bowling, A. (2004). Quality of Life From the Perspective of Older People. *Ageing and Society*, 24(5), 675-691.

Gillinson, S., Green, H., & Miller, P. (2005). *Independent Living: the right to be equal citizens*. London: Demos.

Glasby, J., & Littlechild, R. (2002). *Social Work and Direct Payments*. Bristol: The Policy Press.

Grattan, P., Groombridge, B., Harding, T., Henwood, M., Howard, M., Metz, D., Roberts, E., & Sonlsby, J. (2002). *Age Discrimination in Public Policy*. London: Help the Aged.

Harris, J., Foster, M., Jackson, K., & Morgan, H. (2005). *Outcomes for Disabled Service Users*. York: Research Works, 2005-05, Social Policy Research Unit, University of York.

Hasler, F. (2003). *Users at the Heart: user participation in the governance and operation of social care regulatory bodies*. London: Social Care Institute for Excellence.

- Hasler, F., & Stewart, A. (2004). *Making Direct Payments Work: identifying and overcoming barriers to implementation*. Brighton: Pavilion Publishing.
- Heffernan, K. (2006). Social Work, New Public Management and the Language of 'Service User'. *British Journal of Social Work*, 36(1), 139-147.
- Hodge, S. (2005). Participation, Discourse and Power: a case study in service user involvement. *Critical Social Policy*, 25(2), 164-179.
- Holman, A. (2002). Direct Payments: commentary and review. *Tizzard Learning Disability Review*, 7(4), 17-20.
- Hussain, Y., Atkin, K., & Ahmad, W. (2002). *South Asian Disabled Young People and their Families*. Bristol: The Policy Press.
- Jochum, V., Pratten, B., & Wilding, K. (2005). *Civil Renewal and Active Citizenship: a guide to the debate*. London: National Council for Voluntary Organisations.
- Johnson, R. (2006). *Personal Communication*. London: People First.
- Joseph Rowntree Foundation. (2005). *Response to the Department of Health Green Paper 'Independence, Well-Being and Choice: our vision for the future of social care for adults in England*. Retrieved 3rd May, 2006, from <http://www.jrf.org.uk>
- Keating, F. (2002). Black-Led Initiatives in Mental Health: an overview. *Research Policy and Planning*, 20(2).
- Keating, F., Robertson, D., McCulloch, A., & Francis, E. (2002). *Breaking the Circles of Fear: a review of the relationship between mental health services and African and Caribbean communities*. London: Sainsbury Centre for Mental Health.
- Ladyman, S. (2004a). *Building Capacity in Intermediate Care: Speech at Delivering Independence for Older People Conference*. Retrieved 4th September, 2006, from <http://www.dh.gov.uk>
- Ladyman, S. (2004b). *Speech at Learning Disability Today Event*. Retrieved 4th September, 2006, from <http://www.dh.gov.uk/>
- Luckhurst, L. (2005). *Wider Options: report of a research project into intensive support schemes for direct payments*. London: National Centre for Independent Living.
- MacGregor, G., & Hill, M. (2003). *Missed Opportunities: the impact of new rights for carers*. London: Carers UK.
- McLeod, M., Owen, D., & Khamis, C. (2001). *Black and Minority Ethnic Voluntary and Community Organisations: their role and future development in England and Wales*. London: Policy Studies Institute / Joseph Rowntree Foundation.



Morris, J. (2004). Independent Living and Community Care: a disempowering framework. *Disability and Society*, 19(5), 427-442.

Morris, J. (2006). *Centres for Independent Living / Local User-Led Organisations: a discussion paper*. Unpublished Paper.

NCIL. (2006a). *The Direct Payments Development Fund*. London: NCIL / Department of Health.

NCIL. (2006b). 2nd National Conference, *A Right to Independent Living*. Birmingham: NCIL.

Newbigging, K., & Lowe, J. (2005). *Direct Payments and Mental Health: new directions*. Brighton: Pavilion Publishing.

Parker, G., & Clarke, H. (2002). Making the Ends Meet: do carers and disabled people have a common agenda? *Policy and Politics*, 30(3), 347-359.

Pearson, C., Barnes, C., Jolly, D., Mercer, G., Priestley, M., & Riddell, S. (2005). Personal Assistance Policy in the UK: what's the problem with direct payments? *Disability Studies Quarterly*, 25(1).

People First. (2006a). *What is User Led?* London: People First.

People First. (2006b). *Why it is Important that People with Learning Difficulties are in Charge of Our Own Groups*. London: People First.

Poll, C., Duffy, S., Hatton, C., Sanderson, H., & Routledge, M. (2006). *A Report on In Control's First Phase 2003-2005*. London: In Control Publications.

Priestley, M., Jolly, D., Pearson, C., Riddell, S., Barnes, C., & Mercer, G. (2006). Direct Payments and Disabled People in the UK: supply, demand and devolution. *British Journal of Social Work, Advance Access*.

Priestley, M., & Rabiee, P. (2002). Same difference? Older People's Organisations and Disability Issues. *Disability and Society*, 17(6), 597-611.

Prime Minister's Strategy Unit. (2005). *Improving the Life Chances of Disabled People: final report*. London: Strategy Unit, Cabinet Office.

Robson, P., Begum, N., & Locke, M. (2003). *Developing User Involvement: working towards user-centred practice in voluntary organisations*. Bristol: The Policy Press.

Roulstone, A., Hudson, V., Kearney, J., & Martin, A. (2006). *Working Together: carer participation in England, Wales and Northern Ireland*. London: Social Care Institute for Excellence.

Rummery, K. (2006). Partnerships and Collaborative Governance in Welfare: the citizenship challenge. *Social Policy and Society*, 5(2), 293-303.

Shaping Our Lives. (2006). *What Do We Mean When We Say Service User?* Retrieved 15th September, 2006, from [www.shapingourlives.org.uk](http://www.shapingourlives.org.uk)

Singh, B. (2003). *Improving Support for Black Disabled People: lessons from community organisations on making change happen*. York: Joseph Rowntree Foundation.

Spandler, H., & Vick, N. (2005). Enabling Access to Direct Payments: an exploration of care co-ordinators decision-making practices. *Journal of Mental Health, 14*(2), 145-155.

Spandler, H., & Vick, N. (2006). Opportunities for Independent Living Using Direct Payments in Mental Health. *Health and Social Care in the Community, 14*(2), 107-115.

Stuart, O. (2006). *Will Community-Based Support Services Make Direct Payments a Viable Option for Black and Minority Ethnic Service Users and Carers?* London: Social Care Institute for Excellence.

Vasey, S. (2000). *The Rough Guide to Managing Personal Assistants*. London: National Centre for Independent Living.

Vernon, A. (2002). *User Defined Outcomes of Community Care for Asian Disabled People*. Bristol: The Policy Press.

Watson, J. (2006). *Whose Rights are They Anyway? Carers and the Human Rights Act*. London: Carers UK.

Williams, V. (2006). *How Can Local Authorities Increase the Take-Up of Direct Payment Schemes to Adults With Learning Disabilities?* Retrieved 21st October, 2006, from [www.ripfa.org.uk/publications](http://www.ripfa.org.uk/publications)

Williams, V., & Holman, A. (2006). Direct Payments and Autonomy: issues for people with learning difficulties. In J. Leece & J. Bornat (Eds.), *Developments in Direct Payments*. Bristol: The Policy Press.

Wistow, G., Waddington, E., & Godfrey, M. (2003). *Living Well in Later Life: from prevention to promotion*. Leeds: Nuffield Institute for Health.

Woodin, S. (2006). *Social Relationships and Disabled People: the impact of direct payments*. Unpublished PhD, University of Leeds.

Zarb, G. (2003). *The Economics of Independent Living*. Retrieved 28th October, 2006, from [www.independentliving.org/docs6/zarb2003.htm](http://www.independentliving.org/docs6/zarb2003.htm)