

User-led Organisations Project

Policy

Prepared by Social Care, Local Government & Care Partnerships Directorate

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Contact details:	Mrs Patricia Soward DH Social Care, Local Government & Care Partnership Directorate 133-155 Waterloo Road London SE1 8UG 020 7972 4268
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Contents

Contents.....	5
Introduction	6
Policy context	6
Project principles	7
Definitions	8
User-led organisations and Centres for Independent Living: History and current position	9
Vision and strategic objectives	12
Vision.....	12
Strategic objectives	12
Supporting communities to deliver the vision	13
User-led organisation design criteria	13
a) ULO values.....	13
b) ULO organisational characteristics	14
c) ULO minimum services.....	14
Rationale for ULO design criteria	16
ULO values.....	16
ULO organisational criteria	20
References.....	27
Annex A: Definitions in alphabetical order.....	28

Introduction

1. **This policy document is the Department of Health's (DH) interpretation of the *Improving Life Chances* recommendation 4.3 about user-led organisations (ULOs). It is based on what we have understood from speaking to and working with disabled people, carers and other people who use support, in order to achieve a common understanding. It is not for government to prescribe to organisations every last detail of the definition of a ULO. Therefore, the characteristics identified within the policy have arisen from research and from consultation with a working group of disabled people, carers and local government representatives. DH recognises that the development of ULOs is dependent upon the initiative and drive of disabled people and their organisations. Whilst government can help to facilitate this process, we do not own it. However, it is important to recognise that, if they are receiving public or charitable funding, ULOs will have to meet required standards of governance and performance.**

Policy context

2. In January 2005, the Government set out in *Improving the Life Chances of Disabled People*, (*Improving Life Chances*) an ambitious vision 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 equal members of society".
3. The report argued that disabled people faced barriers in where they live, their personal relationships, their opportunities for education, training and employment; access to healthcare; access to leisure activities; and participation in the life of their local community and in wider society. This was partly attributable to disabled people being expected to fit into services; and partly to policies and practice not paying enough attention to enabling disabled people to be active citizens, or to supporting disabled people to help themselves. The report argued that responses to needs are often more likely to create dependency than enable people to participate in their local communities, fulfil their family responsibilities or be economically independent (*Improving Life Chances*: page 72).
4. Promoting independent living and the active participation of disabled people in the design, delivery and monitoring of resources and services is recognised as being fundamental to the process of improving the life chances of disabled people. This is in alignment with wider public policy

commitments advocating greater levels of inclusion, equality, engagement and participation at both a local and national level.

5. A key recommendation in the *Improving Life Chances* report (p91) states that: “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”. DH established in 2006 the ULO project to address this recommendation. The organisations envisaged by this recommendation are seen as one of the key mechanisms for encouraging the participation of disabled people, carers and other people who use support in the design, delivery and monitoring of resources and services designed to support independent living.
6. It is expected that meeting these desired outcomes will involve:
 - increasing the capability and capacity of existing user-led organisations
 - enabling existing third sector organisations to become more user-led
 - enabling the establishment of user-led organisations in localities where none exist.
7. The first phase of the project has concentrated on establishing the baseline by researching the existing landscape in terms of Centres for Independent Living and other existing organisations that may have the capacity to become ULOs. The research undertaken for the ULO project draws on material from a literature review, mapping work, an in depth look at 6 case study sites and a series of “conversations” or discussions with people from user-led and other organisations.
8. The research activity was commissioned through disabled people and the involvement of disabled people, carers and other people who use support and their organisations has been central both to this research and shaping the proposed way forward.

Project principles

9. An important feature of the ULO project is that disabled people and other groups (who do not necessarily identify themselves as disabled people) have worked together to design the project and shape the policy development. Co-production has been at the heart of the ULO project and is driven by the principles that to achieve the vision disabled people, carers and other people who use support, central and local government and other key stakeholders need to work together in a way that is:

- inclusive of a range of disabled people, carers and other people who use support who have both different and common perspectives as a result of their impairment, experience of accessing or using services and/or their race, religion and belief, disability, gender, sexual orientation or age
- informed in different ways by disabled people, carers and other people who use support throughout the project and policy development phases
- evidence based
- transparent.

Definitions

10. The ULO project uses a number of words and phrases that have come to mean different things to different people or groups. The definitions used within this paper are set in Annex A. However, it is important to acknowledge that language is always evolving and by its very nature it is difficult to reach consensus about preferred terminology and definitions. This is as true amongst disabled people, carers and other people who use support as it is for other interest groups. Therefore, for the purposes of clarity this policy tries as far as possible to use definitions that are in general use amongst different interest groups and stakeholders while recognising that these terms may not be preferred by all concerned. Equally this is not an exhaustive list of definitions but a short guide to some of the key terms that underpin the ULO policy. Wherever a direct quote is used the language used by the author(s) is left unchanged.

User-led organisations and Centres for Independent Living: History and current position

11. “Existing service user organisations and Centres for Independent Living have their history rooted in the disabled people’s and the wider user movement with people coming together to share experiences and bring about change through understanding their collective experience of oppression, discrimination and dissatisfaction with the way services were organised and delivered” (Barnes and Mercer 2006). Since the early 1980s disabled people started challenging the way services were delivered and started organising new forms of provision which put the policy and practice of independent living firmly on the public agenda. Indeed Centres for Independent Living (now also known as Centres for Inclusive Living) emerged as a new form of provision run and controlled by disabled people to promote independent living. An early group, Derbyshire Centre for Independent Living, formulated seven needs of disabled people as central to independent living:

- information
- counselling and peer support
- housing
- technical aids and equipment
- personal assistance
- transport
- access to the built environment.

Hampshire and Southampton Centres for Independent Living, have added to this list:

- inclusive education and training
- adequate income
- equal opportunities for employment
- advocacy
- appropriate health care provision (Woodin 2006).

12. The *Improving Life Chances* report describes Centres for Independent Living as follows:

Centres for Independent Living 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. There are currently 22 fully constituted CILs with another 15 local disability organisations either providing a similar role or working towards becoming a CIL. 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 amongst marginalised groups;
- provide disability equality training;
- carry out consumer audits of services.

(Improving Life Chances: pages 84-85)

13. The functions outlined above are what Centres for Independent Living traditionally do but this is not set in stone. Work around self advocacy and benefits advice are examples of how some Centres for Independent Living have developed their work to cater for particular groups such as older people and people with learning disabilities.
14. Disabled people have been instrumental in putting independent living and direct payments on the policy agenda and shaping the way services are delivered. The continued involvement of disabled people and other people who use support is at the core of supporting independent living. The *Improving Life Chances* report points out: “Local organisations, run and controlled by disabled people, will be a vital part of the implementation of a new approach to supporting independent living” (*Improving Life Chances: page 91*).

15. Mapping work for the ULO project identified 647 local organisations, as at 19 March 2007, that could be user-led in 150 localities. Just over one in ten localities had no existing organisations and the majority (61%) had between one and five. However it is a very fluid map with organisations continually appearing or disappearing as funding fluctuates (Research Reports, 2007).¹
16. Not all existing organisations are based upon or have the potential to be a ULO as their value base and models of working can vary greatly. For the purposes of this project, an underlying principle is that there are two fundamental premises for ULOs modelled on Centres for Independent Living:
 - that their work is underpinned by a social model of disability perspective
 - that the organisation's constituents constitute the majority of the governing and other decision making bodies.
17. The research shows that the sector is “characterised by wide variations in culture, capacity and range. Coverage is uneven, with volume fluctuating over time and the limited development of a pan-disability approach. Overall, the current health of the sector appears inherently fragile, dependent on uncertain and insecure funding arrangements and vulnerable to changes in the wider organisational or political context” (Research Reports).

¹ Research Reports listed in References section at the end of the policy document: Maynard et al (2007), Morris (2006) and Woodin (2006)

Vision and strategic objectives

Vision

18. 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 Centres for Independent Living (Recommendation 4.3 *Improving Life Chances* 2005)

Strategic objectives

19. ULO Project Strategic Objectives
 - to have at least one ULO per locality by 2010 recognising that these will be in different stages of development
 - that these ULOs meet the agreed 'ULO design criteria' in order to meet the Life Chances ULO minimum services
 - to enable disabled people, carers and other people who use support to achieve independent living by exercising choice and control in their lives.

Supporting communities to deliver the vision

User-led organisation design criteria

20. Achieving recommendation 4.3 is challenging, not least because of the recognition that if central government were to directly establish “user-led organisations” they would not, by definition, be led by disabled people, carers and other people who use support. Therefore an approach is required that enables the establishment of such organisations by the people which those organisations represent.
21. It is recognised that to achieve the vision behind recommendation 4.3 and support independent living there is not one single model that can be applied everywhere. Local factors and the constituency of the organisations and available resources will determine to some extent how an organisation is developed and run. However, in order to be identified as a “Life Chances ULO” organisations will as a minimum need to meet the “ULO Design Criteria”. The design criteria are informed by the ULO project research and work with a group of disabled people, carers and other people who use support.
22. The design criteria outlined below aim to define the key requirements to be a viable and sustainable ULO modelled on existing CILs in 2010. It is important to stress that these criteria may be met in a variety of ways according to local demand, resources and circumstances.

a) ULO values

23. A ULO should adhere to a minimum set of values:
 - works from a social model of disability perspective
 - promotes independent living
 - promotes people’s human and other legal rights
 - shaped and driven by the initiative and demand of the organisation’s constituency
 - is peer support based

- covers all local disabled people, carers and other people who use support either directly or via establishing links with other local organisations and networks
- is non-discriminatory and recognises and works with diversity in terms of race, religion and belief, gender, sexual orientation, disability and age
- recognises that carers have their own needs and requirements as carers
- engages the organisation's constituents in decision-making processes at every level of their organisation.

b) ULO organisational characteristics

24. A ULO should have the following organisational characteristics:

- provides support to enable people to exercise choice and control
- is a legally constituted organisation
- has a minimum of 75 per cent of the voting members on the management board drawn from the organisation's constituency
- is able to demonstrate that the organisation's constituents are effectively supported to play a full and active role in key decision-making
- has a clear management structure
- has robust and rigorous systems for running a sustainable organisation (e.g. financial management/contingency planning)
- is financially sustainable as there will be no ongoing central government funding
- has paid employees, many of whom must reflect the organisation's constituency
- identifies the diverse needs of the local population and contributes to meeting those needs
- is accountable to the organisation's constituents and represents their views at a local level
- supports the participation of its constituents in designing, delivering and monitoring of the organisation's services
- works with commissioners to improve commissioning and procurement.

c) ULO minimum services

25. The minimum ULO services to support independent living are defined in *Improving Life Chances* as:

- Information and advice
- Advocacy and peer support
- Support in using direct payments and/or individual budgets

- Support to recruit and employ personal assistants
- Assistance with self-assessment
- Disability equality training
- Support the implementation of the Disability Equality Duty by public sector organisations in the locality (including consumer audits).²

² Note the Disability Equality Duty has come into force since 2006 and was not within the ULO services defined in *Improving Life Chances*.

Rationale for ULO design criteria

26. Each of the design criteria are now addressed individually in the context of the ULO project research.

ULO values

27. There was broad agreement within all strands of the research that issues like diversity, social model of disability, independent living, peer support and accountability must underpin the values that ULOs work from.

Works from a social model of disability perspective

28. Literature review, work mapping existing organisations and a series of regional conversations all point to a consensus that a social model of disability perspective is one of the defining features of a ULO.

Promotes independent living

29. The literature review and conversations placed a very clear emphasis on the importance of independent living. This has been driven by the demand and work of the Disability Movement and is central to the way Centres for Independent/Inclusive Living work. The Disability Rights Commission refers to independent living as “all disabled people having the same choice, control and freedom as any other citizen – at home, at work, and as members of the community. This does not necessarily mean disabled people ‘doing everything for themselves’, but it does mean that any practical assistance people need should be based on their own choices and aspirations” (Policy Statement on Social Care and Independent Living, DRC 2002).

Promotes people’s human and other legal rights

30. An important feature of ULOs is that they work from a basis that recognises people’s human and legal rights. For example, this may mean supporting people to have their human rights met under the Human Rights Act 1998. They can work with people to exercise their rights as citizens, this may be through participating in democratic processes like voting in elections, or it may mean enabling their constituents to access a range of services, benefits and community resources.

Shaped and driven by the initiative and demand of the organisation's constituency

31. "The 'added-value' provided by ULOs is seen to derive from their local knowledge and networks and their ability to present the authentic voice of service users who know what works for them" (mapping and conversations).
32. In the mapping exercise, the researchers did not regard networks set up by major national charitable organisations and a Centre for Independent Living established by a local authority as constituting a user-led organisation (Research Reports).

Is peer support based

33. Peer support is fundamental to the way ULOs operate. This was the foundation stone upon which the Independent Living Movement and Centres for Independent Living were built. Throughout the research the fact that ULOs would be based on peer support was seen as one of the key 'added values' that they would offer.

Covers all local disabled people, carers and other people who use support either directly or via establishing links with other local organisations and networks

34. The first Centres for Independent Living were pioneered by people with physical impairments and support services largely reflect their needs (Woodin 2006 page 2). Centres for Independent Living are not impairment specific and they are open to all disabled people. In practice, restrictions on funding and staff availability have meant that the predominant group of service users is people with physical impairments (cited Woodin page 7).
35. The largest single group of case study organisations were established by people with specific impairments, for self help and peer support. The most commonly cited activities undertaken by the organisations mapped are: 'impairment specific' (largest category), 'general support/help', (second largest) and 'information and advice' (third largest) (Research Reports).
36. The case study organisations were working with a range of local groups: just under two thirds (61%) with older people, just over half (53%) with black and ethnic minority people and just over four out of ten with mental health service users (Research Reports).
37. ULOs may have different models of working if they do not work directly with particular groups of people (eg people with learning disabilities, adolescents

or carers). This suggests they would need to work actively, either individually or via local alliances or wider networks to establish working relationships and ensure the needs of different groups are appropriately met.

Is non-discriminatory and recognises and works with diversity in terms of race, religion and belief, gender, sexual orientation, disability and age

38. The mapping work revealed that the least common group of organisations was those working specifically around gender, ethnicity or on lesbian, gay, bisexual or transgender issues. Gaps were identified in the ability of existing organisations to work with different 'communities of interest' because of capacity problems, which in turn meant some existing organisations could struggle to meet statutory diversity requirements (Research Reports).
39. Within the regional conversations there was unanimous agreement around the importance of addressing diversity. It appears that groups with a community rather than a disability rights or impairment focus were more likely to engage with the more marginalised sectors such as those from black and ethnic minority communities.
40. Some groups are impairment specific, and that is clear. However, others claim to be working with all disabled people but then go on to say they have no involvement with black and minority ethnic communities. If a ULO is working within the social model, it should reach out to all parts of the community it serves, but it would need to be resourced to do that.
41. A specific barrier exists to getting funding for some organisations – including those of disabled lesbian, gay, bisexual or transgender, refugees or asylum seekers, and the Deaf community – which don't always operate within local authority geographical boundaries, but represent 'communities of interest'. They cannot always access specific local authority funding, and may not have the capacity to apply for wider funding such as national charitable funding, the Lottery or Comic Relief. These groups' interests are rarely represented by more established more mainstream groups who may be at a loss as to how to reach them.

Recognises that carers have their own needs and requirements as carers

42. The involvement of carers in ULOs is a contentious one. There is a perception that, historically, disabled people and carers requiring resources and support have been pitched against one another, with both groups feeling that they have to compete to have their needs and entitlements met at the expense of the other. In reality the situation is far more complex as many

disabled people are also carers and for some groups like older people, people with learning disabilities and those from black and minority ethnic communities the split between 'carer' and being a disabled person or a person who uses support is difficult to disentangle. Indeed some disabled people and other people who use support would argue that carers are important allies. For people described as having 'profound' and 'complex' needs carers have often played a key role in advocating on behalf of the individual.

43. Within the mapping work just under half (46%) of organisations worked with family carers. Historically the disability rights movement has argued that carers cannot represent the views and interests of disabled people or other people who use support in general. Nevertheless as mentioned before sometimes carers committed to the concept of independent living have taken on a key advocacy role on behalf of the individuals they support.
44. It is important to accept that disabled people and other people who use support often have different issues than those faced by carers. However, they are not inherently competitive by nature. There needs to be room within ULOs for different interest groups to collaborate and work separately where necessary so that the interests of all groups are accommodated without anyone feeling compromised.
45. The fact that someone is a carer does not preclude them from having a strong commitment to independent living and the social model of disability. Some important partnerships have been developed where disabled people and carers have worked together on common areas of concern or interest, but also been very clear about where the differences between them lie and work separately on those areas.
46. There were strong feelings at the regional conversations that carers cannot be involved in decision making in ULOs. However it would seem that if carers were involved in ULOs with a specific remit to address the needs of carers as people who use support in their own right then the opposition to carers' involvement in decision making may be less of an issue. Also if the ULO has a constituency of carers and disabled people and other people who use support then carers are likely to be part of the decision-making process. Of course where an organisation comprises of different groups of people then all those groups have to sign up to the values and characteristics that are set out in the ULO Design Criteria.
47. Changes in public policy and a shift in thinking has led to a growing acknowledgement that carers have perspectives and support needs of their

own. The needs of carers as a specific group is recognised in the White Paper *Our Health, Our Care, Our Say*. Consequently ULOs in relation to carers means that carers have their individual needs in relation to peer support, advocacy, direct payments, information, advice, user involvement and so on addressed through networks and organisations designed with the input of carers to support carers.

Engages the organisation's constituents in decision making processes at every level of their organisation

48. "Many health, social care and charitable organisations describe themselves as led by the needs of their service users, but in most instances service users do not make executive decisions, such as exercising control over policy or resources" (cited Woodin 2006).
49. Whilst the literature review, mapping and conversations work identified user involvement in governance and management arrangements as key to being a ULO there was also a recognition that their constituents needed to be involved in a variety of ways, such as providing peer support, delivering services, and being involved in monitoring (conversations).
50. The researchers commented that ULOs "...need to ensure the involvement and employment of their users at all levels of the organisation..." (Research Reports).

ULO organisational criteria

Provides support to enable people to exercise choice and control

51. Enabling people to exercise choice and control over their own lives lies at the heart of what ULOs modelled on Centres for Independent Living should be doing. The literature review and conversations placed a very clear emphasis on this.

Is a legally constituted organisation

52. It appears from the mapping exercise that existing organisations are most likely to be set up as a registered charity and company limited by guarantee, although smaller groups are functioning as unincorporated organisations, which limits their activity or increases risk for their members. Some of these organisations see themselves as campaigning, rights based, organisations that have a contribution to make by highlighting access needs and other issues for their constituents.

53. The concept of formalised not-for-profit, Community Interest Company or social enterprise, has been embraced in two areas, as the preferred alternative to a charity based constitution.
54. There was a view from the conversations and case studies that different structures may be needed to fit different local circumstances and organisational histories and that one 'size' will not fit all. However, if ULOs are to be employers, be commissioned to provide services or take on other activities like training or consultancy then they are likely to need to be a legally constituted organisation.

Has a minimum of 75 per cent of the voting members on the management board drawn from the organisation's constituency

55. "There has been much debate about percentages: the number of 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 United Kingdom's Disabled Peoples' Council (formerly the British Council of Disabled People) is only open to disabled people. Mental health service user organisations are more likely to have overlapping links with service providers, while people with learning difficulties employ non-disabled support assistants who may be party to much organisational business" (Woodin 2006).
56. The conversations work revealed that there were strong feelings around the principle that "ULO's are organisations that have at least half of their board or management committee made up of disabled people (including older people)". However, there were mixed reactions about precisely what proportion of the board or management committee should be reflective of the organisation's constituency.
57. A survey conducted by National Centre for Independent Living in 2006 reveals that 50% of the 34 Centres for Independent Living within the National Centre for Independent Living network required their boards to comprise 100% disabled people, with 21% requiring 50 or 51% and 1% requiring 75% (Research Reports).
58. Having the organisation's constituency engaged in governance and other decision making processes is not just a question of numbers or percentages, where actual power rests is at the heart of the matter. A detailed look at the case study sites found that "few (of the organisations) had transparent

governance arrangements, making it difficult to identify the extent to which they are user-led or controlled” (Research Reports).

59. With 75% of the voting members being drawn from the organisation’s constituency there is room for having co-optees or board advisors who offer additional expertise or experience that the board may need.

Is able to demonstrate that the organisation’s constituents are effectively supported to play a full and active role in key decision-making

60. To be effectively run as a ULO its constituents need to be able to play a full and active role in decision-making. This means that disabled people, carers and other people who use support should have their access needs addressed and be fully supported through training, mentoring and other support to be able to play a full and active role in decision making.

Has a clear management structure

61. Linked to the governance of a ULO was the wider issue of having the resources and suitably experienced staff to manage the organisation. In smaller organisations one or two individuals may take on a number of different roles. This can be problematical as too much knowledge and expertise is vested in key people which creates a difficult dependency. Equally there is much higher risk of people ‘burning out’ and leaving the organisation, and taking the knowledge and expertise with them.
62. Given that accountability is fundamental to a ULO and how it works, it is essential that clear management structures are in place.

Has robust and rigorous systems for running a sustainable organisation (e.g. financial management/contingency planning)

63. A range of factors appear currently to constrain the ability of individual organisations to grow their capacity which can also undermine the sustainability of others. These include difficulties in recruiting, training and retaining staff with relevant expertise, particularly in legal and financial matters. Systems for effective financial management, governance and monitoring are relatively underdeveloped. Relatively little access or use is being made of external sources of support and advice, where they exist (Research Reports).

64. In the case studies there was no mention of accessing business support, for instance, from programmes such as Change Up.³ A few mentioned accessing Business Link services and those of their local Council for Voluntary Services, and some were members of the National Council for Voluntary Organisations (Research Reports).
65. The case study data also indicated that, having an organisation with a large membership base, or having an active governing body not involved in any way in the day to day running, can hinder a businesslike approach to the undertaking and can be an unhelpful drain on resources.
66. Factors considered critical to the operation and sustainability of a ULO included:
- having fully trained Board/Committee members or staff, especially in legal and financial matters
 - ability to develop organisational resilience in the face of change
 - preparedness to engage in democratic processes and influence local policy makers
 - ability to understand the power dynamics within organisations themselves as well as in the locality.

Is financially sustainable as there will be no ongoing central government funding

67. Uncertainty about funding was the dominant message from all data sources. Many of the case study organisations are managing on low and unpredictable levels of funding, and few have any exit strategies for when funding ends. Limited or uncertain income is seen to inhibit potential for the expansion and development of services and particularly affects the smaller organisations which are more likely to operate on a 'hand to mouth' basis (Research Reports). A strong relationship with the local authority can help with securing on-going funding.

Has paid employees, many of whom must reflect the organisation's constituency

68. The research revealed that the capacity of existing organisations was limited because of the lack of paid staff. Volunteers played an important role in the operational activity of organisations but an over reliance on volunteers can potentially leave an organisation in a vulnerable situation.

³ ChangeUp is about strengthening the support and assistance to voluntary and community organisations. It is managed by Capacitybuilders an agency at arms length from Government.

69. There was unanimous agreement at the conversations for the statement that “ULO’s are organisations that employ disabled people as well as have them as volunteer board or committee members” (Research Reports).
70. It was clear from the case studies that organisations were a provider not only of employment for disabled people and otherwise disadvantaged groups, but also of work experience that can lead to paid employment.

Identifies the diverse needs of the local population and contributes to meeting those needs

71. The ‘added-value’ provided by ULOs is seen to derive from their local knowledge and networks and their ability to present the authentic voice of their constituents who know what works for them. Particular areas of expertise within ULOs are seen to include knowledge about access, participation and empowerment issues, provision of peer-led support, mentoring, advocacy and self-help techniques.
72. Using local knowledge and expertise to identify the diverse needs of the local population and contributing to meeting those needs is fundamental to the way ULOs operate.

Is accountable to the organisation’s constituents and represent their views at a local level

73. The research found that organisations established by local people were in a very good position to support their constituents in engaging with services and also representing their interests (where appropriate).
74. A ULO should be able to say what its constituents want locally, and be able to work with a range of statutory and voluntary sector organisations to improve local communities and resources. This may mean that the organisation adopts a campaigning and networking role.
75. In order to function as a ULO it is extremely important that the organisation, particularly in terms of its management board is accountable to its constituents. This may be through a formal membership system with everyone having voting rights, or there may be more loosely defined systems for ensuring accountability such as open meetings or some form of quality assurance mechanism. The researchers observed that “...ULO’s need to find other ways to involve members in governance, or consult ordinary members, rather than simply relying on them turning up at meetings – and this requires resources” (Research Reports).

Supports the participation of its constituents in designing, delivering and monitoring of the organisation's services

76. In addition to providing services ULOs can work with their constituencies to, amongst other things, be involved with:
- knowing what accessible features, environments and facilities are required for participation to be physically inclusive to all
 - support for consultation and involvement
 - providing interpreting and transcription services
 - access auditing
 - Disability Equality and diversity training
 - knowledge of the DDA and other disability specific legislation
 - accessible housing and transport
 - delivering research, consultancy and training (Research Reports).

Work with commissioners to improve commissioning and procurement

77. The mapping and conversations work highlighted that “relationships with commissioners are not generally strong, although better with local councils than National Health Service bodies”. There was a general perception that statutory bodies – particularly health - do not know enough about their local user-led sector and the services they currently provide or could develop.
78. The 3rd Sector Market Mapping Report (IFF Research for DH, 2007) notes that a few very large organisations account for the vast bulk of 3rd sector expenditure, estimated at £7.2 billion per annum for social care alone. 62% of the 3rd sector organisations surveyed operated with a local focus and 34% had incomes of under £50,000 per annum. This confirms evidence from the literature review that: “A lot of funding remains tied up in traditional, non-personalised services. Contracting favours larger organisations that offer economies of scale” (cited in Research Reports).
79. Existing user-led organisations argue that they can save money for public bodies by their involvement in preventative work and through new ideas about the best way to provide support and services for disabled people (Research Reports).
80. Local authority support for existing organisations was perceived as ambivalent or hostile, particularly when it is expressed in contract restrictions, such as a requirement not to engage in advocacy or support complaints.

81. Disabled people, carers and other people who use support were rarely involved in setting specifications for services or designing outcome measures. Consequently outputs can be based on quantity, not quality - "... as with all community development work there is considerable lead-in time before groups start to achieve results in terms of changes to services, or projects that they have completed. Too often, in terms of involvement, evaluation is based on activity levels rather than outcomes" (Leeds Involvement Project).
82. "One critical success factor for ULO development appears to be the local authority environment; whether it is where they fit in to local spending priorities; whether the idea of nurturing a strong user voice is seen as important rather than 'difficult' or whether it is down to one or two individuals who have reason to champion the cause" (Research Reports).
83. It has been argued that ULOs are in an ideal position to work with public bodies on not only meeting the Disability Equality Duty but also in terms of fulfilling duties to involve disabled people, carers and other people who use support in developing policy and practice. There is potentially a real strength for local authorities and other public sector organisations (eg NHS bodies) in working with ULOs in building local communities and raising service standards.

References

Barnes C and Mercer G (2006) *Independent Futures: Creating user-led disability services in a disabling society*, Bristol, BASW/Policy Press

Disability Rights Commission (2002) *Policy Statement on Social Care and Independent Living*, Disability Rights Commission

IFF Research Ltd (2007) *Third Sector Market Mapping Report*. Research for the Department of Health, London

Morris J (2006) *Centres for Independent Living/Local user-led organisations: A discussion paper*, July 2006 to be published on Department of Health website September 2007
(<http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics>)*

Maynard Campbell S, Maynard, A and Winchcombe, M., (2007) *Mapping the Capacity and Potential of User led Organisations in England: A Summary of the Main Findings from a National Research Study*, to be published on Department of Health website September 2007
(<http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics>)*
Please note when references are made to this research report it is to the main report and not the accessible versions.

Prime Minister's Strategy Unit (2005) *Improving the Life Chances of Disabled People*, London, The Stationery Office

Woodin (2006) *Mapping User-Led Organisations: User-Led Services and Centres for Independent Living: A Literature Review Prepared for the Department of Health*, Supplementary Report No 1,
<http://www.leeds.ac.uk/disability-studies/archiveuk/index.html>

*** These reports are referred to as the Research Reports within the policy.**

Annex A: Definitions in alphabetical order

1. **Advocacy** means acting in a way that helps a disabled person, carer or other person who uses support to get their views across, representing their interests, supporting them to secure their rights and enabling them to access services and/or other entitlements.
2. There are four different types of advocacy:
 - Citizen advocacy where someone independent (often a volunteer) advocates on behalf of a disabled person, carer or other person who uses support.
 - Peer support where another disabled person, carer or other person who uses support with similar experiences provides support to enable the individual to get their views across and/or access the resources they need.
 - Professional advocacy is where someone acting in a professional paid capacity advocates on behalf of a disabled person, carer or other person who uses support.
 - Self advocacy is where someone speaks up for themselves (with support if necessary) and negotiates the services or resources that they need.
3. **'Carer'** refers to people who provide unpaid care or support to a relative, partner, friend or neighbour who is a disabled person or a person who uses support. It does not include people who work as volunteers or in a paid capacity.
4. It is also important to remember that some people who use services are also 'carers'. For example, many people with learning disabilities support their ageing parents. It is equally true to say carers can be service users in their own right as they have needs of their own as carers (www.scie.org.uk/carers accessed 21.3.07).
5. **Centres for Independent/Inclusive Living** - "There are various definitions of both ULOs and CILs in common use differing by degree of user-control

and membership of the wider disability and service user movement” (Research Reports).

6. “Centres for independent 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).⁴
7. Gibb (2005) summarises the essence of a CIL as having four elements:
 - Peer Support. A CIL can’t happen unless disabled people *come together* and support each other. Their own shared experience will decide what they mean by ‘independent living’ or a chosen alternative. Their own shared understanding of its obstacles will decide aims and strategy. This process can be encouraged by non-disabled supporters, but it can’t be *run* by them.
 - Disabled people’s control. This means that all policy decisions *under an organisation’s governing document* (its Constitution) are taken by an elected body with a majority of disabled members.
 - A social model understanding of disability. The ‘social model’ of disability is a widely known concept by now, but this means that sometimes liberties are taken with it. So when stated as a principle, it should have some illustration of the differences it makes in practice.
 - An integrated view of support needs. A social model can’t be applied by services that meet needs in isolation. This doesn’t mean that a CIL must always run a comprehensive range of services, but it should be a ‘one stop shop’ for access to whatever support people need” (cited in Research Reports).⁵
8. **Constituents/ constituency** is the group or individuals that an organisation represents or is set up to work with.
9. **Disability** is defined in *Improving Life Chances* as:

⁴ Morris J (2006) *Centres for Independent Living/Local user-led organisations: A discussion paper*, July 2006 to be published on Department of Health website September 2007 (www.doh.gov.uk)

⁵ Research Reports listed in References section at the end of the policy document: Maynard et al (2007), Morris (2006) and Woodin (2006)

“disadvantage experienced by an individual ...resulting from barriers to independent living or educational, employment or other opportunities... that impact on people with impairments and/or ill health.

10. A clear distinction needs to be made between disability, impairment and ill-health. **Impairments** are long-term characteristics of an individual that affect their functioning and/or appearance. **Ill health** is the short-term or long-term consequence of disease or sickness. Many people who have an impairment or ill health would not consider themselves to be disabled” (*Improving Life Chances*: page 8).
11. The term ‘**disabled people**’ is used to refer to people – of any age - with physical and/or sensory impairments, mental health support needs, learning disabilities, frailty and/or long-term health conditions who experience disabling barriers of unequal access and/or negative attitudes.
12. **Inclusive living** means being fully included in society with resources to facilitate inclusion.
13. **Independent living** is defined by the Disability Rights Commission as referring “to all disabled people having the same choice, control and freedom as any other citizen – at home, at work, and as members of the community. This does not necessarily mean disabled people 'doing everything for themselves', but it does mean that any practical assistance people need should be based on their own choices and aspirations”.⁶
14. Independent living is an important part of enabling disabled people to fulfil the roles and responsibilities of citizenship. Its importance spans the full range of life experiences faced by disabled people, from early years and transition to adulthood through to adult life and employment, extending into old age (*Improving Life Chances*: page 71).
15. **Other people who use support** is a term adopted to refer to those who may not describe themselves as a disabled person (eg. older people, deaf people), but do need support to exercise choice and control in their daily lives.
16. **Peer support** is where disabled people, carers and other people who use support come together to support and/or provide a service to other disabled people, carers and other people who use support. The shared experience

⁶ Disability Rights Commission (2002) *Policy Statement on Social Care and Independent Living*, Disability Rights Commission

of similar backgrounds or circumstances means that peer support is built on the value of personal experience.

17. **Service user/user(s)** are not terms used in the policy but are employed within the research work used to inform the policy. These terms are generally used to refer to people who need support and/or equipment in order to go about their daily lives. Some groups of service users share a collective experience and identity in terms of their history, experience of discrimination and experience of accessing and/or using welfare resources. These resources may sometimes be delivered as part of the welfare state and at other times, the welfare state will assist in signposting and/or assessing people for resources provided by the private or voluntary sector.
18. The **social model of disability** (adopted in this policy) says that the problem is not someone's impairment, illness, frailty or learning disability but instead, the problem is that they experience attitudinal, environmental and/or institutional barriers that disable them. They may not have the support, equipment or housing they need and they don't have choice and control over their daily lives. Although the social model of disability was initially developed by people with physical impairments, it is just as relevant to people with learning disabilities, older people, and people with mental health support needs. Although not all these groups identify with the social model of disability or as a disabled person.
19. The term '**user-led**', is used for brevity, this means the organisation is led by its constituency.
20. **User-led organisations (ULOs)** are those organisations which meet the design criteria set out within the ULO policy and thereby recognised as a ULO modelled on existing CILs as required in recommendation 4.3.
21. Whilst the emphasis of this policy is on supporting the establishment of local user-led organisations (ULOs) it is recognised that some user-led organisations also operate at a national level. Some national user-led organisations, like the National Centre for Independent Living and Shaping Our Lives National User Network, aim to support the development and networking of ULOs at a local and national level. The researchers commented that "In general the more established organisations, capable of developing towards a ULO, have proved, through the research process, to be affiliated or otherwise connected nationally" (Research Reports).