

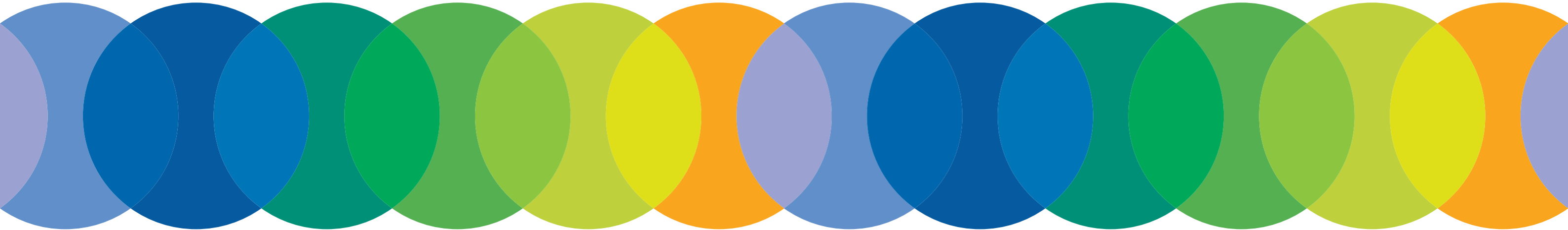
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KEY ISSUES

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# user-led organisations



## introduction

**User-Led Organisations (ULOs) can, and do, play a key role in the transformation of adult social care, as well as the wider drive towards coproduction and user engagement in the public sector. However ULOs and commissioners alike face a number of challenges in ensuring this role can be fulfilled for the benefit of everyone.**

This Key Issue explores the policy context and history of ULOs in order to understand their unique place in the social care economy. It highlights the value added specifically by ULOs and explores a variety of issues that shape ULOs directly and the interaction of commissioners with them. Such issues include the barriers ULOs typically face, how ULOs balance roles between providing a voice and campaigning-type activities, how they can work across different impairment groups and equality strands, and practical things commissioners can do to make the commissioning environment more conducive for ULOs.

## the policy context for user-led organisations

The original policy driver for the establishment and development of User-Led Organisations was Recommendation 4.3 of the Strategy Unit's *Improving the Life Chances of Disabled People* report (2005). It stated:

*'By 2010, each locality should have a user-led organisation modelled on existing Centres for Independent Living (CILs).'*

In the context of the *Life Chances* report, this recommendation was made with a view to supporting disabled people to live independently, recognising that ULOs would need to provide various services to support disabled people of all ages in using what were then individual budgets.

Recommendation 4.3 was taken forward by the Department of Health. At the end of 2007, Putting People First highlighted the importance of independent support services for people navigating the care and support system, irrespective of their eligibility for public funding. Consequently it included provision for at least one local ULO per area, alongside support for mainstream mechanisms to develop networks which ensure people using services and their families have a collective voice, influencing policy and provision.

To achieve both the service delivery and voice elements of PPF, each area was required to put in place a 'strategy to foster, stimulate and develop' local ULOs, which was further embedded in the joint Putting People First milestones developed by ADASS, DH and LGA at the end of 2009, requiring there to be 'at least one ULO contributing directly to the transformation of personal budgets.'

Thus, though ULO policy originally started under the auspices of independent living it became a key part of the Putting People First and Transformation of Adult Social Care agendas.

Fostering the development of User-Led Organisations supports public sector organisations across a wide range of policy drivers, and not just Putting People First. One key area is in supporting public sector organisations in meeting their obligations under the Disability Equality Duty. Similarly, ULOs embody an efficient, embedded and representative way of delivering what is colloquially known as the 'duty to involve'<sup>1</sup>, without the need for cumbersome or isolated entities to be set up in their own right. More broadly, ULOs are a ready-made vehicle for delivering transformation through coproduction.

<sup>1</sup> Section 138(1) of the Local Government and Public Involvement in Health Act (2007) requires local authorities (and other best value organisations) to secure the involvement and engagement of local representatives across all authority functions.

## the policy context for user-led organisations continued

A further role for ULO's is in supporting joined up support across social care and health. Local Involvement Networks (LINKs) were created through the *Our Care, Our Health, Our Say* Health White Paper in 2006. They provide flexible ways for communities to engage with health and social care organisations, as well as to ensure user involvement is at the heart of provision in holding bodies engaged in both the commissioning and delivery of services to account. At present, only two ULOs in England are the host organisations for LINKs. The most recent Health White Paper (2010) proposes retaining the role and function of LINKs under the new name of HealthWatch, thus providing plentiful opportunity for ULOs to engage and drive the continuing work to join up social care and health.

Finally, ULOs – as voluntary sector organisations run by and for their members and clients – can contribute to the overarching agenda created by the Big Society. Through enabling peer-to-peer support for disabled and older people in their local communities, and through encouraging their members and clients to use their social capital in both navigating the social care system and supporting others to do so, ULOs are arguably extremely well-placed to facilitate citizen contributions to the Big Society agenda.

## a brief history and definition of ULOs

Given the long history of Disabled People's Organisations, Centres for Independent Living (CIL) and the policy provenance of User-Led Organisations, it is not easy to define a ULO.

The history of CILs began with war veterans returning to the United States in the 1960s wanting to live independently rather than in institutions. In the UK, similar attempts by disabled people in the 1980s to live independently in the community rather than in residential care led to the creation of the first CIL – a breakthrough that was built on, and significantly accelerated by, the introduction of Direct Payments through the Community Care (Direct Payments) Act in 1996 and the role given to CILs in supporting the roll-out of that legislation.

The *Life Chances* report acknowledged the difference to disabled people's lives such CILs made in the places where they existed, leading ultimately to Recommendation 4.3. The Department of Health took responsibility for the development of ULO policy nationally, producing through coproduction with disabled people and their organisations the 21 Design Criteria which provide the formal, widely accepted definition of a ULO.

These criteria are split into two categories:

1. A set of values to which an organisation should adhere, including: working from a social model of disability perspective, promoting independent living, promoting human and legal rights, and engaging with all local disabled people, carers and other people who use support services
2. A set of characteristics an organisation should demonstrate, including: being legally constituted, having a minimum of 75% of voting members on the management board drawn from the organisation's constituency, demonstrating sustainability, and working with commissioners.

### The essential criteria

The most vital criteria relates to the proportion of members on a ULO's management board: that at least 75% need to be people drawn from the organisation's constituency, i.e. disabled people (across all impairment groups), older people and carers.

## a brief history and definition of ULOs continued

### A third criteria category

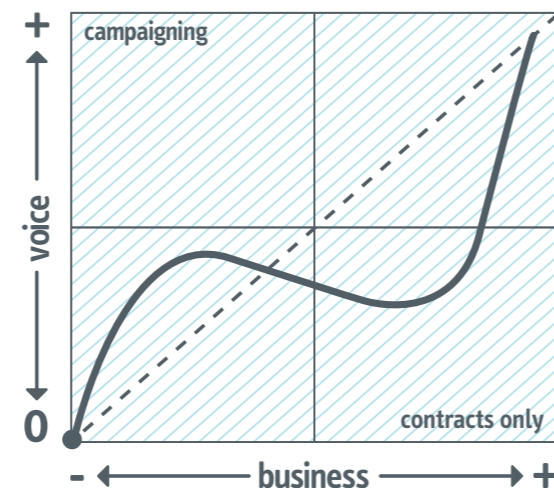
In addition to the two aforementioned categories, the *Life Chances* report also sets out a third category of criteria, a set of ULO services to support independent living, as follows:

- > Information and advice
- > Advocacy and peer support
- > Support in using personal budgets and direct payments
- > Support to recruit and employ personal assistants
- > Assistance with self assessment and support planning
- > (Disability) equality training
- > Support the implementation of the Disability Equality Duty by public sector organisations in the locality.

Though it is not a requirement for an organisation to provide all of these services to be considered a ULO, this is something that has not always been clear to commissioners or ULOs alike.

The three categories of criteria are highly inter-related and lead to two distinct features of ULOs within the social care economy: they operate on both the demand side (i.e. providing the individual and collective ‘voice’ of and for the direct experiences of disabled people, carers and people who use support services) and the supply side (i.e. providing services).

The long history of ULOs means they are familiar with operating on the demand side, their work drawing on campaigning-type activities for which they are often set up. However, the need for sustainability and financial robustness, as well as policy drivers such as



Putting People First, places them in a unique position of being able to consider undertaking more ‘business-like’ activities (e.g. providing support services under contract) alongside this voice-based activity. The diagram presents the typical journey a ULO may take in seeking to find the balance between these dual roles. Commissioner interventions most typically take place in the bottom-left quadrant of the diagram, supporting a ULO in the earlier stages of its development.

In practice, and in areas where they exist, the need to establish both demand- and supply-side activities and existing arrangements within a locality gives rise to a number of potential operating and delivery models for ULOs. These models often build on the long histories of existing organisations and the types of activities they undertake. Such models include:

- > An ‘all under one roof’ approach, where one ULO covers all or the majority of suggested services and constituency groups
- > Umbrella partnerships between existing organisations, with attendant governance arrangements (be they formal, such as a written governing document, or informal, such as a partnership agreement or network)
- > Several ULOs in one area, each providing a specific service(s).

### How many ULOs are there?

Assessing what might be required to achieve Recommendation 4.3, a 2006/07 DH study initially identified 647 potential ULOs across England. However, a follow-up ULO baseline study carried out for the DH in 2009 noted there are only 66 established ULOs that met the 21 Design Criteria and 64 local authorities that have no ULOs at all. The discrepancies in these separate pieces of research were partly explained by the fact the research was based on self-assessment. More generally, it was felt that those organisations who did respond were not familiar enough with, or understood the design criteria sufficiently, to accurately and consistently measure their organisation against them.

Following a significant amount of capacity building work focused on ULOs across a range of initiatives and some interim mapping work carried out by Deputy Regional Directors, a further DH study is being carried out at the time of writing to determine the current national picture as accurately as possible.

## what is the value added by user-led organisations?

The value of User-Led Organisations to the transformation agenda has often been assumed. A recent DH publication *Putting People First: Working together with User-Led Organisations* (2009) went further to outline the benefits that local authorities can accrue when they work with ULOs. These include helping local authorities deliver greater personalisation to improved engagement with hard-to-reach population groups.

Central to the unique contribution offered by ULOs is that they add value to the transformation of adult social care as a whole, and not just to supporting people to have choice and control through self-directed support. Indeed, though ULOs can and do provide SDS services, this isn't necessarily typical across all ULOs.

The value added by ULOs includes, though is not limited to, the following:

- > ULOs provide the 'voice' of disabled people. Though this can focus on service provision, it also includes input to equality schemes, access and involvement groups and other less formal forums
- > ULOs can and do work across more than one policy area, – they are more easily able to 'join up the dots' on the ground, responding to the needs of an individual rather than a care-and-support or housing recipient
- > Where services are delivered by ULOs, they are typically shaped and delivered by service users, meaning they provide a peer-to-peer approach which calls upon direct personal experience
- > ULOs are more nimble than statutory agencies, – they are informed by the 'what works' dynamic and can adjust quicker in response to changing circumstances
- > To find solutions to individual or collective issues, ULOs are able to pool creativity, knowledge and experience. This equates to using the 'lived experience' of disabled people for the benefit of their peers

As such, the following outcomes can be offered uniquely by ULOs, above and beyond any other organisations:

- > ULOs have legitimacy, both with users and service commissioners
- > ULOs offer pathways for service users to realise their social capital, be it formally or informally, and therefore contribute to their local communities
- > ULOs operate from a values base which encompasses the social model of disability and the principles of independent living.

## the key issues

There are a number of key issues currently facing ULOs and commissioners alike, which are discussed below.

### Barriers facing User-Led Organisations

ULO's face a variety of barriers across a number of key areas of business that impact on their ability to contribute positively to the social care economy. Reflecting their historical role as providers of voice in the social care economy, ULOs typically require more support than others in areas such as infrastructure (IT, HR, finance, buildings), staffing levels, performance management, operating on Full Cost Recovery principles and establishing a diverse income base that is not overly-reliant on a single source of funding (e.g. a local authority). Similarly, whilst governance arrangements are vital to the flavour and style of ULOs, ensuring the appropriate governance structure is in place, and the right people with the right skills occupy that governance structure, is a key challenge.

It is this area that work on supporting the development of ULOs has mainly focused on. Support to overcome these types of barriers tends to be most straightforward. Aside from the always-easy solution of funding, innovative solutions include seconding staff from a public body to a ULO for a timebound period, explicitly recognising (and even giving a methodology to do so) organisational overheads as part of any tender process,

and sharing information with a ULO on key areas (like HR and building management) to avoid them having to create it from scratch.

### Voice 'versus' business

ULO's operating across both the voice and business side of the social care economy present a unique strength. It also, however, gives rise to two challenges. The first is for the ULO itself in recognising, valuing and managing the relationship between these two components of its work. Where ULO policy started originally under the auspices of independent living it has since become a key part of the Transformation of Adult Social Care agenda. ULOs themselves remain anchored in the principles of the independent living agenda, which can mean they do not always consider their role to be one focused solely on social care per se, and certainly not one considerably focused on delivering services.

The second challenge is on balancing perceived or real conflicts of interest in these two roles. An organisation that makes use of its members and clients to support commissioners to define a question could feasibly then leave itself open to charges of foul play if the same organisation then helps provide an answer. Similarly, concerns of compromising a ULO's independence can often be found if it is felt to be getting too close to a commissioner. To address these concerns, both ULOs and commissioners should be clear in their

relationships with each other, perhaps by setting out principles for working with each other that both organisations can adhere to. Similarly, if commissioners are able to respect the right of the ULO to represent its members on issues of importance, and perhaps ensure lead political members are aware of any formal or informal partnership arrangements, this can make for productive relationships that overcome any perceived or real conflicts of interest. Solid governance arrangements, particular regarding those elements of an organisation which trade as service providers, also support the successful management of this issue.

### Working across different impairment groups and equality strands

Not all disabled people's organisations cover all disabled people in their work. Similarly, one User-Led Organisation may only represent one defined group of users, such as solely disabled people, as opposed to everyone in a given locality, including older people, people from BME backgrounds and carers.

These complexities can mean it is difficult to understand how ULOs can manage to be representative or work sufficiently together in a joined-up way.

Good practice from some local authority areas, such as Norfolk, North Yorkshire County Council and Cambridgeshire, suggests that addressing this challenge

can be supported as much by a commissioner as it can by ULOs working together. In these areas, commissioners have explicitly encouraged partnership working between ULOs with different impairment or equality strand specialisms. Other areas, such as the London Boroughs of Richmond and Newham, have made training available for different ULOs on other impairment groups or equality strands, provided by colleagues from ULOs who specialise in that area.

Such approaches can also support ULOs to be part of the wider voluntary and community sector communities in a given area, rather than operating solely as a separate group.

### Existing user engagement mechanisms

It is likely that a public body may have existing mechanisms for securing user engagement. These often include Partnership Boards or dedicated service user reference groups for particular areas of work. ULOs can be both a complement to, and replacement for, these mechanisms. The key principles in considering the relationship of a ULO to existing mechanisms are to ensure (a) whatever engagement processes that exist are in the control of service users, and (b) the responsibilities and boundaries of all entities are clear and minimise overlap as far as possible.

## the key issues continued

### Commissioning for ULOs

Targets for the transformation of adult social care require councils to have an enabling framework to ensure that people can exercise choice and control and have access to advocacy, peer support and brokerage systems with strong links to ULOs. There are a number of key facilitators that are under the control of commissioners to positively shape and create such an enabling framework at both a strategic (commissioning-based) level and a more practical (procurement-based) one.

#### Commissioning

**In terms of commissioning, policies can be developed that:**

- > Stimulate the participation of social care service users by encouraging the development of local groups and promoting the use of third sector infrastructure resources to include and benefit service user groups
- > Work in dynamic partnership with individuals, communities and their representatives – such as User-Led Organisations – to define, develop and deliver high quality services

> Foster a level playing field for user-led and carer's organisations to compete in any tendering process

> Look to commission from local providers

> Look to commission from Third Sector providers

> Recognise the added value that user-led organisations can offer

> Recognise the wider role of User-Led Organisations when carrying out their duty to promote disabled people's equality especially in drawing up and implementing local equality plans

> Ensure support enables Independent Living and embodies the ethos of choice, control and for all people to participate as equal citizens in society

> Ensure that local contracting procedures do not discriminate unfairly against small / new / user-led organisations

> Offer Contracts, not Service Level Agreements, in order to give potential ULO providers flexibility over service delivery

> Offer 3- or 5-year funding arrangements, rather than year on year, to support service improvement and provider stability.

### Article 19 and reserving contracts

**Article 19 regulations of the Procurement Directive 2004/18/EC form a part of European legislation that allows organisations to reserve public contracts for supported businesses, meaning it is permitted to invite only supported businesses to bid for the work. A supported business employs disabled people as over 50% of its workforce. For contracts under £144k, it is therefore allowable to simply invite a supported business, – such as a local ULO, – to bid for a contract or offer them the chance to match your best price. Treasury guidance suggests you should have at least one contract with a support business.**

Further information on Article 19 regulations is available through the Office of Government Commerce's (OGC) Guide to Supported Factories & Businesses.

### Procurement

**There are a number of practical things procurement teams can do to ensure procurement processes do not adversely impact User-Led Organisations. These are as follows:**

- > Ensure Third Sector organisations are given adequate time to respond to tenders
- > Consider using a restricted or selective tender list, or a 'single source' approach to target organisations controlled by users (particularly in cases of extending existing arrangements)
- > Ensure ULOs are specifically made aware of potential services particularly noted under the ULO Design Criteria (i.e. Information and advice, Advocacy and peer support, Support in using Direct Payments, payroll, brokerage, support planning, Disability equality training, Support for the implementation of the Disability Equality Duty)
- > Ensure organisations who have not bid for contracts before are particularly aware of new opportunities
- > Ensure procurement portals are accessible
- > Ensure tender documents are accessible and proportionate to the contract in question

## the key issues continued

- > Embed the following specification criteria within procurement processes for services, (particularly those relating to Direct Payments or Personal Budget Support Service). Tenderers must:
  - \_ Work to the social model of disability and the principles of Independent Living philosophy
  - \_ Provide peer-to-peer support
  - \_ Ensure support provided accommodates the diversity of the community
  - \_ Ensure support provided is equally accessible and inclusive of all
- > Ensure that the value for money components of the specification take account of the added value often contributed by local organisations representing potentially eligible users. This should particularly be the case in tender marking scheme (where such components of 'added value' typically form only 5% of judging criteria)
- > Recognise framework arrangements so that large and smaller organisations can submit joint tenders. Larger organisations may be able to bring economies of scale to the contract while smaller organisations may be better placed to provide specialist services
- > Observe good practice during the application process through ensuring:
  - \_ Each tender pack contains an evaluation and a complaints form
  - \_ That tender packs are available in a range of accessible formats
  - \_ Guidance documents are provided that cover equal opportunities, partnership working and how to complete the application form
  - \_ All materials relating to a specific tender process are in one place and easy to access
  - \_ Monitoring systems are in place to record the number of smaller organisations bidding for and securing contracts.

### Re-visiting Recommendation 4.3: a ULO in every area?

**The current position with regard to the number of ULOs across the country is mixed. The most recent research has noted there are only 66 established ULOs and 64 local authorities that have no ULOs at all.**

There may be some areas which are classified as not having a ULO that do, in fact, have a ULO operating in that locality, if not based there. For example, Norfolk Coalition of Disabled People (NCODP) provides support services in both Norfolk and Suffolk. Thus, though Suffolk itself does not currently have an identified ULO based in the area, it does have a ULO (in NCODP) fulfilling the role of a ULO in that area.

Across all local authorities that provide social care functions, there therefore exists the opportunity to consider the options of either:

- > A ULO in each specific area, or
- > A ULO operating across an appropriate and reasonable number of localities.

For example, rather than having separate ULOs for each of the London boroughs, arguably some appropriate and reasonable arrangement regarding a ULO between, for example, four boroughs in South East London could be worth exploring.

Or in metropolitan areas, it is possible a partnership arrangement between a City Council and its neighbouring County Council could be feasible.

Such an approach would be dependent on a number of factors, including any existing arrangements and the key consideration of maintaining the vital balance between local representation and expertise and a one-size-fits-all approach.

the key issues  
continued

Shaping commissioning  
and procurement policy

To support the development of an inclusive commissioning approach, commissioners could consider the following to shape their commissioning policy:

- > Commissioning training from local organisations for commissioners themselves
- > Employing or engaging commissioning experts from the voluntary sector or local SMEs to provide specialist advice and feedback on relevant strategies
- > Mainstream equality and access issues through the commissioning cycle
- > Work with user-led organisations to decide how best to commission local support services. Whatever model is developed, the involvement of service users and carers in the design and delivery of services is of vital importance and will encourage better quality support services

summary

User-Led Organisations are uniquely placed to play a key role in supporting the transformation of adult social care, as well as more generally supporting the reform of public services through co-production and user engagement.

The barriers that ULOs typically face in building their capacity and capability to fulfil this role are relatively well known, and a critical mass of resources and initiatives to help address these barriers are now available from a variety of sources (see Resources section).

But whilst building the capacity and capability of ULOs is important, a wider understanding of the value ULOs add – to their clients, to commissioners, and to the social care economy as a whole – is crucial to enabling commissioners make the most of this unique resource.

At a fundamental level, understanding which organisations are user-led and which aren't will provide a solid starting point, and the DH's forthcoming study should go a long way to establishing this.

But more generally, existing ULOs and commissioners need to work together to capture the value ULOs add across social care. Where the value added by ULOs is currently described, it needs to be evidenced. Where the outcomes ULOs enable service users to achieve are greater, these need to be captured. And where the solutions ULOs generate to help meet the challenge of public sector reform over the coming months and years are innovative-but-small, so they need to be tried, tested and rolled out at the scale commissioners need them to work.

## resources, references and further reading

There are a number of resources focused specifically on building the capacity of user-led organisations, which are listed below. These include a number of case studies of the work ULOs or commissioners are doing to support ULOs.

Department of Health (2009), *Putting People First: working together with User-Led Organisations*  
[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_096859](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_096859)

Department of Health (2010), *Sharing the learning: User-Led Organisations action and learning sites 2008-2010*  
[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_114154](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114154)

Disability LIB (2007), *Details of Disability LIB – a Big Lottery-funded project which aims to build the capacity and capability of ULOs across the country – and its resources are available here:*  
<http://www.disabilitylib.org.uk/>

NCIL (2009), *ULO resources*  
<http://www.ncil.org.uk/categoryid22.html>

SCIE (2009), *At a glance 15: Personalisation briefing: Implications for user-led organisations*  
<http://www.scie.org.uk/publications/ataglance/ataglance15.asp>

SCIE (2010), *A commissioner's guide to developing and sustaining user-led organisations*  
<http://www.scie.org.uk/publications/guides/guide36/index.asp>

Both the Department of Health and ECDP have produced short videos demonstrating the work being done to build the capacity of ULOs, as well as the work some ULOs are doing in their local community. These can be accessed here:

*Mentoring a ULO*  
<http://www.youtube.com/watch?v=P9OfH0l3jio>

*Delivering a sustainable ULO*  
<http://www.youtube.com/watch?v=gla8j4j7FJA>

*Ensuring a ULO engages with everyone*  
<http://www.youtube.com/watch?v=ce8cTtjee4>

*ULO in rural areas: the work of Disability Cornwall*  
<http://www.youtube.com/watch?v=7mLD38MNUGQ>

*ULO working in partnership: learning from Islington*  
<http://www.youtube.com/watch?v=Tg1no-NbiSk>

*ULO supporting personalisation: learning from Croydon CIL*  
<http://www.youtube.com/watch?v=iVQPK8gL7TQ>

*ULO working across different equality strands: learning from Leicester CIL*  
<http://www.youtube.com/watch?v=iPcdRgsez1s>

A number of documents form the framework for the role of User-Led Organisations in social care and health, details below:

Department of Health (2007)  
*Putting People First*

Department of Health (2008)  
*Transforming Social Care: Local Authority Circular 1*

Department of Health (2009)  
*User-Led Organisations (ULO) Baseline Project*

Local Government and Public Involvement in Health Act (2007)  
[http://www.publications.parliament.uk/pa/pabills/200607/local\\_government\\_and\\_public\\_involvement\\_in\\_health.htm](http://www.publications.parliament.uk/pa/pabills/200607/local_government_and_public_involvement_in_health.htm) - specifically Section 138(f)

NCIL, ADASS and LGA (2009), *Joint Protocol between National Centre for Independent Living, Association of Directors of Adult Social Services, and the Local Government Association for the provision of user-led organisations (including Centres for Independent Living) and user-led support services*  
<http://www.ncil.org.uk/categoryid20.html>

Prime Minister's Strategy Unit (2005), *Improving the Life Chances of Disabled People*  
[http://webarchive.nationalarchives.gov.uk/+http://www.cabinetoffice.gov.uk/strategy/work\\_areas/disability.aspx](http://webarchive.nationalarchives.gov.uk/+http://www.cabinetoffice.gov.uk/strategy/work_areas/disability.aspx)

Written for *research in practice for adults*  
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## key issues

This is one in a series of publications on Key Issues published by *research in practice for adults*. The series is designed to provide ready access to relevant policy, available evidence and emerging practice on topics of current importance.

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