A commissioner’s guide to developing and sustaining user-led organisations
The Social Care Institute for Excellence (SCIE) was established by Government in 2001 to improve social care services for adults and children in the United Kingdom. We achieve this by identifying good practice and helping to embed it in everyday social care provision.

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- enhance the skills and professionalism of social care workers through our tailored, targeted and user-friendly resources.
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Introduction

Welcome to this guide for local authority commissioners on how to develop and sustain local user-led organisations (ULOs). There is now a stronger case than ever before for local authorities to invest in and work with ULOs. We hope that you will find the information in this guide a useful way of helping you develop and strengthen ULOs in your local area.

ULOs are essential to the transformation of adult social care. The Life chances report from the Prime Minister’s Strategy Unit recommended that ‘each locality should have a user-led organisation’ (recommendation 4.3, Improving the life chances of disabled people). Local authority commissioners must make sure that they have worked to develop and sustain ULOs by December 2010. This guidance helps commissioners to meet this policy requirement and:

- explains why commissioners must develop and sustain ULOs
- provides background information about ULOs
- offers practical advice for developing and strengthening ULOs
- suggests resources that can help.

‘Where user led organisations do not exist, a strategy to foster, stimulate and develop these locally should be developed’.

Local authority circular (DH) (2009) 1
Understanding ULOs

This section will give you all the background information you need to understand ULOs. This will help you to work with ULOs in the most appropriate and effective ways.

Key messages

- ULOs have a long history, with user group activism really taking off in the 1960s and 1970s
- ULOs are involved in a wide range of activities but in general help people to exercise choice and control over how their support needs are met
- ULOs are organised in various ways: there is no one specific model
- ULOs now need to engage with a diverse population and be inclusive
- although users and carers should work together, organisations made up mainly of carers are best described as carer-led organisations.
What is a ULO and what does it do?

Just because an organisation works with service users does not mean that it is a ULO. This section explains what a ULO is and what it does.

A basic definition

Here is a basic definition of what a ULO is:

A ULO is an organisation that is run and controlled by people who use support services including disabled people, mental health service users, people with learning difficulties, older people, and their families and carers. (SCIE, 2009)

Remember, we are predominantly talking about ULOs that fulfil recommendation 4:3 in *Life chances*, that is organisations that support independent living.

The name ‘ULO’ is not without controversy. For example, Shaping Our Lives, the national service user network, prefer the term ‘user-controlled organisation’ as this more accurately describes the power that service users hold within the organisation.

Typical work of a ULO

ULOs provide support so that people can exercise choice and control over how their support needs are met. Typical activities include:

- information and advice
- advocacy
- peer support
- support in using personal budgets and direct payments
- support to recruit and employ personal assistants
- support with recovery and rehabilitation
- assistance with self assessment and support planning
• equality training
• campaigning
• employment and return to work support
• partnership activities with local agencies, such as civil society organisations, and health and social services.

Not all ULOs engage in all of the above. It depends on the stage of development of the particular ULO, its purpose, how it is funded, and the contracts it has with statutory agencies. Some ULOs undertake additional activities not listed above, for example employment support programmes, access auditing and housing advice.

The Department of Health’s 21 ULO design criteria

The Department of Health has produced 21 design criteria to describe what a ULO looks like and the sorts of services that it provides (DH, 2007). A ULO does not have to fulfil all of the design criteria and, in reality, most do not.

The design criteria cover three broad areas:
• the value base of a ULO (for instance, promoting the social model of disability. For a definition of the social model of disability, see the Open University definition in the online version of this guide. For more on independent living visit the NCIL website.
• how a ULO is governed and managed (for example, that 75 per cent of the members of the management committee are service users)
• the sorts of services ULOs provide (such as advocacy and peer support).

Shaping Our Lives consultation: definition of a ULO
Shaping Our Lives carried out a brief consultation about developing and sustaining ULOs (2009, unpublished). They said that there are some basics that an organisation should be able to demonstrate if it is to be considered a ULO. These can be summarised as values, power and knowledge. First, a ULO is an organisation based on
clear values of independence, involvement and peer support. Second, unlike other voluntary sector organisations, service users control the organisation (power). Finally, ULOs are uniquely identified by their knowledge, which is based on direct, lived experience.

The report concluded that it is crucial that commissioners understand these three key issues – values, power and knowledge – when working with ULOs. In practice, this means that commissioners should explore these issues to understand whether or not an organisation is a ULO.
A brief history of ULOs

While ULOs may seem like a recent phenomena, social and health care users have struggled for many years to have their voice heard.

The struggle for a voice and the influence of civil rights movements
Early social and health care users were united by their disempowering experiences of services and desire for greater control over their own lives and the services they used.

The civil rights movements of the 1960s and beyond were hugely influential in shaping modern service user activism. These movements fought for marginalised people’s rights as equal citizens, arguing that mainstream society ignored, excluded and discriminated against them. They contributed to a political and social climate that emphasised rights and citizenship, which in turn helped service users fight for their voices to be heard.

‘Nothing about us without us’: the disability movement
Modern ULOs of disabled people started with attempts by disabled people in the early 1980s to leave residential care and live in the community. For example, in Hampshire a group of disabled people (still known as the ‘Escape Committee’) wanted to move from residential care to live in the community, supported by their own personal assistants. With the support of some professionals committed to independent living they eventually succeeded. The Hampshire Centre for Independent Living (HCIL) was set up to support them and others like them. Since then many CILs and other disabled people’s organisations have been established, especially after the passing of the Community Care (Direct Payments) Act in 1996.

In the early days, these organisations mainly involved disabled people with physical and sensory impairments. As direct payments became available to more people, and particularly since the development of personal budgets, ULOs have become more inclusive of all service users. However, some ULOs continue to represent single
impairment groups, such as groups for people with hearing impairments. These groups often focus on networking with other disability organisations, rather than expanding their membership to other social care user groups. For more information visit The United Kingdom Disabled People’s Council, Disability LIB or the Equalities National Council websites.

‘We’re not mad, we’re angry’: the modern mental health user/survivor movement

The modern mental health service user/survivor movement has grown rapidly – from a few, mainly national groups in the 1970s and 1980s to now include a large number of mainly local groups today, although there are many examples of earlier activism. While members of the mental health service user/survivor movement share many common concerns, there are also a number of differences. This means that the mental health service user/survivor movement cannot form a single voice that represents all users on all issues. This has led to a philosophy that prizes choice, self-determination and individual and collective empowerment. It also means that there is currently no single model that represents all views (like the social model of disability). Instead, there is a focus on ‘experiential knowledge’, which means that mental health service users and survivors believe that the knowledge of service users is important and valid, and that it should be interpreted by users themselves. For more information visit The Survivor History Group website, NSUN (the national network for mental health service users/survivors: or purchase Some things you should know about user/survivor action by Mind.

Campaigning by other user groups

Other social care user groups have their own unique history, such as looked after children and people with learning difficulties. For more information visit:

- Shaping Our Lives: a national network of service users and disabled people
- Shaping Our Lives also runs a networking website, SOLNET, which has a membership of over 300 organisations and an active noticeboard section for sharing information and ideas
• Putting People First: an organisation run by and for people with learning difficulties
• A National Voice: an organisation run by and for young people who are in or have experienced care
• User Voice: an organisation run by people who have experienced the criminal justice system
• National Pensioners’ Convention: a campaigning organisation run by and for pensioners
• MDF The Bipolar Organisation: an organisation run by and for people whose lives are affected by bipolar disorder
• Radar: The disability network Radar is the largest disability campaigning organisation
• The Multiple Sclerosis Society a membership organisation governed by people affected by multiple sclerosis.

**ULO* s share common values**

What is common to all of health and social care user groups is that they are based on shared values of:

• the right to choice and control
• the principle of ‘nothing about us without us’
• the struggle for full civil and human rights (Morris, 2006).
How are ULOs organised?

ULO may be organised in a range of ways; there is no fixed model. What is fundamental to a ULO is that, as an absolute minimum, over 50 per cent of the management committee or board must be people who use support services. For a ULO to meet the Department of Health’s design criteria, at least 75 per cent of the management committee should be service users.

Structure of ULOs

ULO may be structured in a variety of ways including:

- a single organisation
- a formal partnership between two or more organisations
- a hub and spoke model where a number of organisations contribute to the ULO at the centre.

It all depends on local conditions and the history of service user activism in the community. In some localities, there is a strong ULO with a history of supporting service users to achieve independent living. In other localities, several organisations may exist, some of which may be impairment or social care service user group specific. These ULOs do not want to lose their individual identity but are prepared to contribute to a central ULO or be part of a network of ULOs.

Legal basis for ULOs

There are a number of legal forms a ULO may take including:

- registered charity
- company limited by guarantee
- a charity and a company limited by guarantee
- charitable incorporated organisation
- community interest company.
Again it will depend on local conditions and the opinions of the service users involved. For more information on the legal forms of ULOs, see 'Different models for ULO organisations' produced by Choice & Rights Disability Coalition in Hull.
The diversity of ULOs

ULOs have a responsibility to reach out to all sections of the community and to make sure that they are representing a wide range of voices.

Single issue beginnings
As ULOs supporting independent living are often small and insecure, it has not always been easy for them to reach out to all sections of the community. This is partly because typically funding has come from budgets for specific groups, preventing ULOs from reaching out to other social care user groups. Another reason is that, for some years, direct payments were only available to younger people with a physical and/or sensory impairment.

Ensuring inclusivity
It is important to ensure that all sections of the community have the opportunity to have their voice heard and be involved in ULOs. This means that newly developing ULOs should strive to include:

- all impairment or social care service user groups (including learning difficulties, long-term health conditions, mental health and physical and/or sensory impairments)
- adults of any age
- black and minority ethnic communities
- lesbian, gay and bisexual and transgender service users
- carers.

Resourcing
To achieve a more inclusive agenda, ULOs need adequate resources so that they can reach out to the whole service user community. Organisations representing particular groups in the community should also be resourced and supported to play a part in a central ULO or network of ULOs. This requires careful and sensitive planning, alongside
a commitment to work together in ways that are most appropriate for local circumstances.
Carers and ULOs

Carers are service users too: shouldn’t they be involved in ULOs? If an organisation is run by carers does that mean it is a ULO? This section looks at the arguments that relate to carers’ involvement with ULOs.

A historical divide
The involvement of carers in ULOs is a contentious issue, and it is useful to consider some of the issues that can cause tensions between service users and carers. Both groups have historically felt a need to compete to have their needs and aspirations recognised, sometimes at the expense of the other. If you speak to disabled people they will often tell you that carers cannot speak for them. The interests of a disabled person and of a carer do not necessarily coincide. If you speak to carers they will say that they need access to information, advice, advocacy and peer support that is specific to them.

A shared agenda
There is growing recognition that, although disabled people and carers are likely to have different agendas on a day-to-day basis, fundamentally their interests coincide. The liberation of carers lies in the liberation of disabled people. In other words, if both carers and disabled people have choice and control over how they want to live their lives, they will both benefit.

In reality, the lives of people using support services are complex and involve not just the service user but the network of people around them, including family and informal carers. It makes sense for a ULO to include carers, either within the organisation itself (such as the Multiple Sclerosis Society model) or by working closely with a carers’ organisation.
**Carer-led organisations**

However, it is also important to use clear and simple language. Although ULOs should reach out to carers, calling a carers’ organisation a ULO can confuse things. Because of this, we recommend that organisations made up mainly of service users are described as ULOs, and organisations made up mainly of carers are described as carer-led organisations.
Examples of ULOs

Below we introduce five different ULOs from around the country. The ULOs represent different social care user groups in different areas and demonstrate the diversity of ULOs.

**Action Disability Kensington & Chelsea**

**Where?** The Royal Borough of Kensington and Chelsea in London.

**Members?** Adults with physical, sensory or hidden impairments who live or work in the Royal Borough of Kensington and Chelsea

**Activities?** We are the local voice of disabled people and provide information and advice, advocacy, consultation, policy development, training, individual budgets support, access and volunteers.

**Governance structure?** ADKC is a user-led organisation. Our management committee is made up entirely of local disabled people.

**Core values?** ADKC is committed to working within the social model of disability. As an organisation run by and for disabled people, ADKC ensures that disabled people take part in the planning and management of its work.

**Interesting fact?** ADKC’s membership includes the members of Crazie Productions, an award winning group of local young disabled filmmakers.

**For more information:** go to [www.adkc.org.uk](http://www.adkc.org.uk)

**Bath and North East Somerset People First**

**Where?** Bath and north east Somerset

**Members?** Adults with learning difficulties and other disabilities in Bath and north east Somerset

**Activities?** We run groups on human rights, disability equality, housing, health, employment and personal budgets. We also offer self and peer advocacy and run a travel buddy scheme to offer support for disabled people to use public transport.
**Governance structure?** We are run by a management committee – 90 per cent of the committee and the trustees have a learning difficulty. Our management committee is changing to include other disabled people. This will bring in a wide range of skills, and will help our organisation to represent all disabled people.

**Core values?** We support the social model of disability. We work to achieve social inclusion through peer and self advocacy. The organisation is run by the management committee who are in a strong position to know the views and needs of the other members.

**Interesting fact?** We were the only action and learning site (these sites were part of the DH User Led Organisation Development Project) with its main focus on people with learning difficulties, and have been included in Department of Health action and learning site reports.

For more information: go to [www.bathpeoplefirst.org.uk](http://www.bathpeoplefirst.org.uk)

**Manchester Black Health Forum**

**Where?** North Manchester.

**Members?** Adults aged 50 and over from black and minority ethnic communities who are isolated and who have health and social care needs.

**Activities?** As well as providing advocacy services and peer support, Manchester Black Health Forum run various clubs including luncheon clubs and social care day clubs. We also provide meals to isolated people in the community.

**Governance structure?** Manchester Black Health Forum is a registered charity.

**Core values?** Manchester Black Health Forum works within the social model of disability and delivers services in ways that are sensitive to diversity.
Interesting fact? The chair’s mother was one of the original members of the black health forum, Marahaba.

Body Positive North West

Where? North west of England

Members? Over 1,700 members

Activities? Our services include a health and social care department, a volunteer department, a kitchen and dining room from which hot meals are cooked for our service users, point of care HIV testing from our building and also in a variety of outreach locations, complementary therapy and the availability of a training room.

Governance structure? A not-for-profit social enterprise

Core values? Supporting the lives of people, families and communities affected by HIV, by never losing sight of the individual.

Interesting fact? BPNW is the only organisation in England to offer point of care HIV testing that is completely delivered by the voluntary sector.

For more information: phone 0161 882 2200, e-mail info@bpnw.org.uk or write to 39 Russell Road, Whalley Range, Manchester, M16 8DH

The People’s Forum

Where? Leicestershire County and Rutland

Membership? The group is open to all adult mental health service users in Leicestershire and Rutland.

Activities? The aim of the group is to ensure that service users have a voice and that their views about the planning and delivery of mental health services are heard. We are
currently involved in some exciting projects including one on digital story telling and one which aims to promote wellbeing through involvement in sport.

**Governance structure?** The group is run by and for service users and has its own office with two part-time staff. We have a management committee made up of four elected officers and two invited members, all service user volunteers.

**Core values:** To keep our commitment to service users to be ‘your voice on mental health services’.

**Interesting fact?** In October 2007 we broadcast on BBC Radio Leicester for World Mental Health Day, including the ‘Thought for the Day’, and a pre-recorded feature on mental health followed by an on-air discussion.

**For more information:** email peoplesforum@btconnect.com
**Why develop and strengthen ULOs?**

This section will help you to understand *why* local authority commissioners must develop and strengthen local ULOs. The first part of this section looks at the policy drivers. The second part of the section then explains the added value or benefits of having strong local ULOs.

**Key messages**

- local authority commissioners must demonstrate that they have worked to develop and strengthen ULOs **by December 2010**
- ULOs can help local authorities to meet broader policy requirements, such as the Disability Equality Duty
- ULOs add value: they can help deliver effective services and commissioning, tackle social exclusion, and are based on the authentic voices of service users.

> 'ULO are local and driven by what their users know works for them. With the right level of resources they could be a power-house for social change towards full participation for all as equal citizens because their voice is authentic.'

Maynard-Campbell 2007
Policy drivers

By December 2010, commissioners are expected to have developed and strengthened ULOs in their area. This section presents what commissioners need to know about the policy background driving this.

The ULO policy context

In 2005, the Prime Minister’s Strategy Unit recommended that there should be a ULO in every local authority area with social care responsibility, modelled on existing centres for independent living (CILs) (recommendation 4.3 of Improving the life chances of disabled people).

Putting people first (the 2007 joint statement by a range of key social care stakeholders further highlighted the need to work with ULOs in the transformation of adult social care. Guidance on the roll out of Putting people first stated that local authorities should develop:

…an enabling framework to ensure people can exercise choice and control with accessible advocacy, peer support and brokerage systems with strong links to user led organisations. Where user led organisations do not exist, a strategy to foster, stimulate and develop these locally should be developed. Local authority circular (DH) (2009) 1

Strong ULOs are part of the Transforming Adult Social Care (TASC) milestones

The Association of Directors of Adult Social Services, the Local Government Association and the Department of Health have jointly agreed five milestones against which local authorities will be judged on their progress on the transformation of adult social care. Milestone one is about having effective partnerships with service users, carers and other local citizens. This will be measured in the following way:
every council area has at least one user-led organisation directly contributing to the transformation to personal budgets (ADASS, DH and LGA, 2009).

You can find the milestones on the ADASS website (see the online version of this guide for further details).

**ULOs can help local authorities meet the Disability Equality Duty**

Having strong local ULOs also helps local authorities fulfil their Disability Equality Duty. This is because ULOs are knowledgeable on how to fulfil the duty, and provide commissioners with a simple way of reaching relevant communities with personal experience.

**ULOs can help local authorities meet broader policy imperatives**

ULOs are a ready-made partner to co-produce services. Strong ULOs can also help commissioners tackle inequality, build social capital, understand prevention and commission services in ways that are more relevant and responsive to the local community. For more on the benefits of developing strong ULOs, see the next section, *The added value of ULOs*.

**Local authorities will be evaluated on their progress**

The Department of Health has commissioned the National Centre for Independent Living (NCIL) to undertake a sector audit of ULOs, commencing September 2010. The audit measures a ULO’s progress against the Department of Health’s 21 design criteria (see ‘What is a ULO’ in the section ‘Understanding ULOs’). This includes assessing whether the ULO:

‘works with commissioners to improve commissioning and procurement’ (one of the 21 design criteria).
In addition, Deputy Regional Directors of Social Care regularly report their progress against the transforming adult social care milestones. This includes whether the local authority has at least one ULO directly contributing to the transformation to personal budgets.
The added value of ULOs

The policy endorsement of ULOs is based, in part, on the fact that ULOs offer unique added value. This is because ULOs are founded on shared, core values which have arisen from the lived experiences of local service users.

ULOs can be a one-stop-shop

ULOs can act as a single point of contact and information for commissioners, service providers and local service users.

They are a one-stop-shop resource with expertise in areas such as advocacy, accessibility, self-help and peer support.

ULOs help deliver effective services and commissioning

The knowledge and skills held by ULOs – such as knowledge about the needs of local service users, and the impact of services in the local community – can help make local services and the commissioning cycle more effective.

Because of their emphasis on prevention, ULOs believe they can help commissioners save money over the long term (DH 2007).

ULOs can support personalisation

ULOs can support the implementation of personalisation by helping service users navigate the health, social care and benefits systems.

Research indicates that direct payments have been more successful in areas where there has been a ULO to support their implementation (see for example, Bewley and McCullock, 2004; Murray et al 2006).
**ULOs are an authentic voice**

The voice of ULOs is legitimate and credible, both to commissioners and other service users, because it is based on direct experience.

ULOs hold strong values that reflect local service users’ views. They are uniquely placed to understand how local service users experience services and what they need.

ULOs can also help commissioners reach seldom heard service users.

**ULOs can help to tackle social exclusion**

ULOs provide an opportunity for service users to get involved in running their own organisations and through doing this increase their skills and confidence. They can also be a pathway for service users to get involved in all aspects of service delivery and development, for example, through supported service user representation on partnership boards.

ULOs often help people back into employment (DH 2007).

ULOs can help address health inequalities by supporting service users to access the support that they need (DH 2007).
Where am I now? A self-assessment

Aim

The aim of this section is to help you, as a local authority commissioner, understand more about ULOs in your area, including what they do, who they serve, and how they are funded. You do not need to know all of the answers – but trying to find the answers will help you get a clearer picture of what you need to do to develop and strengthen ULOs where you are, and to enhance their relationship with the local authority.

The questions

Thinking about ULOs in your area…

• What ULOs are you aware of in your area?

There are a number of directories that can start you on the path to finding ULOs in your area:

• SOLNET: Shaping Our Lives runs a networking website, SOLNET, where you can look up groups in your area by region.
• NCIL: The National Centre for Independent Living has a directory of local support services, including centres for independent living run by disabled people.
• Disability LIB: Disability LIB have an interactive map showing disabled people’s organisations.
• You can also contact your Deputy Regional Director, who will have information on what ULOs exist in your region.
• What groups are represented by local ULOs in your area?
  o That is, are all groups of people with rights under the Disability Discrimination Act – learning disability, long-term health conditions, mental health conditions, physical and/or sensory impairment – represented in your area? Also, are carers and older people represented in your area?

• What impairment or social care user groups are not represented by local ULOs?
  o You may need to develop a ULO that is able to represent any overlooked or seldom heard groups, or encourage existing ULOs to broaden their remit so that they are more representative of the local community.

• Are there networking or partnership arrangements between local ULOs that you are aware of?
  o For example, do you know of any formal network of ULOs in your local area? Are there any formal partnerships between ULOs in your area and neighbouring areas?

• What services do the ULOs provide?
  o For example, information, advocacy, benefits support, employment support, direct payments support and so on.

Thinking about each ULO in your area…

• How many people on the management committee or similar are service users?
  o This information is vital. At least 50 per cent of the management committee of a ULO must be made up of service users, and to meet the Department of Health’s design criteria this figure should be 75 per cent. If less than 50 per cent of the group’s management committee are service users, the group is not considered to be a ULO.

• How long has the organisation been operating?
  o Knowing how long an organisation has been operating will give you some indication of its strength and sustainability. This information will be particularly useful if you also explore the funding sources of the ULO.
• Do you know how to contact the ULO, and what their opening hours are?
  o If you want to work with local ULOs, you will need to be proactive in reaching out to them.
• How many paid staff does the ULO have?
  o Knowing how many paid staff an organisation has will give you an idea of its strength and sustainability. For example, a group that relies entirely on volunteers, or a single paid worker, will be more vulnerable to collapse.
• Do the staff in the ULO reflect the full diversity of the organisation’s constituency?
  o The Department of Health design criteria state that ULOs should have paid employees, many of whom must reflect the organisation’s constituency. Therefore, ideally, ULO staff will reflect local diversity.
• Does the group work only in your area or does it work in others as well?
  o A ULO that provides services in more than one area is likely to be more sustainable, as it will be less reliant on funding from one commissioning authority.
• Do you know what the main values of the organisation are?
  o For example, does the group work from the social model of disability and principles of independent living?

Thinking about the commissioner’s relationship with each ULO in your area…

• Does your local authority currently provide any funding to the ULO?
  o For example, this could be through a core grant, a Service Level Agreement, or a contract, or by commissioning it to undertake specific pieces of work.
• If so, how much were the different types of funding worth?
  o This information will help you to understand the overall reliance of the ULO on funding from your local authority, and so the robustness of its overall funding arrangements.
• How long have these arrangements been in place?
  o This information will help you to understand how long the ULO has been reliant on the different types of income. This will enable you to understand both how the organisation approaches its funding over a long period of time, as well as how well established its various strands of activity are.

• What services/projects/programmes does the ULO provide for this funding?
  o For example, does the organisation provide an information and advice service? Advocacy and peer support? Support in using Direct Payments (for example, IAG [information, advice and guidance], payroll, brokerage and so on)? Assistance with self-assessments? Any form of disability equality or other training? Support for the implementation of the Disability Equality Duty?

• Does your local authority provide any other form of (non-financial) support to the ULO?
  o For example, do you provide premises for the ULO at a reduced or negligible rental rate? Do you provide the ULO with any IT equipment or furniture? Have you provided any staff time or training to the ULO?

• Does anyone else provide any funding or support to the organisation for the work it does?
  o For example, does the ULO have agreements with a national body or charity, or receive funding from a civil society organisation?

• Does the organisation generate any income of its own?
  o For example, through providing training to other organisations, undertaking access audits, selling publications, its own membership arrangements, or providing research service

Thinking about service user engagement and co-production in your area…

• What arrangements does your local authority have in place for engaging different groups of disabled people?
• For example, do you have any existing partnership boards, such as those for people with a learning disability? Or do you have a reference group of several civil society organisations?

• How effective are these in engaging people?
  o For example, do they ensure in-depth engagement with the commissioner on decisions, or do they inform the general discussion about service design? Does engagement take place at every level – that is, operational as well as strategic?

• How many service users sit on different decision-making bodies?
  o For example, is there one representative of all disabled people on an entity like the Transformation Programme Board within adult social care (or the equivalent)?

• How are under-represented or seldom heard service users involved in your work?
  o For example, are black and minority ethnic groups (BME) or lesbian, gay, bisexual and transgender (LGBT) groups involved in your work? What about gypsy and traveller communities? If so, are these groups represented in different or similar ways to disabled people?

• Who is involved within the local authority for coordinating this work?
  o For example, is this coordinated by a Public Body Officer, or is it coordinated on your behalf by a ULO?
Summary

How did you do? It is ok if you don’t yet know the answers to these questions. By making contacts with ULOs, and by understanding your internal user involvement structures, you will be in a strong position to develop positive relationships with ULOs in your area. You will also ensure that if you develop a new ULO, it is because there is a genuine need.

Remember, you can start searching for ULOs in your area through:

- SOLNET, the networking website run by Shaping Our Lives
- the National Centre for Independent Living
- Disability LIB
- your Deputy Regional Director.
What do I do next? Moving forward on the ULO journey

This section describes four different scenarios which each represent key stages on the journey to having effective ULOs in your area. The scenarios also outline some of the key interventions you can make to help move further along the journey. Note that this feature contains typical examples you might find in each scenario. There are no steadfast rules about the development of ULOs. This means that a single area, or single ULO, is unlikely to conform to each description. It should also be noted that the journey from having a few committed individuals to having two or more well established ULOs will not always be straightforward or linear.

For more ideas on moving forward on your ULO journey, take a look at the ‘Further resources’ later in this guide. You can also explore the National Centre for Independent Living’s resources by visiting [www.ncil.org.uk](http://www.ncil.org.uk) and clicking on ‘ULO resources’.

<table>
<thead>
<tr>
<th>Number of ULOs</th>
<th>Scenario 1</th>
<th>Scenario 2</th>
<th>Scenario 3</th>
<th>Scenario 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>There is a group of committed individuals or a ULO in the very early stages of development</td>
<td>There is one embryonic ULO that has been developing for some time but still has some way to go</td>
<td>There is a well established ULO that has been around for many years</td>
<td>There are two or more well established, well networked ULOs</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Governance</th>
<th>Meets all ULO design criteria?</th>
<th>No</th>
<th>Some</th>
<th>Nearly all or all</th>
<th>Typically all</th>
</tr>
</thead>
<tbody>
<tr>
<td>Governance arrangements in place?</td>
<td>No</td>
<td>No – but emerging</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Management</td>
<td>No</td>
<td>Not typically – but</td>
<td>Yes</td>
<td>Yes –</td>
<td></td>
</tr>
<tr>
<td>Scenario 1</td>
<td>Scenario 2</td>
<td>Scenario 3</td>
<td>Scenario 4</td>
<td></td>
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<tr>
<td>------------</td>
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<td>------------</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>committee?</td>
<td>emerging</td>
<td></td>
<td>effective committee, typically engaged in effective partnership arrangements</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Funding and business-readiness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Established for how long?</td>
<td>Typically less than 6 months</td>
<td>Typically 6 months to 3 years</td>
<td>Typically 3 years or more</td>
<td>Typically 3 years or more</td>
<td></td>
</tr>
<tr>
<td>Permanent staff?</td>
<td>No</td>
<td>No – maybe some part-time staff</td>
<td>Yes, including management</td>
<td>Yes, including management</td>
<td></td>
</tr>
<tr>
<td>Infrastructure in place (e.g. IT, HR, finance, premises)?</td>
<td>No</td>
<td>No – though some small elements in place (e.g. dedicated computers, some HR policies, hosted in building owned by public or civil society organisation)</td>
<td>Typically yes</td>
<td>Yes – these may be shared</td>
<td></td>
</tr>
<tr>
<td>Business plan in place?</td>
<td>No</td>
<td>Possibly</td>
<td>Typically yes</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Funding arrangements?</td>
<td>No or little funding</td>
<td>-- Small or medium core grant from commissioner -- Possible small grant from a funding body</td>
<td>-- Core grant from commissioner -- Reasonable grant from funding body -- Small contract for some services -- Some self-generated income (for example, from training, access audits and so on)</td>
<td>-- Core grant from commissioner -- Funding from external funders -- One or more contracts -- Self-generated income</td>
<td></td>
</tr>
<tr>
<td>Provides more than one service?</td>
<td>No</td>
<td>No</td>
<td>Possibly</td>
<td>Usually</td>
<td></td>
</tr>
<tr>
<td>Provides</td>
<td>No</td>
<td>No</td>
<td>Possibly</td>
<td>Usually</td>
<td></td>
</tr>
<tr>
<td>Scenario 1</td>
<td>Scenario 2</td>
<td>Scenario 3</td>
<td>Scenario 4</td>
<td></td>
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<td>------------</td>
<td>------------</td>
<td>------------</td>
<td>------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>services in more than one area?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>User engagement</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Covers all social care user groups</td>
<td>No (but possible)</td>
<td>No (but possible)</td>
<td>Sometimes</td>
<td>Typically yes</td>
<td></td>
</tr>
<tr>
<td>Members?</td>
<td>No – typically a group of committed individuals</td>
<td>Not formally – usually a group of many interested people</td>
<td>Yes, as per governing document</td>
<td>Yes, and membership can be large</td>
<td></td>
</tr>
<tr>
<td>Effective mechanisms for engaging service users?</td>
<td>Yes – but on a micro scale</td>
<td>Yes – but tends to be on a micro scale</td>
<td>Typically yes – though not always across all social care user groups</td>
<td>Yes – the approach will typically be joined up</td>
<td></td>
</tr>
<tr>
<td>Networking?</td>
<td>No relationships with other ULOs, BME / LGBT / carers / older people / civil society organisations or wider than social care</td>
<td>Doesn’t typically have relationships with other ULOs, BME / LGBT / carers / older people / civil society organisation s or wider than social care</td>
<td>Could possibly have relationships with other ULOs, BME / LGBT / carers / older people / civil society organisations or wider than social care</td>
<td>Has good relationships with other ULOs, BME / LGBT / carers / older people / civil society organisations or wider than social care. This is the key factor in Scenario 4.</td>
<td></td>
</tr>
<tr>
<td><strong>Essential actions to move to next stop on the ‘ULO journey’</strong></td>
<td>Support individuals – through providing meeting spaces and their travel / PA costs – to meet and explore their ideas -- Provide administrative support to</td>
<td>Identify key areas of work that the emerging ULO can undertake uniquely, and fund it to do these -- Provide as much infrastructure support for as little as possible -- Provide core-grant to the emerging ULO, aligned to</td>
<td>Encourage the ULO to bid for larger local services under contract (for example, direct payments/personal budgets information) -- Share contact details of the ULO with as many service users as possible</td>
<td>Facilitate networking between existing ULOs, including any newly emerging ULOs -- Request established ULOs provide mentoring</td>
<td></td>
</tr>
<tr>
<td>Scenario 1</td>
<td>Scenario 2</td>
<td>Scenario 3</td>
<td>Scenario 4</td>
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</tr>
<tr>
<td>set up more formal governance arrangements</td>
<td>outcomes of a robust business plan</td>
<td>-- Ensure ULO representatives have appropriate opportunities to represent their members / users at commissioner meetings</td>
<td>support to emerging and embryonic ULOs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-- Provide pump-priming to enable dedicated staff to take forward key strands of work</td>
<td>-- Support external ULOs to provide expert advice and mentoring</td>
<td>-- Commission other services from the ULO (for example, training, access audits) on appropriate basis</td>
<td>-- Encourage joint working across social care and health</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-- Ensure your approach is based on flexibility and open dialogue so that the emerging ULO suits local circumstances</td>
<td>-- Ensure your role is one of facilitator: ULO members must be firmly in control</td>
<td>-- Research whether there are any groups that fit scenario one, and encourage these to network with the established ULO</td>
<td>-- Share contact details of the ULOs widely</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>-- Consider releasing local authority staff (who have a strong understanding of the unique value of ULOs) on secondment, and employing service users in ULOs on local authority contracts</td>
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</tr>
</tbody>
</table>
How do I overcome problems? Challenges faced along the way

This section will help you to understand some of the difficulties that ULOs face in becoming strong and sustainable organisations. It also explains the key things that you can do to address those difficulties.

Key messages

- ULOs face a number of barriers including limited income, lack of resources and business acumen, and exclusion from tendering processes
- commissioners can play a vital role in overcoming these barriers by facilitating the development of ULOs in a number of practical ways
- one of the most useful things commissioners can do is to reserve contracts for ULOs, using European legislation and Treasury guidance to support this decision.

‘ADASS, LGA, and NCIL continue to recommend to local authorities that they support the development and expansion of local, user-led support services.’

Recommendation from the Joint Protocol between the NCIL, ADASS and the LGA
What are the barriers for ULOs?

ULOs are usually small organisations that have similar problems to other locally based small organisations in the civil society. They can have difficulties in attracting long-term finance that covers their core running costs, and can struggle to find enough volunteers to keep the organisation running.

Research from the University of Leeds School of Disability Studies (Barnes and Mercer 2006), the National Centre for Independent Living (2005) and Maynard-Campbell on behalf of the Department of Health (2006) has identified six barriers that are particularly associated with ULOs.

**Limited income**
Where ULOs lack income they can become inward looking as they desperately try to maintain their core service. This can result in an unwillingness to work with other organisations.

**Lack of resources**
A lack of resources more generally can foster an intensive competitiveness even with other ULOs in the locality or region. The focus is then on survival rather than working to a longer-term strategy.

**Lack of business acumen**
By their very nature ULOs are often run by people who have been excluded from areas such as employment. This means their opportunities for skill development have often been limited.

**Exclusion from other parts of the civil society**
Parts of the civil society whose remit is development and training, such as councils for voluntary service, are not necessarily good at reaching out to ULOs. This can mean that
ULOIs are excluded from programmes such as mainstream organisation development and capacity building.

**Tendering processes favour large firms**
Much tendering and contracting by statutory agencies favours large organisations with the specialist resources to respond to tenders. Large organisations can also offer savings through the economies of scale.

**Lack of value of what ULOIs do**
ULOIs can find that the unique support that they offer to service users is not valued locally.

**Other barriers include ...**
There are a number of additional barriers that many ULOIs face, including:
- local authority lacks confidence in ULOIs
- local authority lacks will, or tokenism
- local authority and others use inaccessible information and language
- local authority focuses on the outcomes of user involvement, rather than the process
- lack of user representatives on decision-making bodies, including local authority recruitment panels
- lack of infrastructure such as premises and office equipment
- lack of clarity in contracting processes.
What commissioners can do to overcome barriers

There are many ways in which commissioners can support ULOs to overcome the barriers facing them. Remember that good procurement is not just about low prices – it is about balancing whole life cost and meeting social objectives. It is also important to be sensitive to local contexts and cultures, and realistic in your expectations of newly developing ULOs.

Make sure ULOs have access to skills and expertise
You can do this by encouraging umbrella civil society organisations to reach out to ULOs so that they are included in training programmes. You can signpost ULOs to other training opportunities or organisations that can assist in their development. For some ideas of where to signpost ULOs to, see ‘Useful resources’ in the further resources section of this guide.

Work with ULOs to develop their capacity
This can be done by ‘pump priming’, or partnership working arrangements. Provide seed funding where no ULO exists. Consider releasing local authority staff (who have a strong understanding of the added value of ULOs) on secondment, and employing service users in ULOs on local authority contracts.

Encourage mentoring of small or new ULOs
This can be provided by larger, more established ULOs. To learn more about successful mentoring, see the good practice video on developing a new ULO.

Recognise the added value of ULOs
The value base of ULOs comes from the shared lived experiences of service users. This makes them more sensitive to the needs and views of local service users. Local authority champions can be crucial in promoting understanding of, and confidence in, ULOs. For more information see ‘The added value of ULOs’ earlier in this guide.
Work with ULOs wherever possible
Reach out to local ULOs, getting to know what organisations exist in your area and how they can be involved in the work of the local authority. Tackle local fears that ULOs are not capable of delivering services, and work with ULOs to develop their capacity for service delivery and development.

Review the contracting process: reserving contracts for ULOs
Commissioners should consider Article 19 of the EU Public Contracts Directive. In most ULOs, disabled people make up over 50 per cent of the workforce, which means the organisation is considered a ‘supported business’. Treasury guidance says commissioners should have at least one contract with a supported business. Given this, commissioners can:

- reserve appropriate contracts for supported businesses
- only invite tenders from supported businesses to bid for the work
- for contracts under £144K invite the supported business to bid or offer them the chance to match your best price
- for larger contracts, simply tick the ‘reserved under Article 19’ box.

For more detailed guidance on what commissioners can do, please download our pdf, available in the online version of this guide.
Solutions checklist

By now, you should be familiar with the typical barriers that ULOs face in becoming strong and sustainable organisations, and the things that you – as a commissioner – can do to overcome them. In this section, you will find a quick overview of the common problems. For each one, some possible solutions for both ULOs and commissioners to consider are suggested. You can dip in and out of this section as new areas for development arise. For example, if you have identified strong ULOs in your area but find that they are not well networked, you can go to the section on user engagement and look up ‘relationships with existing or other ULOs’.

<table>
<thead>
<tr>
<th>Issue</th>
<th>Possible solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Governance</td>
<td></td>
</tr>
<tr>
<td>Appropriate governance arrangements</td>
<td>• offer legal input to the ULO to develop governance arrangements • support a visit by the Charity Commission or infrastructure organisation (for example, CVS, NCVO) to develop governance arrangements. Also, see support offered by the ODI and Disability LIB in the ‘useful resources’ of the further resources section</td>
</tr>
<tr>
<td>Management Board effectiveness</td>
<td>• support a SWOT/skills audit of the management board • commission support from another ULO to develop and strengthen the management committee</td>
</tr>
<tr>
<td>Funding and business-readiness</td>
<td></td>
</tr>
<tr>
<td>Low staffing levels</td>
<td>• provide administrative support to the ULO to enable existing staff to focus on delivery • provide pump-priming funding or core grant to support appropriate staffing levels in the short- to medium-term • release public body staff on secondment to support time-bound projects or development, ensuring that those staff members have a strong understanding of ULOs</td>
</tr>
<tr>
<td>Lack of infrastructure (e.g. IT, HR policies)</td>
<td>• offer secondhand equipment/furniture and so on to the ULO for free or reduced rates • share model policies and procedures on HR for the</td>
</tr>
</tbody>
</table>
| Lack of accessible premises | • host the ULO in an existing public body building at peppercorn rates
• encourage existing local infrastructure organisations (for example, CVS or volunteer bureau) to host the ULO |
| Lack of robust business plan | • provide project and business management support/expertise to support the ULO
• set out clear commissioning objectives for 1-3 years to enable the ULO’s business plan to focus on these alongside other areas of work |
| Not operating on Full Cost Recovery basis | • commissioners recognise overheads and so on in bids and contract responses
• commissioners fund overhead elements through core grants or provide overhead support at peppercorn rates |
| Lack of sustainable and/or diverse funding streams (or funding is solely from the local authority) | • act as a reference to ULO bids to other funding streams
• support ULO to attend funding conferences/events
• provide bid-writing support through public body funding team/officers
• provide clear and accessible information and timescales for commissioner decision-making processes for annual funding |
| Understanding of commissioning arrangements | • commissioner takes time to discuss political, financial and legal environment within which commissioning takes place
• commissioner observes principles of the Compact in terms of procurement processes (for example, due notice)
• allocate a ULO champion within the local authority to act as the main point of contact for all local ULOs
• encourage umbrella civil society infrastructure organisations to support ULOs and ensure they have access to relevant training |
| Understanding of the wider operating context of local authorities (for example, performance indicators, LAAs, CAAs, local partnerships) | • enable ULOs to take part in the statutory decision-making processes
• provide accessible information to ULOs on the key targets for the local area, and how they can contribute to them |
| Appropriate performance management | • allow ULO managers to take part in commissioner-run management training/development programmes |
| Demonstrating impact | • commissioner provides support to the ULO to demonstrate its impact through its own performance monitoring arrangements  
• commissioner provides shared access to monitoring systems, rather than duplicating across organisation boundaries  
• commissioner requires consistent information from the ULO, and does not change monitoring requirements each reporting period  
• commissioner requests ‘new’ information, not that which it already holds |
| User engagement | • the local authority is clear in its relationships with ULOs and vice versa so there is a shared level of understanding  
• there is a set of principles in place that both organisations can sign up to  
• local authorities respect the right of the ULO to represent its members on issues of importance to them  
• lead political member with relevant portfolio aware of arrangements and accessible to ULO if needed |
| Balancing campaigning activities with service delivery | • encourage partnership working between ULOs with different impairment or social care service user specialisms  
• share contact details of key individuals working in or across different social care user groups  
• support training for specialist ULOs on different social care user groups, provided by ULOs who specialise in that social care user group |
| Working across all social care user groups | • encourage partnership working between ULOs with different equality specialisms  
• share contact details of key individuals working in or across different equality strands  
• support training for the ULO on the equality groups in question, provided by ULOs who specialise in that equality strand |
| Working across all equality strands | • encourage partnership working or mentoring arrangements between ULOs, including ULOs in other areas  
• share contact details of key individuals working in or across different organisations |
| Relationships with existing or other ULOs | • encourage partnership working or mentoring arrangements between ULOs, including ULOs in other areas  
• share contact details of key individuals working in or across different organisations |
| Relationships with other civil society organisations (for example, carers, BME groups, LGBT groups) | • encourage partnership working or mentor arrangements between ULOs  
• share contact details of key individuals working in or across different organisations |
**Good practice videos**

On the website you can watch two videos of real-world examples. The first example is about developing a new ULO, and the second is about strengthening relationships among existing ULOs.

**Key messages**

- when developing a ULO, all participants need to work in partnership, with users setting the agenda
- ULOs need a robust organisational foundation, and should invest in networking and marketing
- commissioners need to champion and facilitate ULOs, and support capacity building
- honest dialogue between ULOs and the local authority is essential to establishing a successful working relationship
- ULOs can promote wider user involvement, and this involvement must be genuinely valued by the local authority.
Good practice video: Developing a new ULO

This section tells the story of a new ULO in Tamworth, Staffordshire, developed in partnership with the local authority commissioners, a ULO from a neighbouring area and local service users.

The MAP story
In 2009 local authority commissioners from Tamworth in Staffordshire partnered with a long-standing ULO from a neighbouring area (Disability Solutions) and local service users to develop a new ULO from scratch: Mercian Ability Partnership or MAP. Disability Solutions offered MAP advice and expertise, while the commissioners helped MAP to access the support, premises and funding it needed.

MAP’s aim is to be a ‘one-stop-shop’ offering advice, information, services and representation for disabled people of all ages, from all social care user groups, and their carers. The organisation has come a long way in a short space of time, and now believes it is uniquely placed to provide what people really need, not what local service providers/commissioners think they need.

On their journey, the MAP team learned much that is relevant to all commissioners needing to develop a ULO from scratch.

Participants need to work in partnership, with users setting the agenda
Crucial to MAP’s success was strong partnership working from the beginning, and building trust with service providers as well as local service users. It was particularly important that the ULO wasn’t seen as part of the local authority by local service users.

With MAP, local service users set the agenda. This gave the ULO the independence it needed to truly reflect the needs of people in the local area.
Commissioners need to champion, facilitate and support ULOs
Commissioners struck a balance between facilitation and support, enabling the ULO to be both strong and independent. Commissioners championed the group, giving it a legitimacy and presence within the local authority.

ULOs need robust organisational foundations
It was vital that the ULO was established as a viable business from the very start. This meant: developing sound policies, procedures and governance structures; developing a robust Quality Assurance system; including funding for training in bids; having secure premises; and focussing on networking.

Having a dedicated, full-time development worker with the skills to manage a new organisation was crucial in successfully delivering milestones. It was important that staff were well supported: they needed time, support and training to develop new skills.

MAP found the experience, knowledge, advice and support of the mentor organisation crucial to its development. For more information on mentoring see the National Centre for Independent Living resources.

Be realistic with milestones and achievements
The milestones and timescales were unrealistic. Everyone involved now agrees that any new ULO must be given adequate time to develop: this means developing over two to three years, not one.

ULOs should invest in networking and marketing
With support from commissioners, MAP networked with other civil society organisations so that the work of each was not repeated, and relationships were supportive.
Having a high-profile launch event attended by well known dignitaries and local service users was seen as vital in getting the group known. Celebrating milestones and achievements was also important in boosting morale and raising the profile of the group.

MAP and the other partners constantly took advantage of opportunities to market the new group and raise awareness of its existence. The group has a dedicated marketing budget.
**Good practice video: Strengthening ULOs’ relationships**

This section tells the story of the Personalisation Expert Panel (or PEP) in Hampshire, where commissioners and ULOs developed a successful approach to developing personalisation plans, strengthening ULOs, improving networking among ULOs, and enabling a dialogue between users, carers and the local authority.

**The story of the PEP**

Hampshire is a large county covering both urban and rural areas. It has some substantial ULOs that have a long association with the local authority. One of the biggest, Southampton Centre for Independent Living (SCIL), celebrated its 25th birthday in 2009. SCIL works closely with many other ULOs, such as Hampshire Centre for Independent Living (HCIL), and also worked with Hampshire County Council (HCC) to set up the Personalisation Expert Panel or PEP.

The PEP brings together a wide range of user- and carer-led organisations with the county’s senior social services managers. Its main purpose is to develop plans for personalisation. But it also provides a way for ULOs to network with one another while also enabling a dialogue to take place between users, carers and the local authority. The PEP is funded by HCC and facilitated by SCIL, who co-chair the group with HCIL and set the agenda for the group. The PEP’s members see the group as being a long-term consultative platform to allow the voice of disabled people in the area to be heard by the local authority and integrated into its work.

The learning that has occurred in Hampshire is relevant to all commissioners who are seeking ways of strengthening both ULOs and their relationship with the local authority.
Key learning points

Local authorities and ULOs need to learn to work together
Commissioners need to respect the autonomy of ULOs, particularly when funding them and hearing opinions that don't necessarily align with their own. There will be disagreements, and all partners need to put in effort to make the relationship work. Fundamental to this is open dialogue and being able to challenge one another.

The PEP in Hampshire is run and controlled by the ULOs and this ensures that users and carers can keep the focus on what is important for them. Over time, the PEP is becoming more influential. The PEP has clear terms of reference that outline what the group can and cannot do. To enable this, it was important that the local authority was honest and upfront about what could and could not be changed. The local authority also clearly explains why things can’t happen if they are not taken forward, and how the group is influencing the strategic direction of the local authority.

Local authorities should help ULOs build capacity
In Hampshire’s case, the hosting ULO has a strong infrastructure so it was easy for them to accommodate the work of the PEP within their existing structures. Local authorities need to help capacity build all ULOs to work effectively, and in Hampshire one of the ways in which they have tried to do this is through having a dedicated Engagement Commissioner whose role is to capacity build the ULOs across the county and act as a ‘communicator’ between them and her colleagues in the local authority. As part of her role, she has established a good practice forum across the south-east on involvement.

The involvement of users and carers should be valued
Users and carers are paid their time and expenses for taking part in the PEP. The PEP’s position is to work with those who have something to offer and not to burden
those who don’t want to work with the PEP, but to keep them informed. The PEP is a vehicle to enable wider networking among users, carers and local authority managers to allow true co-production to start to happen.

**ULO can promote wider user involvement**

Those involved in the PEP are enthusiastic about its potential to be a major influence around promoting inclusion for disabled people. At the same time, they recognise that the PEP isn’t the sole mechanism for user involvement. Part of the value of the PEP is that it can connect to wider groups of people who might like to get more involved in other ways and drive any user involvement strategy. The PEP provides a means for new and emerging groups to gain the support and expertise of existing ULOs.
Further resources

Where can I get further advice?

For further support and advice on developing and sustaining ULOs, contact your local regional ULO or TASC lead, or your local Deputy Regional Director. Further advice and support is also available from ADASS and the National Centre for Independent Living (see websites for details).

Useful websites

www.dh.gov.uk/en/SocialCare/Socialcarereform/Userledorganisations/index.htm: Use this link to explore Department of Health archived pages relating to ULOs. For the 21 design criteria go to the Department of Health’s website at www.dh.gov.uk and search under ‘policy and guidance’.

www.solnetwork.org.uk: This is a networking website for ULOs, and can help commissioners and others find out what ULOs are doing in their area.

www.tasc.org.uk/content.asp?contentid=6: Search for ‘supporting user-led organisations to learn more about the links to transforming adult social care.

http://www.disability-archive.leeds.ac.uk/: This is an archive of writings on disability, particularly that of disability activists.

www.disabilitylib.org.uk: Disability LIB’s website has lots of useful information, including an interactive map showing disabled people’s organisations. See Disability LIB’s Pilotlight scheme (below) for more information about the support available for Disabled Peoples’ Organisations.

www.capacitybuilders.org.uk: This website offers advice and support to civil society organisations. See ODI’s improving support scheme (below) for more information about the specific support available for Disabled Peoples’ Organisations.

Useful resources

East Sussex User-led organisations support pack

The User-led organisations support pack is designed to help voluntary and community organisations to put service users and carers at the centre of what they do. Evidence suggests that the more an organisation is led and owned by the people
that use it, the more likely it is that it will deliver services that are useful and wanted and which help people to achieve their goals in life - a principle that underpins personalisation.

Funded by the Department of Health and produced by East Sussex Disability Association and East Sussex Adult Social Care, in partnership with a team of service user and carer experts, the support pack contains useful tips, templates and advice on how to make your organisation genuinely user led. To download the pack, visit www.eastsussex.gov.uk

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**Developing and sustaining ULO resources**

The National Centre for Independent Living have an area of their website dedicated to sharing information and learning about developing and sustaining user led organisations. You will find lots of useful resources collated under the following headings: management and governance; models of ULOs; finance and quality; service delivery; and equality, diversity and human rights. Go to (www.ncil.org.uk) and click on ULO resources.

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**Youtube short videos**

The Essex Coalition of Disabled People (www.ecdp.org.uk) have produced three videos on developing and strengthening ULOs which you can access using the links below:

- Mentoring: (http://www.youtube.com/watch?v=P9OfFh0l3io)
- Sustainability: (http://www.youtube.com/watch?v=gla8j4j7FJA)
- Engagement (http://www.youtube.com/watch?v=ce8cTjjee4)

The following Department of Health videos are also available via youtube:

- Engagement in a rural area: (http://www.youtube.com/watch?v=7miD38MNUGQ)
- Working with other ULOs: (http://www.youtube.com/watch?v=Tg1no-NbiSk)
- Diversifying and reaching out: (http://www.youtube.com/watch?v=iVQPK8gL7TQ)
Reaching out to seldom heard users: (http://www.youtube.com/watch?v=iPcdRgsez1s)

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Example study day: commissioning for and with ULOs

As part of the Eastern Region Development Programme, Norfolk County Council commissioned the Essex Coalition of Disabled People together with the Norfolk Coalition of Disabled People to deliver a study day for local commissioners. The day’s learning focussed on discussing and sharing good practice, and learning from past barriers and solutions. For more information on the day, you can contact Dr Angela Sweeney on angela.sweeney@scie.org.uk

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Support for new and emerging disabled peoples’ organisations

Disability LIB’s Pilotlight scheme

Disability LIB offer free training, advice and resources to Disabled Peoples’ Organisations including business planning, consortia building, fundraising, leadership and inclusion. As part of its work Disability LIB offers access to business coaching and mentoring through Pilotlight. For more information go to http://www.pilotlight.org.uk

ODI’s Improving Support scheme

The Office for Disability Issues and Disability Association Carlisle & Eden have joined forces to establish a disability ‘portal’. The portal is a dedicated page on the Improving Support website through which disability organisations (and interested others) can search for and share information and news, publicise events, use it to find out what others in their locality or region are doing, and to help build an archive of useful tools and resources available to colleagues throughout the country. Visit (www.improvingsupport.org.uk/disability)

West Berkshire’s experiences of developing a new ULO

This presentation describes West Berkshire’s approach to developing a ULO. Commissioners brought together existing local activists from a range of specific
disability groups. They reached a shared understanding on the need for a central network, together with agreed priorities for further action to directly benefit users of care services. Together, commissioners and service users obtained a grant from the Department of Health South East as a demonstrator site. For more information please contact Nigel Owen on nowen@westberks.gov.uk

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References


**Further reading**


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*, London: National Centre for Independent Living. ([http://www.ncil.org.uk/categoryid20.html](http://www.ncil.org.uk/categoryid20.html))


