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.

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SCIE works to:

- disseminate knowledge-based good practice guidance

- involve people who use services, carers, practitioners, providers and policy makers in advancing and promoting good practice in social care

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

**This report is available online
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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, underpinned by practice and evidence, 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 (2005) made the original recommendation that '*each locality should have a user-led organisation*' (recommendation 4.3, *Improving the life chances of disabled people*). As part of the Putting People First agenda milestones (in effect until March 2010), local authority commissioners were to make sure they have worked to develop and sustain ULOs by **December 2010**. This was captured in the Department of Health's Local Authority Circular no.1 (2008) as follows: 'Where user led organisations do not exist, a strategy to foster, stimulate and develop these locally should be developed'. This intent has since been reaffirmed in the publication of the Care and Support White Paper: *A vision for adult social care: capable communities and active citizens* and other policy documents, as well as in the creation of a dedicated programme to support and strengthening User-Led Organisations at the Office for Disability Issues.

The original guidance from SCIE helped commissioners to meet this policy requirement. This updated guidance reflects updated policy, practice and evidence regarding ULOs and:

- explains the **benefits** of commissioners developing and sustaining ULOs in their local area
- provides **background information** and **evidence** about ULOs
- offers **practical advice** for developing and strengthening ULOs
- gives details of **resources** that can help.

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.

- There is no fixed definition of a ULO, but they all have common characteristics through their *values*, *power* and *knowledge.*

- 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 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 people who use services 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, people who use mental health services, people with learning disabilities, 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.

More recently, the Office for Disability Issues has used the following definition that is more explicit about the centrality of disabled people in user-led organisations, as part of its dedicated programme to support and strengthening ULOs. It defines ULO as those organisations that:

- are led and controlled by disabled people and have a minimum membership of 75 per cent of disabled people on their board

- actively demonstrate their commitment to disabled people by employing disabled staff and volunteers

- actively demonstrate their commitment to the Social Model of Disability.

In this case, such organisations are referred to as disabled people's user-led organisations (DPULO).

The name 'ULO' or 'DPULO' and who they do or do not explicitly include is not without debate. For example, Shaping Our Lives, the national user network, prefer the term 'user-controlled organisation' as this more accurately describes the power that people who use services hold within the organisation.

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, people who use services 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.

There are other names that people use to describe different types of organisation, which are summarised below. It is important to note that each name means a different way in which the organisation is run and controlled. As such, the term ULO and those below shouldn't be used interchangeably.

- Disabled people's organisation (DPO) – This is an organisation *for* disabled people. The key distinction here is that, though the DPO may work on behalf of disabled people, it may not necessarily be controlled or run by them.

- Disabled and D/deaf people's organisation (DDPO) – This is an organisation possibly of and/or for disabled people that explicitly includes D/deaf people.

As well as this, it is worth remembering that the 'ULO' and 'DPULO' do not necessarily mean the same thing. Through this document, we use the term ULO.

The Department of Health's 21 ULO design criteria

The Department of Health 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 **values** 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. The independent living section of the Disability Rights UK website has further information.

- how a ULO is **governed** and managed (for example, that 75 per cent of the members of the management committee are people who use services).

- the sorts of **services** ULOs provide (such as advocacy and peer support).

It is broadly recognised that the 21 ULO design criteria are a useful guide to the sorts of characteristics a ULO should exhibit, but they are not considered a prescriptive list.

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. To achieve this, all ULOs – be they new and emerging or well established – need to strive to include:

- all impairment or social care service user groups (including learning disabilities, 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 people who use services

- carers.

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, and personal health budgets

- support to recruit and employ personal assistants

- support with recovery and rehabilitation

- assistance with self-assessment, support planning and care reviews

- 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 formal relationships it has with statutory agencies (including contracts, service level agreements or grants). Some ULOs undertake additional activities not listed above, for example, welfare/benefits advice, access auditing and housing advice.

How many ULOs are there?

A DH study initially identified 647 potential ULOs across England in 2006/2007. However, a follow-up ULO baseline study carried out for the DH in 2009 found there are only 66 established ULOs that met the 21 design criteria and 64 local authorities have no ULOs at all. The discrepancies between these pieces of research were partly explained by the fact the research was based on self-assessment and a lack of familiarity with the design criteria amongst respondents, making it difficult to obtain an accurate or consistent measure.

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 for Social Care in the DH, a the DH carried out a further study in 2010. This estimated that there were around 150 ULOs in England, though not evenly distributed across all local authorities (for example, some had more than one and some still had none).

The most recent data on the number of user-led organisations at time of publication (April 2013) came from the ongoing work of the dedicated ULO programme at the Office for Disability Issues. This has details for around 340 ULOs.

What work has been done to build the capacity of ULOs?

There has been a range of activity to build the capacity of ULOs, particularly in order to enable them to support the transformation of adult social care.

The DH's Disabled People's/User-Led Organisation (DPULO) Development Fund ran from 2008 to 2010 and supported 25 ULOs. This work was driven by the ULOs involved and created many learning products, the best of which are summarised **here**.

Alongside the ULO Development Fund, the DH and ODI also undertook some ULO capacity building work through the regions, channelling support through the Deputy Regional Directors for Social Care. In 2009/10 each region was allocated resources to try to ensure there was a ULO in each local authority in each region, and to support coproduction more widely.

As well as this work by central and regional government, the disability sector itself has looked to build the capacity of ULOs. Disability LIB ('Listen. Include. Build.') was a partnership of several disability organisations funded from 2008 until 2011 by the Big Lottery Fund. The partnership provided ULOs with capacity building information, advice and support to enable them to be more effective in their activities. Some of the resources developed by this project remain available **online**.

Since July 2011, the Office for Disability Issues (ODI) has run the Strengthening User-Led Organisations (DPULOs) Programme. The programme is a £3 million investment over four years that will aim to promote growth and improve the sustainability of DPULOs.

A brief history of ULOs

While ULOs may seem like a recent phenomenon, 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 emphasized rights and citizenship, which in turn helped people who use services 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 1970s 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 with the introduction of the Community Care (Direct Payments) Act 1996, and particularly since the development of personal budgets (since 2006 onwards, starting with the pilots sites work between 2006-8), ULOs have become more inclusive of all people who use services. However, some ULOs continue to represent single impairment groups, such as groups for people with learning disabilities. These groups often focus on networking with other disability organisations in the first instance, but are increasingly expanding their membership to other social care user groups.

A useful history of ULOs can be found in Disability LIB's publication, 'Thriving or surviving: challenges for [user-led organisations] in the 21st century".

'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 values 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 people who use mental health services and survivors believe that the knowledge of people who use services 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 people who use mental health services/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 and very often have their own, specific organisations. Some are user-led organisations, but this varies considerably and cannot typically be assumed. Examples of such organisations include:

- local branches of Age UK
- A National Voice: an organisation run by and for young people who are in or have experienced care
- User Voices: an organisation run by people who have experienced the criminal justice system
- National Pensioners' Convention: a campaigning organisation run by and for pensioners
- the Multiple Sclerosis Society or the Stroke Association.

Since 2010 and more recently, a new set of campaigning user-led organisations and networks run and controlled by disabled people have emerged. These include, for example:

- DPAC (Disabled People Against the Cuts)
- We Are Spartacus - Pat's Petition, subsequently the WOW Petition

ULOs 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?

ULOs 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 original design criteria and the definition used by the Office for Disability Issues, at least 75 per cent of the management committee should be people who use services.

Structure of ULOs

ULOs 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 people who use services 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 often 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
- social enterprise

It is also often the case that ULOs are not (yet) legally constituted organisations. A considerable number of ULOs would fall beneath the lower income threshold of £25,000 used by the Charity Commission to mean significantly reduced annual returns are required by the Commission.

Again it will depend on local conditions and the opinions of the people who use services involved. For more information on the legal forms of ULOs, see 'Different models for ULO organisations' produced by Choice & Rights Disability Coalition in Hull.

Equality and diversity

Ensuring inclusivity

Many ULOs have equality and diversity at the heart of their roles. They work to ensure that all sections of the community have the opportunity to have their voice heard and be involved in the ULO. This means striving to include:

- adults of any age

- black and minority ethnic communities
- lesbian, gay and bisexual and transgender people who use services

Some groups may also work to be inclusive of children and young people, though this can be a difficult area of work.

Many ULOs now aim to work all impairment or social care service user groups (including learning disabilities, long-term health conditions, mental health and physical and/or sensory impairments) but others may have a role with a specific impairment/user group.

Resourcing

To achieve a more inclusive agenda, ULOs need adequate resources so that they can reach out to the whole service user community and ensure their activities are accessible to all. 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 people who use services 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 people who use services 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 may be confusing. Because of this, we recommend that organisations made up mainly of people who use services are described as ULOs, and organisations made up mainly of carers are described as carer-led organisations.

Examples of ULOs

Below we introduce four 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.

What does it do? 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

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 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 people who use services, 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, email 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 adults who use mental health services in Leicestershire and Rutland.

Activities? The aim of the group is to ensure that people who use services 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 people who use services 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 people who use services to be 'your voice on mental health services'.

Interesting fact? We have 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

- ULOs are embedded in several areas of policy that local authority commissioners are putting into practice in their local areas.

- ULOs can help local authorities to meet broader policy requirements, such as disability hate crime, enhancing peer support, supporting disabled people into employment, and supporting reform of special educational needs.

- ULOs add value: they can help deliver effective services and commissioning, tackle social exclusion, and are based on the authentic voices of people who use services.

Policy drivers

A number of documents form the policy framework for the role of user-led organisations within policy.

The key document that launched the renewed interest in user-led organisations under the previous government was the 'Improving life chances of disabled people' report by the Prime Minister's Strategy Unit (2005). Recommendation 4.3 said that there should be a ULO in every local authority area with social care responsibility, modelled on existing centres for independent living (CILs).

Putting people first (the 2007 joint statement by a range of key social care stakeholders) 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 were therefore 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 jointly agreed five milestones against which local authorities were to be judged on their progress on the transformation of adult social care. Milestone one included having effective partnerships with people who use services, carers and other local citizens. This was measured by every council area has at least one user-led organisation directly contributing to the transformation of personal budgets.

This milestone was underpinned by a significant number of documents to support local authorities to achieve this milestone, including:

- **Department of Health (2008), User-Led Organisations**
- **Department of Health (2009), User-Led Organisations (ULO) Baseline Project**
- **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
- **Department of Health (2009), Putting People First: working together with user-led organisations**

Other organisations also contributed to this work, including:

- **At a glance 15: Personalisation briefing: Implications for user-led organisations** (SCIE)
- **Key Issues no.5: User-led organisations** (ripfa)

Since 2010, the role of user-led organisations specifically in supporting social care and health policy has been maintained. This role has been captured in *Caring for our future*, the social care White Paper, which states:

'Networks of support can often come from organisations led by people who use services and carers, which act as the voice of disabled people and carers, as well as delivering care and support. Last year we announced an investment of £3 million over four years that will aim to promote the growth of disabled people's user-led organisations…

New models of advice and support such as peer networks and user-led organisations could also help to bring different people together to purchase care and support collectively and make better use of their funding. Evidence shows that access to independent advice and support means that people are much more likely to take their care and support funding through a direct payment. This is, therefore, a core part of our ambition to maximise the control that people have over their care and support.'

This support has been captured in the work of the Think Local, Act Personal partnership – for example, in the Making it Real programme to support service providers to make progress towards personalisation

User-led organisations beyond social care

It is useful to note that ULOs – as civil society organisations run by and for their members and clients – contribute to other areas of public service reform. 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, ULOs are extremely well-placed to facilitate citizen contributions.

This role has been reflected in a variety of other policy settings, as outlined below:

- ULOs are central to the government's Disability Strategy, Fulfilling Potential (2012).

- ULOs are a key part of the Home Office's dedicated action plan for addressing hate crime: Challenge it, Report it, Stop it (2012).
- ULOs can enhance peer support in employment support, as recognised by the Department for Work and Pensions in its drive to get more disabled people into mainstream jobs through Access to Work.
- The Department for Education includes the role of user-led organisations in its plans for special educational needs and disability Green Paper.

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 people who use services.

A brief summary of the broad difference ULOs can make is outlined below.

ULOs can be a one-stop-shop

ULOs can act as a single point of contact and information for commissioners, service providers and local people who use services. 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 people who use services, and the impact of services in the local community – can help make local services and the commissioning cycle more effective.

ULOs can support personalisation

ULOs can support the implementation of personalisation by helping people who use services 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 people who use services, because it is based on direct experience. ULOs hold strong values that reflect local people who use services' views. They are uniquely placed to understand how local people who use services experience services and what they need. ULOs can also help commissioners reach seldom-heard people who use services.

ULOs can help to tackle social exclusion

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

representation on partnership boards. ULOs can help address health inequalities by supporting people who use services to access the support that they need (DH 2007).

The evidence of value added-by ULOs: user voice

User-led organisations have formal and informal mechanisms for representing the voice of disabled people locally.

Establishing an effective relationship with a ULO can enable more choice and control for users of care and support. Conflicts of all kinds arising from voice-based activity (of interest, of independence – for example campaigning and/or lobbying) are generally anticipated in theory but happen rarely in practice.

Representing user voice can be broken down into different elements: capturing views, aggregating views, analysing and synthesizing views and representing views.

ULOs can:

- coordinate user networks, which are an effective way of channeling user views on their local social care system
- coordinate coproduction and user engagement mechanisms to contribute to every part of the commissioning cycle: analyse, plan, do, review
- call upon their local community networks and partnerships to ensure all seldom-heard groups are reached
- play a role in quality assurance: they can capture intelligence on how the local social care market is operating in practice.

If ULOs also provide services, concerns about conflicts of interest rarely occur in practice. Indeed, ULOs can work constructively with local authorities to develop the changing social care market and landscape. Furthermore, ULOs can also harness the lived experience of disabled people to build and develop community capacity, for example in the form of peer support.

Evidence of effectiveness

- harnessing the voice of disabled people locally has both quantitative and qualitative benefits
- data from Department of Health on LINks (HealthWatch from 2013), which empower people in the community to have their say or influence local health and social care services, suggests savings of £4.10 for every £1 invested in LINks
- studies on community development which harness local community's social capital suggest this approach can save between £3 to £3.80 for every £1 invested
- community Navigator schemes save at least £900 per person engaged in the first year alone

- the user-led mental health Personalisation Forum Group is estimated to save some £250,000 per year through using users' social capital rather than only statutory services

- Demos reported that coproduction between ULOs and local authorities helped to mitigate or minimize effects of difficult decisions regarding budget changes and/or de-commissioning

- beyond social care, there is a higher incidence of reporting of disability hate crime where independent support services through ULOs exist

- An evaluation by the Scottish Government suggested coproduction of two local housing strategies in Scotland led to better outcomes for tenants and more efficient use of housing resources

The evidence of value added by ULOs: service delivery

ULOs typically have legitimacy and credibility from the perspective of both users and commissioners, and can provide a user-led contribution to all parts of the care and support process.

ULOs operate on both the supply- (i.e. service delivery / business) and demand- (i.e. user representation/voice) sides. They balance these roles to uniquely add value to the local social care economy (and beyond).

ULOs can deliver a range of services drawing on the lived experience of users. Such services typically support people to navigate the care and support system, rather than deliver services at the end. The offer of ULOs can include:

- information, advice and guidance

- supported self-assessment

- support planning

- brokerage

- (non-complex) supported reviews

- personal assistant recruitment and employment support

- training for employers and employees

- advocacy services.

ULOs are increasingly delivering services that people can purchase using personal budgets too, including:

- domiciliary care and support

- payroll services

- equipment services

- leisure services.

ULOs can also act as hubs for coordinating and managing user-led and wider voluntary and independent sector provision.

Beyond social care, ULOs also offer a wide range of services, including (but not limited to):

- welfare/benefits advice
- training, especially disability equality training
- access auditing
- third party reporting centres for hate crime
- alternative format translation.

Evidence of effectiveness

- choice and control in service delivery is an important aspect of the social care economy – valued both by users and government
- 89 per cent of people in an area who experienced user-led IAG secured a direct payment, compared to 13 per cent who used LA-led provision (from **ecdp**)
- **POET survey** and **ODI's Support, Advocacy and Brokerage** project both indicated people who had support from ULOs had better support for navigating the care and support system and that achieved better outcomes
- 100 per cent of people who used independent, user-led support planning service secured a direct payment and felt that they had more choice and control, compared to 17 per cent who used LA-led support planning (from **ecdp**)
- the **Charity Commission** reported that 59 per cent of people agree they trust charities more if they are providing services within their local community
- this support is also deliverable in crisis situations – a good example of this is Leeds User-Led Crisis Service http://www.lslcs.org.uk/
- evidence from **Right to Control Trailblazers** indicates that ULOs can help people to coordinate their care and support across different funding streams. This is partly because ULOs are more nimble in responding to user needs and are able to "join the dots up on the ground" across different (public) bodies.

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:
  - o The ULOs programme at the Office for Disability Issues has the most comprehensive and recent map of all ULOs in the country
  - o SOLNET: Shaping Our Lives runs a networking website, SOLNET, where you can look up groups in your area by region.
  - o Disability Rights UK: Disability Rights UK has a list of all its members organisations on its website
  - o UK Council of Disabled People has a list of its members on its website
- What groups are represented by local ULOs in your area?
  - o are all service user groups – 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 people who use services?
  - This information is vital. At least 50 per cent of the management committee of a ULO must be made up of people who use services, 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 people who use services, the group is not considered to be a ULO.
- How long has the organisation been operating?
  - 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?
  - 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?
  - 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?
  - 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?
  - 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?
  - 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?
  - 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?
  - 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?
  - 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?
  - 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?
  - 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?
  - 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?
  - For example, through providing training to other organisations, undertaking access audits, selling publications, its own membership arrangements, or providing research services

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?
  - 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 people who use services sit on different decision-making bodies?
  - 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 people who use services involved in your work? 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?
  - For example, is this coordinated by a Public Body Officer, or is it coordinated on your behalf by a ULO?

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    - 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.

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.

	Scenario 1	**Scenario 2**	**Scenario 3**	**Scenario 4**
Number of ULOs Governance Meets all ULO design criteria?	There is a group of committed individuals or a ULO in the very early stages of development No	There is one embryonic ULO that has been developing for some time but still has some way to go Some	There is a well established ULO that has been around for many years Nearly all or all	There are two or more well established, well networked ULOs Typically all
Governance arrangements in place?	No	No – but emerging	Yes	Yes
Management	No	Not typically – but	Yes	Yes –

	Scenario 1	Scenario 2	Scenario 3	Scenario 4
committee?		emerging		effective committee, typically engaged in effective partnership arrangements
Funding and business-readiness				
Established for how long?	Typically less than 6 months	Typically 6 months to 3 years	Typically 3 years or more	Typically 3 years or more
Permanent staff?	No	No – maybe some part-time staff	Yes, including management	Yes, including management
Infrastructure in place (e.g. IT, HR, finance, premises)?	No	No – though some small elements in place (e.g. dedicated computers, some HR policies, hosted in building owned by public or civil society organisation)	Typically yes	Yes – these may be shared
Business plan in place?	No	Possibly	Typically yes	Yes
Funding arrangements?	No or little funding	--Small or medium core grant from commissioner -- Possible small grant from a funding body	--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)	--Core grant from commissioner --Funding from external funders --One or more contracts -- Selfgenerated income
Provides more than one service?	No	No	Possibly	Usually
Provides	No	No	Possibly	Usually

	Scenario 1	Scenario 2	Scenario 3	Scenario 4
services in more than one area?				
User engagement				
Covers all social care user groups	No (but possible)	No (but possible)	Sometimes	Typically yes
Members?	No – typically a group of committed individuals	Not formally – usually a group of many interested people	Yes, as per governing document	Yes, and membership can be large
Effective mechanisms for engaging service users?	Yes – but on a micro scale	Yes – but tends to be on a micro scale	Typically yes – though not always across all social care user groups	Yes – the approach will typically be joined up
Networking?	No relationships with other ULOs, BME / LGBT / carers / older people / civil society organisations or wider than social care	Doesn't typically have relationships with other ULOs, BME / LGBT / carers / older people / civil society organisations or wider than social care	Could possibly have relationships with other ULOs, BME / LGBT / carers / older people / civil society organisations or wider than social care	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.
Essential actions to move to next stop on the 'ULO journey'	--Support individuals – through providing meeting spaces and their travel / PA costs – to meet and explore their ideas -- Provide administrative support to	--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	--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	--Facilitate networking between existing ULOs, including any newly emerging ULOs -- Request established ULOs provide mentoring

	Scenario 1	Scenario 2	Scenario 3	Scenario 4
	set up more formal governance arrangements --Provide pump-priming to enable dedicated staff to take forward key strands of work --Ensure your approach is based on flexibility and open dialogue so that the emerging ULO suits local circumstances	outcomes of a robust business plan --Support external ULOs to provide expert advice and mentoring -- Ensure your role is one of facilitator: ULO members must be firmly in control	--Ensure ULO representatives have appropriate opportunities to represent their members / users at commissioner meetings -- Commission other services from the ULO (for example, training, access audits) on appropriate basis --Research whether there are any groups that fit scenario one, and encourage these to network with the established ULO	support to emerging and embryonic ULOs -- Encourage joint working across social care and health -- Share contact details of the ULOs widely --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

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, 2009*

'Disabled people should have choice and independence in how they live their lives. User-Led Organisations play a vital role in making sure they have their voices heard at every level'

Maria Miller, the then Minister for Disabled People, DWP July 2011

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 ULOs 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 ULOs do

ULOs can find that the unique support that they offer to people who use services is not valued locally.

Other barriers include...

There are a number of additional barriers that many ULOs face, including:

- local authority lacks confidence in ULOs
- 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 people who use services 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 people who use services. This makes them more sensitive to the needs and views of local people who use services. 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.

Similarly, commissioners can use the Social Value Act to take account of social value when taking decisions about how to deliver public services. Social value means added economic, social or environmental benefits in delivering services, and ULOs are well placed to demonstrate this added social value during procurement processes

Enabling ULOs to support service user voice

To make the most out of any local ULO that exists, below are some effective options that are relatively easy to undertake to enable them to support service user voice:

- consider enabling ULOs to administer existing or new voice-based mechanisms in the local area, such as partnership boards or HealthWatch

- consider establishing or maintaining a partnership board/disabled people/user network for regular qualitative input on progress towards personalisation

- share contact details of local ULOs to every user of the social care system in the area

- consider establishing a strategic partnership with a ULO(s) in the area. One practical effect of such partnerships can include seconding staff to the ULO or having ULO staff shadow council staff

- broaden consideration of the role of ULOs so they focus on issues beyond social care, e.g. disability hate crime, employment, access to goods and services

- take advantage of developments and their associated funding in other policy areas, e.g. HealthWatch.

Enabling ULOs to support service delivery

To make the most out of any local ULO that exists, below are some effective options that are relatively easy to undertake to enable them to support local service delivery:

- assess current provision of different types of support service, especially those that could be provided by a ULO

- prioritise where ULOs can make the most valuable contribution to strategic priorities

- consider piloting ULO involvement in specific service development opportunities

- consider commissioning specifically from local providers only, particularly those in the voluntary sector or with specific expertise (such as ULOs)

- ensure tendering processes are accessible for ULOs

- use the agreed principles of the Local Compact to inform commissioning arrangements.

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'.

Issue possible solutions	
Governance	
Appropriate governance arrangements	• 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
Management Board effectiveness	• support a SWOT/skills audit of the management board • commission support from another ULO to develop and strengthen the management committee
Funding and business-readiness	
Low staffing levels	• 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
Lack of infrastructure (e.g. IT, HR policies)	• offer secondhand equipment/furniture and so on to the ULO for free or reduced rates • share model policies and procedures on HR for the ULO to adapt for its own purpose.

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 • share model policies and procedures on HR for ULO to adapt for its own purpose

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	
Balancing campaigning activities with service delivery	• 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
Working across all social care user groups	• 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 equality strands	• 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
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, BMEgroups, 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 co-production, 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 people who use services.

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 people who use services to develop a new ULO from scratch: Mercian Ability Partnership (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 people who use services. It was particularly important that the ULO wasn't seen as part of the local authority by local people who use services.

With MAP, local people who use services 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 people who use services 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 (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, now Spectrum Centre for

Independent Living), 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.

Note: Southampton Centre for Independent Living changed its name to Spectrum Centre for Independent Living in 2013.

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 their role, they have 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.

ULOs 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 the **Strengthening User-Led Organisations** programme at the Office for Disability Issues or on its **Facebook** page. This programme includes a dedicated £3m funding stream to support ULOs.

A full overview of ULOs, covering definitions, the number of ULOs, what ULOs do, the value they add, and evidence sources is available **here**.

Useful websites

Think Local, Act Personal has a section of its resources website dedicated to ULOs.

The **Shaping Our Lives Networking** website is for ULOs, and can help commissioners and others find out what ULOs are doing in their area.

Disability Archive UK lists writings on disability, particularly that of disability activists.

Disability LIB's website has lots of useful information which has been archived from the project.

Useful resources

Think Local, Act Personal: Best practice in direct payments support: a guide for commissioners

This discusses what best practice support for direct payments looks like, cost-effectiveness, and the implications of the current policy drive to increase uptake. It also presents a model of good practice for direct payments support, describing 10 key features of the model and, for each, statements about what success means, what is involved, and how to know whether it is working. Brief illustrative case studies are also included.

National Skills Academy ULOs resource

Compass Disability Services: Taking a user-led approach

A toolkit to inform organisations about the user-led model and enable them to take steps towards adopting a user-led approach.

Living Options Devon: Consortium toolkit for user led organisations

A toolkit to support user-led organisations to develop and work together in consortium arrangements.

East Sussex User-led organisations support pack

The *User-led organisations support pack* is designed to help voluntary and community organisations to put people who use services 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 **East Sussex County Council**.

Support, Advocacy and Brokerage projects: how resources can be transferred from traditional care management systems to user-led support, advocacy and brokerage.

This report is the final one from a demonstration project carried out for the Office for Disability Issues to explore the provision of parts of the care management process by ULOs. The findings showed that the ULOs were able to successfully deliver support planning and brokerage to a wide range of people who use services. Support planning was experienced by people who use services as more 'human' when delivered by a ULO than by a LA, with less bureaucracy involved. People whose support plan was facilitated by a ULO were more likely to take their personal budget as a direct payment than those whose support plan was delivered by the LA.

Youtube short videos

The **Essex Coalition of Disabled People** has produced three videos on developing and strengthening ULOs which you can access using the links below:

- **Mentoring**
- **Sustainability**
- **Engagement**

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

- **Engagement in a rural area**
- **Working with other ULOs**
- **Diversifying and reaching out**
- **Reaching out to seldom-heard users**

Social Care TV also has a dedicated video on **personalisation and user-led organisations**

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.

Wider resources on co-production

NESTA has undertaken a dedicated strand of work on **co-production**.

The New Economics Foundation has also undertaken significant work on co-production in social care, represented by its '**Budgets and Beyond**' series of publications.

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A commissioner's guide to developing and sustaining user-led organisations

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, underpinned by practice and evidence, 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.

The original guidance from SCIE helped commissioners to meet this policy requirement. This updated guidance reflects updated policy, practice and evidence regarding ULOs and:

- explains the **benefits** of commissioners developing and sustaining ULOs in their local area
- provides **background information** and **evidence** about ULOs
- offers **practical advice** for developing and strengthening ULOs
- gives details of **resources** that can help.