

Developing and Supporting Independent Living Services and User Led Organisations in Lincolnshire

What is a user-led organisation (ULO):

Disabled people, carers and service users run user led organisations making decisions about issues are important to them. They support other disabled people, carers and service users in their community.

Putting People First
'Working together with user-led organisations'
2009

The basis of user-led organisations is centred around the value of peer support. The development of ULO's is a continuation of the journey for disability rights that started in the 1960's.

ULO's have often started with a group of individuals who are passionate and feel strongly about equal rights for disabled people, carers and people with mental ill health.

The nature and range of ULO's in the UK varies considerably in almost all aspects, with one notable exception – their commonality of purpose in seeking to advance equality and human rights for disabled people. 'Thrive and Survive' Disability LIB 2008

In ULO's the people the organisation supports and represents should have a majority on the management committee or board, so that they are the ones who make decisions about the organisation. This could be carers, people with mental ill health, people with physical disabilities or learning disabilities and it should be inclusive all age groups.

There are a number of criteria that have been put together by current ULO's, setting out the values and characteristics ULO's should have. A list of these criteria can be found in **Appendix 1**

The missions, values, services and support provided each ULO must be decided by its members.

It is important to note that being that user-led, does not mean that the people leading have to be committed to carry out the day to day work of the organisation. However, having paid employees from the organisations membership can be a key element.

What is a Centre of Independent Living (CIL):

CIL are grassroots organisations run and controlled by disabled people and people involved in Independent Living Rights. The first CIL's were established in 1980's with the National Centre of Independent Living forming in 1996 promoting independent living rights.

They provide independent living services such as direct payment support schemes, peer support, benefits advice, equipment hire, housing advice and support to smaller self help groups, they often link into wider regional and national agendas.

Traditionally CIL have been building based centres where people are able to drop in, pick up relevant information and access a range of relevant services. Organisations that provide disability related information may be co-located in a Centre of Independent living making it easier for people to go to one place. However, more recent CIL are taking different forms that are not necessarily building based. Enfield Centre of Independent Living operates virtually, through sharing a website between user led groups in the area and running services jointly.

Why is it important to develop a ULO in Lincolnshire:

“User-led organisations must have a crucial role in a new vision of independent living. They can play an essential role in transforming social care so that services are driven by the needs and wishes of those who use them.

When resourced adequately, local user-led organisations have been found to be the most effective means of delivering a range of services including advocacy, self-advocacy, peer support, and supported decision making”

Centres of Independent Living and Local User Led Groups Morris 2006

This view is supported by the crucial UN Human Rights Convention on the Rights of People with Disabilities which has made the commitment to achieve equality for disabled people by 2025.

The government paper ‘Improving the Life Chances of Disabled People’ 2005 sets out a clear recommendation based on research that has been undertaken, that all local authority areas should have at least one ULO based on a Centre of Independent Living by 2010¹

In support of this and in the context of transforming Adult Social Care, Ian Loynes Chief Executive of Southampton Centre of Independent Living stated at a recent ULO conference in London:

“ULO’s are the only agents of social change and the only ones who can implement the personalisation agenda”

The Independent Living Strategy 2008 advocates the transfer of resources from traditional assessment and care management into user led support, advocacy and brokerage services.

Lincolnshire already has organisations run by disabled people, carers groups, self help groups and other user-led services, why is this different:

The majority of groups and organisations in Lincolnshire that are led by the people they represent are focused around one or two service user groups or communities of interest. For example the Carers Partnership is for carers, LAPD has a majority

¹ Improving the Life Chances of Disabled People (2005) DOH

membership of people with physical disabilities, Headway supports people with brain injuries and their carers, the Shush Service User Self Help group predominantly supports people with mental health problems and GAIN supports people with autism in Grantham.

There are a large number of organisations that represent different groups of people in Lincolnshire but no single organisation bringing these together representing a united voice for independent living rights.

A ULO based on a Centre of Independent Living should cover all disabled people, carers, people with mental health problems, older people with support needs and be representative of all age groups.

What support could a ULO offer?

Each ULO must be driven locally finding out what is important to its members and work democratically developing its own practical solutions.

There are many different models for ULO's and they all differ in what they do. However, the common services provided by a ULO are:

- Information and Advice
- Advocacy and peer support
- Peer Champions
- Support in using direct payments and individual budgets

- Support to recruit and employ personal assistants
- Disability Equality Training, Access audits, implementation of the Disability Equality Duty
- Assistance in self assessment
- Campaigning for disability rights.
- Disability housing and design consultants
- Counselling services
- Training for employers and personal assistants

What ULO's are not:

Due to the variation in ULO's and their structure it is also useful to define what they are not:

- A group of interested parties running groups 'for' people
- A group of well meaning people raising money for trips and activities and non rights based activity
- A local group governed nationally
- A group where decisions are made by non disabled people²

It is important to state that large disabled charities have at times claimed to be ULO's whilst describing the people they support as needing protection rather than rights. Due to the size of larger disabled national charities they have been able to

² Thrive and Survive (2008) Disability LIB

secure often scarce resources allowing them to further expand at the expense of locally led and run service user organisations and groups.

The Disability LIB, an alliance of 6 ULO's have recently agreed to work jointly to overcome previous issues and collaboratively support the development of effective ULO's across the country, to achieve independent living rights for all.

Aims and Objectives of other ULO's:

Southampton CIL was one of the early Centres of Independent Living in the country and started its life in 1984.

Their mission statement is:

'to assist Disabled People by encouraging them to overcome the barriers preventing their independence'

They hold a firm belief that 'independence is not a matter of doing everything for yourself but of having choice and control over your life and a say in what happens to you'.

When establishing a ULO in any area the beliefs, aims and objectives of the organisation must start first.

A key success factor is that it grows and forms in response to the views of local people developing services that are relevant and important to that area.

Some ULO's have very specific criteria about who can be members.

Traditionally many have been led by physically disabled people and have often excluded carers, people with learning disabilities and people with mental health problems. However this is changing as existing ULO's seek to be more inclusive.

Some ULO's have specifically opted to only have people with learning disabilities on their management board due to the dominance of non learning disabled people in mixed boards³. There are a number of ULO's including Newham and Derby Coalition of Independent Living that successfully represent a cross section of groups and age ranges in their management committees.

What are their business models and what are the elements that make them successful?

Each ULO has different sources of funding. Some rely purely on a contracts from the Local authority and some rely on volunteers with very little funding, however, those with diverse income streams inevitably are the most sustainable as they do not rely on just one customer, if income falls in one area it can be made up for in another area.

Sources of funding for ULO's :

1. **Statutory funding**- e.g local authority service delivery contracts, PCT funding for services or projects

³ Thrive and Survive (2008) Disability LIB

2. **Charitable Trusts**- e.g Esmee Fairburn, Big Lottery- these generally will not fund core costs
3. **Private sector**- sponsors, community support, for events, one offs, generally not core,
4. **Income generation:**
 - Charging for access advice to businesses, local authorities, district councils
 - Training courses
 - Investing surplus funds
 - Charging personal budget holders for services e.g payroll,
 - Consultancy
 - Student Social work Placements

Additional important factors in effective ULO's:

'Sustainability is just as much about the empowerment and development of individuals as it is about resources'
Southampton CIL

In order for ULO's to be sustainable they need to include people with a good mix of skills. Particularly in the following areas:

- Management
- Leadership
- Business Skills
- Being a representative Voice
- Networking
- Involvement and Inclusion

It has been highlighted that ULO's can face additional difficulties to other third sector organisations as people may have variable input due to ill health.

It is a crucial element of successful ULO's that the skills required within the organisation do not fall on a few people.

What could a ULO in Lincolnshire do for smaller user-led groups and individuals:

Scoping work and capacity building projects carried out across the country have proposed that **a network of organisations with in a locality**⁴ may be required in order to fulfil the functions of a centre of independent living for all service user groups.

The benefit to this approach are:

- A larger voice to shout louder and influence policy
- Common barriers faced by different groups can bring an important issue to the forefront
- Support between organisations to strengthen each other
- Shared learning, the positive and negative
- Joint collaboration for delivery to win contracts, funding and support
- Shared resources e.g admin support, payroll, HR, funding advice
- Better communication, awareness and publicity
- Addressing the gaps and listening to the needs of local people
- Representation regionally and nationally
- Reaching a wider number of people making diversity its strength.
- Joint branding-greater publicity.

⁴ Sharing the learning-user-led organisations action and learning sites (2010) DoH

- Engage with people who would not be involved in statutory services
- Lobbying for local support e.g free or subsidised local authority venues
- Opportunity to apply for grants on behalf of smaller un-constituted groups
- Bring together databases of contacts.
- Greater influence on shaping social care providers, local councils, public buildings, employers.
- Clusters of groups can work together for the same purpose.

Existing groups working together:

In workshops and events that have taken place in other parts of the country, user-led groups and individuals have been keen to ensure that any new work in meeting the government recommendations for a fully representative ULO, does not 'reinvent the wheel' and cast aside the good work that has already been achieved by groups in a local area⁵

The most successful 'umbrella' ULO's are those that work across impairments, communities and age groups, employ a diverse workforce, work in partnership with community specific user-led organisations and are in touch with the communities they serve.

Disability LIB

⁵ Developing a ULO in Redbridge 2009 'Workshop summary'
www.redbridge.gov.uk/cms/benefits_care_and.../idoc.ashx?...1

In a number of areas including Newham, Surrey and Norfolk user-led groups and organisations have joined together to provide a united voice for disability and equality rights.

User-led support groups and individuals have recognised the value in pooling their creativity, experiences and knowledge and coalition's, alliances, partnerships and cooperatives have formed across the country creating umbrella ULO's.

Different Models of umbrella ULO's

- **The Cooperative Model:** Groups and organisations run by service users join together in a cooperative, sharing resources, providing services and distributing profits between members of this Coop.
- **The Alliance Model:** groups establish alliances with disability charities, local or national organisations, or business sponsors where there is likely to be a mutually beneficial arrangement. E.g a business offers HR support, office space, or some funding in return for free access advice, disability training, product testing.
- **Sharing Services:** Groups join a network of groups to share staff skills in bid writing, business planning, management, obtain discounts from buying together, share infrastructure services e.g payroll services.
- **The Enterprise Model:** Groups carry out services that are profitable and use the surplus to fund non profitable activity e.g

peer support. This can work by groups combining their services under one banner. E.g CroyCILL is a partnership of disability organisations selling different training services to the local authority and businesses.

Listed below are examples of thriving ULO's and the services they provide:

Name of ULO	Area	Description of Service	Notable Features
Vision Sense	Jarrow (North East/ Sunderland)	An independent ULO run as a social enterprise.	Self sustaining, does not rely on grants. Generates income through selling training, access audits, organising accessible events. Uses the revenue generated to run campaigns and services important to its members
CroyCILL	Croydon	Training around disability	CroyCILL is a partnership of disability organisations who have joined forces to provide a full range of training, recognising the specialist skills and knowledge of each member of the partnership. CroyCILL acts as the broker providing one point of contact for business, local authorities and the general public ensuring consistency and quality in what is delivered.
Bath and North East Somerset People First	Bath	Run training course to support people to speak with confidence	Supporting people with learning disabilities to become peer and self advocates. They support people to be involved in improving services both locally and nationally by becoming involved in Human Rights issues, Disability Equality Duty, personal budgets, health, housing and employment.
Derby Coalition of Disabled People	Derby	Counselling Peer mentoring Direct payments Payroll	Have 4 trustees under the age of 30 including their chair. They have worked hard to present ULO's in a younger more accessible way inspiring a new generation of leaders.

Name of ULO	Area	Description of Service	Notable Features
Herts PASS	Hertfordshire	Supported young people to self direct.	Employ 3 young disabled people as apprentices to run Workability a user driven project providing work experience opportunities for disabled people.
Breakthrough UK	Manchester	Independent Employment Advocacy Volunteer and Peer mentoring Training Research and Consultancy Hate Crime Policy Development	<ul style="list-style-type: none"> • 681 people were supported through employment, training, and advocacy services. • 56 people were supported into paid employment. • 70 people were supported into voluntary work. • 800 people took part in training of which 97% said as good or excellent
Southampton CIL		Accessible venue hire, Training,	Strong roots in the Disability Right Movement and supporting people in their own personal development to have their rights recognised. One of the first CIL's. A Community Interest Company. Has full membership with voting rights and non disabled associate members (allies)
Norfolk Coalition of disabled people		Disability rights representation. Run a disability Pride event celebrating difference Mental health advocacy Direct payments Appropriate adult support vulnerable young people.	Made of 45 user-led member groups including access, support groups and sports clubs. Strong mental health involvement. Youth forum for 14-25 run by young disabled people.

What lessons can be learned from other ULO's that are useful for Lincolnshire and what pitfalls are there to avoid?

Involvement:

There are 11 million disabled people in the UK and only a very small minority are engaged in the disabled people's movement. To give this strength more people need to be engaged. Many disabled people work and do not necessarily have any contact with disabled people organisations. A broad cross section of people should be engaged with to ensure continued existence including young people, and those in residential settings. There also needs to be a focus on attracting professional disabled people to ULO's.

Involving people with diverse physical disabilities, learning disabilities and mental ill health can be problematic as people have different views, experiences and different ways of communicating. Bringing people together requires careful facilitation to ensure all voices and opinions are heard and respected by all.

Access is not just about getting around a venue, people need to feel safe and given time and space.

Consider ways of reaching an audience that wouldn't normally be associated with ULO's i.e leaflets in charity shops, libraries, going into universities, colleges, using social networking sites, district council, community hubs and access centres.

There need to be strategies for obtaining a new generation of leaders. Younger people need to be

encouraged to join ULO's responding to issues that are meaningful to them.

Over reliance on a few people, exhausting people who do come forward to get involved.

Difficulties accessing appropriate training for board members and staff where access has not been properly considered in the way the course is delivered. Disabled people can find themselves training the trainers rather than picking up new skills.

Disability charities and services providers must not be used to represent disabled people. This would not happen with any other rights based group.

Funding:

Focus from the government around ULO's being self sufficient and providing public services. Previously many ULO's have not sold services and when grant funding runs out for particular projects they face financial difficulties

Those that are successful financially, have set up with the delivery of services written into their model e.g Breakthrough as a provider of employment services now operates as a successful user-led social enterprise with a surplus generated to fund services to their members that are not easily saleable .

Contracting:

It is hard for ULO's to compete with larger disabled people organisations often they do not have dedicated IT, HR and other specialist staff to complete funding bids, policy requirements and other time

consuming jobs required to win contracts that fit with commissioners.

Campaigning for disabled people by ULO's often highlights poor service of a local authority who may be contracting with the ULO. This relationship needs to be managed to protect the missions of the ULO in representing its membership whilst not jeopardising its funding.

Some ULO's are in small geographical areas and contracts are let on a countywide basis thus excluding these organisations. Alternatively groups may be focused on one area of support e.g mental health and contracts are let for all areas.

Avoiding duplication, one of the benefits of organisations working together is that they can pool resources, directories and prevent the overlap of projects.

For ULO's to survive they need to work with each other, third sector organisations, local and national government.

ULO's work together for the benefit of disabled people and people with mental ill health providing a united front. They recognise service users for their professional insight.

Innovation in ULO's

Helpline Direct in Lancashire operates a telephone helpline in rural areas through Timebanking. Users support each other and gaining and using Timebanking credits.

Information Database's should be run by user led organisations.

Some ULO's run Service User Review Teams. Local authorities top slice contracts to providers which is then used to pay ULO's to check and give ratings to organisations.

What is happening in Lincolnshire to develop a ULO:

At an event in Newark organised by the East Midlands Regional Improvement Partnership, organisations were invited to bid for grant funding from the Department of Health to support the development of a ULO in areas that did not already have one that was fully representative of all groups and met the criteria listed in **Appendix 1**.

In order to strengthen the chances of Lincolnshire being able to get this grant, a joint bid was put in by a carer and direct payment user, the Individual Budgets Network Lincolnshire (IBNL), Lincolnshire Association of People with Disabilities (LAPD), Speaking Up and supported by Lincolnshire County Council. The bid was successful and Lincolnshire received £45000 to support the development of a representative and inclusive ULO or umbrella ULO.

The partnership above was created purely to give strength to the bid and the group invites any individual or organisation to become involved in how the project is taken forward. The focus for involvement will be for existing user-led groups in the county and individuals who have an interest in the disability rights and equality.

Building on what we know:

A number of consultation exercises have taken place in Lincolnshire through the local authority, LAPD,

IBNL and the Mental Health Involvement project to find out what people accessing services and support would like to see to improve their quality of life and the services they access.

We can use this feedback as a starting point for a ULO to build on.

The key issues that appear in the feedback from this are:

1. Support to Self Help/ smaller user-led groups. Potential here to link groups together through a self help cooperative/network
2. Options for employment of carers and support workers E.g Care Cooperatives
3. Lack of available care in rural areas
4. Effective communication of information: A directory of directories!!
5. Pooling and managing personal budgets
6. Peer support/Expert Patient
7. Local area representatives to address rural or area specific issues
8. Transport
9. Being listened too and feeling valued.
10. Making a difference through involvement.

What will a ULO do that is different to LINK, Partnership boards, forums, the new involvement contract, how will it work together?

The Local Involvement Networks (LINK):

Give everyone the chance to say what they think about their local care services public, private and voluntary sector – what is working well and what is not so good

- Give people the chance to check how care services are planned and run
- Feedback what people have said about services so that things can change for the better.

The LINK does not provide any services like peer support and training but provides a voice for local people to influence all types of care in their area. LINK's have additional powers to go into organisations to review issues identified by their members. They do not work on single cases but where there are reported to be common experiences.

Partnership Boards:

are generally funded by local authorities and enable people to influence local authority commissioning and practice, raise awareness of issues like Hate Crime, Accessibility and provide networking between related organisations. They are generally divided into different areas of interest:

Local Implementation Group- for mental health

Learning Disability Partnership Board

Physical and Sensory Impairment Partnership Board

They do not provide services but enable dialogue between public bodies and service users. In some areas the ULO's chair the partnership boards.

Total Voice (Speaking Up and The Healthy Hub)

The new advocacy and involvement contract will support people in Lincolnshire to become involved in how their services are delivered and how their needs are met. This could include involvement in your own care plan, involvement in projects and research, being a trustee or member of a user led group.

Speaking Up are a partner in the ULO bid and therefore will support any individuals and groups to be involved in the development of the ULO. This support could be around accessing appropriate training for people to be involved.

What next:

With support from the National Centre of Independent Living (NCIL) an event is being planned for July 2010, inviting individuals and user-led groups with an interest in disability, equality rights and working together for the future. Other ULO's and Centre's of Independent Living will be speaking at the event to talk about the work they do, the differences its has made to the people they represent and the challenges they have faced. Different models of ULO's will be invited to speak to give a wider understanding of the various possibilities for Lincolnshire.

Outcomes:

For people to find out about the role and benefit of a ULO's

Find ways to build on what already exists in Lincolnshire

Raise awareness that everyone has skills and insight to offer to a ULO.

Get together user-led groups and individuals with an interest in the disability rights movement, equality, independent living and the barriers that people face.

Strengthen a user led movement in Lincolnshire

Explore different models for a ULO in Lincolnshire learning from the steps taken by other organisations.

Create a project steering group

Provide an opportunity for people to state what they would want from a ULO.

Input to the business plan for the ULO

Input to the development of services suggested by people in consultations.

Opportunities to be included in the future work of the ULO.

Appendix 1- Criteria for a ULO based on a Centre of Independent Living

Values of a ULO:

- Works from social model of disability perspective
- Promotes independent living
- Promotes people's human and other legal rights
- Shaped and driven by the initiative and demand of the organisation's constituency
- Is peer support based
- Covers all local disabled people, carers and other people who use support either directly or via establishing links with other local organisations and networks
- Is non discriminatory and recognises and works with diversity
- Recognises that carers have their own needs/requirements
- Engages the organisation's constituents in decision-making processes at every level of their organisation

ULO Design criteria – characteristics

- Provides support to enable people to exercise choice and control
- Is a legally constituted organisation
- Has a minimum of 75 per cent of the voting members on the management board drawn from constituency
- Able to demonstrate that organisation's constituents are effectively supported to play a full and active role in decisions
- Has a clear management structure
- Has robust systems for running a sustainable organisation
- Is financially sustainable
- Has paid employees, many of whom reflect orgs constituency
- Accountable to constituents and represents their views at local level
- Supports the participation of constituents in designing, delivering and monitoring its services
- Works with commissioners to improve commissioning and procurement