



disability nottinghamshire

A guide to user led organisations (ULOs)



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**This booklet is also available in large print,
audio tape, Braille, plain text format and other languages**

Who are Disability Nottinghamshire?

We are a countywide charity based in Nottinghamshire providing a free, confidential and independent advice service relating to any aspect of disability for disabled people, carers, family, friends, professionals and students.

Disability Nottinghamshire has been user led since our formation in 1984 as Disability Information and Advice Line (DIAL) Mansfield & District. Renamed Disability Nottinghamshire in 2009 to reflect the area of operation and widening the scope of services available to users, the organisation continues to help disabled people across the county.

If there are any terms in this booklet that you do not understand, then please refer to the '**Jargon buster**' on page 18.



Contact us

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Background of ULOs

"A user led organisation (ULO) is an organisation that is run and controlled by people who use support services including disabled people, mental health service users, people with learning difficulties, older people, and their families and Carers." (Social Care Institute for Excellence (SCIE), 2009)

"What is a ULO?"

"A user led organisation is one where the organisation represents, or provides a service to, have a majority on the Management Committee or Board, and where there is clear accountability to members and/or service users." (Morris, 2006)

"An organisation where the service users dictate what services are provided" (Disability Nottinghamshire ULO survey, 2011)

The rudimentary components of ULOs are embedded in the health and social care field with their roots dating back to the independent living movement of the early 1980s where disabled people didn't want to live in residential care but instead live within their community. The Independent Living Strategy recommended the development of ULOs as organisations run by, and for, disabled people who can promote all aspects of independent living in order to achieve equality and inclusion.

This booklet looks at explaining what a ULO is and aims to equip individuals with the information to have the confidence be able to start their own ULOs.








What do ULOs do?

ULO's provide a unique role within the local community by providing a point of contact for information and advice services. The Department of Health has created 21 design criteria (explained in more depth on page 12 and 13) to illustrate what a ULO looks like and the services and activities a ULO can provide.

The 21 design criteria cover three broad areas:

- The group's value base (e.g. promoting the social model of disability)
- How the group is governed and managed (e.g. 75% of the members of the Management Committee being service users)
- The services the group provides (e.g. advocacy, information and advice, peer support)

Typical services and activities of a ULO might include:

-  Advocacy and peer support
-  A variety of care and support services
-  Information and advice
-  Producing policies and services in conjunction with local statutory providers (e.g. local council)
-  Support in employing Personal Assistants
-  Support in using personal budgets and direct payments
-  Training

Why adopt a user led approach?

The work of a ULO should be informed and driven by the needs of its users, operating in a way which removes any barriers to participation (e.g. access). Their service users take the role of managing the organisation, deciding on its priorities and how they should be addressed. With the objective of deciding on what services to provide and how they should be provided.

“What exactly does a ULO aim to achieve?”

Ability to work with hard to reach groups: They can help tackle social exclusion by providing service users opportunities to get involved in running their own organisation therefore increasing skills and confidence. They also provide a platform for service users to become involved in all aspects of service delivery and development

Address inequality: They can help address inequalities in society through service user involvement such as barriers to participation as well as health inequalities by supporting service users to access the support they need

Avoid barriers: They are able to highlight barriers which exist for marginalised groups and find innovative ways of overcoming them




Collective forum: They provide a voice based on direct experience of disability which is credible and genuine

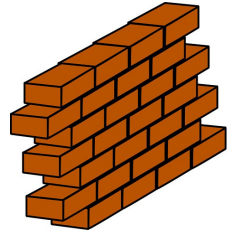
Community based: They work with and for local people

One stop shop: They can act as a contact and information point for service users, service providers and commissioners with expertise in areas such as advocacy, self help and peer support

Specialist expertise: They possess the knowledge and skills to help make local services and the commissioning cycle more effective




Challenges and Barriers

-  **Limited income:** Difficulty in attracting long term, secure/sustainable funding especially to cover core operating costs
-  **Business acumen:** ULOs are often run by persons that have been excluded from society in some way which means their opportunities for skills development has been limited in the past
-  **Competition:** ULOs may find it difficult in tendering for local authority contracts as they tend to favour larger organisations with specialist resources



“What processes need to be implemented in creating a ULO?”

“What do I need to consider when thinking of becoming a ULO?”

-  **Consultation:** Engage everyone from the off set and ask people to contribute to the process so they have a sense of ownership
-  **Communication:** Keep all persons up to date with what is going on, in particular when milestones are reached in order to maintain momentum and enthusiasm. It may be worthwhile having a dedicated place, either physical or online so that persons can find out more information and the process is transparent
-  **Clarity:** Clarify the reasons why your organisation is becoming user led and the benefits that will be available for all

The following pages (pages 8 - 13) explain each of the 6 points listed above and gives some hints on how to address them successfully.

Limited income

Finding funding is a time consuming and sometimes quite tedious task. Listed are a number of organisations where funding can be obtained (See page 19 –21 for website addresses).

- Big Lottery
- District, Borough and County Councils
- Focus on Funding
- Funding Central
- Local CVS
- Nottinghamshire Community Foundation

In addition to the above, various foundations, trusts and hospices offer funding such as Boots and The John Eastwood Foundation

Income can be created via other avenues apart from funding. It may even be a good idea to explore creating your own income, it may only be small but it all helps towards your organisation achieving its goals.

Membership: Members can pay a fee to be part of the organisation and help contribute towards running costs

Donations: This can be done in the form of appeals in local publications, churches, schools and community centres

Fundraising: Hold fundraising activities such as tombolas, raffles and cake stalls for your organisation at local events as well as doing supermarket bag packs and starting an eBay shop

Sponsorship: Have people participate in charity fundraising activities (sponsored swim, run etc) for your organisation. This will not only increase funds, it will promote your organisation as well

In order to be **sustainable**, it is important that your organisation tries to establish a diverse income stream and takes a proactive approach in looking for potential opportunities. For more information, please see the National Council for Voluntary Organisation's (NCVO) website section on 'Sustainable Funding' which is very useful.

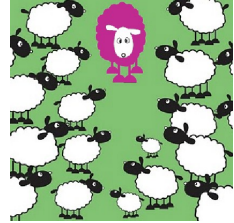
Competition

Starting something new is always going to be tough, especially when there are numerous other groups competing for the same funding and service users.

"How do I stand out?"

TOP TIP TOP TIP TOP TIP

When tendering for funding bids focus on smaller contracts to build confidence and familiarise yourself with the procedures



-
-  **Be innovative and have unique ideas** that haven't been perused before will have added appeal to potential service users. Try to come up with a unique selling point to stand out
 -  **Develop a brand** that informs people what your organisation is about. This involves creating a logo, colour scheme and mission statement
 -  **Establish a link** with a similar organisation that have gone through a similar process and ask them if they would consider mentoring
 -  **Excellent communication** between service users. This can be either face to face or over the phone. However, the internet is a useful tool with social media such as Facebook and Twitter
 -  **Have a flexible approach** as an organisation with a willingness to change and receptive to new ideas
 -  **Identify the competition** by mapping of local and national organisations that provide a similar service and see if there are any gaps in provision
 -  **Partnership working** with other organisations will enable you to share knowledge and expertise as well as being able to put your resources together when applying for funding bids or combine tenders and contracts
-

Business acumen

It may be that the ULO will have to think outside the box in order to find business acumen, but in doing so, great value will be added to your group.

"How does a ULO acquire business acumen?"

Having a person from the business world on board will have great benefit to the organisation. Below is a list of industries and the skills that people from these industries can bring:

Finance: Good with numbers, able to manage funds and allocate them to most appropriate area





Management: Able to manage people and make sure that the organisation is on track in terms of aims and objectives

Marketing: Is able to promote the organisation and organise publicity campaigns through a variety of media

Manufacturing: Process driven, able to see things as a start, middle and end

"How do I gain business knowledge to benefit my organisation?"

There are organisations which offer information, advice and guidance to voluntary and community sector organisations such as:

-  **Business Link:** Offer advice and guidance on all elements of starting a new business
-  **East Midlands Funding Advice Network (EMFAN):** Offer advice on funding opportunities
-  **Local council's Regeneration team:** Offer support and information on business and the community
-  **Social Enterprise East Midlands (SEEM):** Offers training, support and development services to the third sector



Consultation

Any change requires consultation. As a member or service user you are entitled to be consulted. These are some of the questions that might arise:

- What benefits could a ULO bring?
- Will other services and opportunities be accessible to your organisation?
- Will it mean fundamental changes will be required in order to embrace the user led approach?
- What roles will your Board of Trustees undertake?
- What implications might it have on your work/organisation?



Advantages of consultation

- 👍 Bring up questions/concerns etc that one person alone couldn't foresee
- 👍 Enables evaluation/assessment to be carried out
- 👍 Influence in decision making
- 👍 Sense of ownership and democracy



For **successful consultation**, it is important that you are clear, timely and have direction on what you want to know from the people you are consulting. Aim to use as many different methods with a wide range of stakeholders.

Examples of consultation include:

- 🐦 Focus groups and meetings
- 🐦 Mail outs and questionnaires
- 🐦 Online forums and chat rooms
- 🐦 Telephone conversations



Communication and Clarity

How user led are you? How user led do you want to be?

Communication internally and externally are the keys to success in any organisation. It is therefore important to look at the **ULO assessment criteria** below and establish how user led you are now and how user led do you want to be in the future?

No.	ULO assessment criteria	Do we do this?	
		Yes ✓	No ✗
Values			
1	Works to a social model of disability	<input type="checkbox"/>	<input type="checkbox"/>
2	Promotes independent living	<input type="checkbox"/>	<input type="checkbox"/>
3	Promotes people’s human and legal rights	<input type="checkbox"/>	<input type="checkbox"/>
4	Shaped and driven by the initiative and demand of the organisation’s constituency	<input type="checkbox"/>	<input type="checkbox"/>
5	Is peer support based	<input type="checkbox"/>	<input type="checkbox"/>
6	Covers all local disabled people, carers and other people who use support either directly or via establishing links with other local organisations and networks	<input type="checkbox"/>	<input type="checkbox"/>
7	Is non discriminatory. Recognises and works with diversity in terms of race, religion and belief, gender, sexual orientation, disability and age	<input type="checkbox"/>	<input type="checkbox"/>
8	Recognises that carers have their own needs and requirements as carers	<input type="checkbox"/>	<input type="checkbox"/>
9	Engages the organisation’s constituents in decision making processes at entry level of the organisation	<input type="checkbox"/>	<input type="checkbox"/>
10	Provides support to enable people to exercise choice and control	<input type="checkbox"/>	<input type="checkbox"/>

No.	ULO assessment criteria	Do we do this?	
		Yes ✓	No ✗
Organisational criteria			
11	Is a legally constituted organisation	<input type="checkbox"/>	<input type="checkbox"/>
12	Has a minimum of 75% of voting members of the Management Board drawn from the constituency of the organisation	<input type="checkbox"/>	<input type="checkbox"/>
13	Is able to demonstrate that the organisation’s constituents are effectively supported to play a full and active role in key decision making	<input type="checkbox"/>	<input type="checkbox"/>
14	Has a clear management structure	<input type="checkbox"/>	<input type="checkbox"/>
15	Has robust and rigorous systems for running a sustainable organisation (e.g. financial management and contingency planning)	<input type="checkbox"/>	<input type="checkbox"/>
16	Is financially sustainable	<input type="checkbox"/>	<input type="checkbox"/>
17	Has paid employees, many of which must reflect the organisation’s constituency	<input type="checkbox"/>	<input type="checkbox"/>
18	Identifies the diverse needs of the local population and contributes to meeting those needs	<input type="checkbox"/>	<input type="checkbox"/>
19	Is accountable to the organisation’s constituents and represents their views at a local level	<input type="checkbox"/>	<input type="checkbox"/>
20	Support the participation of its constituents in designing, delivering and monitoring the organisation’s services	<input type="checkbox"/>	<input type="checkbox"/>
21	Works with commissioners to improve commissioning and procurement	<input type="checkbox"/>	<input type="checkbox"/>

How to take a user led approach?

There is, by no means, a straight forward answer to this question. However, it is important to bear in mind the following:



If your organisation already has a Board of Trustees, then a Board meeting will need to be called to discuss how you can take a more user led approach.

Other important things to consider:

- Will the user led approach fit within your organisation's governing documents such as your constitution.
- If not, will you be prepared to alter the governing documents or would you abandon the user led approach?
- Will there be policies that need reviewing in order to accurately reflect the organisation's user led approach?

It is recommended that an **action plan** is created. An action plan will enable you to keep a **record** of what you have achieved so far and what needs to be done in the future. It is also a useful tool in putting and clarifying thoughts on paper and in a logical manner. An example of an action plan is shown on the following page (page 15).

TOP TIP TOP TIP TOP TIP TOP TIP

Take every challenge as an opportunity to do something new, exciting and succeed at it

Action plan

What	How	By Who and When	Resources and Budget	Measurement
What is your overall objective?	What actions need to be undertaken to achieve the objective?	Who will undertake these actions and when does it need to be done by?	What costs will be incurred? What is the budget to achieve the action?	How will you know when the task has been achieved? What will be the result you are aiming for?
Make sure that everyone knows who should be doing what, by when, why and what their targets are/how they know when they've done it	There may be more than one action to achieve the objective	Set an achievable deadline (SMART plan) so that progress can be monitored	List all resources and the cost. Remember to note staff as they are a valuable resource	Try to be as specific as possible. This will act as a target to aim for

Mentoring

What is mentoring?

Mentoring is a partnership between a mentor and mentee, normally working in a related field or sharing similar experiences. Within this relationship, the mentor offers advice and support whilst the mentee is the learner.

Why is mentoring important for a user led organisation?

A more developed ULO can adopt the role as a mentor to provide support and guidance to a developing or emerging ULO. As the mentor has first had experience of going through the process, it is able to share this experience and notify what has worked well, what hasn't and why?

Mentors provide:

- Advice
- Information
- Provide useful contacts
- Support
- Experience
- Knowledge
- Share best practice e.g. policies
- Valuable insight

A successful example of mentoring in popular culture

The X Factor: Each judge has responsibility for a group of contestants (groups, under 25s and over 25s), offering support, experience and useful contacts in how to succeed in a competitive industry.



Mentor: Tulisa

Mentee: Little Mix

The same scenario occurs in the voluntary sector which will be explained in more detail in the case study on the next page (page 17).

Mentor case study

Disability Nottinghamshire is a user led organisation for disabled people and their carers in Nottinghamshire run by a dedicated team of volunteers, many of which have disabilities themselves, as well as employees in paid positions.

Mansfield, where Disability Nottinghamshire is based, has a high number of people of working age who have disabilities as well as younger disabled people needing help to live independently. There was nowhere in town where people could receive advice from peers with personal experience of organising life with a disability.

We approached DIAL Doncaster in 2008/9 to be our mentor which included specialist information, advice and guidance from their staff and volunteers on writing funding bids, governance, policies and procedures. It was also identified that we had been working with clients from outside of our Mansfield birthplace. The Trustees recognised this as an opportunity to reach out to the wider community and undertook a rebranding exercise in 2009, changing its name from Disability Advice Line (DIAL) Mansfield & District to Disability Nottinghamshire.



Before



After

TOP TIP TOP TIP TOP TIP TOP TIP

Disability Nottinghamshire is willing to be a mentor for any emerging ULOs. Please contact us on 01623 658060 to enquire

Jargon buster

Board of Trustees: This can also be referred to as the Management Committee

Constituents: The members of the organisation also known as service users

Core operating costs: The funds needed in order for the organisation to remain in operation e.g. room hire, utilities, postage, office supplies

Focus group: This is where people are asked their opinions, perceptions and beliefs on a particular idea, product or service

Forum: A voice where the views of disabled people can be heard

Networking: gaining contacts and information of other people/organisation with similar interests and objectives

Service users: People who receive, have received or are eligible for services

SMART plan: This stands for **S**pecific, **M**easureable, **A**chievable, **R**ealistic and **T**ime specific. It is used to set objectives in project management and develop and is a useful tool when looking at starting a new project

Social enterprise: An organisation run following business methods and principals but the profits are put back into the community

Tendering: The process of offering your group's services in return for a contract

User led organisation (ULO) : Local organisations, run and controlled by disabled people

Useful ULO resources

Capacity Builder

Offers advice and support on how to initiate, develop and sustain charities and community organisations.

www.capacitybuilder.co.uk

Tel: 028 9024 3022

DIAL UK (Scope)

A national organisation for a network of approximately 120 local Disability Information and Advice Line services (DIALs) run by and for disabled people.

www.dialuk.info

Tel: 01302 310 123

Disability Alliance

Disability Alliance is a national registered charity which works to improve the living standards of disabled people.

www.disabilityalliance.org

Tel: 020 7247 8776

Disability Independent Advisory Group (DIAG)

DIAG is made up of groups and individuals who advise on the needs of disabled communities. They hold regular meetings throughout the year.

www.disabilitynottinghamshire.org.uk

Tel: 01623 658 060

East Midlands ULO Network

This online forum is designed to provide networking and information between ULOs in the East Midlands.

groups.yahoo.com/group/eastmulandsulo

Useful ULO resources

National Centre for Independent Living

A useful resource on all aspects surrounding independent living including ULO resources.

www.ncil.org.uk

Tel: 020 7587 1663

Office for Disability Issues

A website dedicated to all issues surrounding disability.

odi.dwp.gov.uk

Self Help Nottingham

A useful website for people looking at starting up their own group.

www.selfhelp.org.uk

Tel: 0115 911 1661

Social Institution for Excellence

Further general information on ULOs.

www.scie.org.uk

Tel: 020 7024 7650

SOLNET—Shaping Our Lives Network

A networking website for ULOs which serves to help others (organisations, potential service users) find out what ULOs are doing in their area.

www.solnetwork.org.uk

Tel: 0845 241 0383

Funding and Business resources

Big Lottery Fund (BIG)

Offer funding to community groups and projects that improve health, education and the environment.

www.biglotteryfund.org.uk

Tel: 020 7211 1800 or 0300 500 5050

Business Link

Offer advice and guidance on all elements of starting off a new business.

District, Borough and County Councils



Ashfield District Council

www.ashfield-dc.gov.uk

Tel: 01623 450 000



Bassetlaw District Council

www.bassetlaw.gov.uk

Tel: 01909 533 533



Broxtowe Borough Council

www.broxtowe.gov.uk

Tel: 0115 917 7777



Gedling Borough Council

www.gedling.gov.uk

Tel: 0115 901 3901



Mansfield District Council

www.mansfield.gov.uk

Tel: 01623 463 663



Newark and Sherwood District Council

www.newark-sherwooddc.gov.uk

Tel: 01636 650 000

Funding and Business resources



Rushcliffe Borough Council

www.rushcliffe.gov.uk

Tel: 0115 981 9911



Nottinghamshire County Council

www.nottinghamshire.gov.uk

Tel: 08449 808 080

SOLNET—Shaping Our Lives Network

Offer advice on funding opportunities.

www.oneeastmidlands.org.uk

Tel: 0115 934 8436

Focus on Funding

Works with community groups across Nottinghamshire offering a range of services including: funding advice surgeries, training courses and workshops, information on funding sources and fortnightly email updates on funding opportunities.

www.focusonfunding.org.uk

Tel: 0115 934 8405

Funding Central

A one stop shop for all aspects of funding including information and advice, support and funding opportunities.

www.fundingcentral.org.uk

Local CVS



Ashfield Voluntary Action

www.ashfieldvoluntaryaction.org.uk

Tel: 01623 555 551

Funding and Business resources



Bassetaw CVS

www.bcvs.org.uk

Tel: 01909 476 118



Broxtowe Voluntary Action

www.vcb.org.uk

Tel: 0115 917 8080



Gedling CVS

www.gedlingcvs.org.uk

Tel: 0115 987 1981



Mansfield CVS

www.mansfieldcvs.org

Tel: 01623 651 177



Newark and Sherwood CVS

www.nandscvs.org

Tel: 01636 679 539



Rushcliffe CVS

www.rushcliffecvs.org.uk

Tel: 0115 969 9060

National Council for Voluntary Organisations (NCVO)

Dedicated to providing information, support and guidance to the voluntary sector through a range of media including web, publications, events and consultancy.

www.ncvo-vol.org.uk

Tel: 020 7713 6161

Nottinghamshire Community Foundation

Provides information and a database on funding opportunities within Nottinghamshire.

www.nottscf.org.uk

Tel: 01623 636 365



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