



Centre for  
Independent  
Living CIC

**How Should ULO's  
Implement the Dept of  
Health's ULO Design  
Criteria?**



## Aim of document:

- This publication has been developed to help interested parties to understand what the key issues are in creating an effective and engaging User Led Organisation (ULO). The Department of Health developed a 'Design Criteria' of 21 criteria's for ULO's to aspire to. Whilst SPECTRUM broadly supports these, we do recognise they are complex and can be off-putting to many. However, we also know that being an effective ULO is a lot more than just having a majority of the organisation's user-base on the Management Committee or governing bodies.

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<https://spiritdisabilityplatform.wordpress.com/>

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## **SPECTRUM's Guidance concerning: what are the unique characteristics of a ULO?**

SPECTRUM Centre for Independent Living is an organisation run and controlled by Disabled People<sup>1</sup>. We formed in 1984 as one of the first organisation in the UK that were run and controlled and managed by Disabled People.

We are therefore a User Led Organisation (ULO) and have been since our formation, and indeed, before the term 'ULO' was even coined.

With this history and experience, we have built up a range of resources and expertise to guide organisation that wish to be a ULO, and for commissioners who want to encourage the development of more ULO's. We are able to provide training and consultancy services on request.

This information leaflet has been developed to help interested parties to understand what the key issues are in creating an effective and engaging ULO. The Department of Health developed a 'Design Criteria' of 21 criteria's for ULO's to aspire to. Whilst SPECTRUM broadly supports these, we do recognise they are complex and can be off-putting to many. However, we also know that being an effective ULO is a lot more than just having a majority of the organisation's user-base on the Management Committee or governing bodies.

SPECTRUM has worked with many ULO's, organisations wishing become a ULO and with commissioners. As a result of this work we have developed this guidance for new and evolving ULO's to make sense an understand what the essential and desirable characteristics of a ULO are.

### **Understanding what a ULO is:**

The starting point for understanding what a ULO is, is the definition developed from the Department of Health's User-Led Organisation project, which defined a ULO as **“an organisation that covers all local Disabled People, Carers and other people who use support either**

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<sup>1</sup> By Disabled People we refer to people with any form of impairment, including people with a physical, sensory, intellectual, psychological, emotional, age related or any other hidden impairment(s). We therefore include people with learning difficulties, Deaf People, Blind and visually impaired people, mental health system users and survivors, people living with chronic illness and Older People with age related impairments.



**directly or via establishing links with other local organisations and networks”.**

It is recognised and accepted that not all new and emerging groups would meet all of the design criteria at the early stages of their development, although they would normally be expected to be working towards meeting them over time. The Department of Health policy also acknowledges that these criteria may be met in a variety of ways according to local demand, resources and circumstances.

It is also important to note that it is not strictly necessary for a ULO to describe itself as such in order to meet the criteria. What a group does, and how it is run, are more important than what they call themselves.

SPECTRUM has observed that the design criteria were not necessarily a good fit for all types of groups (especially non-disability groups). To fix that, we have adapted the criteria in consultation with other ULO’s so that they make more sense in the specific context of ULO development.

These revised criteria are detailed below, providing clarity and comment about what is an essential characteristic and what is desirable or a longer term aim:

Criteria	Emerging ULOs	Established ULOs	Comments/Notes:
1. works from a social model perspective	Essential	Essential	This includes other model approaches that might be called something different but share similar principles to the social model (e.g. the recovery approach for mental health service users)
2. promotes independent living or choice and control for users	Essential	Essential	
3. promotes people’s human and other legal rights	Essential	Essential	



Criteria	Emerging ULOs	Established ULOs	Comments/Notes:
4. shaped and driven by the initiative and demand of the organisation's constituency	Essential	Essential	
5. is peer support based	Essential	Essential	
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	Desirable	Desirable	Clearly the project would encourage ULOs to be as inclusive as possible but it is quite legitimate for a ULO to be set up to support their particular peer group
7. respects the need to avoid unjustified discrimination, and recognises diversity in terms of race, religion and belief, gender, sexual orientation, disability and age	Essential	Essential	This does not prevent working only with particular peer groups (e.g. a Mental Health service users group). It simply means that – subject to any legitimate capacity issues - they should not exclude people on the grounds of age, faith, sexual orientation etc). There would however be legitimate exceptions (e.g. an older people's organisation could obviously discriminate on grounds of age).
8. recognises that carers have their own needs and requirements as carers	Essential	Essential	



Criteria	Emerging ULOs	Established ULOs	Comments/Notes:
9. engages the organisation's constituents in decision-making processes at every level of their organisation	Essential	Essential	
10. provides support to enable people to exercise choice and control and ensures that it does not do anything to restrict choice and control	Desirable	Desirable	Would depend on nature of the organisations activities and can be achieved by a variety of means (e.g. education, training, peer support etc)
11. is a legally constituted organisation	Desirable	Essential	May be difficult in short term for new/emerging ULOs
12. Ideally, has a minimum of 75% of the voting members on the management board drawn from the organisation's constituency	Desirable	Desirable	
13. is able to demonstrate that the organisation's constituents are effectively supported to play a full and active role in key decision-making	Essential	Essential	



Criteria	Emerging ULOs	Established ULOs	Comments/Notes:
14. has a clear and effective management structure	Desirable	Essential	A clear management structure is important to ensure accountability. But this may take time for new/emerging ULOs. Also, some may prefer a more co-operative model. The key issue is that any structure works effectively for each organisation.
15. has robust and rigorous systems for running a sustainable organisation (e.g. financial management/ contingency planning)	Desirable	Desirable	Clearly good financial management is highly desirable but each organisation will find its own way of working that suits them.
16. is financially sustainable as there will be no ongoing central government funding	Desirable	Essential	
17. has paid employees, many of whom must reflect the organisation's constituency	Not essential	Desirable	This may not be appropriate for smaller ULOs (particularly in early stages)
18. identifies the diverse needs of the local population and contributes to meeting those needs	Desirable	Essential	It is understandable that emerging ULOs may not have capacity to be fully responsive to diversity but an established ULO should aim to be fully inclusive
Continued...			



Criteria	Emerging ULOs	Established ULOs	Comments/Notes:
19. is accountable to the organisation's constituents and represents their views at a local level	Essential	Essential	
20. supports the participation of its constituents in designing, delivering and monitoring of the organisation's services	Essential	Essential	
21. works with commissioners to improve commissioning and procurement	Not essential	Not essential	Unlikely to be relevant to all ULOs
27. Equality training	Desirable	Essential	
28. Support the implementation of the Public-Sector Disability Equality Duties	Desirable	Desirable	Would depend on capacity.









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