



Centre for
Independent
Living CIC

**A Case Study in the
Setting up of a Local
ULO Network**



Aim of document:

- To show, from SPECTRUM Centre for Independent Living's experience, how a locally based (i.e. County or City) network of User Led Organisations (ULO) can be developed which has a clear remit: acting as a peer-support network for small ULOs, and having a consultative/co-production and influencing role within the Local Authority

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



Introduction

Most User Led Organisations are created with aims focused around equality and rights for Disabled People¹. However, as part of a larger project to promote the development of ULO's in Hampshire (see ULO11 Toolkit publication) we were asked by Hampshire County Council to facilitate the development of a ULO network which acted as a peer-support network for small and evolving ULO's within Hampshire. SPECTRUM and Hampshire both believed that ULO principles could apply to any group of disadvantaged people from any of the Equality Act diversity strands. Therefore we agreed to develop a terms of reference and working structure for a ULO network which was attractive to any disadvantaged group of people. Such a network would help build partnerships, and understanding between communities but also encourage learning and development through shared learning and experiences. This was felt to be an initiative and experiment of wider relevance to the singular needs of Hampshire.

In developing an agreed Terms of Reference and a decision making functionally co-operative network, we worked with a wide range of ULO's within Hampshire, including groups of Disabled People, Older People, Gay Lesbian, Transsexual, and BME people.

The key issue, which is addressed in this document, was in developing an inclusive definition for what a ULO actually is within the construct of a ULO network. Members wanted an inclusive definition which was wide enough to enable small or evolving groups to be members, as well as organisations which may wish to become user-led (and need the support of the network to achieve). However, members did not want a ULO definition which was so wide as to allow any organisation that simply provided a service to a disadvantaged group, but which had no real user decision making or control to be members. The pre-existing ULO Design Criteria (Originally developed by the Dept of Health – see our ULO8 Toolkit Publication) was felt to be too restrictive to be a useful definition for a small locally based ULO network as there would be very few (if any) ULOs within the locality which was able to meet ULO8 Toolkit Criteria.

¹ 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.



This publication records the outcome of this project: A Terms of Reference for a Hampshire Focused ULO Network

Terms of Reference for the: Hampshire User Led Organisation's Network (HULON)

(A peer based network of User Led Organisations (ULO's))

Mission Statement

HULON's main aim is to build a strong collective voice and identity for all Hampshire based ULOs and user-led community groups from all diversity strands and communities.

HULON exists to empower ULOs user-led community groups to come together to share experiences, develop ideas, and help each other, as well as supporting the development of new groups which share common values and principles. HULON enables ULOs to develop and engage with a range of influencing and co-production opportunities with statutory bodies, assisting them in welcoming, supporting and working better with ULOs in the future to build individual and collective sustainability.

Objectives

The objectives of HULON are:

- To become a progressive user-led organisations network committed to the empowerment and full inclusion of all user-led organisations and community groups, whilst promoting individual choice and control.
- To enable the collective and representative voice of ULOs to inform and encourage the work of our principle statutory partners.
- To aid the development and sustainability of all user-led organisations in Hampshire, and to become one-stop-shop for peer support, advocacy and advice for user-led organisations
- To create development opportunities for members to enable them to develop and become sustainable ULOs, and to collectively



problem solve barriers to development and sustainability through working together, learning from each other and mutually co-operating in the best interest of all members.

Membership:

- Full (decision making) membership will be open by invitation to all ULO's within Hampshire that meet HULON's criteria and whose activities are consistent with HULON's aims, values, and principles.
- Statutory bodies interested in ULOs would be associate/affiliate members and attend meeting, but will not have right to vote in decisions.

Decision making:

- In order to be sustainable and not create unnecessary, or resource heavy, requirements, HULON was initially to be created as an un-constituted network of like minded individuals.
- Generally decisions about HULON's activities will be made by members as they attend meetings and communicate generally.
- However, provision is agreed that should the need arise; Full Members will elect a small (variable size) steering group of its members to ensure HULON is able to deliver on its agreed functions.

What is a ULO? – definition accepted for HULON full membership:

- ULOs are groups that are run by, and for, people who either:
 - a) use (or are potential users of) support services in Hampshire;
 - or,
 - b) face particular forms of exclusion or disadvantage that they share in common.
- ULOs may be made up of Disabled People, Older People or Carers, LGBT groups, Black and Minority Ethnic communities, or other groups.
- The critical factor that all ULO's will have in common is that they are run by themselves and their users in order to represent their own needs and lived experience of the particular forms of disadvantage or exclusion that their members face.

What is a ULO - essential criteria:



- A group does not need to call itself a User Led Organisation to meet this definition. What a group actually does, and how it is run, is more important than what they call themselves.
- For the purposes of criteria for HULON membership, a ULO is an organisation or group that:
 1. is shaped and driven by the initiative, demand and lived experience of the organisation's or group's user/membership base
 2. engages the organisation's or group's users/members in decision-making processes
 3. is inclusive, avoids unjustified discrimination, and recognises diversity in terms of race, religion and belief, gender, sexual orientation, disability and age

An organisation or group cannot be considered to be a ULO (In terms of HULON full membership) if it:

- Does not meaningfully involve its users/members in decision making and determining its direction and activities. For example, a disability organisation/group that 'represents' Disabled People or disability issues but has no Disabled People involved in running it, or no accountability to Disabled People, could not be a ULO as it fails to meet at least 2 of the 3 essential criteria outlined above;
 - Simply shares a common identity or common interests rather than representing needs or experiences related to a particular form of disadvantage or exclusion. For example, a 'disabled sports club' or a cultural social club would not be a ULO unless it also engaged in meeting particular user defined support needs or tackling particular forms of disadvantage or exclusion that it's users/members share in common.

End of Terms of Reference







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