



Centre for
Independent
Living CIC

**Case Study of the
Setting up a Regional
ULO Network**

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SENDPO



Aim of document:

- This publication details how Disabled People's User Led Organisations planned for the creation and initial development period of the **South East Network of Disabled People's Organisations (SENDPO)**. SENDPO was created as a network of Disabled People's Organisations (DPO's) in the South East region of the UK. SENDPO is managed collaboratively by its DPO members for mutual benefit, to aid co-production and to facilitate the development and support of new DPO's.
- This publication recalls the planning, aims and ambitions that led to the creation of SENDPO in 2011. In 2017 SENDPO has developed into a much valued and strongly supported peer-support based network. We offer this case study to help develop valued and sustainable ULO networks elsewhere.

Prepared by:

- SPECTRUM Centre for Independent Living:
Email: info@SpectrumCIL.co.uk
Phone: 023 8020 2625

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1. Introduction

This document details plans for the creation and initial development period of the **South East Network of Disabled People's Organisations (SENDPO)**. SENDPO is being created as a network of Disabled People's Organisations (DPO's) in South East region of the UK. SENDPO will be managed collaboratively by its DPO members for mutual benefit, to aid co-production and to facilitate the development and support of new DPO's.

This plan, as a sustainable strategy for the development of SENDPO has been developed by a number of established DPO's in the South East and facilitated by a small grant and the active support of the South East Health & Social Care Partnership.

This plan is compatible with similar, but separate, initiatives in other parts of the UK.

2. Raison d'être

The Prime Minister's Strategy Unit report "Promoting the Life Chances of Disabled People" (2005), recognised for the first time the leadership contribution that organisations, run and controlled by Disabled People, make to the development of progressive social policy initiatives (i.e. Direct Payments, Independent Living, Social Model of Disability etc).

The report recognised that Disabled People are best placed to take the lead in identifying their own needs and in identifying the most appropriate ways of meeting such needs, by way of user-led service provision.

Recommendation 4.3 stated that by 2010, each locality should have a user-led organisation (ULO) modelled on existing CILs. It is recognised that the effective implementation of the Government's Independent Living Strategy, the Disability Equality Duty and the Personalisation Agenda cannot be achieved without such organisations.

This document outlines the valuable contribution that SENDPO will make to the meaningful realisation of recommendation 4.3; as well as proposing a strategy and workplan for its creation.

This plan is specifically for the development of a user-led network of DPO's. We define a DPO as a sub-set of the more generic term 'ULO'. This proposal supports the growing understanding that separate (but linked) entities are necessary to effectively meet the differing needs of Disabled People, Carers



and other service users. It may be considered valuable to consider a similar, parallel model to meet the needs of Carers and other service users.

3. Passing the baton from Government, back to users

In order to realise recommendation 4.3 the Department of Health (DoH) have developed various initiatives aimed at defining the characteristics of ULOs and developing the capacity and sustainability of existing and evolving ULOs.

However, whilst these initiatives have had an undeniable impact, the reality is that almost all of these initiatives have been under the control of central or local government. This plan belief is that if Government is to deliver its commitment of choice and control to Disabled People and Carers, then it has now to commit to passing the baton for the next phase of ULO development to the control of Disabled People, Carers and their representative organisations. If, as a nation, we want Disabled People to take control of their own lives, then we have to practice the rhetoric of “**nothing about us without us**” and create role models and peer-leaders and find commissioning solutions which encourages the development of small, locally based ULO’s (and specifically within this plan, DPO’s).

Those peer-leaders who are themselves running DPO’s, or trying to develop a new DPO, are best placed to work with others, using self-help / peer-support principles, to develop initiatives to deliver more numerous and more sustainable DPO’s. These leaders have first-hand experience of the barriers to DPO sustainability, co-production and empowerment.

These people have the skills and experience to develop innovative social policy solutions (as demonstrated by the near monopoly of innovative progressive social policy developments by DPO’s over the last 30 years). During this time, DPO’s have existed with little or variable Government or Local Authority support or core resourcing; we therefore understand what the issues to development and sustainability are for new and evolving DPO’s.

4. SENDPO Mission, Vision, Governance, Structure and Function

Mission: (1) To enable South East based DPO’s to share experiences and build sustainability; (2) To encourage the development of new DPO’s which meet recommendation 4.3 of the ‘Life Chances’ report; (3) To facilitate



effective high quality co-production between DPO's and national and local Governmental and other statutory bodies.

Vision: A society where Disabled People routinely develop and deliver policy and services which empower them to enjoy the same opportunities and citizenship which non-disabled people take for granted.

Governance & Structure: It is envisioned at this stage that SENDPO will be an un-incorporated, network of DPO's within the South East.

Full (voting) membership will be open to all DPO's within the South East that meet our criteria and whose Trustees/Directors are able to adopt SENDPO's values and philosophies (in line with DoH ULO Design Criteria).

Associate (non-voting) membership will be open to those organisations working towards full membership, or to organisations and individuals who wish to support SENDPO's work.

Decisions will be made by full members. SENDPO members will work collaboratively to agree and deliver its mission and vision.

SENDPO will communicate electronically, and meet as necessary to enable it to deliver its mission. Mailing lists and organisation of meetings will be collaboratively managed by members supported by a part time Policy officer seed funded by Partners.

SENDPO will co-produce policy and initiatives with the following bodies:

- South East Health & Social Care Partnership (SEHSCP)
- ADASS (South East Branch)
- National Centre for Independent Living (NCIL)
- Think Local Act Personal Reference Group (TLAP)
- Other bodies as appropriate who share the objectives of SENDPO

5. Long Term Objectives

Whilst the next section provides details of SENDPO's initial workplan and objectives; this section details our longer term objectives:

- A network co-managed by DPO's based locally in the South East; ensuring control lies with Disabled People



- Promotion and practice of an inclusive, non-impairment, non-age specific, non-discriminatory culture which celebrates and positively encourages equality and diversity
- Promotion of disability equality as a human rights issue, as recognised in the Human Rights Act and UN Convention on the rights of Disabled People
- A progressive user-led social policy ‘think-tank’ committed to the empowerment and full inclusion of Disabled People within society through the promotion of Independent Living; with clear terms of reference, principles and value base
- An active network providing added value and positively aiding sustainability of all involved
- Developing sustainable co-productive relationships with statutory bodies who share our aims and wish to invest and support a network which enables them to deliver their duties in respect of involvement, diversity, empowerment and personalisation
- Creating opportunities for members to problem solve barriers to sustainability, working together to learn from each other in the spirit of self-help and mutual co-operation in the best interests of the empowerment of all Disabled People
- Creating personal development opportunities for Disabled People to become empowered and understand principles such as Independent Living and the Social Model of Disability and understand the value of these in transforming their self confidence, motivation and belief in their right to be active citizens
- Working with Disabled People to support the development of more DPOs
- Working with statutory partners to develop procurement and commissioning systems which encourage locally based, user-led service delivery
- Researching, developing and publishing high level guidance and toolkits to both statutory organisations and ULOs to aid ULO development, to minimise ‘reinvention of wheels’ and ensure developments happen from the shared experiences of other ULO leaders



- To enable the collective and representative voice of Disabled People and DPO's as user-led service providers, to inform and encourage the work of our principle statutory partners
- Develop links with other bodies, providing 'feed-up' information to a central DPO (National Centre for Independent Living (NCIL)) able to use this information to develop national co-ordination of DPO activities and inform future legislative lobbying activities by Disabled People and their allies

6. Initial Year One Workplan and Objectives

It is expected that the following workplan will enable SENDPO to develop its ability to become sustainable and able to meet its longer term overall objectives.

- Agree this document as our initial strategy & business plan
- Develop relationship with HSCP South East, ADASS (South East), TLAP & NCIL. Contribute to business plans, initiate and undertake co-productive activities where relevant to the aims of SENDPO
- Conduct a strengths and weaknesses and geographic audit of DPO's in the South East; identifying what services and skills we are individually and collectively strong and weak at to aid mutual support and sustainability; geographic hot and cold spots for DPO's; what tools we have available to aid sustainability and development of new DPO's
- This audit to inform funding applications (particularly to new £3M ULO fund announced by ODI) to aid future DPO developments in the South East
- Develop a DPO directory for the South East, listing organisations, contact information, services and skills, providing a resource for Commissioners as well as the DPO Network.
- Co-produce with statutory partners proposals which seek to develop procurement and commissioning processes which are compatible with the development and sustainability of small, locally based ULO's/DPO's
- Work with statutory partners to influence and respond to Government consultations and policy development impacting on the lives of disabled people.



- Develop communication methods to enable the quick and effective communication of SENDPO members and those who are potential members
- Develop membership forms/values statements for DPO's to sign up to who wish to become SENDPO members (full and associate)

It is anticipated that this initial one year plan can be realised through a £5k pump-primed grant already secured from the South East Health & Social Care Partnership and a sponsoring Local Authority agreement to provide seed funding or seconded resources to enable SENDPO to access the human resources necessary to support its initial development.

7. Values, Principles and Ethos

It is recognised that DPO's share a common set of values and principles and work to a shared ethos. DPO's and Government alike understand these to be a fundamental USP (Unique selling point) to the empowerment of Disabled People and the success of DPO's in the development of progressive social policy affecting Disabled People over the last 40 years.

SENDPO will promote and develop an understanding of these factors. Appendix 1 to this plan illustrates these values, principles and ethos.



APPENDIX 1

A proposed 'High Water Mark' on values, principles and ethos for DPO's and for SENDPO

We believe that there is a real opportunity with the creation of SENDPO to set a 'high water mark' on the values, principles and ethos which will, if adopted, set a new standard for User-Led-Organisations and, specifically for SENDPO, DPO's.

What is the difference between a ULO and a DPO?

The terms ULO and DPO are both 'what-it-says-on-the-tin'. A ULO can exist for any group of users for any service or organisation. A DPO is a specific type of a ULO. DPO's are therefore a subset of ULO's.

The term 'ULO' has come to be overused, and at times misused. SENDPO is concerned that some organisations calling themselves a ULO may in reality have very little leadership from their users.

DPO's share the following features:

- Peer based
- Run, controlled and managed by Disabled People
- Service users are predominantly Disabled People
- Accountable to a membership, where only Disabled members have a vote
- Work to the Social Model of Disability and the principles of Independent Living
- Common set of values, principles and ethos
- Committed to the development of progressive social policy designed by Disabled People to enable the empowerment and inclusion of all Disabled People.

DPO's include organisations who are CIL's (Centres for Independent Living), that commonly provide services to support Independent Living; and Coalitions of Disabled People that commonly act as campaigning umbrella organisations.

If we are able to be transparent, clear and specific of our values, principles and ethos, then there is a real opportunity to reconnect ULO's to what was envisioned by DPO's, when 'Life Chances' recommendation 4.3 was developed.



The Department of Health's research and consultation work around User-led Organisations (ULOs) identified a number of criteria which organisations need to meet to be identified as a "Life Chances ULO". This refers to recommendation 4.3 in the Government's report "Improving the Life Chances of Disabled People" that by 2010, each locality (defined as an area covered by a Council with social services responsibilities) should have a ULO modelled on existing Centres for Independent Living.

The 21 design criteria aim to define the key requirements to be a viable and sustainable ULO. The Department of Health policy acknowledges that these criteria may be met in a variety of ways according to local demand, resources and circumstances.

Not all ULOs are, or aspire to be, a DPO. Many other smaller organisations may be involved in just some of the activities or services associated with DPO's. They are likely to be part of a local federation or network of ULOs working with, or combining to provide the services of a full DPO. Organisations working towards becoming user-led may take some time to meet all the design criteria, but these are central to any organisation's progress towards becoming a ULO.

Values

1) Works from a social model of Disability perspective.

One of the defining features of a ULO should be that it works from a social model of Disability perspective. This is a way of explaining that the individual Disabled Person is not the 'problem', rather, the 'problem' is that Disabled People (which includes people with physical, intellectual or sensory impairments or long-term conditions) are disadvantaged, and often discriminated against, by the way society is built and organised. The social model of Disability is a fundamental principle from which ULOs work.

2) Promotes independent living.

What do we mean by this?

- Many people believe that independence is about doing everything for yourself, and therefore as Disabled People often need assistance in their everyday life, they cannot be independent.
- Disabled People challenge this assumption. We say that independence is not about doing everything for yourself, no-one lives in isolation, we all inter-depend on each other, this is why we all live together as a society.



- It is this fundamental understanding that gave birth to the Independent Living Movement. Choice and control over how you decide to live your life are two of the most important factors often denied to Disabled People. Disabled People refuse to accept that non-Disabled People have the right to deny them choice and control over their own lives.
- Independent Living is therefore not about being able to do everything for yourself; but is about having choice and control over your life and an important say in what happens to you, with support/advocacy appropriate to your needs.
- Disabled People have identified twelve basic rights, which if met would enable them to live independently and fully participate in society, members of SENDPO are committed securing these as rights:
 - Full ACCESS to our environment
 - A fully accessible TRANSPORT system
 - TECHNICAL AIDS/EQUIPMENT
 - Accessible / adapted HOUSING
 - PERSONAL ASSISTANCE
 - Inclusive EDUCATION and TRAINING
 - An adequate INCOME
 - Equal opportunities for EMPLOYMENT
 - Appropriate and accessible INFORMATION
 - ADVOCACY (towards self advocacy)
 - COUNSELLING
 - Appropriate and accessible HEALTH CARE provision

All SENDPO's workstreams will focus on facilitating Disabled People to achieve one or more of these basic rights.

3) Promotes people's human and other legal rights.

Promoting human and other rights is an important feature of ULOs. Examples of how it might be done include supporting people to have their human rights met under the Human Rights Act 1998 and the UN Convention on the rights of Disabled People, and working with people to exercise their rights as citizens, such as through participating in democratic processes like voting in elections, or enabling them to access services, benefits and community resources.



4) Shaped and driven by the initiative and demand of the organisation's constituency.

Providing services which are shaped and driven by an organisation's service users gives added value because, as well as having local knowledge and networks, they have the ability to present the authentic voice of service users who know what works for them.

5) Is peer-support based.

Peer support is fundamental to the way ULOs operate. This is where Disabled People, carers and other people who use support come together to support and/or provide a service to other Disabled People, carers and other people who use support. The shared experience of similar backgrounds or circumstances means that peer support is built on the value of personal experience

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.

It is recognised that many organisations are set up primarily to work with specific groups of people. However, if there are particular client groups that they do not currently provide services to, they need to find ways of working actively, either individually or via local alliances or wider networks, to establish working relationships and ensure the needs of different groups are appropriately met

7) Is non-discriminatory and recognises and works with diversity in terms of race, religion and belief, gender, sexual orientation, disability and age.

This means that rather than simply saying that an organisation works with all disabled people in terms of their impairment, it must actively reach out to all sections of the community who are Disabled People, e.g. Disabled People from Black and Minority Ethnic (BME) backgrounds, those who are lesbian, gay, bisexual or transgender (LGBT), people of different ages, and so on.

8) Recognises that carers have their own needs and requirements as carers.

It is important to accept that Disabled People and other people who use support often have different issues than those faced by carers. However, they are not inherently competitive by nature. There needs to be room within ULOs for different interest groups to collaborate, or work separately where necessary, so that the interests of all groups are accommodated without anyone feeling compromised.



The fact that someone is a carer does not preclude them from having a strong commitment to independent living and the social model of Disability. It is possible for Disabled People and carers to work together on common areas of concern or interest, at the same time being very clear about where the differences between them lie and work separately on those areas.

If the ULO has a constituency of carers and Disabled People and other people who use support then carers are likely to be part of the decision-making process. However, where an organisation is comprised of different groups of people then all those groups have to sign up to the values and characteristics that are set out in the ULO Design Criteria.

There is a growing acknowledgement that carers have perspectives and support needs of their own, such as peer support, advocacy, direct payments, information, advice, user involvement and so on.

It should also be noted that some carers may also be Disabled People or others who use support services, so the two groups may have considerable areas of overlap.

9) Engages the organisation's constituents in decision making processes at every level of the organisation.

ULO's need to ensure the involvement and employment of their users at all levels of the organisation. This means that they need to be involved in making executive decisions (e.g. exercising control over policy or resources), as well as a variety of other ways in paid or unpaid positions (e.g. providing peer support, delivering services and being involved in monitoring).

Organisational Criteria

10) Provides support to enable people to exercise choice and control.

Enabling people to exercise choice and control over their own lives lies at the heart of what ULOs should be doing

11) Is a legally constituted organisation.

It is acknowledged that different organisational structures may be needed to fit different local circumstances and organisational histories and that 'one size' will not fit all. However, ULOs wishing to be employers, to be commissioned to provide services or take on other activities like training or consultancy will need to be a legally constituted organisation such as a registered charity, company limited by guarantee, not-for-profit, Community Interest Company or social enterprise. This decreases the risk and liability of those managing the organisation.



12) Has a minimum of seventy five per cent of the voting members on the management board drawn from the constituency of the organisation.

With 75% of the voting members being drawn from the organisation's constituency there is room for having co-optees or board advisors who offer additional expertise or experience that the board may need.

13) Is able to demonstrate that the organisation's constituents are effectively supported to play a full and active role in key decision-making.

For an organisation to be effectively run and let by its service users, its constituents need to be able to play a full and active role in decision making. This means that Disabled People, carers and other people who use support should have their access needs addressed and be fully supported through training, mentoring, 'buddying' and other support to become empowered and able to play a full and active role in informed decision making.

14) Has a clear management structure.

Given that accountability is fundamental to a ULO and how it works, it is essential that clear management structures are in place. Although it is recognised that some smaller organisations may rely on one or two people to fill several roles, this can create problems if one of those people leaves the organisation, as the expertise and knowledge of the organisation will go with them

15) Has robust and rigorous systems for running a sustainable organisation (e.g. financial management / contingency planning).

Factors considered critical to the operation and sustainability of a ULO include:

- having fully trained board / committee members or staff, especially in legal and financial matters
- the ability to develop organisational resilience in the face of change
- being prepared to engage in democratic processes and influence local policy makers
- the ability to understand the power dynamics within organisations themselves as well as in the locality.

16) Is financially sustainable.

Although it is recognised that uncertainty about funding is a key factor for many organisations, it is recognised that locally based small ULO's face



particular challenges. A strong relationship with the local authority can help with securing on-going funding, and the development of diverse and innovative income sources are important.

17) Has paid employees, many of which must reflect the organisation's constituency.

ULO's need to be organisations that employ disabled people, carers and others who use support as well as have them as volunteer board or committee members. The capacity of an organisation can be limited because of a lack of paid staff. Volunteers play an important role in the operational activity of organisations but an over-reliance on volunteers can potentially leave an organisation in a vulnerable situation.

Staff wise, all decision makers and most front-of-house staff should be Disabled People.

To provide an environment where DRP can recruit Disabled staff with the right skills and experiences (and values) SENDPO members will need to provide progressive empowerment programmes.

However, we also recognise the important role of non-disabled allies, both as Trustees and as staff.

A policy will need to be developed for existing non-disabled staff. We need to ensure they feel welcome, included and valued. NCODP for instance have developed a policy which retains their existing non-disabled staff, but as staff move on, their role are evaluated and then if felt necessary, are designated through recruitment for Disabled People only

18) Identifies the diverse needs of the local population and contributes to meeting those needs.

Involving an organisation's constituents in the running of its services gives added value because, as well as having local knowledge and networks, they have the ability to present the authentic voice of service users who know what works for them. Particular areas of expertise within ULO's can include knowledge about access, participation and empowerment issues, provision of peer-led support, mentoring, advocacy and self-help techniques.

Using local knowledge and expertise to identify the diverse needs of the local population and contributing to meeting those needs is fundamental to the way ULO's operate.

19) Is accountable to the organisation's constituents and represent their views at a local level.



Organisations established by local people are in a very good position to support their constituents in engaging with services and also representing their interests (where appropriate). A ULO should be able to say what its constituents want locally and be able to work with a range of statutory and voluntary sector organisations to improve local communities and resources. This may mean that the organisation adopts a campaigning and networking role.

In order to function as a ULO it is extremely important that the organisation, particularly in terms of its management board, is accountable to its constituents. This may be through a formal membership system with everyone having voting rights, or there may be more loosely defined systems for ensuring accountability such as open meetings or some form of quality assurance mechanism. ULOs need to find ways to involve members in governance, or consult ordinary members, rather than simply relying on them turning up at meetings. This requires resources.

20) Supports the participation of its constituents in designing, delivering and monitoring the organisation's services.

In addition to providing services, ULOs can work with their constituencies so that the organisation (on its own or with other local ULOs) may be involved with:

- disseminating information about what accessible features, environments, support and facilities are required for participation to be inclusive to all
- providing support for consultation and involvement
- providing interpreting and transcription services
- access auditing
- providing or being involved with Disability Equality and diversity training
- disseminating knowledge of the DDA and other Disability specific legislation
- accessible housing and transport
- delivering research, consultancy and training.

21) Works with commissioners to improve commissioning and procurement.

ULO's are in an ideal position to work with public bodies on not only meeting the Disability Equality Duty, but also in terms of fulfilling duties to involve Disabled People, carers and other people who use support in developing



policy and practice. There is potentially a real strength for local authorities and other public sector organisations (e.g. NHS bodies) in working with ULOs in building local communities and raising service standards.

ULO's can save money for public bodies by their involvement in preventative work and through new ideas about the best way to provide support and services for Disabled People.

It is important to build relationships with public bodies, and also for Disabled People, carers and other people who use support to be involved in co-producing commissioning strategies, setting specifications for services or designing outcome measures. Evaluation of services should not be based on activity levels, but instead on outcomes.





Centre for
Independent
Living CIC

CONTACT DETAILS



Address:

**SPECTRUM Centre for Independent Living
Unity 12
9-19 Rose Road
Southampton
SO14 6TE**



Website: www.spectrumcil.co.uk



E-mail: info@spectrumcil.co.uk



Telephone: 023 8033 0982



Minicom: 023 8020 2649

SPECTRUM is also on:



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