



The future of User-led Organisations

This briefing sets out the current crisis being experienced by User Led Organisations (ULO) and seeks to stimulate discussion leading to positive action to ensure their sustainability. Shaping Our Lives and the National Survivor User Network (NSUN), two key national disabled people's and service user networks, have worked to identify key areas of concern:

1. The loss of knowledge, peer support opportunities and advocacy through the disappearance of ULOs.
2. The social and wellbeing impacts of no collective voice for service users and resulting power imbalances.
3. The unique and valued role of ULOs in the individual self-empowerment and involvement of service users.
4. The particular capacity of ULOs to support diverse involvement and to challenge the exclusion of BME and other marginalised groups.
5. Funding trends that exclude or severely disadvantage ULOs.

Background

Historically, Disabled people and people with mental health problems/experiencing distress have lacked a voice. They have not been involved in decision-making and have been at continual risk of social exclusion and discrimination. Collectives of oppressed and marginalised people have been campaigning to have a voice for centuries through civil rights movements and lobbying for legislative changes, but it is only over the last few decades that we have seen Disabled People's User-led Organisations (DPULO) and User-led Organisation (ULO) becoming established, formally recognised and resourced.

A user-led organisation (ULO) is run and controlled by people who use or need the support of health and social care services, including people with physical and sensory impairments or learning disabilities, mental health service users, people with long term and life limiting conditions, older people and their families and carers. User-led organisations have become firmly embedded in the health and social care environment, particularly since the principles of involvement and 'user-centred care' were enshrined in legislation in the early 1990s.

[Service User Involvement in Health and Social Care Policy and Legislation](#), NSUN 2015

User-led groups have traditionally been about self-help, advocacy, peer (mutual) support and campaigning. They are founded on shared, core values which have arisen from the individual and collective experiences of people previously only on the receiving end of services. Shaping Our Lives and NSUN define what makes a user-led group in terms of value, power and knowledge. An organisation must be able to demonstrate the following if to be considered a user-led organisation:

- It is based on clear values of independence, inclusive involvement and peer support.
- Disabled people and/or people with lived experience of distress control the organisation through leadership of decision-making.
- It is uniquely identified by the direct lived experience and full inclusion of Disabled people and/or people with lived experience of distress.

Over the last 20 years many user-led groups have become service providers, providers of activity, advocacy, involvement and peer support with an emphasis on prevention. For many people, being involved in or leading a user-led group has meant overcoming a 'state of powerlessness' (WHO 2010), gaining more self-esteem and exerting more influence on social and political decision-making processes.

The value of user-led groups

- **Power** - working to redistribute power within initiatives where the independence, agency and autonomy of service users/survivors is being eroded or ignored.
- **Knowledge** - challenging the hierarchy of evidence and promoting the validity of experiential knowledge.
- **Authentic voice** - legitimate and credible because it is based on direct experience and not heard by proxy or influenced by an organisational or provider agenda.
- **Specialist expertise** - the knowledge and skills held by user-led groups about the needs of local service users can help make commissioning decisions and existing service provision more effective and efficient.
- **Inclusion** - identifying and overcoming barriers for marginalised and racialised groups to tackle exclusion by providing opportunities to develop confidence and skills, social networks, a sense of community.
- **Influence** - improving services and support through involvement and co-production activities and independent, changing perceptions through collective action.
- **Information** - sharing of personal and professional resources to make lives better as well as a single point of contact for commissioners and service providers about current issues and ideas for improvement.
- **Prevention** – creating resilient communities through leadership and the direct voice of experience promoting good health and wellbeing.

The scope of the problem

At the end of 2016 NSUN conducted a review of its member groups and found that over 150 had closed and 55 new groups had joined the network. By July 2017 another eight organisations had closed, totalling 158 closures. In comparison, the previous review found that 20 groups had closed and about the same amount joined. The 158 closures over an approximate 18-month period included user-led groups and non-user-led groups/and smaller to medium-sized organisations. 74% (n=117) of the closures were user-led groups.

Shaping Our Lives has deleted 124 user-led groups from our national network since 2016 and updated details for 60 members. This is a loss of 26% of our user-led groups from the national network in less than three years. Our own evidence and other trends identified across the sector reveal a startling fact that the diversity of our sector is under threat.

NCVO's UK Civil Society Almanac 2018 states that the voluntary sector's economy is dominated by larger charities (with an annual income of over £1m). *"Only around 3% of all voluntary organisations have an annual income of over £1m, but these large organisations account for 81% of the sector's total income. While the number and proportion of small organisations is decreasing, the number and proportion of large charities is increasing. In 2013/14 we decided there were enough organisations (39) with an income above £100m to*

create a separate category of super-major charities. Their number continues to grow; there were 45 in 2015/16, compared with 42 in 2014/15."

(UK Civil Society Almanac 2018, NCVO <https://blogs.ncvo.org.uk/2018/05/09/almanac-2018-what-does-the-data-tell-us/>)

Why has this happened?

A) Austerity cuts to government funding

In recent years, many ULOs have received grant funding from local government. However, continued severe cuts to public funding means that this type of funding has disappeared - (analysis by the Local Government Association (LGA) has revealed that, overall, councils will have suffered a 77 per cent decrease in the government funding between 2015/16 and next year, dropping from £9,927m in 2015-16 to £2,284m in 2019-20

<https://www.independent.co.uk/news/uk/home-news/england-council-budget-cuts-government-austerity-social-services-essential-care-safety-a8559486.html>).

A trend to award large contracts to national private sector organisations to manage the sub-contracting of smaller contracts has intensified the problem. ULOs have often lost their existing service contract to these large operators and then been asked to deliver the same service for a much reduced budget. ULOs have reported that they are not prepared to lower the quality of their services to the extent necessary and/or cannot afford to continue to deliver the service.

Those ULOs that are still receiving Local Authority funding, either through grants or commissioned services, have reported that the work they do to protect the lives of service users is now sometimes in conflict with the actions of their local government. This is creating tensions, pressurising ULOs not to speak out about damaging local service cuts because they fear losing contracts if they do.

B) Other funding

The 'Strengthening DPULO programme' ended in March 2015 and many of the development initiatives and funds to create sustainable ULOs are no longer available. Although grant making trusts and foundations have shown commitment to funding the user-led sector, there is often a focus on 'service' delivery in a project funding model. ULOs stepped up to the funding demands, but there is now increasing evidence that they are unable to sustain longer term project funding and finance their core running costs on project funding alone.

Survival of ULOs is being threatened by funding policies that restrict the amount of a grant as a proportion of turnover. As funding has disappeared from traditional sources, the turnover of ULOs has shrunk and consequently they can only apply for small grants, making capacity building very difficult and creating structural barriers in the way of their sustainability.

C) Blurring of identities

The varying success and recent demise of user-led groups has led to a situation where the boundaries and definitions for user-led groups have become blurred. Other organisations

working with 'users' but not run by 'users' have adopted the language and approaches of user-led organisations, and although this has been encouraging and indeed what many groups have lobbied for, this has been to the detriment of user-led groups with larger charities and provider organisations shifting from being supporters of user-led organisations to competitors. For small user-led groups this has been an impossible environment within which to thrive and at worst, survive.

D) Individual capacity

The people who set-up and grow ULOs are now the same people who are experiencing some of the worst deprivation, poverty and life chances in our communities. Their resilience and ability to struggle both personally and on behalf of others is now greatly diminished. The diminishing voice of ULOs means that there is less opposition and influence both locally and nationally to oppressive policies.

E) Community and social impacts

It is widely recognised that working alongside communities to understand their issues and build on existing strengths, assets and resilience is key to prevention. It can be argued that user-led groups demonstrate the ambitions of many policy papers and approaches such as promoting an Asset Based Community Development approach (ABCD). For many years' user-led groups have been enabling individuals and communities to be active participants in planning, prioritising and implementing health and social care improvement actions. They have played an important role in being community connectors and capacity builders and as a matter of course do things that are beneficial to individual wellbeing. ULOs have played a significant role also in developing appropriate and skilled employment for Disabled people and other service users, as well as supporting their skill development. While service users do not see paid employment as necessarily possible or appropriate for all, ULOs have created an important source of skill development and employment opportunities for service users as well as offering them high quality much valued support in the process.

F) Increased risk

The unique operating model of ULOs has traditionally allowed a range of opinions and experiences to be inclusively considered, allowing ULOs to make informed and safe recommendations to people seeking support. However, if ULOs are unable to fund the involvement of the people they represent, or the ULO in an area no longer exists, there is a greater risk that the quality and accuracy of information will be poor.

References

Branfield, F. Beresford, P. with Andrews, E.J. Chambers, P. Staddon, P. Wise, G. and Williams-Findlay, B. (2006), *Making User Involvement Work: Supporting service user networking and knowledge*, York, Joseph Rowntree Foundation, York Publishing Services. This research report highlights that ULOs are particularly effective in supporting the development and sharing of user knowledge and service user networking, but that their impact and effectiveness is limited by the dominance of large non-user-led charities.

Barnes, C, Mercer, G, 2006, *Independent futures: Creating user-led disability services in a disabling society*, Bristol: Policy Press in association with the British Association of Social Workers. This is the final report of the largest and most detailed research study of ULOs and the services they offer. It found that these services and support were particularly valued by disabled people and other service users