

Austerity is denying patients and care service users a voice

[Peter Beresford](#) - Published in The Guardian – Januari 19, 2019

Decades of progress on public participation are being lost as grassroots organisations face financial problems and closures.



‘The movement for participation has led to some important innovations in policy, practice and research.’ Photograph: Dean Mitchell/Getty Images

For years, the mantra in public services has been that patient participation and user involvement are key, and that service providers should listen to what their customers want. Here lies the route towards empowerment and cost-effectiveness. A whole literature and new ways of working have developed, and requirements for such involvement are [enshrined in law](#).

Over the past 40 years, this movement for participation has led to some profoundly important innovations in policy, practice and research.

User involvement in professional education was [pioneered in social work](#), where service user and carer involvement is required at all stages. Students, service users, carers and educators all strongly support such involvement and see it as a key way of improving the culture of practice.

Research has been transformed by new approaches that focus on making positive personal and social change. This has gone hand in hand with a revaluing of lived experience or “experiential knowledge”.

The pressure for participation has also led to the development of a different kind of voluntary or community group: user-led organisations (ULOs). Historically, charitable or voluntary organisations have tended to be based on a model of one more privileged group getting together to help another disadvantaged one. Herein lies the achilles heel of traditional charity, and the essential inequality of its relationships. ULOs are democratically controlled by those they are intended for: disabled people, mental health service users/survivors, people with long-term conditions and others. Services provided by user-led organisations [are particularly valued](#).

Wonderful new services have developed inspired by disabled people's and user-led organisations. Direct payments, putting people in charge of their support needs, are perhaps the best known. Other innovations include helplines staffed by people with direct experience; non-medicalised crisis centres run for and by mental health service users; social care cooperatives; advice, information and self-advocacy schemes, which have equipped people receiving social services with new skills to help each other; and peer support schemes where people with lived experience provide new forms of emotional and practical support.

Amazing transformative changes have also taken place at policy level. The [Health](#) and Care Professions Council requires effective user and carer involvement in all the allied health profession courses for which it is responsible.

Research organisations and funders increasingly monitor research programmes, projects and applications for meaningful public, patient and user involvement. Improvement agency the Social Care Institute for Excellence has from its creation built user involvement into its governance and priorities, and established a [co-production network](#). In 2018, the first text [highlighting global progress on participatory public policy](#) was published.

Yet such involvement is at risk. Service users and their organisations are increasingly concerned about stalled progress. They talk about “tokenism” and being used to rubber stamp decisions already made. Exclusions particularly along lines of ethnicity, age, communication access and housing status [abound](#). Cruel cuts in social care and arbitrary “welfare reform” that has impoverished tens of thousands and led some people [to consider killing themselves](#) give the lie to official participatory rhetoric such as [“We Asked, You Said, We Did”](#). Instead, there are growing fears that participatory schemes [have fallen victim to spending cuts](#).

Local mental health and disability ULOs [have been closing at a high rate](#), facing big problems of inadequate funding and financial insecurity. ULOs that offer the most direct and effective expression of user voices [are being lost at an unprecedented rate](#).

Key networks such as the [National Survivor User Network](#) and [Shaping Our Lives](#) have faced serious funding difficulties. Yet there doesn't seem to be widespread or [official recognition](#) of this crisis. Without these organisations, we can have little hope that the pressure for participation will be maintained.

User and public involvement [commands enormous popular support](#) and its [achievements have been groundbreaking](#). But austerity has been a poor bedfellow and all too often, policymakers pay it lip service while implementing policy cuts. Retreat from meaningful involvement impoverishes public provision, undermines accountability and creates a vicious circle of ever-diminishing engagement and support.

It is time for renewal. The lead has to come from central government, which would do well to return to earlier ideas of developing a national network of local user-led organisations as part of a [unified strategy for independent living](#). This must start by supporting the grassroots, reviewing the grossly unequal distribution of funding between ULOs and traditional charitable and other organisations providing services, research and professional learning – all areas that service users and their organisations have shown a remarkable capacity to advance and improve.

The lesson of the past 40 years, which risks being lost, is that this offers the most hopeful route to the cost-effective and responsive services and benefits at an especial premium, as the number of older and disabled people in our population rises rapidly.

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- *In the UK, Samaritans can be contacted on 116 123 or email jo@samaritans.org. In the US, the National Suicide Prevention Lifeline is [1-800-273-8255](tel:1-800-273-8255). In Australia, the crisis support service Lifeline is 13 11 14. Other international suicide helplines can be found at www.befrienders.org.*