

Using Experiential Knowledge: Shaping Our Lives

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The disability movement is a jigsaw – each piece is vital for the true picture to emerge

(Campbell and Oliver, 1996)

The Social Model: 'the big idea'

Impairment: the functional limitation within caused by physical, mental or sensory impairment

Disability: the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers

(DPI, 1981)

Disability: a form of social oppression, not something people 'have'

(UPIAS, 1976)

We break through the idea, presented to us by the medical profession and disability charities in particular, that our situations are different and unrelated, and come together not as the blind or the deaf or the epileptic, or the spastic or the arthritic, but as disabled people

(Sutherland, 2004)

The UK Disabled People's Movement

BCODP 1979

Coalitions of Disabled People 1984

Centre for Independent/Inclusive Living 1984

Disability Arts Forums 1986

Disability Equality in Education and the Alliance for Inclusive Education 1980s

Disability Studies 1990s

Disabled People's Direct Action Network (DAN) 1990s

(Cameron, 2014)

Shaping Our Lives: 1996

a non-profit making user-led organisation specialising in the inclusive involvement of Disabled people and people from other marginalised communities.

a small staff team and a National User Group. We also use a range of experts from diverse communities to support the delivery of projects.

demonstrates that by removing barriers and promoting inclusion, the value of lived experience can be equal to other professional competencies.

Promotes system and social change through the voices of those people most often excluded.

Instrumental in supporting national policy development and we provide practical support for user groups and others.

Promotes the voices of different equality groups who use health and social care services, and other services provided by the public and voluntary sectors.

Most – but not all – of our work is with Disabled people because 70% of health spend and most of adult social care spend is on Disabled people.

Our expertise, however, is of working with people with multiple identities and disadvantages.

What do we mean when we say 'service user' (rather than 'experts by experience')?

It means that we are in an unequal and oppressive relationship with the State and society.

It is about entitlement to receive welfare services.

It may mean having to use services for a long time, which separates us from other people, making some think we are inferior and that there is something wrong with us.

Being a service user means that we can identify and recognise that we share a lot of experiences with a wide range of other people who use services.

This might include, for example, young people with experience of being looked after in care, people with learning difficulties, mental health service users, older people, physically and/or sensory impaired people, people using palliative care services and people with drug and alcohol problems.

Recognising our shared experiences of using services, whoever we are, makes us powerful and gives us a strong voice to improve the services we are given, and more control and say over what kind of services we want.

Types of involvement:

consultation

engagement

co-production

Inclusive Involvement

Involvement activities enable people to have a say in policies and services that affect their lives. It can mean sharing experiences:

- of using services

- of being part of a diverse community

- of having an impairment or long-term health condition.

Examples

focus groups with local authorities

sharing lived experiences with students on a social work degree course

one-off consultations

a series of engagement events equal partnerships of service users and service providers to co-produce a service or research study

Involvement Opportunities

Disabled Children's Rights: Pilot Participatory Cataloguing Workshops for the Scope Archive

Young Adults who Grew up in Informal Kinship Care

Exploring the connection between language use and social experience of autistic adults

Carers' perspectives on shared decision-making in risk assessment and management in mental health

Oldham Mental Health Lived Experience Forum member

Oxfordshire Domestic Abuse Lived Experience Advisory Group

Looking for researchers with lived experience of psychosis

What we offer:

Support to take part in Involvement

Support to run Involvement

Involvement Opportunities Board

Research and Reports

Match making in research: Practical reflections on partnerships between user-led organisations and universities (2023, with King's College, London)

Tickboxes and Tokenism? Service User Involvement Report (2022)

Engaged or Ignored? – Reflections from Patient Participation Groups about the Impact of COVID-19 (2020)

Including the Missing Voices of Disabled People in Gypsy, Roma and Traveller Communities (2020)

Improving Understanding of Service User Involvement and Identity – Service User Identity Research Findings (2017)

Assisted Dying: Developing the Debate – Exploring the issue of assisted dying and its legislation in the UK (2017)

From Mental Illness to a Social Model of Madness and Distress(2016)

Funding

Precarious, but okay for the moment (hopefully)

Gina Barrett, SOL National User Group Member

They have supported me by always being interested in what I've got to say. In some other organisations they won't give us the power to speak up and talk about how we are feeling. SOL gives us the power to do that, speak up and say our views. They care what we think and they put our views into what they are thinking. They always ask what we think about what they are doing. They always ask us, have you got anything to say.

(Cameron, Taylor and Barrett, 2026)

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