

**Meaningful Involvement:
If you want a change- be the change**

***Sharing power, responsibility and
achievements***



Learning Outcomes:

- To put the Service User Involvement Movement in context: historically and via key policies
- To use some tools to assess and map and develop service user involvement
- To analyse challenges and opportunities of service user involvement
- To discuss and see evidence of why it's important
- To see an example of what organisations and people can achieve – Fulfilling Lives' SUI
- To plan next steps to develop your service user involvement practice.

CITIZEN POWER

CONSUMERS

RIGHTS

MUTUAL AID

GROUPS

CITIZEN

PARTICIPATION

COPRODUCTION

SERVICE USER

INVOLVEMENT

PARTNERSHIP

PEERSUPPORT

SURVIVORS MOVEMENT

EXPERTS BY EXPERIENCE

CONTROL

ENGAGEMENT

MENTAL HEALTH SERVICE USER

MOVEMENT

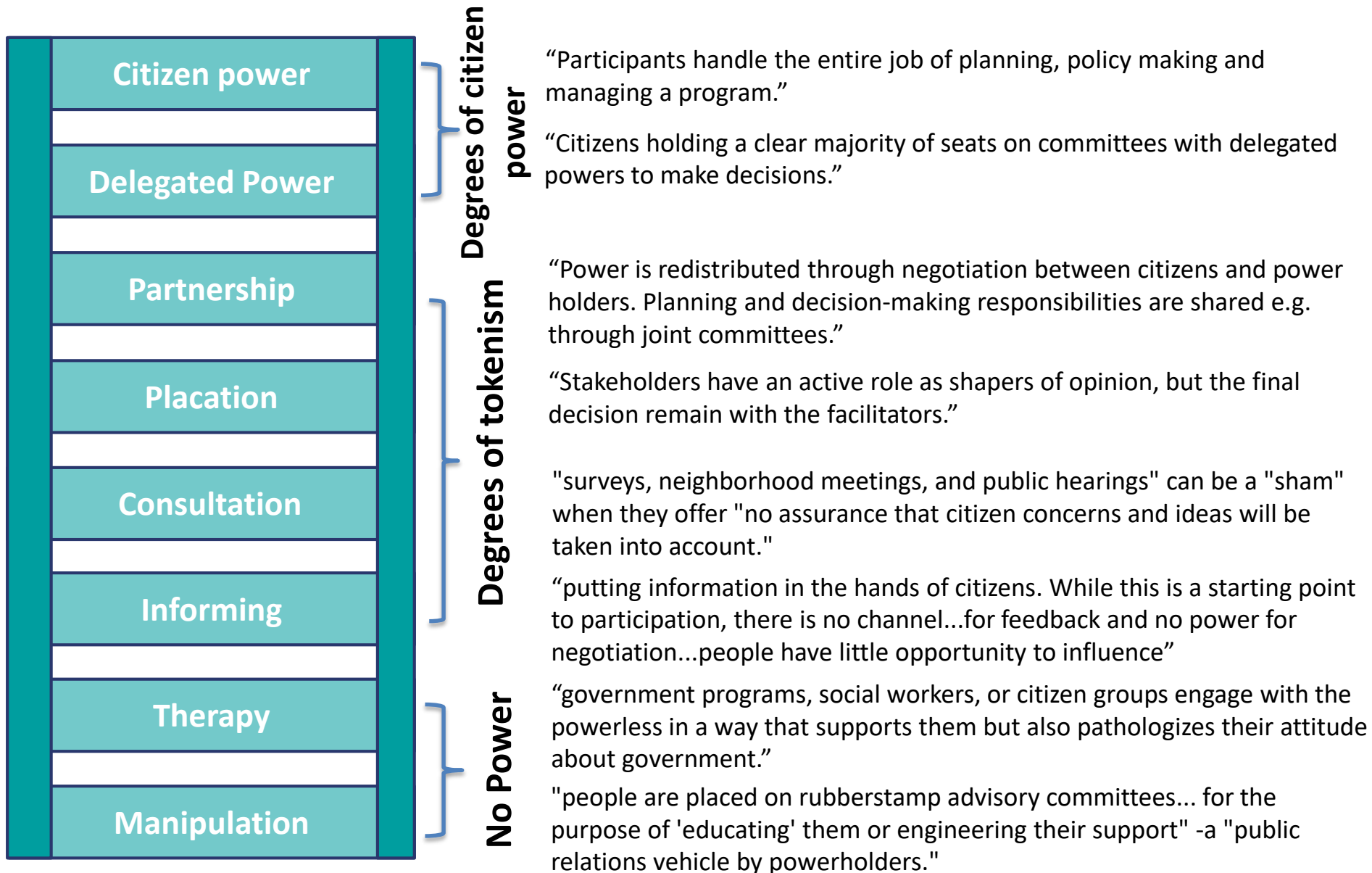
What is Service User Involvement?

- Service user involvement is about making sure that mental health services, organisations and policies are led and shaped by the people best placed to know what works: people who use mental health services. They are experts by experience. **nsun- Network for mental health**
- Service user involvement refers to the process by which people who are using or have used a service become involved in the planning, development and delivery of that service. **NHS England**
- Service users clearly have unique experiences, skills and abilities that enable them to provide 'expert advice' in this field. Substance misuse strategies and services are likely to be more effective if they are developed and delivered with the direct involvement of the people who use them. **Substance Misuse Treatment Framework(SMTF)**
- The people and families who have experience of the Criminal Justice System (CJS) are a vital source of intelligence about how to improve services. Involving these 'experts by experience' is key to the difference we can make in the lives of offenders - improving the quality and impact of the services on offer, and enabling services users to build a new identity which supports their journey to desistance from crime. **CLINKS**

Brief history of Service User Involvement

- 1620s Precursor of modern day advocacy groups: Inpatients in psychiatric hospitals came together to speak out as early as the 1620s, with the 'Petition of the Poor Distracted Folk of Bedlam'.

○ 1969, Arnstein's Ladder of Citizen Participation



Citizen Participation is Citizen Power

“The idea of citizen participation is a little like eating spinach: no one is against it in principle because it is good for you. Participation of the governed in their government is, in theory, the cornerstone of democracy—a revered idea that is vigorously applauded by virtually everyone. The applause is reduced to polite handclaps, however, when this principle is advocated by the have-not blacks, Mexican-Americans, Puerto Ricans, Indians, Eskimos, and whites. And when the have-nots define participation as redistribution of power, the American consensus on the fundamental principle explodes into many shades of outright racial, ethnic, ideological, and political opposition.”



○ 1970-80s, Service User Movement begins in England

The Context:

1. The disability movement: campaigning to show that disability is a 'quality of the physical environment that excludes individuals from social and economic environment'.
2. Anti- psychiatry movement: questioned the effectiveness of some drugs and encouraged other means of care and treatment for people with mental health problems.
3. Consumerism: move from 'patient' to 'consumer'. People using services are regarded as health care consumers thus having rights on giving their opinion of the service they receive.
4. Reliance on non governmental organisations

Patient-only groups: the Mental Patients Union and COPE, which became the Campaign Against Psychiatric Oppression (CAPO).

Charities such as Mind and the National Schizophrenia Fellowship (Rethink) created at this time.

Broad alliances of a wide range of interest groups but not run by service users themselves.

1980s formation of local user forums for mutual support and user involvement work

In 1985, the Mind/World Federation for Mental Health Conference was held. Dutch and US patient groups met UK user/survivor groups for the first time. This stimulated the growth of the movement, in particular, service user-led advocacy.

First TV programme made in 1983 by service users/ survivors, called 'We're Not Mad, We're Angry', was a critique of the psychiatric system and described personal experiences of treatment.

Service User Involvement in Policy

- The NHS and Community Care Act 1990. This was the first piece of UK legislation to establish a requirement for user involvement in service planning.
- Modernising Mental Health Services 1999, the National Service Framework for Mental Health (NSF) 1999 and the NHS Plan 2000. place a strong emphasis on the role of users as key stakeholders in service provision and the need to transform services in direct response to users' needs.
- Section 11 of the new Health and Social Care Act 2001. This places a duty on NHS trusts, primary care trusts (PCTs) and strategic health authorities to make arrangements to involve and consult patients and the public in service planning, operation and in the development of proposals for changes.
- Making shared decision-making a reality: No decision about me, without me, 2011. The government's vision is for patients and clinicians to reach decisions about treatment together, with a shared understanding of the condition, the options available, and the risks and benefits of each of those.

The Service User Involvement Movement in Brighton

The Ladder of Involvement



Service Users take lead in activities from beginning to end or start new initiatives are independent from the service

Service Users and professionals have got an equal part in a process; they take decisions jointly, all have active roles, and responsibilities.

Service users take part in decision making, but responsibility and active roles falls on to the professionals.

Service users are consulted about some aspects of a service; they may provide feedback, etc. Professionals may use that feedback to make decisions, shape a service etc.

Professionals inform service users of some aspects of the service, changes, activities, etc.

Service User receive a service, this is unidirectional

Service User Leadership Spectrum

Beginning of Service User Involvement

- Service user consultation via:
 - Surveys
 - Service users attending staff meetings to feed back information collected
 - Meetings between staff and service users with no formal agenda and no time to plan
 - Service users attending meetings where the agenda is set by the organisation
- Staff not required to act on service user feedback
- Quality measures use clinical standards only
- Staff training content contains no service user input
- Priorities determined by systems, rather than people
- Leadership and vision is seen as the domain of staff

Good Service User Involvement

- Independent Service User perspectives present all levels
- Service users influence governance, policy and practice
- Internally, service users lead some initiatives through to completion
- Externally, service users originate and lead some organisational initiatives with minimum influence from the organisation
- Service user groups preparing to become independent of host organisation
- Organisation remains responsive to service user leadership even if it doesn't plan to become service user led
- Pro-actively building local service user led organisations and initiatives (may include capacity building for a national infrastructure to support this)

Service User Led

- Service users lead on governance
- Service users lead on authentic peer support
- Service users articulate and measure quality of practice and service outcomes
- Service users lead policy development
- Contributes to capacity building of service user led groups and development of a national infrastructure to support this
- Supports independent service user led groups
- Leadership and vision owned by people who services and carers, as well as professionals and staff
- Community-based or 'of the community'
- Co-production is service user led around agreed, shared agenda

Levels of Involvement

Involvement in their
own care or
treatment plan

Involvement in
strategic development
and commissioning

General SUI

Peer Support

Recovery-focused
organisations, social
enterprises and
recovery communities

Video- No More Throw Away People

Parable of the 'blobs and squares'

<https://www.youtube.com/watch?v=C107PQ3h8Kk>



Involvement in Fulfilling Lives- Coproduction is the goal

PRINCIPLES

➤ **Two-way relationship**

ACTIVITIES

Each individual has got a personal plan and a mentor assigned to work on that plan. They decide what they want to achieve by being involved and work towards that goal
Our goal is to empower people so that they can truly get involved

TOOLS/RESOURCES

Monthly mentoring sessions
Access to training
Empowerment model

➤ **Involvement at all levels**

Representatives at Core group (governance)
Service Delivery
Staff recruitment
Involvement is a key outcome
Backbone of our Service Improvement Work
Involvement in own support
Feedback about the support offered
Team meetings
All staff/team events
Delivering training

Involvement imbedded in project outcomes
Employment-Project Consultant team
Volunteering

Involvement in Fulfilling Lives- Coproduction is the goal

PRINCIPLES

ACTIVITIES

TOOLS/RESOURCES

➤ Training and support to be involved

Each individual has got a mentor assigned
Regular mentoring sessions
Debriefings
Support to attend events
Support to prepare for meetings and activities

Mentors- Mentoring sessions
Skills and Assets Forms
Development plans
Induction period
Tailored training
Briefing- purpose and jargon buster in agendas
Wellness Action Plans

➤ On going learning

Open attitude
We do not get it right all the time
Seek feedback all the time
Ask people what they think of their involvement and be open to criticism
Use reflective practice with staff to learn and improve practice

Volunteers and beneficiaries surveys
Informal feedback
Reflective practice
Plain English guide

➤ Value

See people as assets and value their contributions
People will feel value if you truly listen and act upon their views and suggestions
Be prepared to share power
Acknowledge and reward people for their contributions



Attendance to events
Budget for fun activities
Training certificates
Volunteers certificate of achievement

So what's the point?

Group discussion:

What are the challenges and the opportunities when we do Service User Involvement?

Despite these...

Why?

What are the benefits of meaningful involvement?

For individuals:

- ✓ Improves wellbeing
- ✓ Reduces levels of dependency
- ✓ Creates mutual aid networks
- ✓ Promotes positive mental wellbeing and healthy life styles
- ✓ Empowers service users
- ✓ Increases feelings of control
- ✓ People are more positive about the services they use, thus engaging more with the service and the support offered

For services and professionals:

- ✓ Service users help improve the quality and safety of services
- ✓ Help tailor services to need and improve efficiency
- ✓ Utilise service user and carer expertise and knowledge
- ✓ Help to inform commissioning and set priorities
- ✓ Reduce complaints
- ✓ Increase ownership of, and compliance with, agreed treatment plans
- ✓ Service Users can deliver alternative services or new partnerships – more possibilities

Service User Involvement at Fulfilling Lives

Interview with Neil Jones

Volunteer at Fulfilling Lives 2016

Paid BHT worker 2018



Let's take some action

Each attendee to write on their postcards

3 SMART goals/actions that they are taking to their
organisation/service

Resources

- Valuing Involvement. Strengthening Service User and Carer Involvement in NIMHE. Good Practice Guidelines for involving mental health service users and carers (National Institute for Mental Health in England)
<https://www.nsun.org.uk/Handlers/Download.ashx?IDMF=e87639b8-e2e7-459e-9015-b5a8b7c7421d>
- TV program: 'We're not mad, We're angry'
<https://www.youtube.com/watch?v=qD36m1mveoY>
- Service user involvement- A guide for drug and alcohol commissioners, providers and service users. Public Health England.
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/669061/Service-user-involvement-a-guide-for-drug-and-alcohol-commissioners-providers-and-service-users.pdf
- TOGETHER Guidance on SUI and how to measure your organisation's SUI:
<http://www.together-uk.org/wp-content/uploads/downloads/2014/06/Service-User-Involvement-briefing.pdf>
- CLINKS- Good practice in Service User Involvement
https://www.clinks.org/sites/default/files/2018-10/clinks_good-practice-sui_final.pdf
- The 4th National Recovery Walk Brighton:
<https://www.youtube.com/watch?v=TX820BO8-qq>

Fulfilling Lives South East Project



FULFILLING LIVES
South East Partnership

