

# CITIZEN POWER

**PARTNERSHIP**

**PEER SUPPORT**

**SURVIVORS MOVEMENT**

**EXPERTS BY EXPERIENCE**

**CONTROL**

**ENGAGEMENT**

# SERVICE USER INVOLVEMENT

**CONSUMERS**

**RIGHTS**

**MUTUAL AID**

**GROUPS**

**CITIZEN**

**PARTICIPATION**

**COPRODUCTION**

**MENTAL HEALTH SERVICE USER  
MOVEMENT**

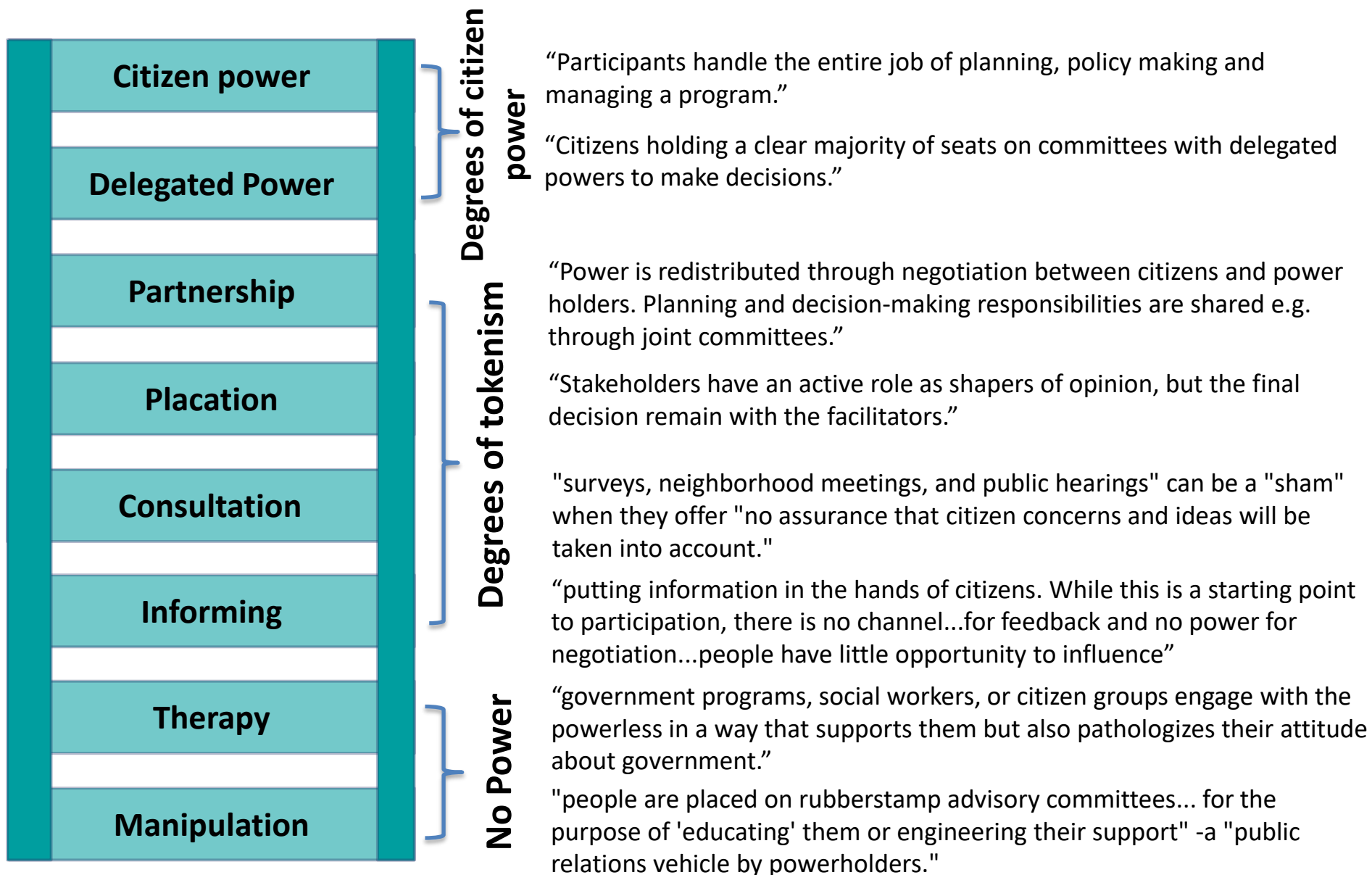
# What is Service User Involvement?

- 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.



# Video- No More Throw Away People

Parable of the 'blobs and squares'

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



# 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

# 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](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](https://www.clinks.org/sites/default/files/2018-10/clinks_good-practice-sui_final.pdf)
- The 4<sup>th</sup> National Recovery Walk Brighton:  
<https://www.youtube.com/watch?v=TX820BO8-qq>