

Where's the evidence?

**The contribution of lay
knowledge to reducing health
inequalities.**

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The presentation

- **What is lay knowledge?**
- **How can it inform action to reduce health inequalities?**
- **Why isn't it taken more seriously?**

What is lay knowledge?

This is a book made much from **talk**, the talk first of men and women fifty or more years ago, of ideas and views repeated in family, street, factory and shop and borne in mind with intent!?? Many among them shrewd and thoughtful could not only *recapitulate experience* they knew how to *assess its value* in relation to their lives....

(The Classic Slum, Robert Roberts, 1973, 9-10).

What is lay knowledge?

- Robust empirical approach to **understand**, **explain** and **assign meaning** to contingencies of everyday life
- Naturally represented as **stories** – presented in narrative forms
- **Subjective** (viz objectivity claimed for professional knowledge)

What is lay knowledge?

- **Science seeks to answer questions about causality:**
- **What causes a particular phenomena**
- **Lay knowledge seeks to answer questions about 'meanings':**
- **Why me?**
- **Why now?**

What is lay knowledge?

- Generally viewed within ‘science’ as *primitive* remnant of former unscientific less rationale age
- Historically studied to understand ‘*non-compliant*’ behaviours

But growing recognition of *sophistication* of lay knowledge

How can lay knowledge inform action to reduce health inequalities?

***Quality of care**

***Individual behaviour**

***Wider determinants of health inequalities**

1. Improving quality of care

- **Individual treatment decisions:**
 - **Re-thinking non-compliance e.g. Medication as a resource**
 - **Expert patients don't need programmes HIV/AIDS**
 - **Collaborative decision making and health outcomes**
- **Collective voices**
 - **Parents in hospitals movement in 1960's**
 - **Transformation of mental health services**
 - **Community/group control and delivering of services.**

2. Better understanding of behaviour

- Health Damaging behaviours – not primarily a question of lack of knowledge**
- Need to understand ‘meaning’ of behaviour in context of everyday life e.g.**

e.g. Smoking and coping amongst working class white women

3. Address wider determinants of health inequalities

An example:

The nature and significance of lay theories about the causes of health inequalities.

At the beginning of the conversations

- *Divergent responses to the initial question about health inequalities*
- *People living in poorer areas disputed the evidence whilst those in wealthier areas did not*
- *I don't believe it...*
- *That puzzles me....*
- *I can't believe em..*

Why?

Some people didn't trust statistics - evidence contradicted the 'facts' as they understood them

I would think, actually that they, the rich, weren't as healthy as the poor cos of all the spirits they drink and stuff they eat. I mean if you eat the basics like we do I think you're much healthier...I mean they just make the figures look bad.. I don't trust statistics as all

Why?

More commonly people rejected the labelling and inevitability of pre-mature death implied:

I don't believe it...They look at Salford as being a dump. They think nobody lives there..they are seen as outcasts. Yes there's pollution but other than that it's attitudes.. They are making out that it's all like scum and they're all dying... it doesn't make sense

And as the conversations moved on....

**People provided accounts of the lived
experience of inequalities**

I'm a strong person. I can deal with a lot of things but this particular area and living in this area has made me ill.. At the end of the day you've got to feel happy in the place your living in cos that is your source, it's where you're based. I can't deal with it.....

But how did they explain the problems?

- **Indirect mechanisms** emphasised as linking poor material circumstances and ill health.
 - ‘Stress’
 - ‘Social comparisons’ a source of stress

It's only obvious that we would not feel health wise as someone would who has all the comforts and luxuries around them. You know they go on holidays three times a year..whereas we can't afford to go on one holiday so that's the difference. Their outlook on life is more relaxed and at ease and comfortable. Whereas we are struggling day to day with pressures and to keep up with things.

But ‘strength of character’ emphasised as the most important protective factor

The first thing you do when you get up is see the graffiti, the vandalism and it doesn't help. But at the end of the day if you let it get to you it just causes you ill health. I mean I just lock the door and forget about it. It's how the individual deals with it all. If you let it get you down, you are going to have the health problems

And no lack of understanding about wider social determinants

I mean everybody has a bit of worry. But it's our own worry brought on by ourselves.. .but outside worries that you haven't got any influence on changing that has a bigger effect on you I think. You can't sit down and think 'well I've got this problem and how can I solve it'. Cos you can't solve it if it's outside your house... It's an outside influence that you can't control, you can't change it, you haven't the power to change it and it takes over your life....

What are the 'purposes' of lay theories?

- Recognise complexities and life-course but also seek to:
- Assign 'meaning' to experience of inequalities by:
 - **'Reconstructing' moral worth** at individual and collective level
 - **Re-asserting individual control** emphasis on indirect mechanisms which 'strength of character' can control
 - **Reconcile need for control with wider determinants** – no lack of knowledge about structural constraints

A Policy & Practice Audit Framework?

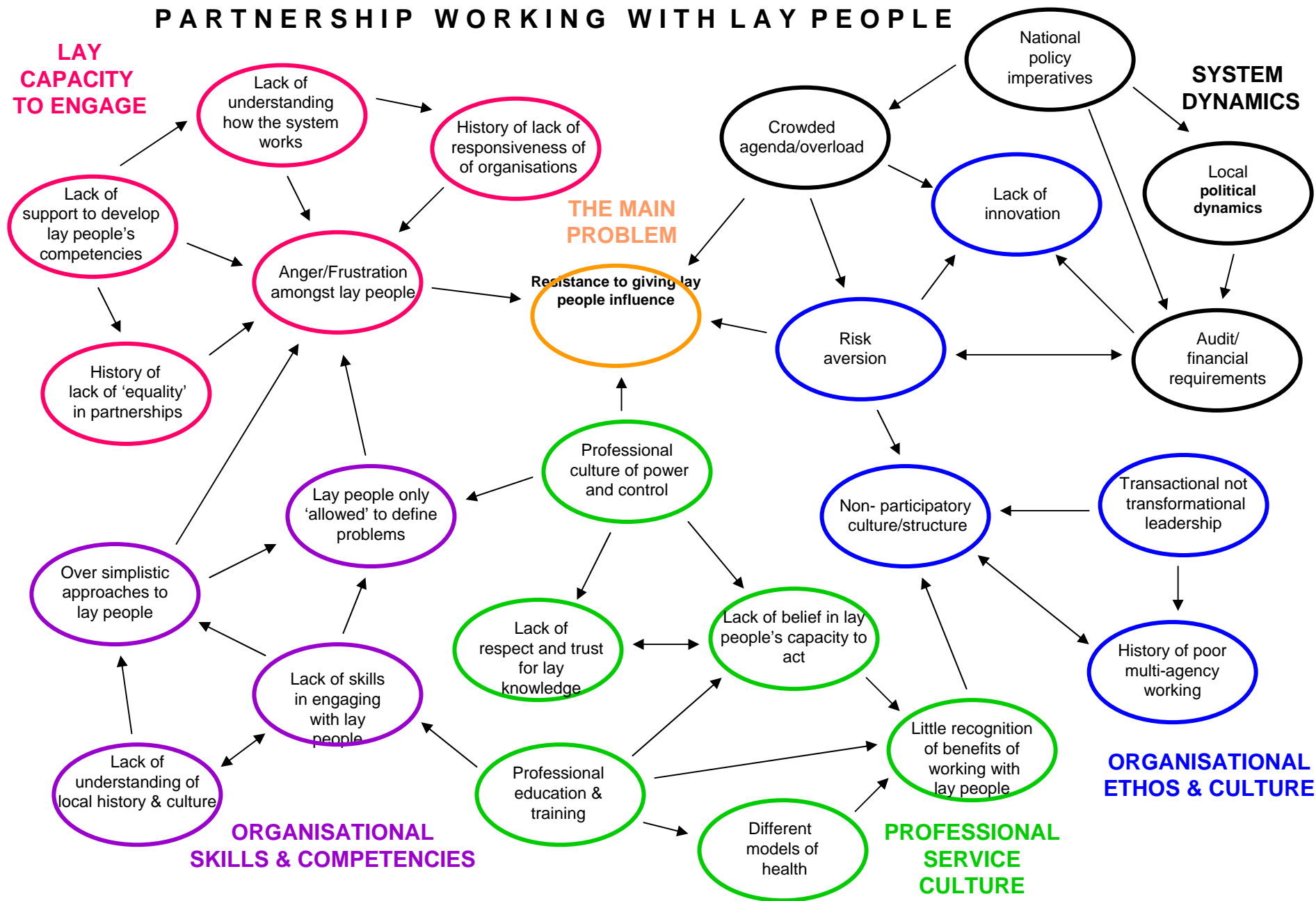
- **Does policy & practice aimed at reducing health inequalities:**
 - **Recognise the moral nature of health inequalities?**
 - **Seek ways to avoid increasing the stigma of inequality?**
 - **Give people real control over the design, delivery and evaluation of interventions?**
 - **Take lay knowledge & expertise seriously?**

**So is lay knowledge taken seriously in
policy and practice?**

NO – well not in England !

WHAT IS GETTING IN THE WAY?

BARRIERS CONSTRAINING CAPACITY FOR PARTNERSHIP WORKING WITH LAY PEOPLE



A MESSY MODEL!

BUT REAL LIFE IS LIKE THAT!

Highlights barriers to community engagement

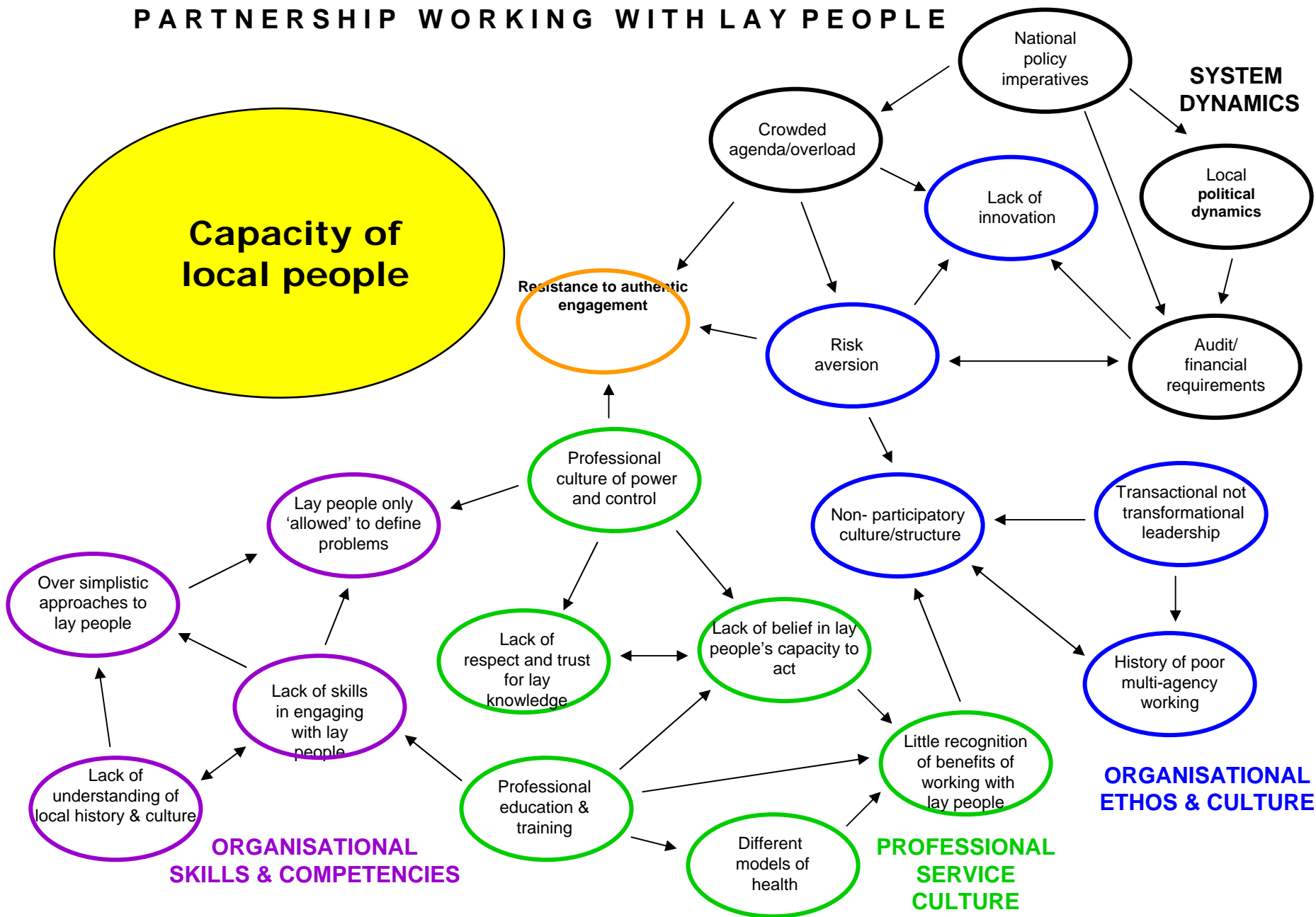
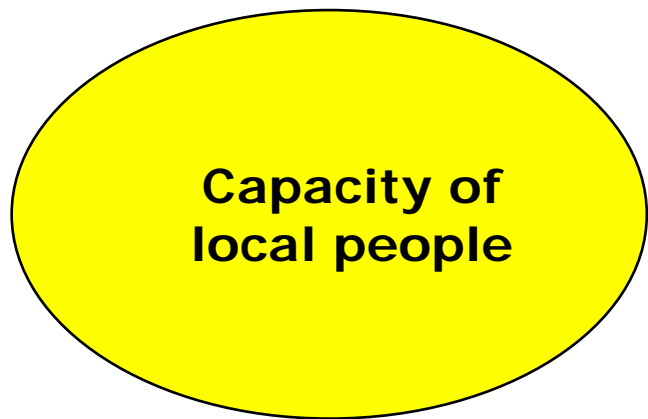
Public sector barriers arise from:

- **Lack of appropriate skills and competencies**
- **Professional and organisational Cultures**
- **Wider system dynamics - the quick win!**
- **Lack of clarity of purpose – delivery mechanism or something more?**

Paternalism is a problem

- **Assume poor people have to learn to participate**
- **Professional 'experts' teach and dictate terms**
- **Processes for involvement can and do reinforce dependency and inequalities in power**

BARRIERS CONSTRAINING CAPACITY FOR PARTNERSHIP WORKING WITH LAY PEOPLE



Research has shown us:

- **There are barriers in the way of lay people working in partnership with professionals to address health inequalities**

BUT

- **These are not a lack of innate capacity or knowledge**

Fish Head Soup

Lay people's attitudes to engagement

- **Say they will act collectively if they believed that:**
 - **there were important and relevant issues**
 - **and collective action would be effective**
- **Identify many relevant and important concerns**
- **But few people engaged to change things**

People Acting on evidence!

- **The 'engagers'** – experience had transformed their lives.
- **The 'disillusioned'** experience had had significant negative impact on their lives
- **The 'reluctant'** – never engaged, no evidence it changed things and so don't see why they should.

A CENTRAL PARADOX

- **Widespread and genuine commitment in the public sector to take lay knowledge seriously and engage people more equally in decisions impacting on their lives (and health);**
- **Widespread capacity for engagement in ‘disadvantaged communities’ but people learn from experience that it won’t be effective – acting on the evidence base!!!!**
- **Profound cultural and structural changes are required to release community and organisational capacity for more effective engagement.**

So what is to be done?

- Taking lay knowledge seriously not a silver bullet**
- Engagement can damage people if not done well.**
- The challenge is to release capacity not build it**
- Recognise and reduce barriers to capacity release.**
- Power has to be seen to be redistributed and engagement having real impact**

Taking lay knowledge seriously is:

- Not about involving people in decisions about 'how their money gets spent'
- Involving people in enduring processes to allow them to have a real say in 'how life is to be lived'

a struggle over 'meaning' not 'resources'