

What have we learnt from coproduction with Disabled people over the last three years, and how do we use the learning to improve the health and well-being of Disabled people in the Borough.



Mike Smith and Ellen Kennedy - 20 March 2023



What makes us “Real”

Our vision

Real’s vision is of an equal and diverse society free from the barriers that stop disabled people from living their lives the way they want.

Our mission

Real’s mission is to protect and uphold the human rights of disabled people in Tower Hamlets, and overcome discrimination, to enable disabled people to live as equal citizens.

We aim to help disabled people to live independently - where they choose, how they want, with all the support they need, and with the money and resources they need to do it.

"Nothing about us, without us"

Our place in the disability rights movement, user-led

Supporting all impairment types, all ethnicities, et cetera

Focus on multiple identities

Disabled people are not (inherently) "vulnerable"

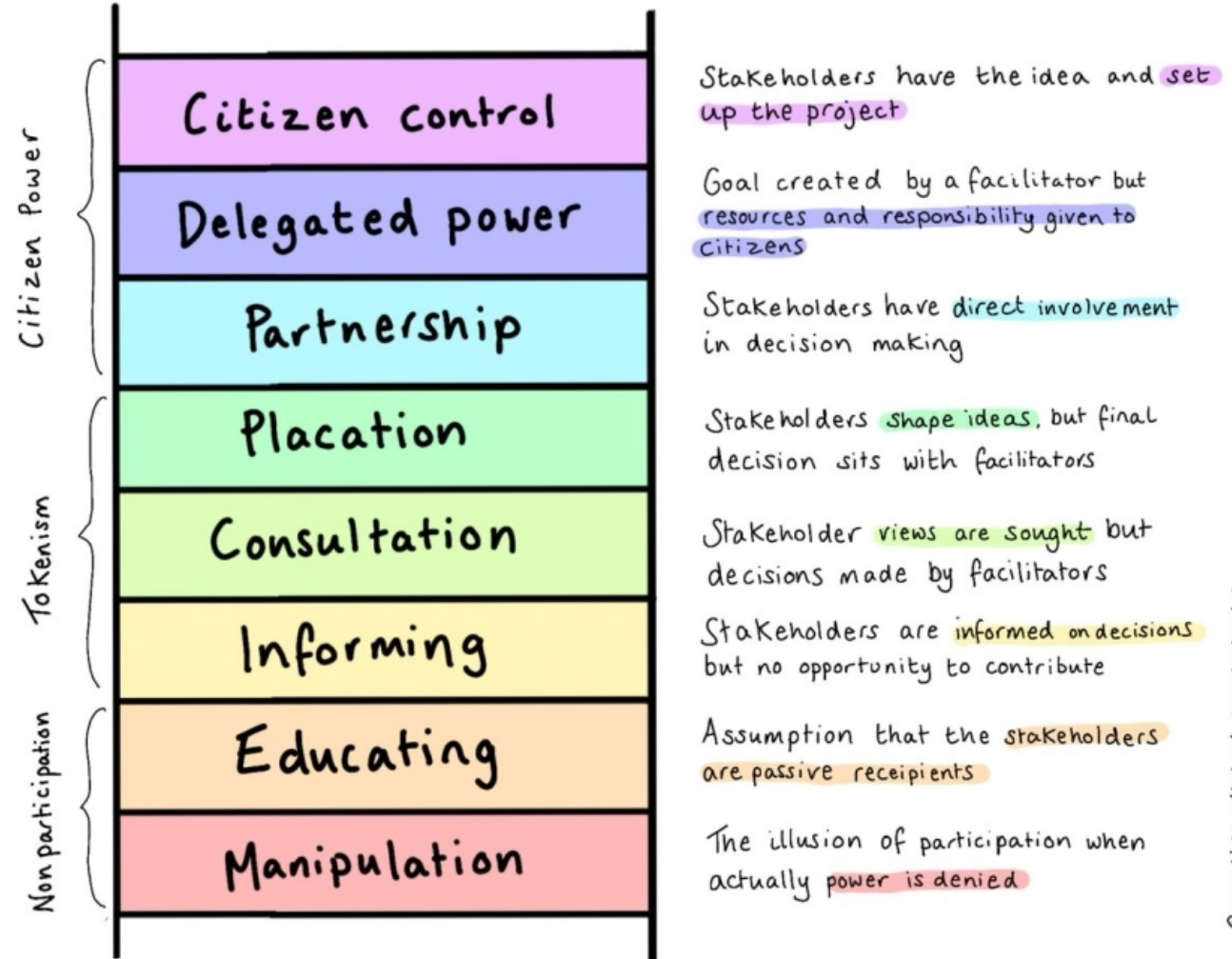
Staff, volunteers and languages

Reach

Ladder of participation/
engagement

Ladder of Participation

(Arnstein, 1969)



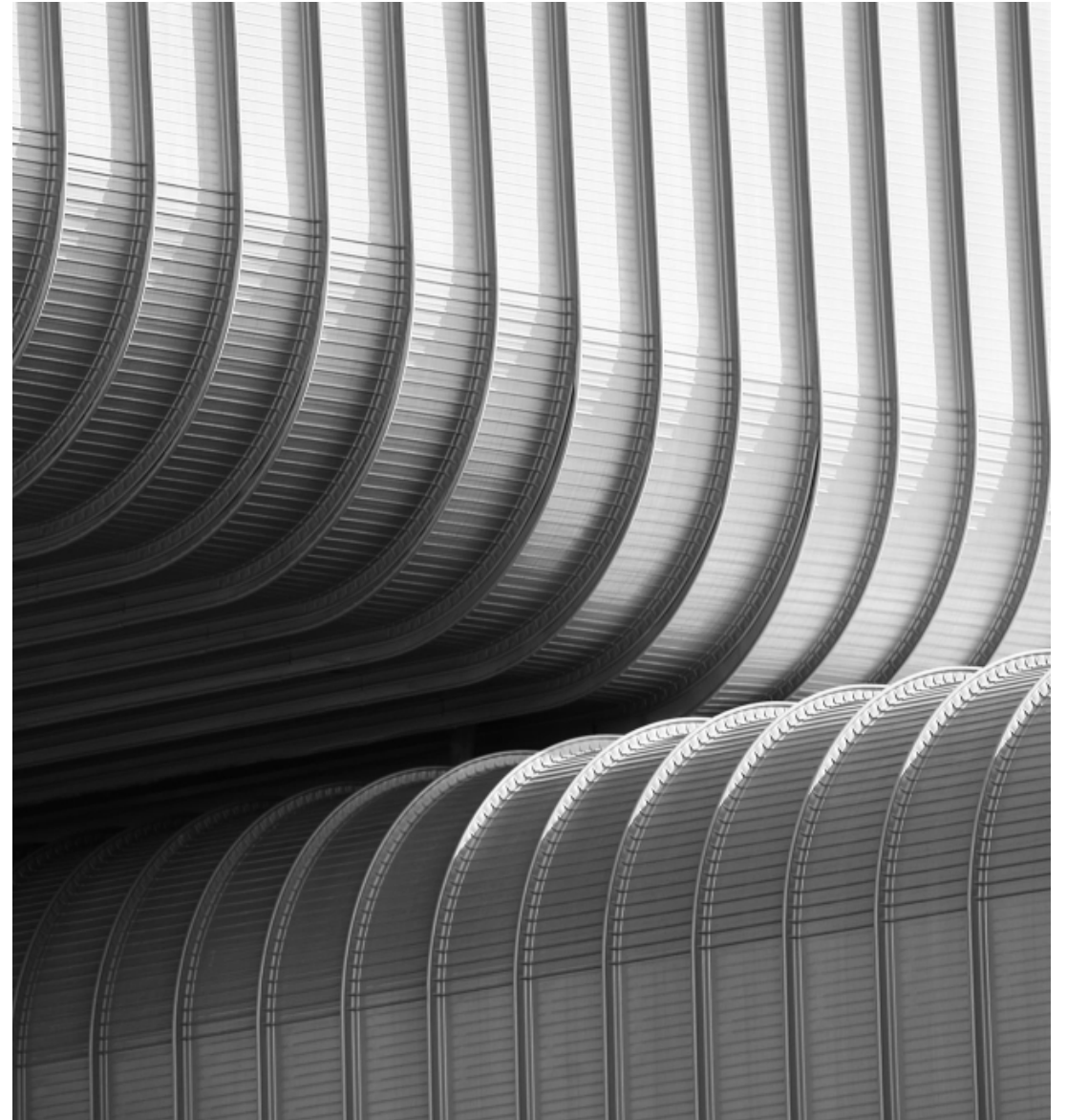
@creative.clinical.psychologist

Drawn by Juliet Young

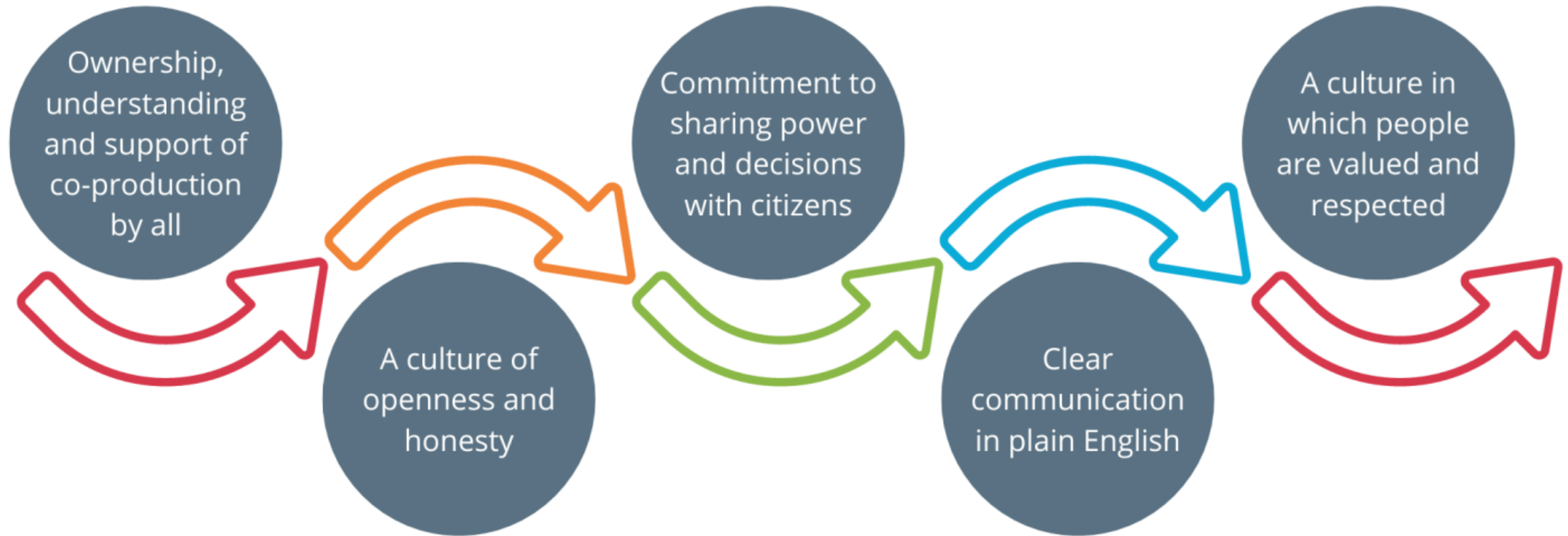
What is coproduction (NHS England)

Co-production is a way of working that involves people who use health and care services, carers and communities in equal partnership; and which engages groups of people at the earliest stages of service design, development and evaluation.

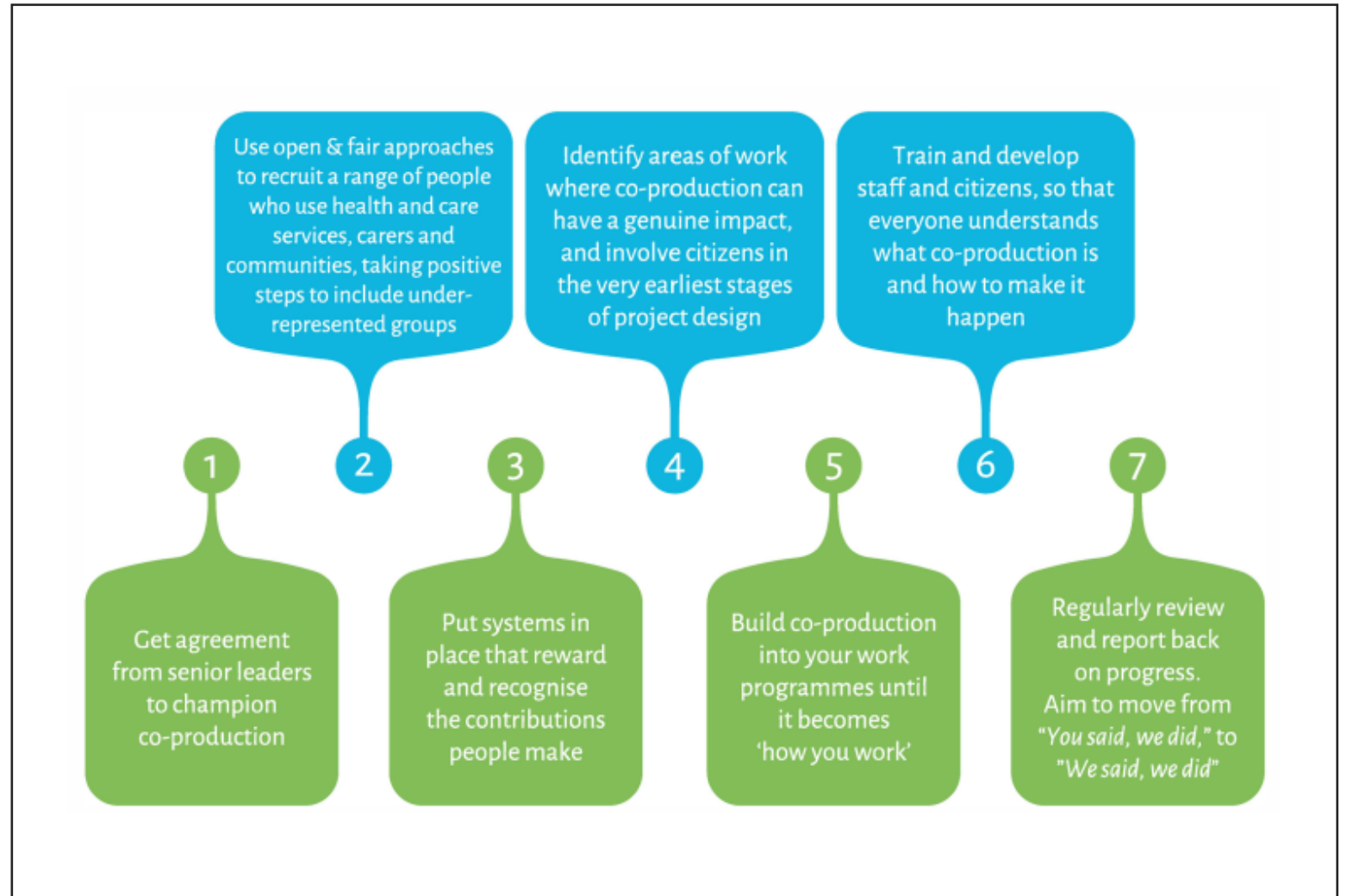
Co-production acknowledges that people with 'lived experience' of a particular condition are often best placed to advise on what support and services will make a positive difference to their lives. Done well, co-production helps to ground discussions in reality, and to maintain a person-centred perspective.



Five values



Seven steps




A large orange circle on the left side of the slide, partially cut off by the edge.

And from
Social Care
Institute for
Excellence

"The Care Act 2014 specifically includes the concept of co-production in its statutory guidance. The guidance defines co-production and suggests that it should be a key part of implementing the Care Act.

In particular, co-production should be used to develop preventative, strength-based services, support assessment, shape the local care market, and plan information and advice services."

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“Co-production is not just a word, it's not just a concept, it is a meeting of minds coming together to find a shared solution. In practice, it involves people who use services being consulted, included and working together from the start to the end of any project that affects them.

”

“A way of working whereby citizens and decision makers, or people who use services, family carers and service providers work together to create a decision or service which works for them all.

The approach is value-driven and built on the principle that those who use a service are best placed to help design it.

”

“A relationship where professionals and citizens share power to plan and deliver support together, recognising that both have vital contributions to make in order to improve quality of life for people and communities.

”

SCIE: Co-production has been broken down into the following activities

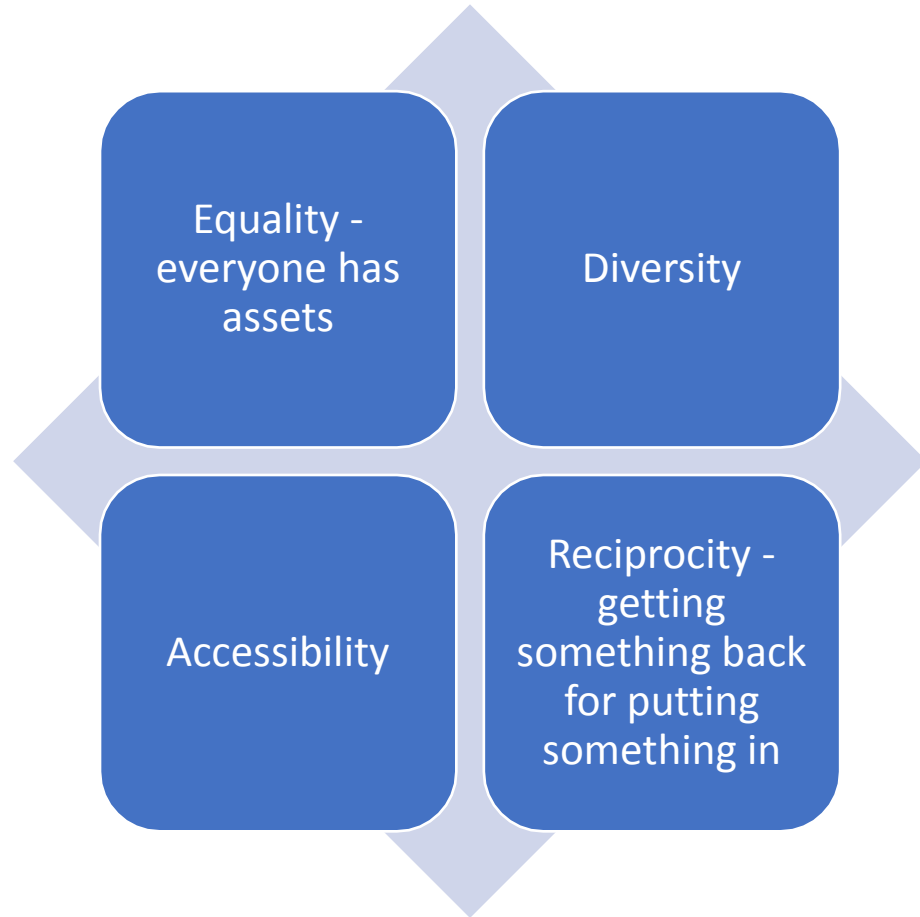
co-design, including planning of services

co-decision making in the allocation of resources

co-delivery of services, including the role of volunteers in providing the service

co-evaluation of the service

SCIE's principles of coproduction



They also have excellent information on:

- The link with personalisation
- Economics of coproduction
 - the costs
 - potential savings
 - improved outcomes (value for money)

“Evidence shows that incorporating co-production principles into programmes for people with long-term conditions can help them to gain knowledge, learn skills and adopt behaviours that are thought to be important in achieving better health and wellbeing.”

<https://www.scie.org.uk/co-production/what-how>

Real's previous coproduction work

Local Voices (more engagement)

Previous guidance on disability-related expenditure in charging

Communities Driving Change

Pandemic work on impact of COVID 19

LCF - THEN & NOW

LCF - Taking Control of Your Life

Development of Adult Social Care Strategy

Coproducing Disability Access Project



Focus on..

- THT - Improving local health and care services by learning how to work together better
- Loneliness and Disability
- Embedding Disabilities Access Pilots (EDAP)

Loneliness and Disability

Post covid 23% of Disabled adults said they felt lonely on a typical day and 53% reported feeling lonely sometimes.

Aim: Coproduce engagement activities to improve connections and reduce the impacts of loneliness, and evaluate their effectiveness and scalability.



ON OUR
RADAR



Concepts Tested

- Coffee and Connect
- 'Find your Voice' - confidence workshops
- Self Massage
- Self Care
- Music and Movement
- Community Cooking
- Community Trips



Ernest said: "Thanks to Find Your Voice I was able to be confident enough to speak and engage in meeting in which I wouldn't normally participate"

Kamrul said: I really enjoyed the music and movement class. We were showing everyone our moves and we created different dances together

Feedback

Henry said: 'it was a pleasure to catch up with, and gain support from, other disabled people.'

I hope there's room for this project to expand as it really did give me something out of the usual to do."

Participants report lower feelings of loneliness but....

- The project did not reach those who are the most lonely
- What happens next? Some of the concepts can be self sustaining but many have a cost or resource requirement.
- There is no plan for what to do with the learning.



Embedding Disabilities Access Pilots (EDAP)

Aim: Coproduce and deliver a Deaf and Disability Awareness Training Programme for health professionals and front line staff.





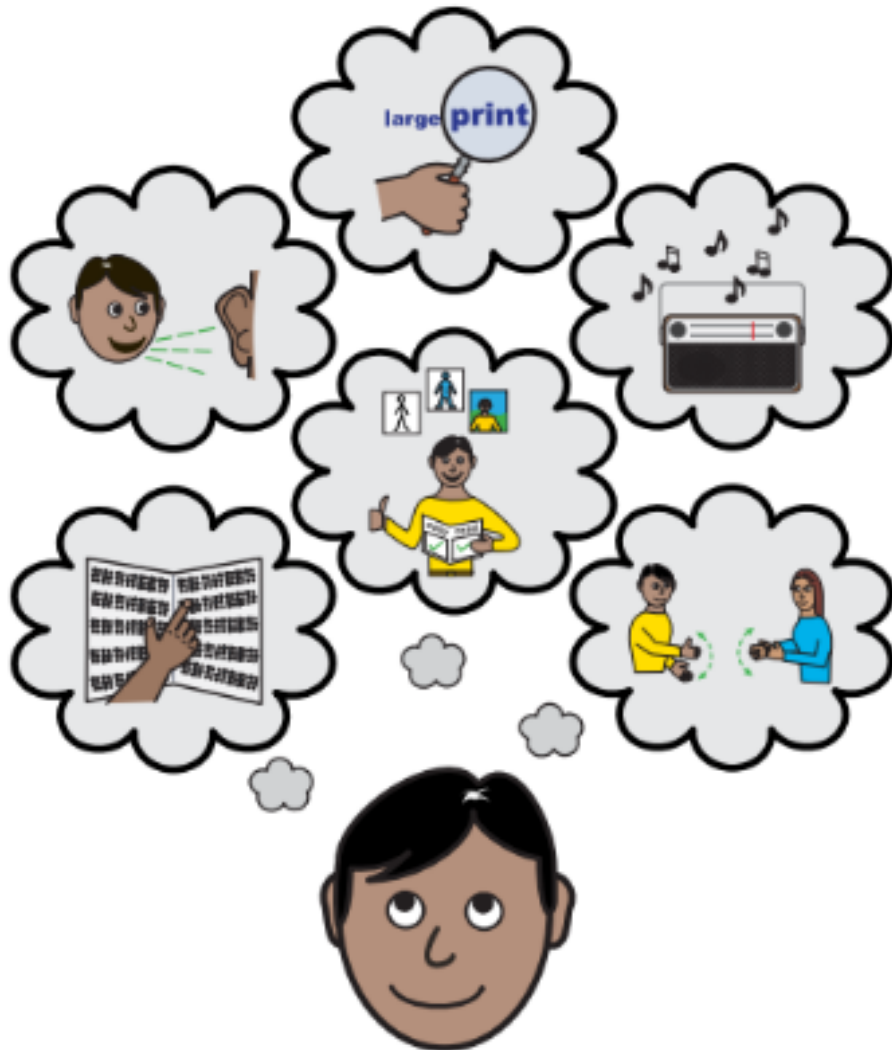
- We have recorded video scenarios based on Disabled people's real-life experiences of accessing health services.
- We share these scenarios with attendees and open-up discussion about what could (and should) have been done differently.
- We provide an overview of the statutory requirements of health professionals and give them practical tips about how they can change the way they (and their staff) support disabled people.

Feedback

“For me I don’t know many people with disabilities... Hearing other people’s experiences has been impactful. It has been nice to know I am not the only one, and it’s something I try to bring to the disabled voice on campus at uni”



Coming Up - Accessible Communications



- Working with different impairment groups across Tower Hamlets to improve the accessibility of health communications.
- Working with two communications teams to assess the accessibility of their communications.
- Coproduce a best practice guide and training session

Engaging Disabled People to Transform Health and Social Care

Embedding Co-production in Tower Hamlets decision making across several projects

- Direct Payments Support Service
- Hostels Recommissioning
- Digital Inclusion
- Care Technology Transformation



Quality of life



Using a validated tool to interview 1000 Disabled residents over 2 years.

Analysing qualitative and quantitative data about their Quality of Life over 8 domains.

Will generate a rich source of data to inform future projects and influence our strategic work with THC/THT

Feedback from our coproduction participants

“I felt empowered that someone wanted my feedback and input in certain issues. That felt good. I felt important and included rather than the opposite which can often be the case with any difficulty and especially vision, you feel excluded from society and feel that you are no use or that you can't be of use.”


“I have had a huge boost in confidence since I started taking part in these things. Main thing would be communication. Moving forward I could bring this in so many other ways and groups such as public speaking. I think about those things now, whereas before I would shy away. I learnt this about myself.”

“I gained more confidence, learning from other participant's experiences. Their testimonies make me a stronger and knowledgeable person, able to deal with problems or any difficulties that I may face.”



Quote from THC
officer

“Working with you and Real has been a true highlight for my career. The most powerful learning experience ever for our team and, I believe, for the Council”



Key learning (1)

- support for people with barriers to having an equal voice
- important to hand over some power
- it's a continuous process, you can't expect some people to keep coming back
- but those people are gaining skills and experience which is useful in other parts of their lives
- if you do it well, it really isn't consultation





Key learning (2)

it benefits from active, independent facilitation (especially where there is a power, knowledge or skills imbalance)

this requires a mindset change, and a genuine belief that (disabled) people can influence positively

you need to reach different groups in different ways (not everyone will identify as disabled)

consortium/collaboration is hard but gets better results

look towards the Hammersmith and Fulham model

Challenge
questions
for the
board and
THT to
consider (1)

Coproduction seems to work best in pilots and smaller projects.

How are you going to learn, scale up the learning, and make things business as usual (because currently that doesn't happen)?

Challenge questions
for the board and
THT to consider (2)

**How are you
going to
resource this
going forward?**



How are you going to
make decisions on
when to use
coproduction?
(reference DPSS)

Challenge questions for the
board and THT to consider (3)





Challenge questions for the board and THT to consider (4)

If you want genuine increases in I-statement results, especially ones around "choice and control", you need to do things differently.

Ultimately it's about improving quality of outcomes, and getting Value for Money

In summary



You should be proud of what you have done and delivered so far.



But you are not getting the best from that work and investment.



You have the opportunity to be truly transformative in the way that you design and deliver effective public services that improve health and well-being outcomes