



National Development Team for inclusion

Making Participation in Decision Making More Than Just Words

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The Valuing People Mantra

Nothing About Us Without Us



What Do I Mean By Participation?

People (with learning disabilities) being involved at the centre of decision making so that:

- Their voices directly affect decisions about their lives
- People in 'professional' roles understand how their actions impact on people's lives
- Services and communities work in ways that reflect what people say they want and need – not what others think they need.

i.e. People have more control over their lives

Other Words

- Power
- Control
- Influence
- Rights
- Respect
- Autonomy
- Co-production
- Being listened to
- Being heard
- Being included
- Being valued
- Being a partner
- Being a citizen
- Being a person

What Authority Do We Give to People's Voices? (1)

The Industrial Relations framework for trade union recognition might help:

- Information – we tell people what is happening
- Communication – we tell people what we are doing but might change things if they make a really good case
- Consultation – we discuss what we intend doing, but at the end of the day we have the right to decide what happens
- Negotiation – both parties must be happy with the end position

Is there a fifth one?

- Handing over Control – the person calls the shots, and services do what the person wants them to do?

What Authority Do We Give to People's Voices? (2)

In an honest review of how your organisation involves people in decision making – which approach would describe how you involve people?

- Information
- Communication
- Consultation
- Negotiation
- Handing over Control

Participating Where?

We need to think about participation in decision making in a number of different places:

- People's own lives – overall hopes and day to day decisions (**Personal context**)
- Organisational decision making – including about a person's own service and support (**Service context**)
- Major strategic decision-making at regional or national level (**Policy context**)
- What happens in a person's own community – beyond the boundaries of 'serviceland' (**Community context**)

A Quick Word on Community Participation

If services are not supporting people to be participating members of their local communities, then what sort of life are people being supported to achieve? Services need to think of strategies to:

- Promote social and community inclusion
- Use tools like community mapping
- Maximise use of 'non-service' resources in the community
- Support people to be community members not tourists
- Support activities that promote real relationships e.g. paid work
- Evaluate services by whether they promote inclusion

Person Centred Planning

What it is

- People working out their own vision for their lives
- A set of hopes and aims that informs services assessments
- A living process that changes as peoples' lives change
- Support plans that then describe how this will be made to happen

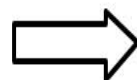
What it isn't

- Something done by staff to and with people that the organisation owns
- As assessment process or part of one
- A set of forms of a defined process that has an end to it
- About how services will 'fix' the negative things said about a person

Person centred support planning

Understanding what being “person centred” means

Service/professionally centred



Person centred

- Planning for you
- Starting with assessments
- Talking about you
- Starting with what's wrong
- Health & Safety dictate where you live
- “Dead” plans updated annually

- Planning with you
- Starting with dreams and visions
- Talking with you
- Starting with what's important
- Health and safety addressed *where* you live
- Living plans – change with the person

Using a range of approaches

There is no one way or best way of being person centred. Do what works for the person:

- Essential Lifestyles Planning
- PATH
- Circles of Support
- Etc etc

A central point is that your organisation has giving power to people at the heart of how it thinks and behaves

‘Deciding Together’s’ Six Building Blocks Organisational Participation

1. **Leadership** that leads by example, builds committed teams and allows time for change to happen
2. **Communication**, listening to people, improving staff communication skills, esp. for those who don’t use words
3. **Changing Organisational practice**, nothing about us without us, do meetings differently, employ people.
4. **Work with advocacy groups**, as partners, with everyone having access to advocacy (in all its forms)
5. **Empower staff**, because disempowered staff will not empower the people they support
6. **Partnership working**, think whole-life, multi-agency partnerships include people themselves

Coproduction

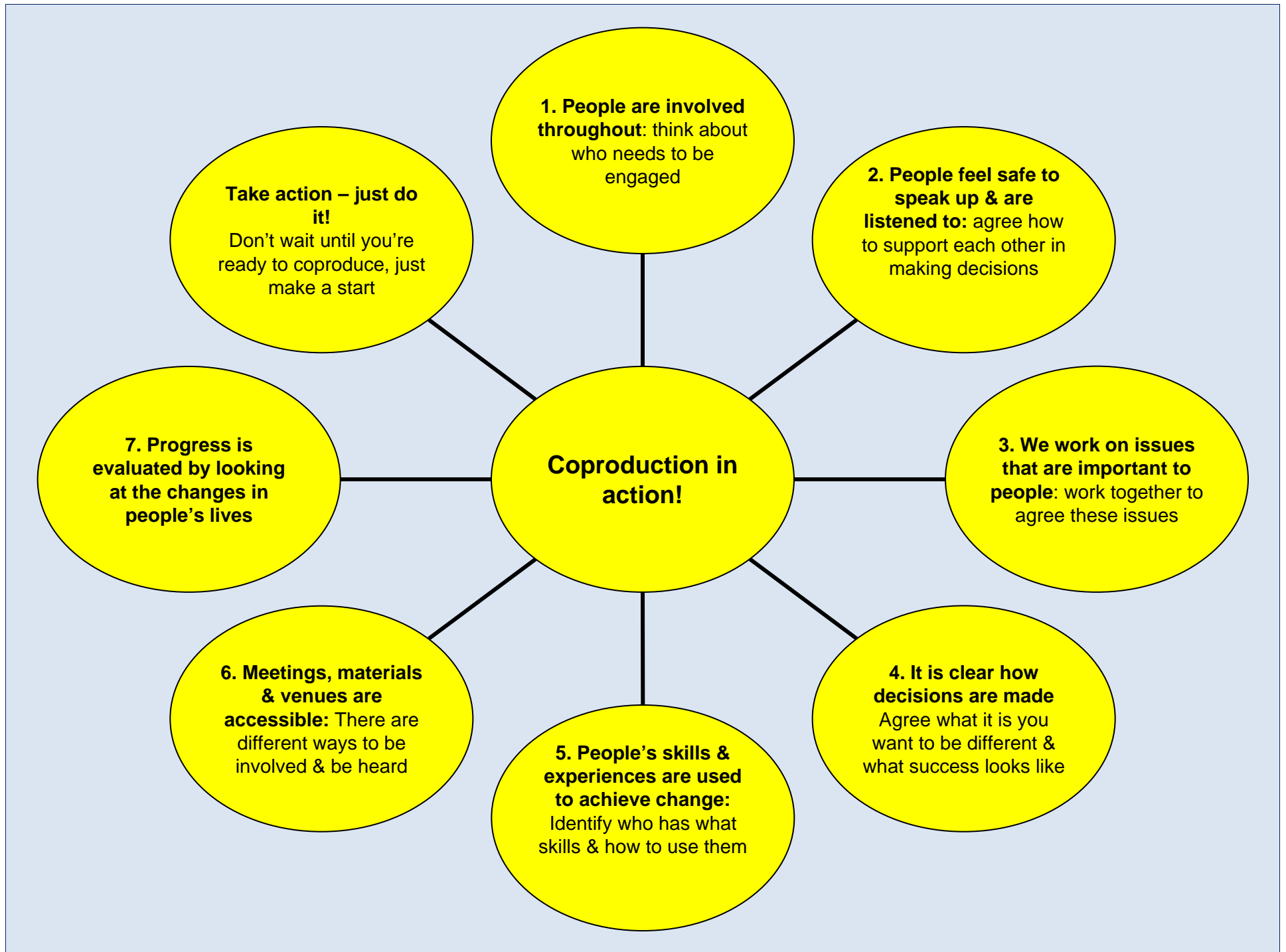
An idea that has come from disabled people and is now national policy in England.

The concept is that:

- People are recognised as experts in setting their own support needs and those of their peers
- People have things to contribute to planning and decision making about their lives
- People are involved from the outset in a partnership around decision making
- These ideas are built into the whole organisational and planning system

Seven Principles of Coproduction

1. People involved throughout
2. People feel safe to speak up and are listened to
3. We work on the issues that are important to people
4. It is clear how decisions are made
5. People's skills & experiences are used in the process of change
6. Meetings, materials & venues are accessible
7. Progress is evaluated by looking at the actual changes in people's lives



Coproduction – pro's and con's

Potential Benefits

- Value for money
- Additional expertise
- Health benefits and prevention
- Practical skills
- Social capital

Potential Challenges

- People will often need support to coproduce
- Those with the power will feel challenged or threatened
- It needs sustained support and independence

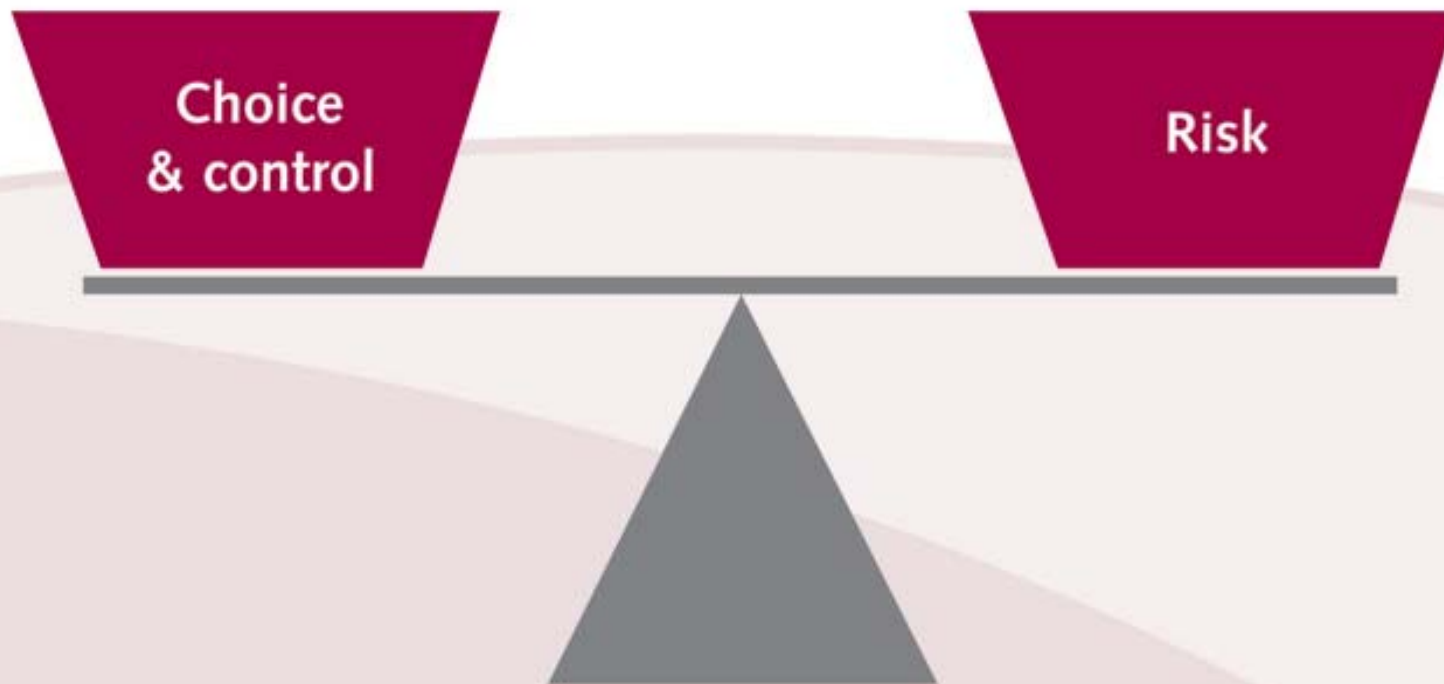
Making all this happen - The pitfalls we all step into

- Tokenism
- Easy read materials that tell people nothing
- Poor quality support
- Only involving people about the small matters
- Expecting people to be able to do anything – just because of their ‘label’
- Only working with the ‘easiest’ people
- Not realising almost everything affects people with a learning disability

The really big challenges to consider if participation is to be real

1. Coproduction – understanding what this means for / with people with learning disabilities
2. Person centred support planning – so services respond to the person
3. A whole system approach – so we think whole life
4. Giving people control over the money spent on their services
5. A flexible and diverse market – because if we only offer people a limited range of choices that isn't (their) control
6. Ensuring participation and risk taking work hand-in-hand

Ensuring personalisation & risk taking work hand in hand



Maximising choice and control, whilst effectively managing risk

A whole system approach

- Joining it all up:-
 - Information, advice and advocacy
 - Early intervention & prevention
 - Community inclusion
 - Access to mainstream public services (e.g. health, housing etc)

- Wider public service reform - Total Place?



Some Practical Steps to Get Started

- Make a commitment to ‘nothing about us without us’
- Define coproduction for your organisation
- Build a group to champion this work – a group that includes people themselves
- Develop a strategy for building person centred skills
- Think community and start building skills for getting beyond services
- Develop a positive risk taking policy
- Employ people with a learning disability in your organisation
- Be honest with yourselves