

Advancing self-management support: opening the gate and working together

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Thinking about self-management support....My 10 thoughts and ideas



1. Is it all about stroke?



I had to convince myself that I should be confident enough to say 'I cant do this'- even though I might feel stupid, I actually say these are my limitations, its taken me a long time to do that and its one of the things I am still working on



I've got lots of diaries, I've got an iPad at home, and there's an app on there that is called day 1, its like a journal and you can attach your pictures to there and links to websites, so its good to be writing in there. So I have a little diary in my bag which is for appointments and things. And then I use this day 1 for feelings and things like that I don't want to be writing on paper.



I mean you have to adapt things. All of a sudden I found myself adapting in ways of putting on my socks on. Well I did building maintenance before so I would adapt things. So thinking ok instead of doing it like this I have to do it like this.

Every time she came in she would say 'can you do this?' and 'Can you do that?' and if there was an improvement she would count the sections that I did, and the seconds I could balance and tick it off on her list'



"I was directing it but they were pointing me in the right direction. They listened...They said 'right what do you want to do?'- 'Drive' 'Well lets break it down' "

2. Whose behaviour needs to change?

3. Are we any different?

Ask these questions of yourself

What do you want to change?

What works for you

What barriers to you see

What would it take for you to do it?

What's your first step

Who knows about it?

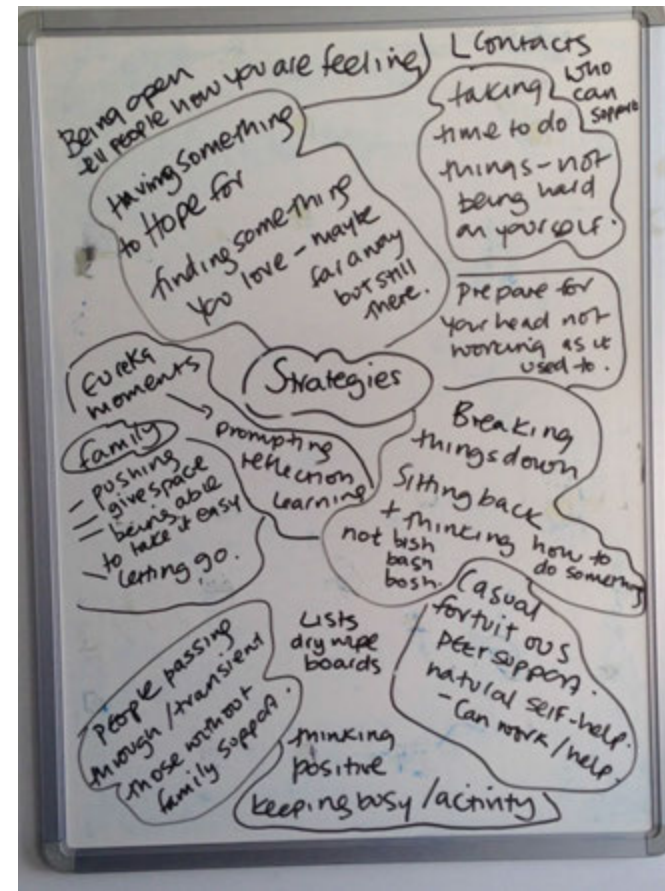
How will you know if you have done it?

'I suddenly sat down and thought, well what project am I going to do today? And I planned it day by day and I thought 'hang on' this is like being back at work and everything started clicking.' (5- 212)



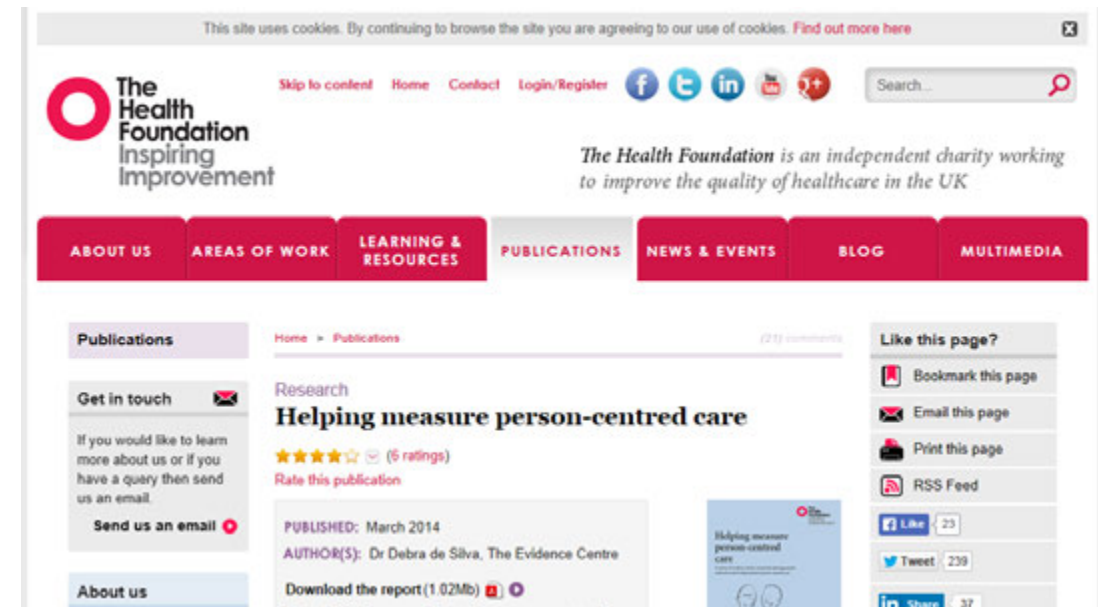
4. Co-design, co-produce and co-deliver

- “Co-production describes a relationship where professionals and citizens share power to plan and deliver support together, recognising that both partners have vital contributions to make in order to improve quality of life for people and communities”
- National Co-production critical friends group (2013)



5. Measure what matters

- No silver bullet
- Everyone measures something different
- A combination probably the best approach



Who are the beneficiaries?

What is your intervention trying to change

Is at personal, professional or organisation level

Context?

'She said right I want you to get from that settee, stand up go over there and walk back. And she'd say that's not bad that's 21 seconds.'

(12-376)

6. Creative ways to sustain?



Normalisation process theory
(Murray et al 2010)

- **Coherence** e.g. Is the intervention distinct from other interventions?
- **Cognitive participation** e.g. Will people think its a good idea?
- **Collective action** e.g. How will it effect normal work and practices?
- **Reflexive monitoring** e.g. How will people perceive it over time?

Self-management is
for EVERYONE

Specific interview,
lead by Assistant
Practitioners to find
out hopes, dreams,
targets, past skills

MDT working is
focused on self-
management support
driven by interview

New staff who
haven't been trained
do struggled

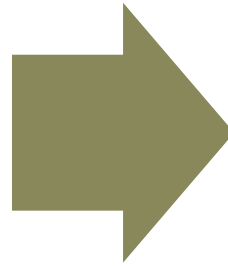
Old habits die hard –
we have to keep
focused

Success happens
when a team changes
its processes to make
self-management their
focus



Success happens when you tailor support to an individual...

As a nurse I like to make people look neat-then I realised that's what I like



When shaving/ dressing with a patient – looking neat didn't matter to him but being independent did – however he got there!



7. Evaluation, implementation, clinical research

DOES IT WORK?

Does ...it work only at my place?

It.....what is it?

Work....for who?



1. How to make change happen
2. How to make change happen in different settings and contexts
3. Using existing evidence
4. How to understand the barriers to evidence implementation



- no data without stories
-
- no stories without data

| Multilevel model | | |
|-------------------------------------|--------------------------------------|-------------------|
| Change at 6 weeks, adjusted for age | Change at 12 weeks, adjusted for age | Composite p-value |
| 2.89 | 4.51 | 0.14 |
| -0.06 | -0.45 | 0.87 |
| -0.93 | -0.59 | 0.36 |
| 0.02 | 0.05 | 0.91 |
| -0.03 | -0.08 | 0.87 |
| 0.13 | 0.16 | 0.52 |
| 0.04 | 0.14 | 0.72 |
| 0.61 | -0.07 | 0.91 |
| -3.92 | -2.20 | 0.31 |
| 2.20 | 2.17 | 0.30 |



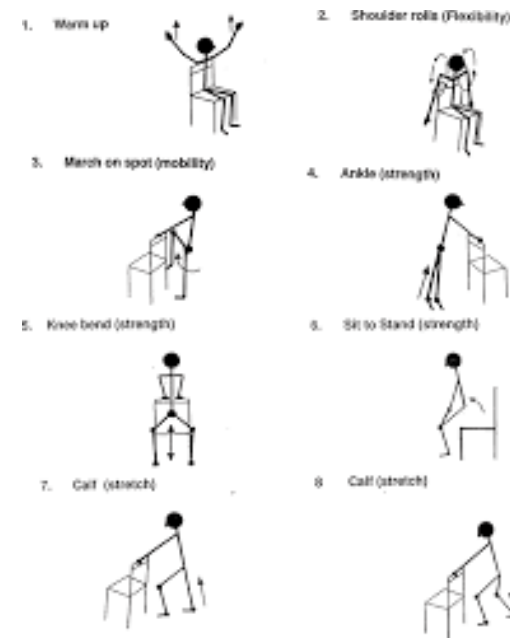
8. Localise, contextualise

If the intervention (service innovation) is a 'seed', then the context is the 'soil'. Some species of interventions are fairly robust and will thrive in a variety of environments, while others are very sensitive to the type of local 'soil'.
Health Foundation 2013



9. Drop the term Self-management education

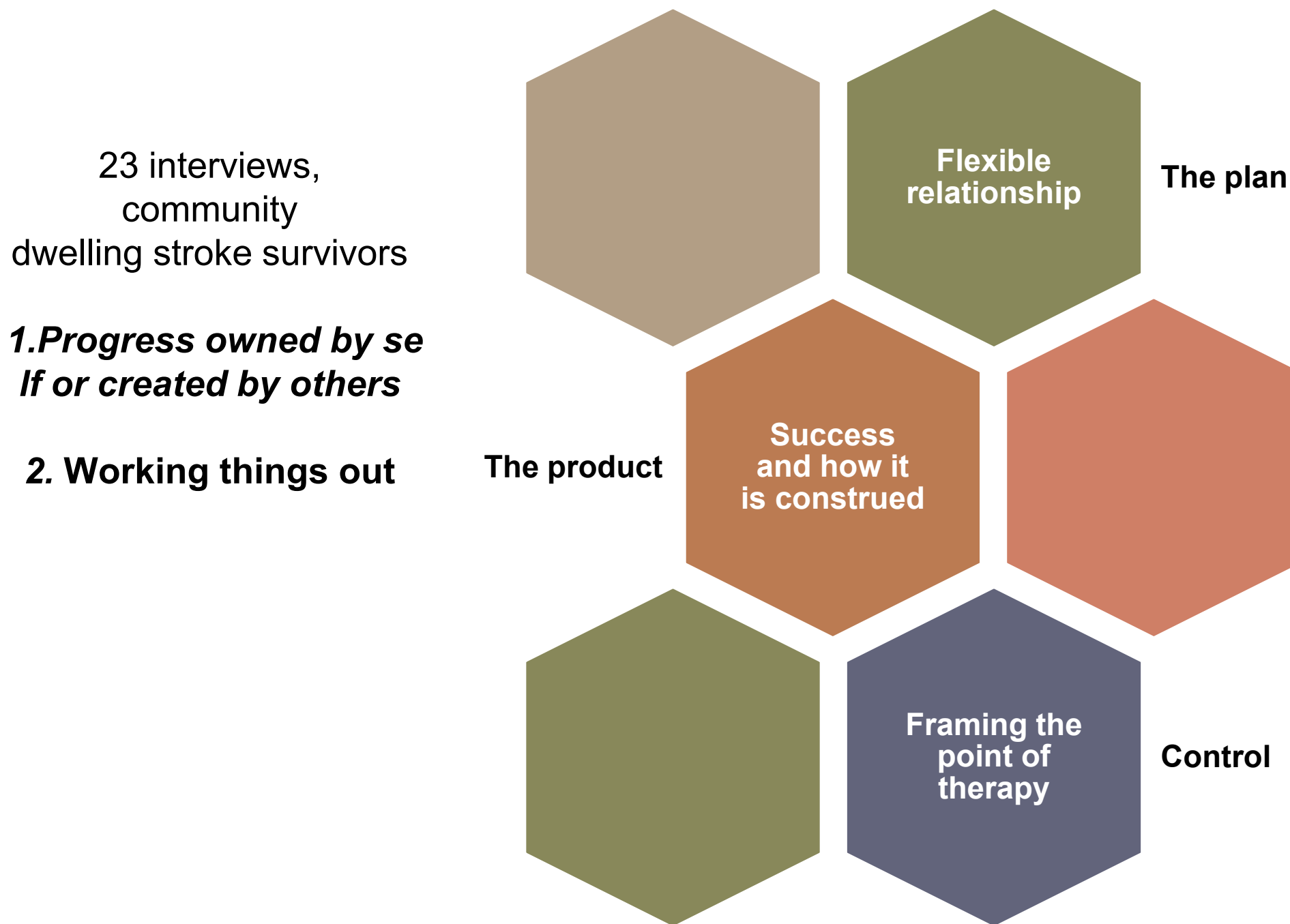
- **Synthesis of 600 studies on self-management interventions in the UK and internationally (De Silva, 2011)**
- **Self-management initiatives can be categorised along a continuum**
- **Little evidence about the best way to provide support**
- **Low intensity didactic interventions are least effective**



Thank you Sally Costell for your diagrams



10. Who owns the space?



Ponderings

...

- Stroke is a complex LTC ; sudden onset, defined periods of rehabilitation,
- Rehabilitation is a technical intervention
- Mechanisms of change;
 - Capabilities and relationships : learning about life after stroke and how to cope with new challenges
 - Relations between patients and clinicians: how does it help to develop potential
 - What matters to patients?

- How does our work extend Bodenheimer's and Health Foundation models ?
 - Interaction status
 - Goal setting
 - Patient activation
- Deeper and subtler aspects of clinician-patient relations
- Therapeutic relationships are formed using a combination of collaborative and traditional approaches
- Not all conducive to supporting self-management and activation

Bridges (stroke self-management)



Training workshops



Self-management tools

Research



Our projects focus on the people, where they live, the issues they face.

People are different....tailor interventions

Offer people a range of support options

Tools alone are not enough

Changing professional roles, behaviours and mind sets is not impossible

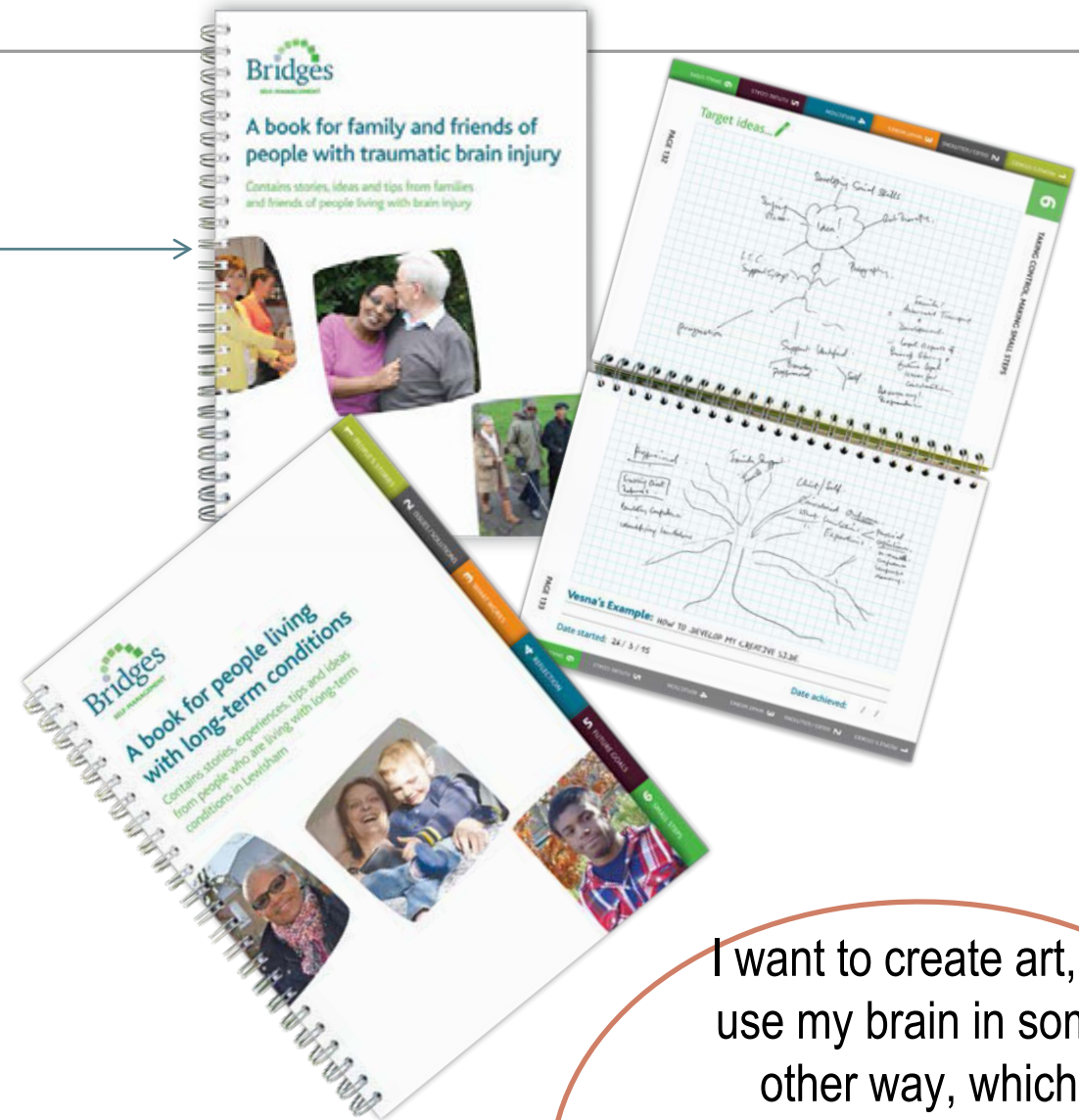
Involve voluntary and community sector

Use a whole systems approach to implementing change

Consider sustainability from the outset

Evaluation should be incorporated into programmes from the start

Offer people a range of support options



I want to create art, or use my brain in some other way, which doesn't rely on recall. Its useful to function as a different person, so dementia doesn't define me

Our projects focus on the **real issues** faced by practitioners, we get to know about their everyday work, training is **principled** rather than prescriptive

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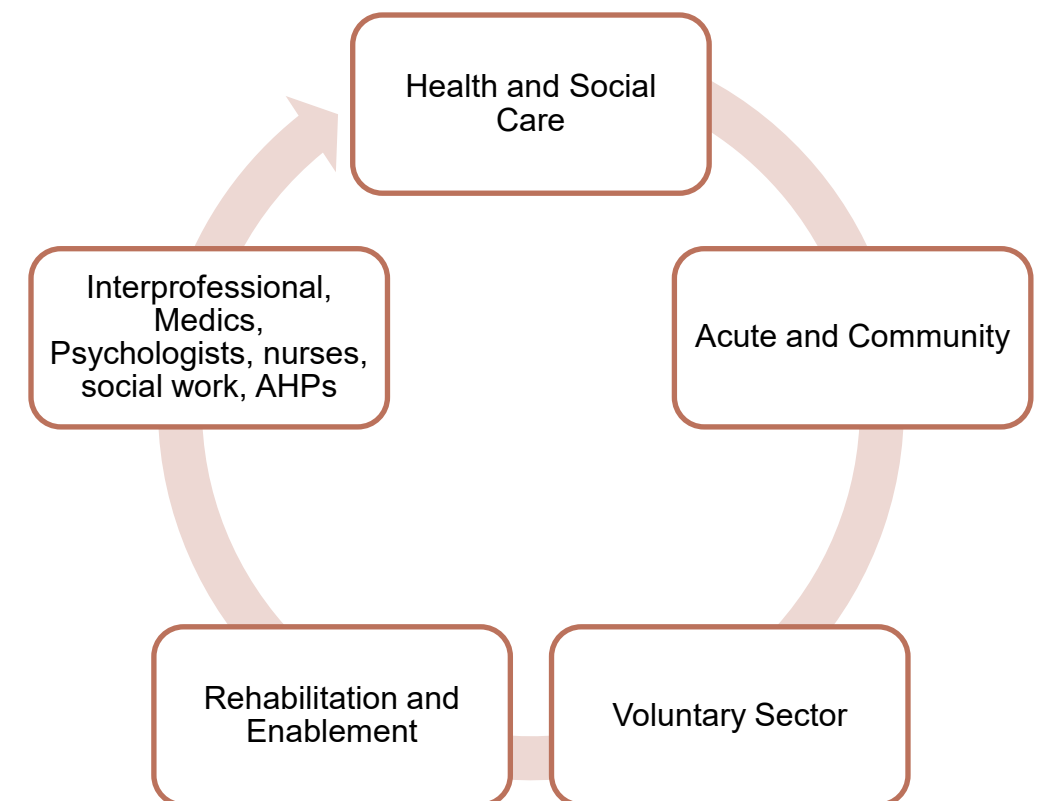
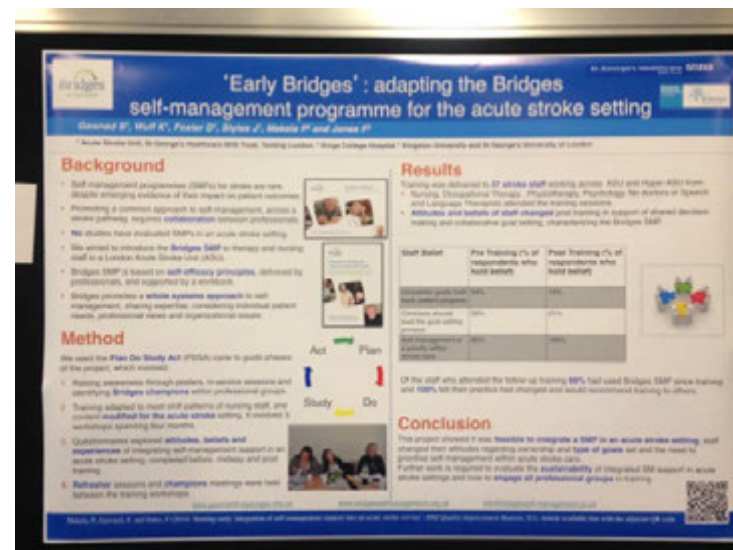
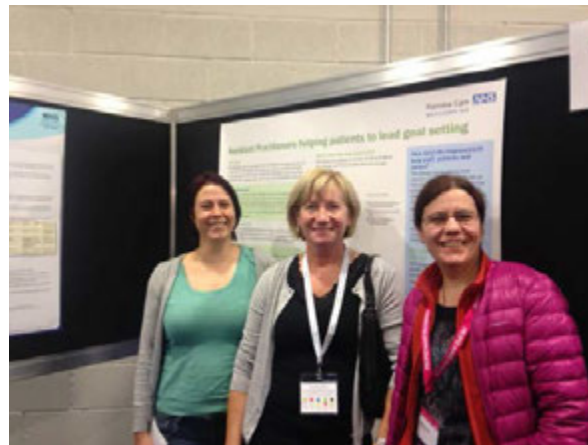
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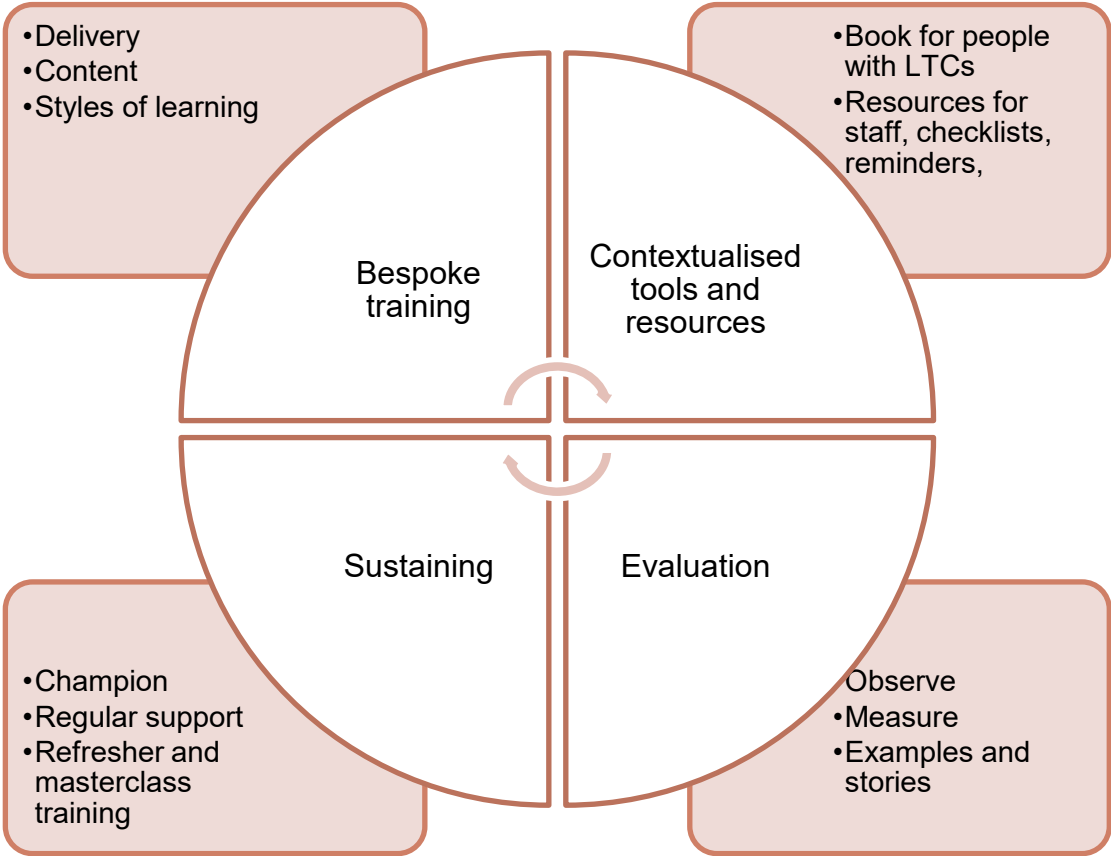
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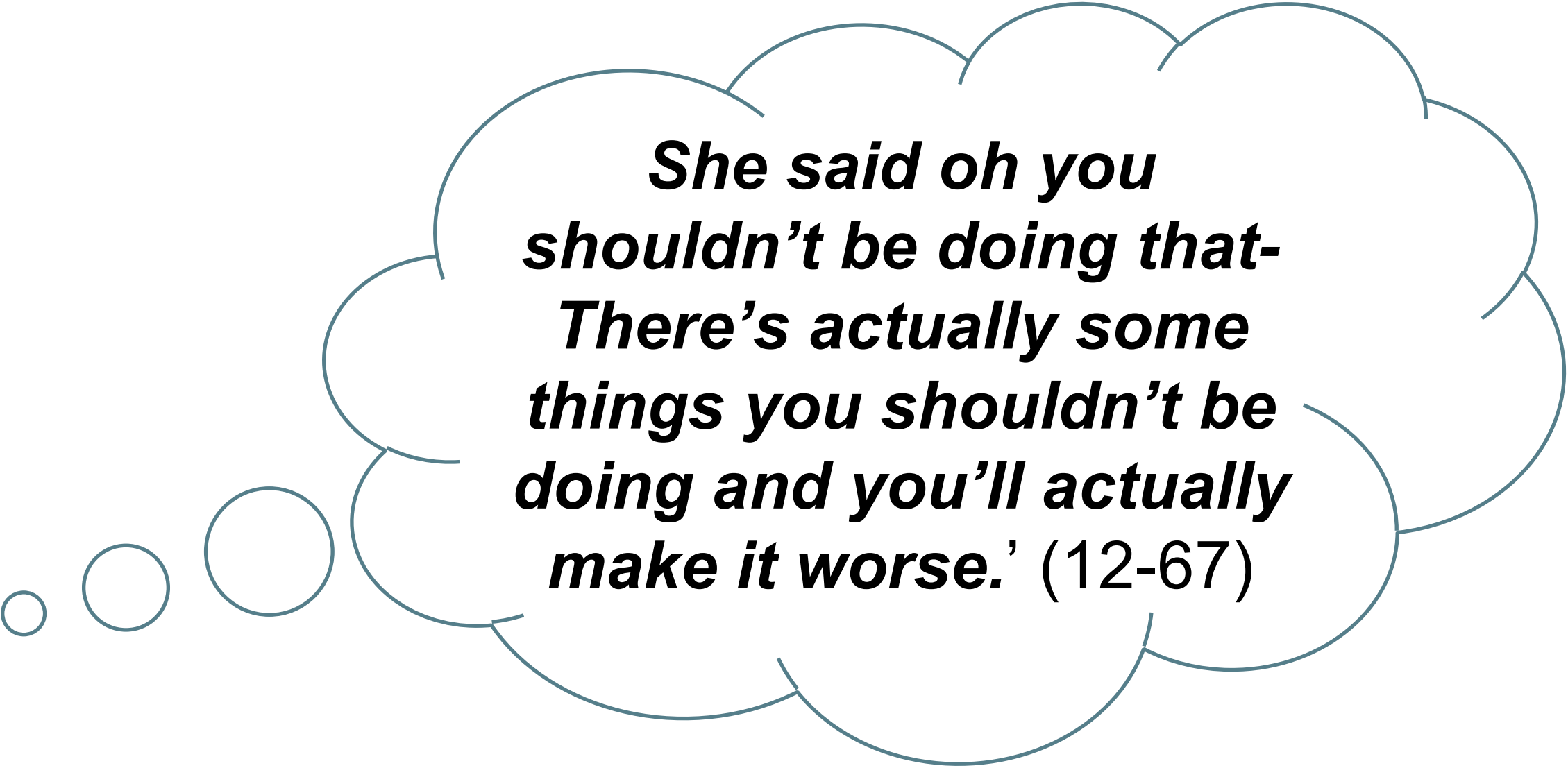


Our projects work with **organisations** such as Your Healthcare, to deliver a system wide change.

- People are different....tailor interventions
- Offer people a range of support options
- Tools alone are not enough
- Changing professional roles, behaviours and mind sets is not impossible
- Involve voluntary and community sector
- Use a whole systems approach to implementing change
- Consider sustainability from the outset
- Evaluation should be incorporated into programmes from the start
- Offer people a range of support options



Ask yourself a question- could this have been you?



***She said oh you
shouldn't be doing that-
There's actually some
things you shouldn't be
doing and you'll actually
make it worse.' (12-67)***

Who owns the gate ? And whose is it to open?



