NHS England

Maximising Life Chances through Appropriate and Caring Support

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The brief

- People with a learning disability or autism or both should be enabled to fulfil their full potential and be offered the opportunities to do so by providing relevant and comprehensive support.

- Offering choice, protection and equality in healthcare are essential to ensure they are afforded the same rights as the rest of the population

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History

- "If you don't know your history, you're like a leaf that doesn't know it's part of a tree"
- Project 81 - a group of residents. including John Evans who lived at Le Court Cheshire home in Hampshire in the late 1970s.
- They concluded that if health and social care authorities gave them some of the money that they currently gave the Leonard Cheshire Foundation, 'we could find another way of meeting our needs.'
- This was the radical idea that opened the way to what became the campaign for Direct Payments, and underpins all the thinking about and work on Personalisation and personal budgets.
- NOT just about the money, but about giving disabled people control over how their support needs are met

Jenny Morris
29th January 2014
http://jennymorrisnet.blogspot.co.uk/2014/01/if-you-dont-know-your-history-youre.html

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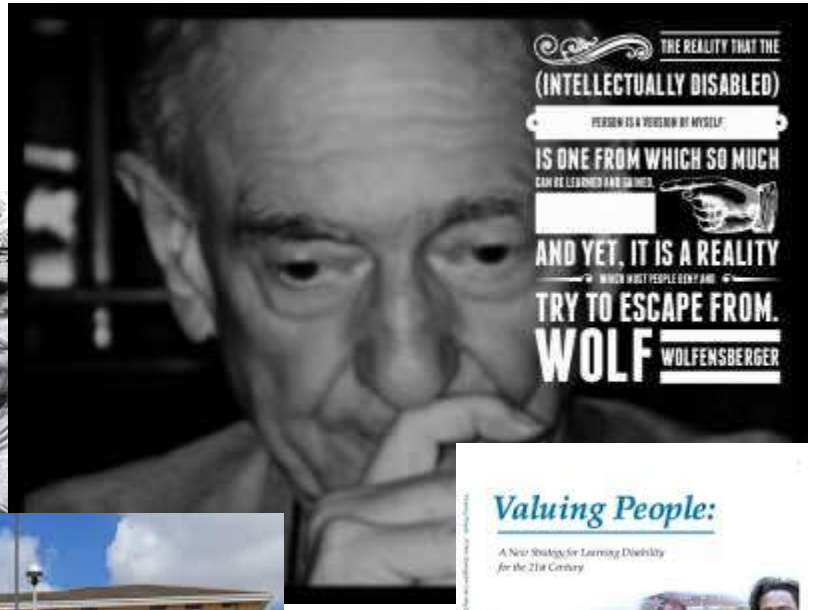
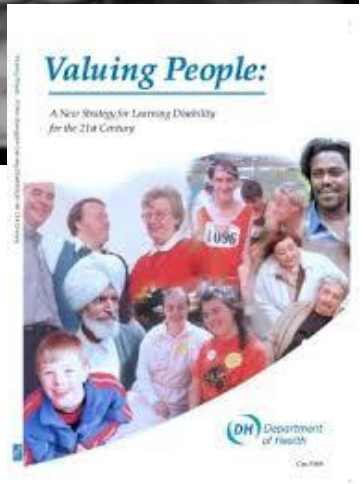
Background





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"People should have **choice and control** over how their health and care needs are met – with information about care and support in formats people can understand, the expansion of personal budgets, personal health budgets and integrated personal budgets, and strong independent advocacy."

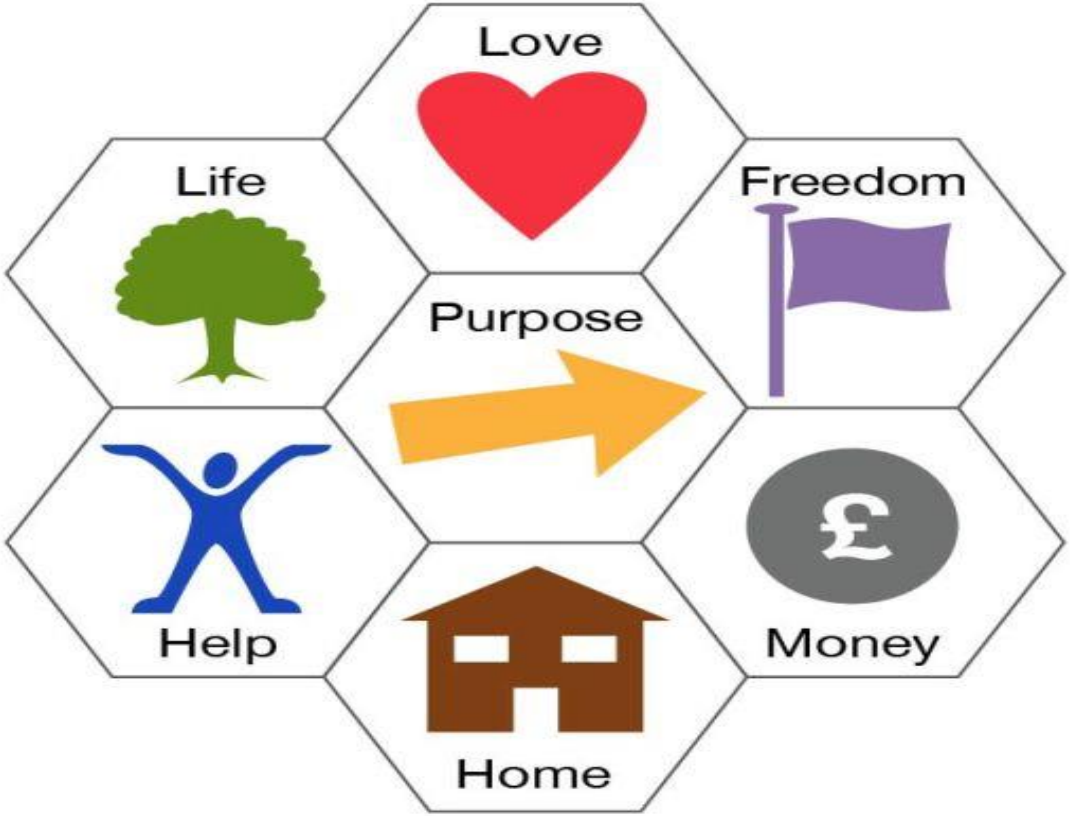
A question

How do you measure how good YOUR life is?

My good life

- I have time to spend with the people I love
- I am a member of at least one (but preferably several) choirs
- I am able to go swimming at least 3 times a week
- I have time to read
- Being able to control how I live my life
- Having the ability to contribute at work and do a good job
- I am able to live somewhere I have chosen and am part of my local community
- I have a least one (but hopefully more) trips/holidays planned with my other half
- A good gin and tonic!!

7 keys to citizenship



Simon Duffy
www.centreforwelfarereform.org

Professional gift model

The underlying system of power: 'we know best'

- Professionals and commissioners work out, in good faith, what they think is needed
- They buy things they think will help
- People have to slot in
- People feel they should be grateful as they stay as passive recipients

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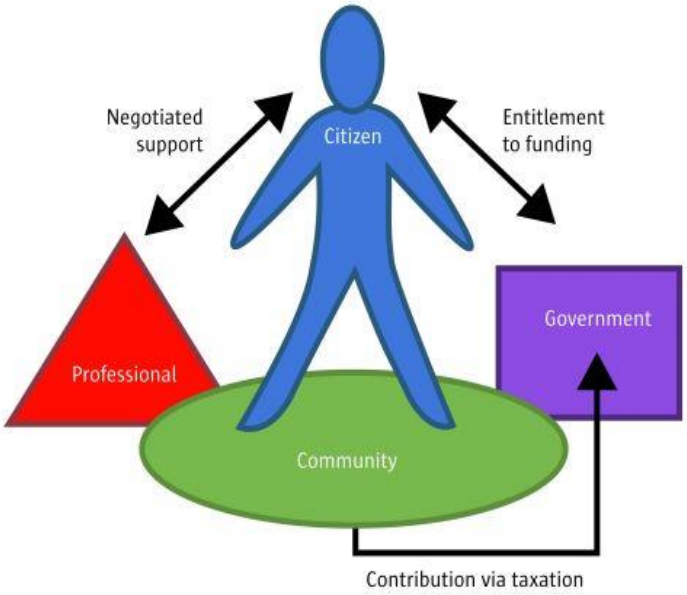
Citizenship model

Citizen at the centre:

- Services and support negotiated
- Entitlements defined
- Community fully engaged
- **Outcomes** improved = life is better



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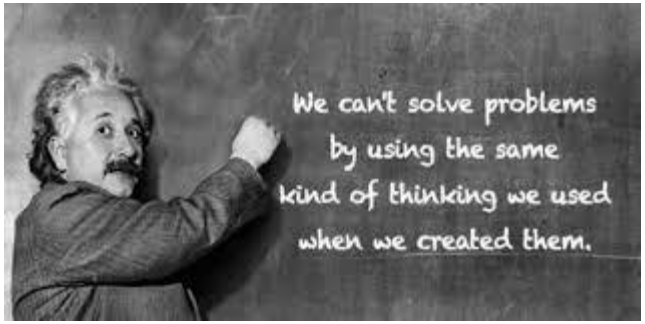
Getting an ordinary life: some tools

- **Personal Health Budgets/ Personal Budgets/Integrated budgets** Shifts the balance of power when the individual has the money
- **Individual Service Funds** (ISFs) flexible use of funds to enable choice and control
- **Individualised service plans** and **person centred care and support planning** build support around an individual focussing on what is important to them
- **Self care programme**: supporting individuals to manage long-term conditions
- **Patient Activation Measure (PAM):** helps build confidence and self reliance
- **Shared Lives**. supporting people within a family environment

BUT…….

Fundamentally it’s about **<u>thinking</u>** in a different way!



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How can we think differently?

'But if thought corrupts language, language can also corrupt thought'

From Politics and the English Language

George Orwell

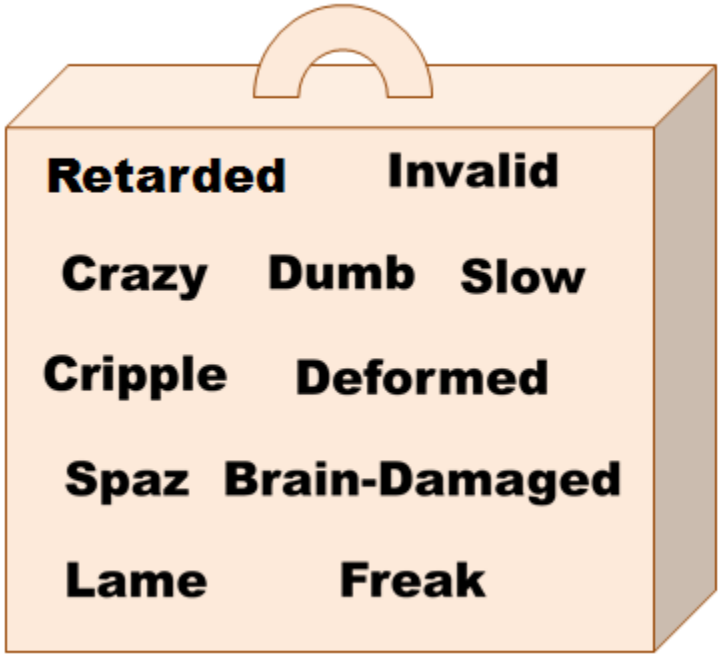
A good way to start - words we use

- Words and language are powerful – they can change how we see people and situations. .
- There are many words that we don’t use anymore because they are offensive to the individuals or groups of people to whom they refer
- Are we still using words about people with a learning disability, autism or both that still offend but are harder to identify?

An example…….

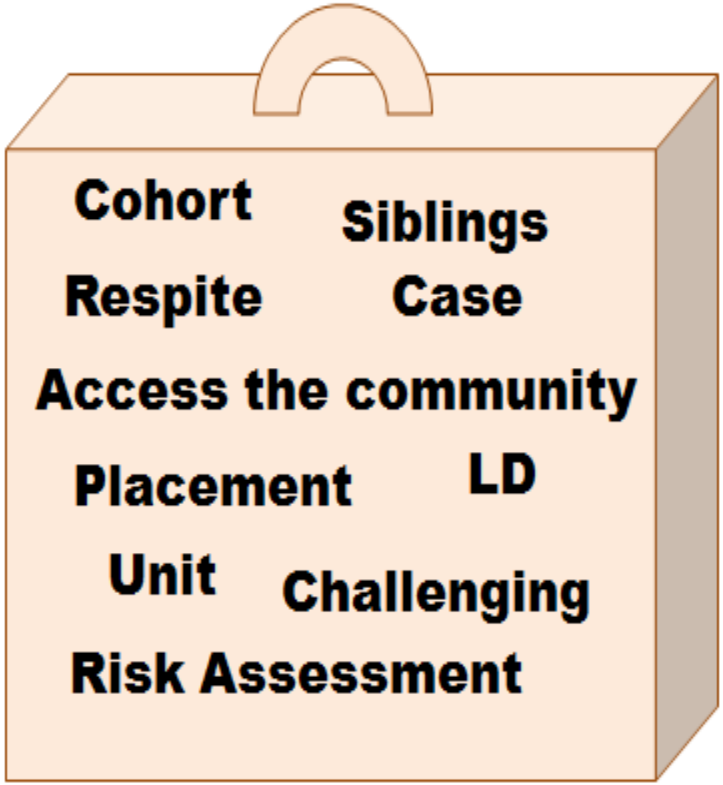
- The words on this slide are horrible – but these are words that many disabled people carry around with them

- These words are incredibly negative!



But what about these?

- We often use **different words** to describe disabled people
- These words are not used to describe how non- disabled people live their lives



Service Land

- Words like these are about being in **Service land**.
- If you are trapped in **Service Land** it's really hard to be a citizen and be seen as equal to non- disabled people and be described like everyone else

The Club!

- Health and social care have developed lots of acronyms and shorthand language that mark out the ‘club’, for example medical jargon.

- This may simply make it easier for people within the ‘club’ to communicate and foster a sense of belonging but for those outside the ‘club’ it can be alienating, de-personalised and de-humanising.

- So, what can we do……..

Use different words

NOT SPECIAL NEEDS - YouTube

https://www.youtube.com/watch?v=rsjnHCZOfg8

- Use ‘people first’ rather than ‘diagnosis or ‘problem first’ language
- Don’t use ‘special’ words to describe people and what happens to them, use everyday language and say it like it is (shorter isn’t always better)!
- Talk about people as if they were a member of your own family and if in doubt – ask what they would prefer!

To conclude

- Changing the words we use seems like a small thing but……it has a **BIG** impact!
- It's not about services but supporting people to have **'a gloriously ordinary life**' (www.tricianicoll.com)
- It's about hopes, dreams, aspirations – the same thing that all of us want?
- We have to get this right **now** – people have just the one life!

Questions