

Wokingham  
Learning Disability  
Partnership Board

# Minutes from the Self Advocate's Workshop

Bradbury Community Centre,

Tuesday 13<sup>th</sup> October, 2009

## “Treat Me Right!”



Dawn Johnson

**Who was at the meeting:** Julie Weller, Frankie Brewer, Viv Harris, Andrew Hoyle, Peter Waite, Phillip Pearce, David Chaffe, Jason Archer, Paul Clarke, Paul Rickson, Roz Gilbert, Julie White, Jennie Grieve, Jodie Newman, Fi Shailes, Marlana O'Donnell, Tina Gayle

**Guest:** Dawn Johnson from Voice 4 Kent

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Phillip welcomed everyone to today's workshop which was about **treating people with learning disabilities right!** The agenda for the meeting was:

- A look back at how people with learning disabilities used to be treated.
- Labels – what's in a name?
- How I want to be treated by the NHS

### Icebreaker

We introduced ourselves using our **full name** (the name we were given when we were born) and then said the name we liked to be called – our “label”. For example, Frankie's full name is Francesca, but she likes to be called 'Frankie'.



### A look back at how people with learning disabilities used to be treated:

We started off the meeting watching a film called “**Perfect People**” which talked about how people were treated in the past. The film talked about why people with learning disabilities were sent to live



in institutions or hospitals all their lives, and why things like getting married and having children wasn't allowed. They were treated as 'patients' and not as people - and their human rights were ignored. The film talked about Kevin who was put into a long-stay hospital when he was only 6yrs old, and how he feels now that he is older and lives in the local community.



*Treat us fairly and with respect!*

### Thank goodness times have changed!

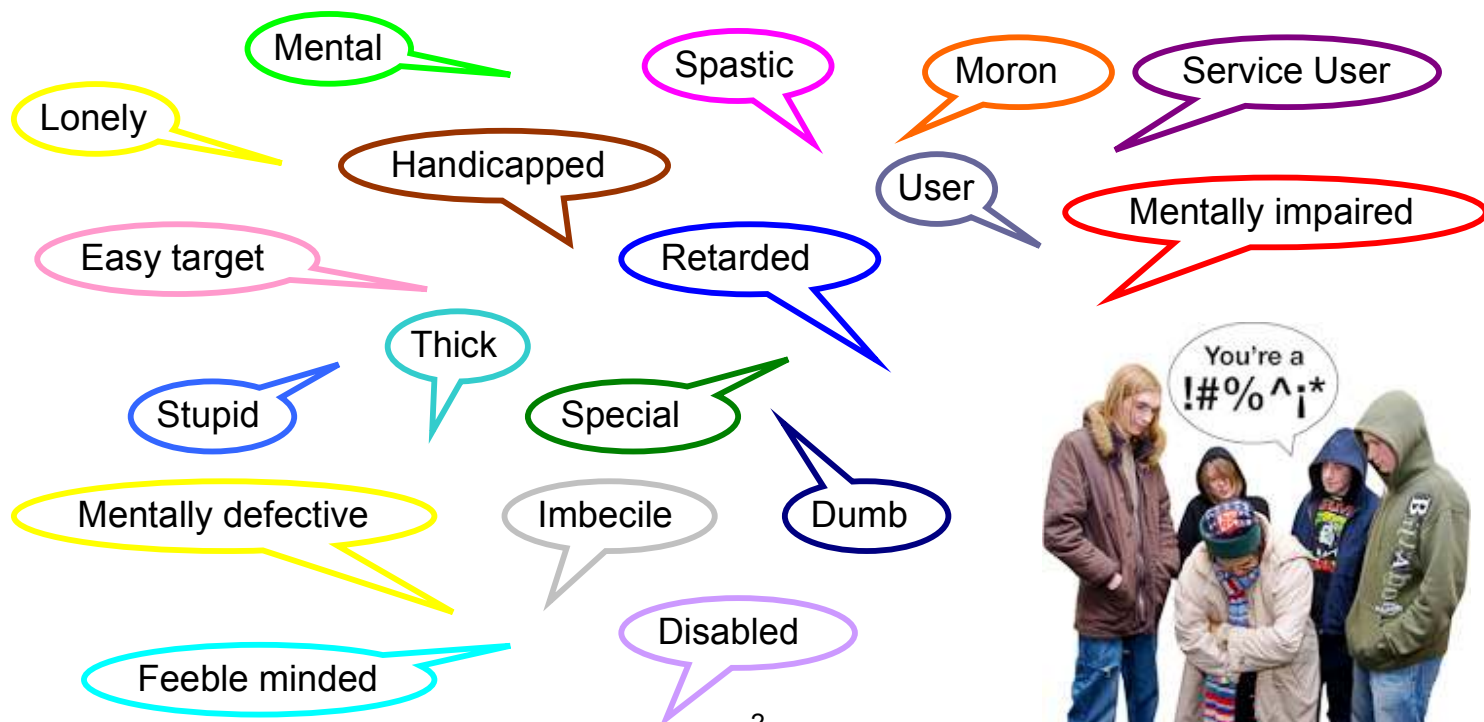


After the film, Dawn gave a presentation which showed the history of how people with learning disabilities have been treated in the past, and the dates when laws and acts came into place, giving people their human rights.

Valuing People and Partnership Boards have made a huge difference to people's lives. We are all working towards making sure that we move forward and never go back to the way people with learning disabilities were treated in the past.

### Labels – what's in a name?

Next we thought about the names (or labels) people with learning disabilities have been called in the past... and sometimes still are!



## We thought about how this makes us feel:



## Then we thought about the good and respectful names that we can use:



A **bad example** is “suffers from” – people with a disability don’t always think of themselves as ‘suffering’ from a disability. Their disability is part of who they are - just like the colour of their eyes. Another bad example is “disabled person” because **we are people first and our disability comes second**. It should be “someone with a disability”.

We had a vote on these 2 examples and nearly everyone agreed!

A **good example** is saying “**people who have a learning difficulty**”.



More good examples were:



- ✓ Learning difficulties
  - ✓ Learning disabilities
  - ✓ People who have support
  - ✓ Social care customer
- (Marlena and Fi at the Council are starting to use this term instead of Service User. We had a vote to see who liked “social care customer” and 13 people thought it was a much better label!)

We also thought about being labelled for other reasons – for example our race or our religion.

## How I want to be treated by the NHS!

After the break **David** and **Dawn** talked about how we communicate with people in hospitals and in GP surgeries, and whether a booklet about ourselves would be useful when talking to medical professionals.



### **Royal Berkshire Hospital's (RBH) Communication Booklet**

Sarah Stancer is a nurse in the Accident & Emergency department at the RBH. Sarah has made a communication booklet to improve the care given to patients with learning disabilities, and wanted our comments. We worked in small groups and went through the booklet thinking about each question and whether there was anything we would like to have added or taken away.

**This is what we thought:**

#### **Were the questions clear?**

We thought some were clear, but we might need someone to help us to fill it in.

#### **What did we think about the pictures?**

We liked most of the pictures, but some weren't very clear. Also, it would be good if they were a little bigger and there was more space between each one.

#### **Was there any jargon?**

We thought 'professionals' and 'environment' and 'next of kin' were difficult words. It would be good to have each word explained, or an example used.

#### **Do we think the booklet is a good idea?**

Everyone said **YES!!!** We even thought that other areas of the country would benefit from having these

**Anything Else?** Here are some more suggestions:

- Phillip and Paul thought that some of the questions on the back page were quite personal. Jodie suggested there could be a clear sentence at the beginning saying that some people might not need to answer all the questions - unless it would help with their care (for example, help with going to the toilet).
- We wondered what is being done to make these booklets easier to understand for people with visual impairments?



We will tell Sarah about all our comments.

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**Tina Gayle** came to today's meeting because she works for the Primary Care Trust (PCT) and part of her job is to visit all Partnership Boards and be a link between the health service and ourselves! So, if we have any suggestions or comments, or would like to be involved in something that the PCT is doing, we can talk to Tina and she can take the information back to the PCT for us.

That was the end of our Workshop. We gave a big thank you to Dawn for coming all the way from Kent to talk to us today!



Our next workshop will take place on:

**Tuesday 24<sup>th</sup> November 2009, 10am–12noon,  
Bradbury Community Centre**

The theme for this workshop will be:

**Technology  
Using things like phones and computers  
safely, as well as to keep safe.**

