

Language shapes how we think. The words we use, how we use them and the meanings we attach to them reveal how we see ourselves and others, says **Louise Pembroke**

Mind your language

I've increasingly noticed suggestions in mental health journals that we 'shouldn't' use certain terms to describe ourselves because they are 'inappropriate' or convey the 'wrong' message. This rallying call has come from both experts by experience and profession – and notably those who are both. It begs the question as to what descriptions we 'should' use.

I'm not keen on trying to find generic terms to which we all subscribe, as this diminishes our autonomy. Nor am I desperate to seek out the most positive-sounding terms in this era of recovery-movement-enforced positivity. As a former officer of Survivors Speak Out, we promoted *self-advocacy* as the highest form of advocacy, and this included the right to self-definition. Later, the 'reclamation' or 'ownership' of experience became promoted within the hearing voices movement. So rather than trying to agree on terms we can all use, let's celebrate, respect, understand and agree to differ from other people's definitions. The resulting debate is more interesting.

Our self-descriptions often evolve over time, reflecting changing experience and analysis. I no longer refer to myself as a 'self-harmer' but as a 'person who self harms' because I want to stress that the person comes before the act. I don't wish to be defined by my actions alone because I do other things apart from self injury. Listening once to a clinician on a committee describe people who self harm as 'cutters' made me take a stand and remind him that we are more than our actions and our physical scars. I pointed out that if the committee had been discussing guidance in relation to psychosis, members probably would not have referred to people with a diagnosis of schizophrenia as 'schizos'. My request to not refer to people who self harm as 'cutters' went unheard.

Yet when a representative from the Samaritans asked members not to use the expression 'commit suicide' because it reflected a time when suicide was a crime, and instead refer to people who 'die by suicide', everyone immediately agreed.

Why was my request ignored? Many experts by profession are unused to service users defining themselves and their actions, and dismiss what they say with, "That's just their opinion." Recently, a service user development worker told me how hard he found it to offer a critical perspective to a staff group when he was met with, "That's just your opinion." Why *just*? Perhaps the response could be: "Well that's *just* your opinion that it's *just* our opinion!"

In the 1980s our views were dismissed with the phrase "You're not representative." Apparently 'prominent' activists were personality disordered and therefore not representing the 'properly' sick; those deemed to have schizophrenia or bipolar disorder – even though most of us actually *did* have those diagnoses!

Those of us who became activists in the 1970s and 1980s all went to great pains to correct professionals introducing us as offering *The* service user view on a given subject. We would stress that we were offering a view, and not attempting to represent everyone who had ever used services. In saying that, social movement knowledge is by its nature collective and never just the insight of one person. That's part of its power.



According to some people who have used and worked in mental health services the terms 'service user' and 'survivor' are 'wrong'. This leaves me perplexed. I've used many descriptions as an activist depending on the circumstances. On a committee I typically need to be identified as a 'service user' as this is understood by funders. I don't feel insulted by the description, even though it is not my preferred one. I *do* use services. I take the point that we are not *using* a mental health service like we *use* Sainsbury's, where we are *customers* – although the thought of asking for an exchange or refund on your CPN is amusing. However, I don't think the description 'service user' has helped achieve more power and responsibility for people within mental health services any more than the change from 'psychiatric' to 'mental health' nurse achieved any difference in nursing culture.

Who are service users? There is a hierarchy of diagnosis whether we care to admit it or not, with the supposedly more 'serious' schizophrenia and bipolar diagnoses at the top and other conditions viewed as more 'ordinary'. I've

never understood this distinction because it's pretty *extraordinary* for the person viewed as agoraphobic not to have left their house for several years, and *serious* that eating disorders carry the highest mortality rate of all 'mental illnesses'. What does qualify someone as a service user? I don't want to see a hierarchy of experience and service use, but I do feel that a few sessions with a Hampstead psychotherapist is not quite the same as using NHS mental health services. Chosen private therapy remains just that; private.

Other terms have arisen around 'service user' to denote a hierarchy of status, mostly from academics writing about social movement activism they have had no involvement in. 'Celebrity service user' is one of them. Arguably a small number of service users have courted celebrity; this occurs within *all* areas of activism. The description is offensive because our experience has been expensively gained: we struggle to get our projects funded and 'user involvement' within the statutory and voluntary sectors depends upon the unpaid labour of service users.

It raised a wry smile from a friend when I was once referred to as a 'prominent' service user. We discussed whether there might be a grading of service users we were unaware of, including a higher grade of 'eminent' service user, akin to the clergy's Reverend and Very Reverend.

A nurse once complained to me about my email address because of two words in it: 'thepsychotic' and 'loopy'. I explained to him about the reclamation of language and humour, and that I am known as Loopy-Lou to friends. It amuses me how nurses and doctors can be shocked by the word 'loony' yet be happy to use derogatory

Although we can be proud ourselves as people who just happen to have psychiatric diagnoses, does anyone celebrate the four-stone anorexic? I can't celebrate the times when I can't face being with people because of my voices. I can't celebrate needing surgery for my injuries.

Mad Pride has its limits for me, but I appreciate the potent use of the word 'mad'. Many years ago in Japan when I spoke of the British survivor movement I wore a T-shirt with 'MAD' emblazoned across it. Japanese service users really liked this and felt that I was openly supporting them at a time when they could be less vocal as activists. Similarly,



descriptions and diagnoses that for some people feel like character assassination and value judgements dressed up as science. These descriptions are permanently in medical records and can cause 'diagnostic overshadowing' in general healthcare.

'The mentally ill' has been a popular description among journalists. Other patient groups are not referred to by their condition in quite the same way. How often have we heard crimes reported with tagged-on words such as 'psychotic' in the absence of a diagnosis in order to stress the heinousness of the person's actions. Bin Laden was described as 'psychotic' without any known diagnosis, but it's rarely stressed that war criminal Radovan Karadzic had been a psychiatrist.

Meanwhile, the charities struggle to find terms that don't offend. 'Mental illness', 'mental health', 'mental ill health', 'mental health illness', 'mental distress', 'mental health issues', 'mental health problems': sometimes the combinations of words can get amusing. Understandably, those of us who are subject to these awkward descriptions can end up preferring plain old 'mad'. 'Mad' and 'crazy' are earthy descriptions, often 'reclaimed' with strength and pride – hence the Mad Pride movement.

Personally, I don't feel that Mad Pride is entirely the same as, for example, the struggle for black people and women.

after a service user roadshow at Broadmoor, where groups took their information to the people detained there, my cartoons relating to self-harm treatment were boldly posted up on bedroom doors. The pictures expressed what those detained could not say themselves.

As a writer or speaker I describe myself as a 'survivor activist' because I wish to assert my politics. 'Survivor' means different things to different people: surviving distress, life experiences or mental health services and treatments. The term 'survivor', primarily promoted by Survivors Speak Out in the 1980s, was a powerful 'coming out' statement. It didn't have an ounce of victim in it. It felt strong, strident and proud, like a Black Power salute, and I feel inclined to hold on to that word as a symbol of our struggles and resilience.

In the USA and New Zealand 'consumer' is a more common description. In 1989 I addressed a conference of Canadian and American peers in Montreal and introduced the term 'survivor'. Explaining my rationale for this I quoted the late Eric Urwin, a member of the 1970s Campaign Against Psychiatric Oppression (CAPO), who said: "People are as much 'consumers' of psychiatry as woodlice are of Rentokill." I had no idea how much these words would initiate debate. David Reville, a former politician who was there, now teaches 'Mad people's history' at the School of Disability Studies, Ryerson

University, Toronto, where they still refer to that debate.

I was certainly aware back home how much the term annoyed some members of the National Schizophrenia Fellowship (now Rethink), who referred to us as 'sufferers'. Although not a term I would choose myself, I would fight for the right for anyone with first-hand experience to use it about themselves because self-definition has to respect difference.

I also refer to myself as an 'activist' by definition – and especially by this definition: 'One who latches on to a cause like a terrier to a postman's trousers; an energetic meddler whose efforts can be as tiresome as they are tireless.' (www.sneer.net/definitions/a.shtml) I was born to be an activist in some shape or form. If it had not been mental health activism, I would probably be sitting in a Greenpeace boat in front of a harpoon.

In general medicine if I am asked about my psychiatric diagnosis I refer to 'psychosis', as the term is readily understood in that context. Outside of that setting I describe myself as a 'voice hearer', which again asserts my politics because it does not ascribe a specific frame of reference or theory in the way that 'schizophrenia' does. To know about my personal frame of reference I would have to be asked. 'Schizophrenia' has essentially one meaning, that of disordered brain chemistry, whereas 'voice hearer' can mean anything in origin, from spirits and bullying, to abuse and aliens.

'Recovered voice hearer' is a newer term within the hearing voices movement. I don't use it because I think the so-called recovery movement is a mishmash of previous concepts such as self-management and social inclusion promoted as something 'new'. It has nice rhetoric but fails to represent those who still need support, and never speaks of recovery from abusive psychiatric or medical care. It has been bolted onto a medical model and politically hijacked but alleged to have been instigated by survivors. I don't *feel* recovered (whatever that is), so to get my point across I'll sometimes refer to myself a 'failed voice hearer', because my life is not black and white, well/recovered or unwell/sick.

Therein lies one of the many contradictions around popular words such as 'recovery' and 'psychosis'. 'Recovery' is promoted by some activists as the antithesis of the medical model, yet 'recovery from psychosis' implies recovering from an illness because 'psychosis' is a medical

term. Some recovery promoters will say we can either 'complain' or 'contribute' but we must not be anti medical model; yet other activists will stress the non-medical bias of recovery from an illness. Confused? Me too.

'Survivor activist' and 'voice hearer' are not descriptions intended to equate my *entire* identity. They are used to identify something of myself quickly when speaking or writing in a mental health arena. But I've also pointed out my love of music, singing, dancing, films, chocolate, 'cake crisis intervention', dogs, Star Trek and Daleks, together with my desire to make some positive difference in the world and my resolve never to use evil PowerPoint, which has it in for me along with computers, Hoovers and all electrical devices. We are *all* more than our service usage or service provision.

Some people *do* identify primarily with their diagnosis, which is understandable given how these experiences and responses to them can take up large periods of our lives. And some people have experienced being treated as little more than their diagnosis. If a person chooses to identify themselves in that way, who am I to tell them otherwise? What I do object to is *health services* defining us by our 'condition' or actions – like the ward nurse who announced me as a 'mutilator' to her colleagues.

Instead, I support diversity and self-definition. We should be able to describe ourselves and our experiences however we like. Services and our circumstances can take away choices, and this is the one thing we can choose for ourselves. Please let's not take that away or attempt to regulate it.

I suggest we draw up a glossary of all the weird and wonderful words we use to describe ourselves. My own glossary of alternatives to service/treatment jargon and abbreviations may offend some, but I do have an equal opportunities policy: I'll take the piss out of anything, including myself. Here's a taster:

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| CBT | Can't Believe Therapist |
| DBT | Doing Bollocks Therapy |
| CPN | Can't Print Name |
| BPD | Bullshit Psychiatric Diagnosis (courtesy of <i>Women at the Margins</i>) |
| NICE | National Institute for Clinical E. coli |

All this WRAP, WAP and so on makes me long to see someone stand up at a conference and talk about how they piloted W**K in their Trust. That might just cure me.