

Video transcript: using language insensitively undermines people who care

Katie Clarke: I've been called 'Mum' at meetings and it's just felt that the professional who's called me that hasn't bothered to find out really anything about me. But also it de-humanises the whole conversation and puts me in a box. So, very disrespectful. The power and the control as well: it disempowers me the person, the unique person who's got lots of expertise and skills.

Kate Sibthorp: I think it would be really helpful if local authorities just thought about using normal everyday language that everybody else uses. So would you, working in services, like yourself to be called 'the cared for'? I doubt it very much. If you're going for coffee with friends, would you refer to it as: 'I'm accessing the community today'?

KC: my name is Katie Clark and I'm a parent carer. I have six children and a daughter who is nearly 30. Her name is Nadia. She had a twin brother called Liam and they were born prematurely and Liam lived just a week. We then had a very medicalised beginning to her life. We were very passionate that she would be included in absolutely everything. We carried on trying to have what - inverted commas - was 'an ordinary life'. Which also meant being inclusive. Being inclusive within the family home, wanting the same education as her brothers and sisters have, being given the same opportunities as they would have.

KS: my name is Kate Sibthorp and I'm a family carer. I have three children and one of my daughters is autistic and has learning disabilities. At the moment Maddy has direct payments from our local authority which I run on her behalf. We use those direct payments to employ a number of PAs who just support her to go out and about every day and just enjoy life in ways that make sense to her.

KC: I've got many memories of where we've interacted with professionals, with services. And unfortunately I've got memories of times where words hurt and where the language that people used actually stung, and stayed with me.

KS: I think that the words we use within the health & care system to describe people really matter because they reveal underlying values that the system attaches to them. I think that's why language is continually evolving because it reflects current thinking within the system and within society. So you can go back in time, and people like my daughter Maddy were referred to as imbecile or cretin or mentally retarded or sub-normal. And we've moved on, now we talk about people with learning disabilities, and language has to keep moving to reflect current values.

KC: When you hear things, and the impact that has on you as a person, and the value you have for yourself, [it] impacts on how you bring up or care for the person that you love. So how I feel about myself, and the value I place upon me, impacts how my daughter Nadia feels about herself. And like Kate, [I feel] it's a world that disables our young people as they grow up.

KS: So it's a bit of a quagmire, but it comes down to, I think, when you're talking face to face with people, asking them what they want to be called, how you want people to relate to

you and maybe just acknowledging - when you talk about websites - rather than just putting in the bog standard definition of what a carer is, maybe acknowledging that carers are mums, dads, sons, and daughters, and that we know you love the people that you care about. The whole system is very dehumanised. I shouldn't have to change my perception of who I am to fit the system and to access services. Carers are mums, dads, daughters, sons, friends, and it's not necessarily a good thing for us to think of ourselves as carers because it can impact on how we think, how we relate to people we care about. It throws into the pot questions about duty, obligation, responsibility, when actually all I'm really interested in is my natural relationship of loving somebody and caring about them.

KC: Carer - I feel that there's a great deal of people that don't understand what that word means and don't see themselves as a carer. My children, for instance, have grown up with Nadia and they definitely don't see themselves as young carers and never did. They're her brothers and sisters.

KS: Words I find really annoying: things like 'the cared for' and people talking about 'respite' which means something difficult and unpleasant. Just within the system I think I talked about the word 'special' and when Maddy was growing up and it was a birthday I would really struggle to find a birthday card that didn't have the word 'special' in it, because that's a word that sort of it gets attached to your child quite early on, and it's got lots of negative emotions around it for me. Lots of people I know don't like the words 'service user' because it implies you're using the system and taking advantage so we prefer to talk about people who 'access services' or people who 'draw on services'. I don't like the way the system talks about 'beds'. They always commission 'beds' when actually, you're talking about, you want a room, you want somewhere nice for somebody to go to have a really good break or a great time. It's not about getting a bed for somebody.

KC: Other words that really annoy me are things like case studies and cases. My daughter is not another number she's not another 'case'. Her case is about to go to 'panel' and that's another word that I don't like. We don't even know who is actually at the panel. Other words that seem to be a bit of a bugbear for me are labels, [such] as 'unpaid carers' - that's a label and to me, labels are for jam jars. So avoiding labels, describing the person, or the strengths that they bring. And the same describing carers, you know we're not all the same. Each parent carer, each carer is a unique person in their own right. Being called 'the sibling' or having 'peers' going to 'activities' rather than - we went to a gig on Sunday night in Manchester. We were on the accessible platform which was great, we saw Tom Odell, it was amazing. That's like having a life, it's not 'an activity'. It's not something that is....it's a life, it's an ordinary life .

KS: I notice that when people are talking about services for usually older people, the language we use as a society is to talk about 'putting people in care homes' and I just hate that concept of putting a human being anywhere. So why don't we talk about enabling somebody to move to a different place to live or about getting a different life or a better life or better support? For older people, and some disabled people as well, the system talks about toileting and feeding and they're words I hear relating to people when they're very young, so children, babies and toddlers, you might use that language. So I just find that very disrespectful. And also even training, All the time you hear about people going on 'moving

and handling' training. People aren't objects to be 'moved and handled', it's about helping people to move. So what's always missing is the word 'people' or 'person'.

KC: The language around toileting, perhaps it's easier for professionals and commissioners to see it like that rather than the support that is needed, because if it's 'toileting' it can be something that's done in 15-20 minutes. Supporting somebody to go to the loo is a whole different picture. It could be a conversation beforehand and it could be giving choice and it could be actually making that experience as positive as possible when somebody actually needs somebody else to wipe their bottom. So I think that for professionals it's much easier to use this terminology, because it makes their lives, especially at a time when there are so many cuts, it makes it easier to reduce services, because that person only requires 'toileting'. It would be really helpful if councils actively listened and involved disabled people, family, carers, in all aspects of decision-making, and that goes back to co-production, and learning from us. We've got solutions, we understand the system. We bring a human aspect, we bring a social model aspect. Get involved and listen to our stories.

KS: I think that it would help if people who work in services could recognise that some of the language that they use is de-humanising and offensive.

KC: One of the key messages is to see us all as humans, and to see us as people. And to be kind. Ask us how we are, find out a little bit about us, who we are, what we did beforehand. We've all got a history, we've all got lots to offer, and we've also got immense knowledge and are experts in what we do.