

Whose Story Are We Telling Anyway?

A Keynote Talk for BILD PBS Conference, Liverpool, May 2024

In the early 1990s, I had hair, and maybe that's what overheated my brain.

I thought it was about time I got a qualification to back-up my experience – doesn't that tell a story in itself? That I needed a bit of paper to be heard?

And so on my first day at what had only recently become the Tizard Centre, created by Jim Mansell, a very frightening man came into the classroom. He glowered at the thirty students – all of whom were professionals, and had decades of experience. I like to think that was when I caught imposter syndrome, which is a social disease. I was only a senior support worker, and only a family carer. Everyone was talking about their work. Their disability and challenging behaviour qualifications. And whose 'resident' was the more dangerous. The most expensive. All I knew was my family had no support, and that many of the services I'd seen were terrible.

The one good service I'd experienced was in Canterbury. Part of the Special Development Team project on deinstitutionalisation. We'd had Jim Mansell spend weeks teaching us how to do our job, and more importantly, why we should do things his way.

He was my first experience of seeing a practice leader in action. He didn't just train us in a classroom, but kept turning up at the service. I couldn't help but notice he brought everything back to those we were supporting; Jim kept asking us what *we* thought. He trusted us to come up with ideas that might feed into solutions.

Only in hindsight did I realise part of his immense skill at being a practice leader was growing new practice leaders. Jim infected many of us with his passion and smartness, and a lot of us went on to new projects in new places carrying a little Jim on our shoulders. He inspired us to be doers, not talkers.

Jim is why I went to Tizard to study. But on that first morning in class I thought I'd made a big mistake. I didn't think I belonged. I was made by many of the students – and one or two staff – to feel that what I thought mattered, didn't matter.

The newcomer who walked into class – I say class, but it was a *hut* – was distinguished, *very* Italian, and intimidatingly confident – Michele Di'Terlizzi. Once the housekeeping was out of the way he asked the whole group why hospital and community services in the UK were by and large appalling. (He didn't *say* appalling; he used an Anglo-Saxon word.)

I began to like him.

Well his new students, with probably a thousand years of expertise, were not going to stand for some foreign fellow telling them they were doing a terrible job, even if he was a psychologist and stylishly dressed in a sweater and slacks. They objected. To each

objection Michele provided research to back up his critique. He made the professionals look like they were *whining*.

The problem, some students said, was their stupid managers. Michele nodded. He worked at a university – he knew all about *stupid* managers. The university was infected with stupid managers. Stupid got you promoted! What are you doing about your stupid managers, he wondered.

Some disability nurses said a lack of disability nurses was the problem. Michele was not convinced. Are the people you support so sick they need *nurses*?

I raised my hand, eager to say services don't listen to people who live in services, but Michele ignored me. Maybe my vigorous nodding put him off. He didn't want a fan, but tutees who thought. He asked, 'So *why are services so terrible?*' When nobody answered, he pointed and said, 'Because *you*.'

He didn't actually say 'you'. He said word associated with fornication. His use of that rude collective noun told me I'd *love* the next two years.

Michele said because we did not know enough to challenge bad decisions, we did not know how to change what had not worked in institutions. We thought about patients not people. We thought about single problems not whole lives. But he and his colleagues were here to fix that. If we wanted. If we were prepared to make it not about us.

On reflection, very few of us wanted to be fixed and challenged. Most people wanted to pass assignments, be applauded at graduation,

and earn a promotion by passing with a distinction. I made the rookie mistake of taking seriously what Michele, Jim, Sue MacDonald, David Hughes, Michelle McCarthy and Paul Cambridge and others taught us – that our job was to use the research to improve how we did things – not for ourselves, but the people we supported.

Jim once mentioned that solving challenging behaviour is easy – he didn't say *easy* – he used an English vernacular expression used to show a thing was a really simple. Anyway, Jim said the real challenges are to competently lead rather than manage, to empower and guide staff, and to influence commissioners and policy makers, who often failed to have a bloody clue.

Jim didn't say 'bloody'.

I learned from Jim and Michele that the story of good support was never meant to be about us; it was about people who relied on us to get our shit together.

Di'Terlizzi's often overlooked 1994 paper changed my practice. It was called 'Life History: the impact of a changing service provision on an individual with learning disabilities'. It followed one woman – her story. The thing about stories is they are often lost among the data, narratives told by others about disability.

That disabled people need fixing or amending, that they are not good enough as they are. Michele's paper dared to suggest our policy changes produced confusion and uncertainty in professionals but not a great quality of life for people using services.

Organisations became too focussed on their story and status, and so the stories of people relying on services became even less important. Michele wrote how hard it was to follow the woman's story because the only record of her life was written in clinical notes. Her story got *lost*.

In times of policy change, services seldom notice people. They notice only that their livelihoods are threatened.

Michele's paper was published in *Disability and Society*. It got some good citations, but it was generally ignored because it was about a woman, a disabled woman, a *lone* disabled woman. Michele showed the power of telling another's story, advocating for individuals.

You see how one person can change your life? Michele doesn't even know how often I remember him. He became part of the story of who I am, and who I am is what I bring to the party when I work with families or individuals or organisations. And so we pass on, down a line of transmission, the stories we accrue.

Our lives are our stories, and we think they're about us, but they are really about every person who has helped us along the way. Not only good people but arseholes. Every time you encounter an arsehole, you're learning how not to be. An arsehole is just as much a blessing as someone who helps. My son Noah concluded this when he was not even ten. So when I heard a BCBA telling me consent did not matter because it interfered with her work, I learned how not to be. When the same expert described one year old Noah not as a boy or a son but as a

subject, I learned what not to do. (I learned to not let my wife near that kind of expert.)

My wife often says there are eight billion humans on the planet and very few arseholes – our planet has a low-density of arseholes – so when I do encounter one, I shouldn't let them spoil my day. There are seven point nine billion better people waiting *not* to be arseholes.

There are a group of people whose stories are often not heard. Instead we record their data, their numbers, their nursing problems, rather than their accomplishments. Our narrative about them is dominant, and we say what they are not, what they lack; we use, as Herb Lovett said, diagnoses rather than stories, and our clinical accusations overwrite the story they might tell of themselves. And so we carry on creating people for services, not services for people.

I'm pleased that today we are beginning to listen to the stories of people, and respecting who they are. My autistic daughter is not broken, she is pretty damned near perfect. My brother was not broken, despite being told so often that he was, that he came to believe it.

Eventually I finished my studies. Sure enough I became a manager of services, then worked in an NHS psychology service, then Jim kept asking me to teach sessions at Tizard. Eventually I got a full-time lecturing job despite people saying 'he mentions arseholes too often.'

Then I grew old and took retirement and redundancy, wrote two books, took up mentoring, working abroad, but mainly I shop for food

and cook and look out for the family, but I have always remained, fundamentally, a support worker who is a practice leader.

I work mainly in Europe because the UK feels a little broken; here services seem more interested in money than people. The stories organisations and professionals tell are too often about them rather than the people they support.

Unless a story has a happy ending; then you might see an excerpt on a website, used to promote the organisation. Too often the real stories of people are sad and full of our errors. Our barriers are their burdens. Our thinking remains their obstacle.

So as I approach sixty years I am happy to be told the only thing people might remember about what I've done are the stories I've shared about other people. Well, that's pretty cool and I'm happy. Nothing is more important than telling stories of people who are often made to remain silent.

In PBS we carry the traumatising stories of those whose language is hurt, whose vocabulary is distress. People tell their stories to us even when they can't speak, often because others choose to not listen. In PBS we listen. We listen *hard*. Someone *has* to listen. It's not a burden, but a privilege to hear their often traumatised stories.

And then all we do is try and do something about supporting them write better stories. We usually support carers to reframe their thinking about the person.

At this conference we've heard of innovative approaches. Knowing that stories and relationships and belonging and hope and

choice are as important as data and formulations is a huge relief. I'm glad to hear people critique how PBS is done in order to imagine how we might do better.

The story of PBS is not really about us; our bit of the story is only about how useful we are. The story of PBS is not about how cool or clever our organisation is, but how we contribute to a person getting all the life they can. The real story of PBS is people. If PBS is to be valid, it needs to feature faces as well as numbers are seen. Because for peoples' stories to be included is to see them as human. If we continue to exclude their stories we banish them all over again to the institution of the mind. Knowing, and acting on their stories, is actually our safeguard.

We are on this planet for only moments, so let us contribute good moments. A little happiness goes a long way, even if it's hard to measure. Many of us know being person-centred and working in partnership to get good things in place often negates the need for restrictive interventions.

Herb Lovett wrote that "Positive approaches are not about cheerfully reinforcing people to do what we expect them to do but about listening to their preferences and good reasons for what they are doing, no matter how difficult what they are doing might be" (Lovett, 1996, p.xiv). He noted, "One author has written 'what used to be called behaviour modification is now called positive behavioural programming for challenging behaviour.' So far as I know, anyone can put a grass skirt on a cow, but it still won't hula" (Lovett, p.xv).

Herb is why in my first book the longest chapter is called *The Elephants in the Room*. It describes things to look out for before prescribing medication or having your own meltdown.

Now, one elephant is called *Belonging*. Does the person whose behaviour is freaking out others have equal and loving relationships? The next elephant is called *Person-Centred*. Is the person supported in the way they need, or the way we can?

Another is called *Interesting Life*. Is the person living a meaningful life for them? Not a life determined by some stranger who turns up with an activity schedule they photocopied from a manual written in 1981 advocating horse-riding, bowling, and hydrotherapy.

The next elephant in the room is *Time to Be Themselves*. Is there *time* to hang out with people they like in places they prefer? Are they allowed to *be* as well as *do*? This is just another way of asking whether we see great rapport? The fifth elephant in the room I called – brace yourselves – *Communication*. Not just from the person to others, but from others to the person, and crucially, from staff to staff. The sixth pachyderm I named *Health* (are they well, are they in pain?).

The seventh I named *Families*. I appreciate not everyone wants or has a family, but family isn't always who you were born to, but who you choose. Does the person have people who are not paid to help them get a good life? The eighth elephant is a big one, which is *Competent Services* (in other words, have staff got their shit together?). The very biggest elephant, the *mother* of all elephants, I named *Happiness*. If the

person isn't living a life that creates happiness, what would you expect to happen if *not* challenging behaviour?

Get rid of the elephants before you call a psychologist. Re-home these elephants, and what seemed challenging will prove to be nothing of the sort, rather, exotic communication.

May I suggest you leave conference and use ABC forms for happiness and laughter and good things? Try measuring what matters most to people.

If you were read my wife's ABC records of my problem behaviour (how long have you got?) you'd come away with a pretty skewed idea about me, but my 'challenging' behaviour accounts for maybe 5% of my time and those data are not my whole story. I have good reasons for getting pissed off, and so do the people we are lucky enough to work with.

Let me wrap this up because you want to go home. I want to go home, too, so my wife can write more ABCs about her layabout retired husband.

Now I'm aware I've spoken about the importance of people's stories yet blathered on about me. So before I wrap up let me share - with her consent - a story of a woman I am beginning to know. Each time I want to use her story I ask her permission afresh, because just because someone gives their consent to talk about their experiences, their story, I don't think it follows we can use their story all the time forever after. That's not consent, that's blank cheque, and that's different. Anyway, she lives on the Mediterranean. She says 'hello'.

You'd like her. She's feisty, fun, and forthright. She lives in a service. She uses a wheelchair but often to run over people who get in her way. Now the organisation spent time trying to discover what kind of service and life she wanted, but were only able to deliver a little of it. There's a broken implied promise right there.

"I don't want to sound rude but they say you're independent. But I'm not. If I had the opportunity, I would run. I want to do things for myself. They say this is our home – but it's not even my own body. I'm not myself. Here, you never know what will happen tomorrow. You do not know who will arrive to help you. I would prefer to wait a day – for my own staff to come. It's frustrating – people may not share my language. They give me a lot of help but it's hard to cope. People do not understand because they are not in my situation. They do what they think is right. I don't know if it was true or whether they wanted to scare me, but they said if I didn't stay here, I'd have nowhere. I want my own home. I don't want to be ungrateful. This is their property. They take care of it. It is their staff. They can put you in a palace, but if it's not your vision, it can feel like hell. The kitchen is not suitable for people who like to cook."

(We went to the kitchen. She showed me how her chair does not fit below the worktop).

"We weren't asked. I did not choose who I live with. I have to ask permission to change things. I need support. I need a job. I love kids and one day would love to be a mum – but... I don't want anyone to pity me. I want people to give me the ability to go forward. To be

included. They don't want you to be like them. Even if you don't like it, give me the opportunity to tell you my experiences and hopes. I don't give many talks now – I wanted to speak more honestly. For example, they do some charity events, and they ask us if we want to be on some video, and I say yes, this year I say no – I feel a little bit used. I want to be heard. As me. This is the first time they've given me an opportunity to speak to someone outside the island. I don't want to scare you, but before here, I didn't go out, I was trapped in my room, and I thought about taking my life. They give you hope, then let hope fly away. There is the possibility of living alone – they know my wishes – but, look, here I am. Oh my goodness I hate this: this is my home but they write notes – about me – what we eat, what time we eat, what we say – I hate it – it's like an institution, not my own home. A handover to other staff – in your home? I was so pissed off one day, I told the worker, and she said, 'I need to write that down.'"

The point here is that when I told the service what this lady shared with me – with her permission, even though she knew the *risks* of doing so – I was surprised and disappointed to hear senior service staff rewrite her story. She was difficult and manipulative, I was told. She changes her mind! God forbid a human changes her mind. Heaven forbid a woman who has been promised one thing and is obliged to accept a different thing complains. If we're going to listen we need to do that, and if we can't deliver what we promise, we need to say just that and take it on the chin when they complain, whilst we work to keep our promises.

The old pattern was to write people's stories for them, and it turned out this is what the service tried to do – they told me a different story about her. How she's the problem. How's she's never satisfied. We tried our best but she's unrealistic and unreasonable. Well, so are many staff, and so what?

My point is that it's easier for us to change the narrative to one that suits us than to really listen to people relying on services. If a person is not at the centre of what you do, if they're not interviewing staff or part of the organisational structure, I don't think you can call your organisation person-centred or person-led. You're not that different from what's gone before, only using nicer net curtains. If the person isn't actively involved in deciding what to work on and how, don't call it PBS. It's just the same as before but using a nicer vocabulary.

A final thought before I leave you in peace. I was lucky enough to met Dave Hingsburger a few times. He made me laugh, but above everything he made me think. On one occasion after a class he asked, 'Tony, how many people with intellectual disabilities have you met?'

I blathered on about having years of experience and working here and there, and he interrupted me kindly, and repeated his question. I told Dave I knew thousands of people, and I saw, I swear, the face of Michele Di'Terlizzi superimposed over Dave's features, and whereas Michele was telling me the problem in services was me, Dave simply spoke more softly, and more slowly, obliging me to really listen, giving me the space and time to be honest.

‘Tony. How many people with disabilities have you *met*?’ and I thought, *gosh, this isn’t a question about my role, but about me.* While I was still processing I said to Dave, ‘Oh, hundreds,’ and Dave being Dave – how I miss Dave – said even more gently, ‘Tony, how many of the people you work with do you *know*?’

And frankly I wanted to cry, because unless we make time, the people we work with become people we don’t know, they become ignored, they become lonely, they get angry.

We have to make time to meet the person rather than the issue, and we need constantly to be reminded to listen.

‘Less than a dozen,’ I confessed, feeling insignificant. Dave (being Dave) leaned back in his chair and he grinned and said, ‘That’s great. Better than none!’

Dave allowed for my processing lag. He made time for me to become a little less of an arsehole.

Dave suggested the next time I was at work I try to meet another person. Really meet them. Form rapport, trust. Keep my promises to do what they would like. Work with them, not on them. To not just resolve a behaviour issue. A behaviour issue is only a complaint, a cry, a communication. Challenging behaviour – though impactful and sometimes life-threatening – is no big deal. We can’t use life-threatening behaviour justify life-limiting restraint. There’s no point in fixing a behaviour if the life remains broken.

Dave helped me understand co-production by showing me co-production. He was a great practice leader. And so my second book

about practice leadership was written to amplify the wisdom of Michele, Jim and Dave. I'm just an ugly cheerleader who uses the word 'arsehole' way too much.

You have to experience person-centred PBS in order to understand why it is important.

So the next time you're at work, do what Dave asked: try to meet a person. Be a meaningful part of their story.

You *will* change lives. For better or worse.