

## A Parable Concerning Values & Challenging Behaviour: *The Joy of Wandering*

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Thanks for inviting me to speak. I won't keep you long. I tend to wander about when I'm speaking. You may wonder as I wander how a man so keen to move could be such a size. Well, those thoughts are yours. I won't tell you what to think if you won't tell me what to do or how to be or what I do is wrong.

But wandering is not a problem for me. It's just what I do. Wandering helps me think and articulate. Besides, it is hard to hit a moving target. Wandering is what I'm comfortable doing.

Oh. Sometimes my language is a little colourful. Like a Mardi Gras rainbow, actually.

Both wandering and having an extensive vocabulary might be considered socially inappropriate in some places. I know the person recording my lectures at the University of Kent thinks both my wandering and language are socially unacceptable. This is because I annoy him wandering about. He says I make his

camera go out of focus. And he believes English should not contain expletives other than his own.

But I'm not looking for sympathy (a little empathy never goes amiss though), and I'm certainly *not* looking a functional assessment to establish why I wander or swear, a little, at times. Because your doing a functional assessment might lead you to think you need to *change* my behaviour. That you've the *right* to tell me how to behave. Even if you wander yourself, and swear, you might hold a position of power or knowledge that means you view yourself as different to me, and so different rules apply. Because a functional assessment is too often biographical – it's about what you think of me. Whereas an autobiographical functional assessment – a piece of exploring that includes *my* perspectives, *my* words, *my voice* – well, that would be something, would it not? Then the document would be about me *and* you, not just you.

But here's a thing. The reality is I'm quite happy wandering, pondering, talking (and sometimes swearing). And if you need to know why I wander and swear, don't call a psychologist (they are expensive) or a behaviour analyst (even more costly in all kinds of ways), and don't find someone *like* me (bald, male, white, 54) claiming to speak on my behalf, just because they are more eloquent than I: simply ask me or keep an eye on my experiences.

Likewise, sometimes, to understand challenging behaviour, you need to look away from the behaviour and think about the contexts in which it happens. Because challenging behaviour is a symptom, as my wandering (and swearing) is a symptom. Not of a disorder or an illness, not matter how keen you might be to label me based on your own prejudice or standpoint. Rather, my wandering and swearing are a symptom of... drum roll, please... me. These behaviours, or habits, or responses,

whatever you wish to call them, they are clues to what is important to me, and who I think I am, and how I wish to be seen. Just watch, just ask. I wander because I think better wandering. I feel *moved* and so move when I speak.

And the swearing? Well, there's growing evidence a human with a fine creative vocabulary isn't averse to the odd expletive. And here's a declaration. When I swear, moved by injustice, angry at indifference, trying to wake people to the horror of so much support in the UK today, I am also testing you. You with your training wrapped about your shoulders, clouding your mind to other perspectives. If you offended by the word 'shit', well frankly my dear, I don't give a damn. You should not be offended by words when there is so much more to be offended by. By sexual abuse, by not listening to people, by cancelling the future of autistic people or people with intellectual disabilities: perhaps be offended by these things, not a four letter word. You should be offended, I'd suggest, by the fact public money buys hospital places and community services that are not fit for the people living in them – and often not fit for those working in them, either. Are we so offended by the sounds of certain words we are deaf to shit commissioning and crap care?

So say you decide to ask me about my wandering, about my swearing. But you don't understand my voice or actions. If you cannot grasp what I am telling you or showing you, you might resort to ancient ways of thinking – namely, that it is not you, it is me: my fault, my difference, your Othering. And so you ask for a biography of my story and my life (and my behaviour), written by someone qualified and trained to talk about people like me, not with people like me. Except... I'm fairly unique. And your expert might not even recognise my individual attributes, so caught up are they in ticking this, and ticking that, and producing a formulation about me.

I'm not asking you to change my thinking or my behaviour, though you certainly hold the power to do so. My wandering does not limit my opportunities. And you can modify my behaviour by being nice, for example, or developing rapport with me by discovering what I enjoy. And all without the need to resort to differential reinforcement or token economies or extinction programmes – those little tricks of the trade you've been taught in Wales or Kent, on distance learning courses or through analysis of *celeration* charts. No one under-estimates the power of your knowledge or skills. Just the wisdom of using it.

And that's a value, right there. A value is a principle that informs what you do, and what I do. A value is like a rule or at least a guideline about what and how we might think or do. So here's how things stand. It's your behaviour that gives the proof of your actual values, not your words, and certainly not your own thoughts about your worthiness. It's what you do that counts. Not having an ethical code. It's not the code that determines whether I'm treated with dignity, but how it is applied and how it informs what you think of me, and what you recommend others do to me.

For example, if commissioners and care managers pay people to keep autistic people or people with intellectual disabilities, or people whose behaviour challenges in a hospital, they're saying they think those people are ill, when really, with just a few careful questions, by meeting the person directly, it might be discovered they're not ill, just complaining, just communicating in an unusual way, or experiencing a life that pisses them off. (Sorry about the swearing.) Buying hospital places not person-centred places is a powerful statement about their real values as opposed to their language. Saying 'she is ill otherwise her behaviour wouldn't be so unusual or harmful' shows us how little you know: challenging behaviour is impactful and real, but it is also a social construction.

It's like someone talking about diversity who then does nothing but criticise diverse perspectives. There's a jarring dissonance that is unhealthy for the person and those around them. It's like being *told* to volunteer. Foolish as assuming representative democracy is actually democratic.

Values grow like coral beneath green oceans if the ocean is healthy. Or values can dissolve and become bleached by toxicity. We need to keep practicing our values, and we need to ensure our environments support us to practice our values and grow. It's easy for a value to become eroded. When I think of *Valuing People* I think of eroded promises.

My values today have grown over the years, informed by the people I've met, my own thinking, my experiences, my reading, my life. It seems today too often our values are of little value, and that social care knows the cost of everything and the value of nothing. I suspect there are a lot of broken-hearted people wearing business suits wondering how the hell they came to be doing the very things they swore they'd avoid when power came their way.

A value of mine is to keep finding new things to do and consider – to keep me interested so as to not die too young – and so I'm doing this talk without the aid of a safety net, or at least a PowerPoint.

(If I do drop dead – if this happens in front of you – then it doesn't mean you *have* to be traumatised. I've had a good time and dropping dead is perfectly normal. Honestly? It would be a relief not to face the M6. Anyhow, the trying of new things will have made my life a good life no matter the length.) So a new thing this: no PowerPoint, only notes.

Values are often thought of as nebulous things. Unlike behaviour. You can *see* behaviour. It's right in your face. You can even *feel* behaviour, especially if it hurts you or makes you feel good, but values sometimes seem a little otherworldly. It's hard to weigh a value.

But you can measure its effect. Unless enacted a value is just a theory that keeps us warm at night. A value is a bit of a story we write about ourselves. If a theory isn't enacted, it's pretty worthless- like having a million in the bank untouched. It's like the opening of a story about ourselves that doesn't go anyplace.

So values can be seen if they are enacted, otherwise they're hidden. Hidden stuff makes scientists either itchy to discover what is hidden or to decide it is too tough to discover hidden stuff so they'll focus on the blindingly obvious. Or at least, what is funded.

For example, too much of our history in trying to understand unusual or challenging behaviour features the latter – if we can't see it, we won't measure it. This tells you more about science than any number of books.

So this kind of science about challenging behaviour is like saying 'we can only measure the nose on your face if we can see the nose on your face'. It ignores the *benefits* of the nose on your face or the *meaning* of the nose on your face. It's just a nose, right? But the nose on my face isn't just a place to perch my glasses, it's not *just* evolved to make me appear dignified or drunk because it's a big nose or often red. No, it means I can smell (and weirdly, taste). I *use* my nose to smell the soft hair of my wife, to know when the cats have been doing things they shouldn't in the bedroom, to determine the kind of food I might want to eat, and to work out when

something doesn't smell right in the Moody Hills of Serviceland. A nose is not just a nose, and a challenging behaviour is not just a problem.

Values are thinking rules. Not all values are good. Donald Trump has *lots* of values. I may not agree with him, or what he does, or thinks, or the way he uses his family, or treats women, or asks blond women to stand up so often during press conferences, the way he speaks of minorities, how often he speaks of himself, and changes tack more often than a yacht in the America's Cup, or about money, loans, other humans, a certain country spanning two continents, or hair products, but my values tell me not to judge others. Though I can be made to push that rule a little out of shape in an emergency. Or when the future of the planet depends on it.

I've always been interested in values, because values are like a disease, infecting people, spreading. (I bet you never thought of values as being like Zombies.) You can't vaccinate against ideas or values, but in the same way you can fight infection with antibodies or lifestyle choices, sometimes values come up against competing values that constrain them.

So let me set out my values. I think person-centred planning and person-centred support is most often the right approach to take. Why? Well, it is nice, it requires me to be empathic, which is probably a useful attribute to develop, but it is also a pragmatic thing. To arrange a situation likely to result in the person living a good life has lots of benefits for everyone. Because if they live a good life – one that is enviable, of good quality (as defined by them), a life that enables them to grow and enjoy the place and people around them – then in terms of challenging behaviour, we might see less challenging behaviour.

Why? Because challenging behaviour isn't in the person, but in the space between the person and the places they spend time. I have a lot of challenging behaviour available to me – I can unpack my bag and show you if you like (heaven knows my colleagues might be nodding even as you read this)– but if I'm tired, and missing my family (in other words, if my quality of life is poor), and if I'm asked to do one too many things I don't actually enjoy, you might find me use the word asshole more often than if I'm content.

We can all challenge. And that challenging behaviour isn't about my pathology, or my diagnosis, it's often about my quality of life. It's not because I'm a man, though heaven knows as a Guardian reader I feel I should think it is. No. You see, when I challenge, it's because I've learned to express myself that way. When my quality of life is good – when I'm happy – you might find less challenging behaviour and more not challenging behaviour. Delivering a life is the ultimate antecedent intervention. When I am ignored or belittled or analysed, then that reduces my quality of life, just a tad, because quality of life for me has a big helping of other people. Other people who take me seriously, or think I'm ok, and who listen. Even if I'm behaving a little bit like an asshole. *Especially* when I'm behaving a little bit like an asshole. My real friends don't give up on me because I'm being an asshole: they want to help me *not* to be an asshole by asking if I'm ok.

This is obvious as the nose on my face. The nose you can measure, and say, 'My, what a great place to put glasses' or 'Hey, Tony drank some wine last night, his nose is red!' (I've actually got a cold not a Rioja). You can – like a good behavioural scientist – say 'Nice nose – here are the dimensions of Tony's nose' but you know what, standing outside of me, measuring me, won't tell you why using my nose to smell food or the wonderful aroma of my wife's hair is so important to me.



Sure you can measure my nose, its colour, how often I sniff, but it might not tell you why, or why if I cry it runs. You simply say, “Tony, blow your nose, behaviour yourself” as Dave Hingsburger might say.

In the same way you might say ‘Stop wandering, Tony’ and ‘It’s inappropriate to say arsehole’. When if you knew anything about me, you might appreciate I need to wander – it’s honestly not a significant problem – and you might appreciate that by telling me I shouldn’t say arsehole, makes, you, well, an arsehole.

If I tell you, “I’m missing my family, so I’m crying, so my nose is running”, you can listen to me and try to help me fix things so I can see my family. Or you can take a scientific behavioural view and say “Well, I’m not here to listen to your subjective experiences, that’s not scientific, because I can’t verify what you’re telling me, I can only measure what I see”, and then I know despite your scientific credentials, despite your status and your power, you’re not listening to me. You’re not taking me seriously. You’re writing my story from your perspective.

And then we’ll see challenging behaviour, because if there’s one thing worse than missing my family, it is missing my family whilst some expert tells me how I feel is not important and to go blow my nose.

So my values – to try to take the person seriously by listening, by involving them in co-constructing a shared understanding, by working in partnership – are based not only upon taking people seriously but good scientific principles, too. More listening, more conversation, less challenging behaviour.

You want a sure fire methodology to reduce challenging behaviour? Grow rapport, learn to communicate, learn to listen, learn to deliver the life people need and want.

You can thank me later when you're not rolling around the floor with some arsehole trying to teach you physical interventions, who speaks from both sides of his mouth when telling you about low arousal or de-escalation approaches. Honestly. Just give the person a cup of tea, or a trip out, or your time. *Even* if they're calling you an arsehole and your team-mates are telling you their behaviour is inappropriate. Stop, and wonder whether their behaviour just might actually be appropriate. Get off the person's case, and trying getting on their side.

If we have things in common, if we keep talking and negotiating meaning, we might agree to avoid conflicts. I might learn from you, and you from me. Good rapport and better communication isn't about being nice wholly but about what works to deliver a life the individual welcomes because it tends to result in less challenging behaviour. Research *will* follow where our values lead, eventually. Though most of the time research follows where there is money. And where money lies, waiting for researchers to warmly embrace it, and write, eventually, that more research is needed, where money lies is ultimately a values-based decision. What do funders think is important? This is sometimes like the tail wagging the dog.

Quality of life can be simply stated – from *my* perspective, *my* values – as people living interesting active lives within a network of relationships with people who like them, in an ecology they enjoy. I think quality of life is important because these are my values. I happen to like people. Well. Most people. People are valuable because of who they are not what they are not. Everyone is someone. Everyone contributes. Everyone has value. Even arseholes.

So when I speak about challenging behaviour, as well as thinking of the science behind understanding why it happens, I think of its value and meaning *to the person doing the challenging behaviour*. What message is it sending? Does the person have

so little control over their lives, so few options arising from a lack of learning opportunities, that they need to hurt themselves or others that they end up in hospital miles from home, away from the people who love them? A young woman who self-harms because some family member has whispered she is fat and so lacks value in his eyes, who harms her flesh to feel present and alive or autonomous, or a young man who wishes not to be here any longer because he doesn't fit or belong, these are not clinical cases to be peeled apart by investigators snapping pictures of moments from their lives. They are our fellow humans, our brothers & sisters, our parents and children, to be understood and shared with. These people are us. And we are all we have to work with, so better get to it.

I'm not suggesting we love one another like we do our families, because there are people in my family I'd at times happily toss to sharks. But we can agree to hopefully be civil, and only *imagine* the shark tossing.

Let us be honest and truthful: we are none of us perfect, and it is our scar tissue that makes us the wonderful people or the hurting people we are. Here's a value: does what we do in our work with young people help them belong or become? If not, what the fuck is it that we are doing? If our research makes a lasting difference to the person taking part in that research, then that's a constructive thing.

So here are my values: people are important, more important than their behaviour. Behaviour that challenges is a symptom of an unhappy life, denuded opportunities, of not being happy, of learning issues, of perhaps ill-health. We determined the label we give any behaviour. Challenging behaviour then is about us as much as it is about the person doing the behaviour.

The child rocking in a corner, or declining to engage, or hitting themselves, may not be showing challenging behaviour. It may be a call to action to support the child in a more meaningful way. It might be a wake-up call to remind us our presence needs to support the person to belong, and our job is to mend ruptured relationships.

It's not up to us to change behaviour as a first response. That's why for me Positive Behaviour Support is not a cult or pure science. PBS is a method of seeking to understand people. It asks us to not only know what we *could* do, but what we *should*.

The first step is the most important – to ponder as we wander enough to ask where the person is at, wonder about what they value, and how we might contribute to their being taken seriously. If they love Lego, go buy Lego with them, don't limit their access in fear of obsession. If they stick Lego up their nose (heaven knows I've tried this), show them what it *is* for. The more you limit the more you craft a burning desire for Lego. The less you teach the harder you make their lives.

John O'Brien (whose words remain precious) wrote, "Some people's ways of communicating leave the important people in their lives unable to hear their views about a life that would make sense. These other people have little choice but to create a story with a valued and central role for the person, whose preferences remain ambiguous. Then, these people make adjustments based on the person's responses to the real settings and experiences that resulted" (O'Brien, 2002, p.412).

It's not rocket science.

O'Brien knows – without qualifications in behaviour analysis, but with qualification in human life – that behaviour carries meaning, and we can think of it as sending a

message, even if the person themselves is not intending to do so. As our behaviour, our actions, our thoughts, our feelings, impact others, so the behaviour, actions, thoughts and feelings of others impacts us. We better learn to work together rather than tear one another apart.

Don't tell me to not wander. Don't tell me to wipe my nose. Don't try to teach me to wipe my nose if you don't know for sure why I'm crying. Because sometimes crying helps me feel ok. And sometimes screaming does. And sometimes rocking helps me cope with the absence of the people I love and the need to feel I belong, to feel I am whole, to feel I am loved. I am not independent, I am interdependent. To change my behaviour in a way that separates it from me or meaning is like putting me in solitary confinement, then complaining that my nose is running.

Don't tell me about this cool programme where I can be given a trip out to the seaside once a month if I stop crying just a little bit. Don't give me little tokens to reinforce my not crying. If you promise not to manipulate my behaviour – my performance you find so fascinating to measure – if you promise not to reinforce this or ignore that, then I promise to not think you're an asshole.

Your job is to help me achieve the life I value. And if you don't know what that is, then what business do you have claiming you're supporting me? You're merely managing me. You're merely placing me in a situation you might likely find unacceptable for the people you love. Is that your values in action?

You want to teach me to challenge really well? Move me to a place that doesn't suit me.

You want to teach me not to trust your smile, your suits, your words, your policy documents, your units, your business agreements, then keep on doing what you're doing – not insisting on a person-centred plan, insisting on diagnosing me, not listening to my unique and valid perspective, insisting nothing counts unless it comes from a suitably qualified person who doesn't know me.

Because you view me as a transaction not as a person, not as a customer but as cattle, I will continue to be obliged to challenge. What you view as challenging behaviour others might see as self-determination. As complaining.

Because in the UK right now – in 2019, when by now I imagined not only would we all be driving electric cars and have saved the planet but that we'd be better at supporting people better - we buy beds, placements, and analogues of homes.

We don't buy listening. We buy loneliness and wasted lives. We don't buy hope. We invest in bricks not relationships, in contriving to believe humans are machines not whole, and we buy ourselves out of doubt by spending a fortune on specialists. We purchase our qualifications as if crafting a professional identity, with good wages, with inspirational web pages as if doing so is sufficient to understand and serve people labelled as divergent, different, and Other. What we buy we pay for dearly. Only it is not we who pay the price.

If you say you have values, let's see them in action. If you say people are important, let's see how you treat your staff. If you say you listen, let's meet the families who say you've delivered what you promise. If you view me as a commodity, as a unit of economic generation, as coins of your realm, then I'm afraid I shall continue to think you are an arsehole.

So, what does this all result in?

It seems to me the key to supporting people around challenging behaviour – and by this I don't mean only directly supporting the person whose behaviour is considered challenging, but also the people around them endeavouring to support the individual, too - is having a really good balance between knowledge around the science of behaviour support (you know, evidence-based and evidence-supported work) and an insight into the relationships and empathy needed to make support a success. Because the decider on what to do isn't automatically the science – the *could* – but the identity of the person, the preferences of the person and the contexts around them. We could do anything, but we might be better off considering the *should*. *We could* send this child to hospital miles from home. But *should* we? Why not better support the child near home?

To understand why people's behaviour challenges us we need empathy – insight into not just their behaviour but their whole person. Their situation. Their experience, as far as we can.

A functional assessment might show a person gains attention from a particular behaviour but that assessment may not tell us why such attention is needed. Though the science behind a functional assessment actually *does* tell us that if someone's behaviour gains attention then attention is in short supply at other times. You then don't simply provide attention before the person is obliged to resort to challenging behaviour – you ensure the person has plenty of attention, delivered in way they prefer, whenever, wherever, however.

To do that you need to understand the person not just their behaviour, and that requires empathy to take us outside of ourselves and our own agendas, and to try to

bridge the gap between one human and another. So for good behaviour support you need great lifestyle and person centred empathy. You need to meet the person, not the behaviour. Salutogenises is a useful model, I think.

So, completing a functional assessment is most often vital to understand challenging behaviour because it clarifies where, when and why (and with whom) issues arise. But sometimes you need empathy more. But if you do complete a functional assessment, and graph your findings, please don't think you've solved me, don't think you understand my life and wishes, my wandering and words, because all you've really done is describe the dimensions of a couple of my thousands of ways of expressing myself. Your functional assessment is not an end in itself. It is merely the beginning of my story. A functional assessment is the opening line of a novel.

A functional assessment always reminds me of 'Once Upon A Time'. It's so common to hear 'it's for attention, it's for escape, it's for a tangible, it's because it feels food'. Imagine a story that started and ended with 'Once Upon A Time' and that took you no further. Not much of a story. You'd want to say 'So what?' or 'So what happens next?' But for many people a functional 'Once Upon A Time' assessment is presented as the whole of their story. Once Upon A Time and a functional assessment are both clichéd openings to a bigger, longer, more complex story.

I shall continue to wonder who actually has the learning disability here. Who is it that has such rigid thinking and a lack of empathy they are worthy to be considered suitable for a diagnosis of Autism? Because to me it seems plain as the nose on my face.

O'Brien, J., (2002) The Ethics of Person Centred Planning. In S.Holburn & P.Vietze Person Centred Planning: research, practice and future directions, p.399-414, Baltimore: Brookes