

## *Get Some Perspective:* What Being Serious About Quality of Life Might Mean For Us

*On being asked to speak at a conference largely populated by people whose wages are earned through teaching others to employ physically restrictive interventions to manage the risk arising from behaviour that challenges. The title comes from the keynote I gave at the conference. The tone of the presentation is more conciliatory than this paper (though I wonder if it should be). Still, one has to engage and suggest there are alternatives to custom and practice.*

How can a non-autistic man comprehend the experiences of an autistic woman being restrained? Can a fluent and skilled autistic child define an older autistic woman's quality of life if she is unable to speak such remarkable things herself? Who determines what is important to others? How can we claim our measures of success matter to people if we've failed to involve them in designing an evaluation?

A good quality of life is not a gift we can deploy as if it were a treat for a well-trained animal. It is not some token, not a procedure to make us look competent during inspection. It is not a policy we can wave in front of the confused faces of commissioners. It is neither a fig leaf nor a justification for the status quo. It is a false metric if produced merely by our own measures for our own benefit. To cite quality of life without the involvement of the person we're describing is not authentic. All we'll do is negate the principle of quality of life. Quality of life is much more than scatter plots on paper or a bold statement on a website.

The best judges of the quality of life of children or adults using services often come in bodies that can't talk. You have to look what people do rather than what they don't say. Sighing, 'well, we'd *love* to involve people but it's just too hard' says more about our inabilities than theirs.

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What people do is a kind of language. (The poet Alden Nowlam observed each touch is a kind of kiss.) What we do transmits our true intent. A colleague may claim to be supportive yet seeks out every opportunity to point out to others your errors; a partner may swear undying love until the moment you say 'no' then through their expression, face, deeds or words transmit what they actually think of you, and what their real agenda seems to be. We're all familiar with these concepts – body language, true meaning, and real intent. But when it comes to organisations, we're often blindsided. Which is strange given organisations are merely groups of people gathered together, magnifying human characteristics (for good or ill).

What organisations do is a kind of language. There are obvious meanings and then there are tacit implications, and cultures within cultures. Human service organisations may be good with rhetoric about person-centred support yet treat their staff like cattle, people using services worse. Some may be terrible at celebrating in words their fantastic achievements on behalf of people using their services. Some may aspire in words but not in deeds.

There may be a disconnect between the intent and hope of organisations and the actual contingencies operating on their behaviour. For example, in order to be granted money to support someone an organisation may highlight quality of life outcomes in a way sufficient to be awarded a contract but never be obliged to actually deliver proof that such a life is delivered. (Ah, the strategies employed when failed delivery is spotted – let me count the ways!)

The promise is sufficient to gain the cash. The organisation (or rather, the people running it) are reinforced for promises not delivery of a quality of life. My guess is in the UK today it is words that are measured not outcomes. So we are left in a situation where poor quality or broken services, being not reinforced for actual delivery of quality of life – because it is not metric used by those purchasing services – stay in business. There's no motivation to deliver actual quality of life when doing the bare minimum suffices to generate further contracts. Jim Mansell always told his students to “follow the money”.

A broken service is one that cannot do what is needed. A broken service does not teach people living in that service new skills because service managers and staff don't know how to do so, and no one holds them to account for these omissions. A broken service does not deliver a quality of life or happiness. A broken services continues to stagger about the place like a Zombie without contributing to societal happiness. A broken services does not do what it says. If a human were to say one thing (“I have faith, I believe in the value of all humans”, say) but is seen to do another (“I value you because you are attractive to me, you benefit me”) we might steer clear of the hypocrites as much as we can. But in terms of services, we just award them more contracts.

A broken service is kept in business. Jim Mansell (again!) used to tell us a service may well be dysfunctional at delivery of quality of life but it is functional for some purpose still. Behaviourism teaches us behaviour is maintained because it is reinforced. Broken services are reinforced. What we need is differential reinforcement – where broken services are not reinforced (and so, in time, extinguished) whereas good services (here defined as delivering what they promise – a person-centred, quality of life focussed experience) are reinforced. Money is a

big reinforcer for organisations. Organisations promising to keep people safe, secure and sometimes out of sight, seems a big reinforcer for some commissioners.

It seems right now sending people to the Moon and Mars is more important than sending people to places on Earth able to deliver a quality of life. We're more focussed on the stars than delivering what research shows words to make people happy. Humans are a funny old species, and the world a funny old place, though only some of us are laughing.

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People challenge not because they are broken but because they have not been enabled by circumstances to learn new ways of getting their needs met. Keeping them in broken environments that are working to reduce restraints and harm and pain is surely better than keeping them in places that are blind to the consequences of restraints but these environments remain broken. But make no mistake the archaeology of the broken environment will out unless a new culture is actively fostered and then actively and coherently maintained. You can reduce the use of restraints easily enough – actually, it's bloody hard, but the methodology is clear – but the challenge is to keep the restraints reduced when new managers and staff appear carrying an adherence to old tropes.

If we truly are committed to enabling quality of life then we have to change our perspective, our measurement, and the stories about our work. We need to think longer-term. We need to include diverse perspectives. We need to ask what matters to people trying to live their lives in Serviceland. Additionally, we need to enable staff to not be turned into arseholes by the systems they inhabit.

There's a lot of money at this conference, an awful lot of business goes on. And to be frank, there is insufficient pressure on business to evidence the production of quality lives. Quality of life matters to the people whose lives we cite, but to businesses less so, unless it is made to be the real measure of value for money, unless we make it an explicit outcome. The bottom line usually involves quantity not quality.

We need to take a long look at ourselves: despite all of our endeavours, many children, young people, adults and families will tell you stories of the slow cancellation of their future. The children and adults experiencing restrictive practices, whose behaviour is being managed, are paying a high price for business profits.

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I'm currently writing a second challenging behaviour book about practice leadership and communities of great practice, but a novel keeps restraining my endeavours by intervening. It thinks I should be writing it not some book about ancient ideas the world has always ignored. I hate to encourage it but within this persistent novel one character assesses the dress of another and concludes, "a cheap belt is no replacement for a well-tailored pair of trousers."

Likewise, a functional assessment, a functional analysis, or a behaviour support plan is no replacement for delivery of a good quality of life. I've worked with plenty of people who overlook the need to challenge when their lives are improved, when their needs are met, when their happiness is supported. You know, the clue is in the name: *human* services. I mean it may not be obvious to everyone but there's no accounting for people, I guess.

If I were to create a *human* service, I'd expect I would want to engineer a system that creates friendships, fun, and happiness in big dollops, along with opportunities for reciprocal healthy relationships and belonging, chances to learn skills, places for meaningful contributions to community, rather than replicates the ancient models from the past. I'd apply it to staff and families, too, and seek to educate those responsible for purchasing services they don't have to opt for the lowest bidder. I suspect the only way I could create a *human* service is to ask divergent humans what makes humans happy – and have those as the 'products' of our endeavours. A *human* service would deliver what it promised not what was required to meet minimum standards.

Challenging behaviour is a symptom not a disease. Managing it is not the same as improving the quality of life of a person. Replacing physical restraints with other restraints is like leaping from the Titanic into a sinking lifeboat: the outcome in both is a cold damp night with the risk of Leonardo DeCaprio dropping in to ask if he can paint a picture that holds no resemblance to you whatsoever.

A functional assessment *should* tell you why behaviour occurs and it *might* suggest ways to reduce challenging behaviour. The writer of such an assessment might reasonably assume that if behaviour happens to gain attention then the child or adult is not receiving the attention they need. It's obvious as the nose on your face. This is why we can think of challenging behaviour as a critique of how the person is being supported. Too often our plans fail, however, to consider why attention happens to be so important for that person. Quality of life, you see, is the intervention *and* the outcome.

And this is before we even consider a fundamentally important but often overlooked question: who defines which behaviour is challenging, who describes its

dimensions? This is more complicated than it at first appears. We have our clinical terminology, of course: it's a behaviour that is harmful or impactful to the individual or others. But who decides? All manner of power dynamics arise here.

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How do we define quality of life? I think we can describe some typical indicators of a quality of life whilst keeping ourselves open to exceptions. Sure quality of life might typically involve things like emotional well-being, rights, choice, physical well-being, a clear social identity, to name a few common domains, but each of us have different interpretations of what these involve and so we have different ideas about their value to us. I happen to not be able to stand soggy pasta but one of my kids loves the stuff. It's all pasta, right, but... well, you get the idea I'm sure – you look the kind of insightful person I like to hang around with to me.

And thus my own working definition of quality of life is fairly open to interpretation but I guess that's as it should be because being a therapeutic imperialist isn't particularly high on my bucket list. My idea of a quality of life is that it features all manner of people living interesting active lives within a network of respectful relationships comprising people who like each other, in places they enjoy.

I think we enable people we work to support to define what quality of life means for them. A child may not have our clever words, our experiences, but they're not stupid, they know what they prefer, and they probably know what they need to feel good about themselves despite our slightly odd views as parents or grandparents or friends. Heaven knows their behaviours should teach us a thing or two. But their language often is too unconventional to be taken seriously by us. This is a matter of regret. Because small behaviours are big clues about what matters to them.

To say a child is resistant, or defiant, or challenging, or the thousand other euphemisms we employ to obscure the experience of the individual, enables us to write our own version of their story. It's us interpreting them in a way that justifies our authority. The codes and euphemisms we employ exclude people. It denies people of their voices – voices of experience, voices of hurt, voices of loneliness, voices of anger. We pathologise people we do not comprehend. We disallow their anger and hopes and wishes and laughter from our standardised assessments. The outcomes tells people more about our agenda and less about them. Kids and adults who challenge will continue to be Othered so long as our assessment, our understanding, and our responding to them do not involve them. Likewise, our description of their quality of life is a poor description unless authenticated by their inclusion.

We buy beds, placements, and simulacrums of homes. We don't buy listening. We invest in bricks, and specialists and we purchase our qualifications as if crafting a professional identity, with good wages, with inspirational web pages, as if these things are sufficient to understand and serve people labelled as divergent, different, and Other.

Fewer physical intervention, more proactive and positive ways of supporting people that amend predictors and antecedents to conflicts, greater use of strategies that avoid all those tributaries to the wild rivers of challenging behaviour, that teach alternative ways of getting needs met, that reduce consequence-driven strategies convoluted as an Escher print, these are laudable achievements and ambitions. But less behaviour support plans, less measuring and focussing upon challenging behaviour should also be an ambition, because then we might change the agenda from what goes wrong to what goes right. (Too often it is us that go wrong.) It is our



services and our thinking and our methodologies that go wrong for them. Seldom for us. We go home. We accrue pension pots. The same cannot often be said of those who we say we support.

Why no ABC records for happiness? Why so few ABC records for great staff support or near misses? Why no support plans for parents, staff or teaching assistants? Why no person-centred plans for stressed professionals? Why are the shelves of our offices (our offices in *their* homes?) lined with descriptions of their lives written in our handwriting? Imagine telling staff to measure fun, great rapport, or enabling communication partnerships. Imagine listing the antecedents for smiling, for going out more, for learning. You'd find someone trying to define and limit smiling soon enough, I suspect; they'd head off happy to engineer a simulacrum of happiness through engineering and reinforcing 'smiling behaviour'. A smile is a symptom of happiness, and challenging behaviour is a symptom of distress.

Here's the bottom line. Each human has a gift to contribute. But the system we work within has commoditised humans. We each have a cost and a value. Someone with *this* condition is worth *that* much cash each week. And if we add challenging behaviour to the stories we tell about people, why that price might be vastly inflated. And so hedge funds and pension funds have grown fat on the misery of people being stripped of their humanity and farmed for the money their disability earns. A price is much different than being valued. Focussing on the price of a person is akin to saying our worth is framed by the market price of the minerals and chemicals that comprise a human body.

The system we work within has taught us to know the cost and the price of humans but not their value. We do this to people seeking to live what passes for a life in Serviceland, and we do it to staff too often, also. Families are often not valued, either.

What can they contribute to our equations beyond hassle? Families asking difficult but honest questions are considered troublemakers. It is important to realise it is not unrealistic to want the person you love to be happy. Someone is not a troublemaker if they question you about why their son or daughter is being held down, ridiculed, locked away, or drugged up.

They actually want what you claim you provide to their loved one: a quality of life. You need to evidence that what you claim is what you provide.

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You know the organisation you represent, the people you work with have lost their moral compass when colleagues speak of voids, of beds, and vacancies, but not the preferences, person-centred plans or privileges associated with knowing another human. Regardless of their reputation, their diagnosis, their background, do the people about you speak and act in ways that help promote the person's quality of life? (A student once thanked God he didn't have to think about quality of life, "because these are residential kids. We just have to keep the parents happy not the kids.") That was a revealing insight into the tacit ways of thinking people experienced in that particular culture.

You know the organisation you represent is corrupt if behaviour that challenges is viewed as pathology not as communication. Such places are corrupt because the evidence is fairly clear that challenging behaviour is to be understood as exotic communication, as conveying a message. Such places are corrupt because they value the adhering to a lie.

What happened to the promises following Ely, following each scandal since, all the very many Winterbourne Views? Where are the promises to put people first? Have we transformed care or continued indifference? Where do values appear in the bottom line? Is the very fact such abuses continue not evidence that our tired arguments about bad apples should no longer to be believed? Perhaps it is time to consider the bad barrels we have crafted with such loving indifference – Herb Lovett suggested we have created services for what people are not, not who they are. And we're still building. Because we have the money, and the control – these two hammers make us think everyone we encounter looks more like a nail than a person.

If the first thing your manager does on their first day in the job is to read the files not meet the person, you're screwed. If the first thing your consultant does is review the data not listen to the experiences of those who know the person best, you're screwed. If the first thing the support worker is told to do is to read the plan, not learn the language of the person, you're screwed. If practice leadership for your organisation is awarded to those with the most qualifications or the best connections to management then I have no words of sympathy for you when things turn up screwed. (Organisation psychology is fairly clear on this: the organisational culture you have is the one you've grown. You've no one else to blame here.)

If the first thing your organisation does is defend itself, deflect, deny, or throw a dead dog on the table, you're screwed, and no matter how many expensive consultants you call in so you appear you're taking seriously the concerns of others, you're even more screwed than you need be. You may not actually need consultants if you had leadership. You may simply need new ears, new eyes, and new ways of thinking; you may simply need to appreciate what families or children or adults using services have been saying to you for decades. You might simply need to

comprehend that challenging behaviour is a symptom not only of the individual's life but also about your organisation.

If we rely on restrictive practices, we've lost the moral high ground. Herb Lovett gave a speech before he died in the mid-1990s, and wondered, aloud and loudly, who has the so-called learning disability: human services or people living in them. It seems as pertinent a question today as it ever was. We don't need to be historians to understand the past: we simply need to look at what we have and how we do things. The archaeology of institutionalisation is alive and well in today's culture and is being commissioned as you read this. Eugenics simply faded into the shadows.

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There's a basic behavioural principle we need to be aware of: negative reinforcement. As you know negative reinforcement doesn't mean bad any more than positive reinforcement means good. Here negative reinforcement means if something is removed or avoided as a result of a behaviour and that behaviour increases or maintains over time, it has been negatively reinforced. A behaviour has been learned because it was successful in getting rid of something.

I often wonder that when we teach people to use physical restraints we're not putting them on an unplanned intermittent schedule of negative reinforcement. An incident happens, staff respond by physically intervening, and the incident, in time, dissipates. Obviously, the sense of control and power the staff might experience is a bonus of powerful positive reinforcement. Won't this potentially shape up the restraining behaviour of staff? Isn't it kind of addictive? A quick fix of a heady blend

of negative and positive reinforcement? Perhaps we're teaching staff to be junkies. And what's worse, unless they follow the restrictive practices policy, staff get punished. Way to go to create a destructive culture.

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I don't really feel qualified to speak at a conference concerning itself with squaring the circle of restrictive practices and the central importance of quality of life in authentic and genuine positive behaviour support. In part this is because I've managed to avoid being obliged to use restrictive practices for twenty years.\*

But I've experience of alternatives. In the same tongue-in-cheek manner I use to describe myself (as Eric Emerson once did) as a 'recovering behaviourist', I'm someone who is in remission from restrictive practices.

Even though it's been thirty years since I gave up heavy enjoyable smoking, I have a view on smoking. Once I thought filters were for wimps. (In the same way I thought non-physical interventions were for left-wing do-gooders too busy advocating unrealistic group hugs to be part of the real world of autism and disability support.\*\*) So even though *I* stopped smoking one day (just go ahead and do it, give yourself permission to take control of yourself), it's up to you, of course, if you wish

\*You can say I'm lacking recent hands on experience.

\*\* I also remember when mindfulness was thought weird. It is something I've practiced intermittently since I was eighteen, though often in secret. (I enjoyed a misspent youth in a band, on an athletic track, and in a monastery.) These days mindfulness seems compulsory.

to continue to smoke: it's your call. And provided you don't stink in my presence or blow chemicals in my face you're welcome to live the life you choose – because it's not up to me to tell you what your quality of life should be. At a push I might say it's not a thing I would choose to do, I guess because I value my children and grandchildren's DNA. But then, I can choose to walk away from smokers, I have some control over my life, I have status and agency and autonomy – as far as any of us do.

Likewise restrictive practices. There are so many low-aversive, low-arousal, respectful alternatives; I'd prefer to spend time exploring these with people. I won't sell them a standard package of interventions. I won't sell them a subscription or certification deal, with annual refresher courses. I think if people continue to smoke or use physical restraints then there is a deeper issue that needs resolving but that's just my view.

Unfortunately many of the people we serve are seen not as having status or agency or autonomy, but as having disorders and problems. Unfortunately too many people's behaviour is seen not as a message to be understood, not as a form of exotic communication, not as a complaint about their poor quality of life, but as a problem to be controlled, managed, and contained. For me, challenging behaviour is a message, and a message denotes agency and autonomy, and the right to be.

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Robert Sutton's follow up to his insightful *The No Asshole Rule* book is *Good Boss, Bad Boss*. It can teach us a lot about practice leadership, I think. In it he writes that smart people – who are often senior managers and bosses – have a considerable incentive for saying things that are incomprehensible. They call white black so

convincingly they manage to talk the donkey whose legs they've talked off to keep walking. He says the world is replete with 'jargon monoxide' because people able to talk it are thought of as experts. But where does that leave divergent people, whose language is different, whose lives are the topics experts speak of? Sutton argues the best leaders act as simplicity police. They cut through the crap. So a good leader will call the thing what it is, not use euphemisms. Herb Lovett suggested new phrases run the risk of becoming euphemisms for old habits. I often wonder what Herb would make of our rebranding of old techniques.

So here's my offering, in honour of Herb's call for honesty, and Sutton's calling out 'jargon monoxide'. I'm sorry if you're offended, but what is happening is too often offensive. If you use physical or other restrictive practices, I think you've failed. I think if you talk about quality of life for autistic people or people with intellectual disabilities, and if you don't know them as individuals, their fears and hopes, you're not qualified. You're not simply mis-representing people, or extrapolating, or putting a spin on something, you're bullshitting.

And when a person gets hurt or dies, or learns to be frightened of beds or small spaces, or tall snarling men or small vindictive woman, you don't issue a statement saying how seriously you take the rights of vulnerable people, because that's clearly bullshit, too. You don't blame a rogue nurse or an employee – you employed them, you oversaw their induction, you are responsible to ensure they act appropriately. To say otherwise is bullshit. You allowed someone you are paid to care for and support to be bruised, cut, locked away, hurt, medicated and killed. And that's bullshit.

Self-justification is, as the Sufi say, worse than the original offense. Call it what is it. Torture. Don't call it treatment. Don't bullshit the people who pay for your mortgage.

You need simple metrics, you need simple strategies to improve quality of life of people your services are making money from. You need to do what is right by people, not what everyone else is doing. It is said the founder of the Hilton Hotel group was once asked what advice he'd give to people visiting his hotels. 'Put the shower curtain inside the tub,' he said.

When wondering why services still don't deliver a service, it might be as simple a matter as that shower curtain advice. Put the person first, ask their views, and if they inhabit a body that isn't so good at speaking, listen to their behaviour. They are telling you every day that you need to put the shower curtain *inside* the tub.

Tony Osgood  
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