

Becoming An Ally

Tony Osgood, BILD 2023 PBS Conference

Burton Blatt wrote 'Some stories enhance life; other degrade it. So we must be careful about the stories we tell, about the ways we define ourselves and other people.' I will share some stories today and hope you find them useful, because whilst PBS is guided by data, stories are a form of information often overlooked. My story is very simple: being person-centred is good science. If we don't tell *that* story, other narratives will dominate.

I learned about behaviour analysis and what was to become positive behaviour support many decades ago. Shortly after, I was taught about person-centredness by Dave Hingsburger and stalwarts, and person-centred planning by, amongst others, Simon Duffy. So for me, science and values have always been packed in the same useful tool bag. Some people prefer science to values, and many ignore science on account of their values. People tell stories about which is best when really both are needed.

When I was taught behaviour analysis I learned about consequences and predictors, and the usual functions. Positive punishment and negative reinforcement, and all the other tautological descriptions provided.

It was quite robotic, mechanistic. I thought it ironic how much of the teaching about behaviour analysis was so bad, and spoke of subjects not people. One day people mentioned, during sessions on different types of antecedents, a thing called establishing operations and I became inordinately excited. If antecedents might predict conflict, *different* antecedents predicted ways of preventing conflict. So, why not spend time creating conditions for those *better* antecedents. I convinced the staff team to do ABC charts on happiness and constructive interactions. The knowledge we gained helped create more person-centred support. Whilst we were busy enabling people to enjoy their lives, we noticed many utterly overlooked the need to challenge. Funnily enough, the stories we told about people changed, too. We started speaking of people and partners, not problems and patients. Isn't this what PBS boils down to: figuring out how to prevent conflict, to teach alternatives, to reinforce effective alternatives?

When I was taught about behavioural interventions such as extinction, I recalled the emotional impact of *not* getting the consequence I was expecting. When I was taught how to restrain people, I imagined how I wouldn't just comply, but *feel* angry or confused by being controlled. I read about the efficacy of differential reinforcement. Of teaching new capacities. Of communication and Listening. Enriching lives. Enabling. Changing how we worked.

All these fairly simple and logical strategies, outlined by Rob Horner, Thom Willis and Gary LaVigna, jigsawed with the work of John O'Brien on person-centred approaches.

Despite knowing we didn't need to use punishment, that such techniques resulted in trauma and self-defeating learning – just imagine what people learn when being punished or punishing – despite knowing low-arousal and low-aversive strategies worked, people usually received awful support in most places I visited. This is why it is important for people who claim to be knowledgeable about PBS to look at whole lives, not single behaviours. The truth is people using services are often oppressed, and denied their human rights because of the stories told about them. People working in services are often oppressed, too. The language we choose to use reveals the stories we tell ourselves.

Serviceland speaks about absconding. Allies speak about leaving unhappy places. Serviceland talks about challenging behaviour. Allies talk about communication. Serviceland earns a fortune by preaching about clinical or pathological challenges. Allies talk about humans in distress. Serviceland talks of vacancies and beds and treatment. Allies talk of homes and belonging and learning.

It makes sense to work to create competent environments tailored to the individual, to figure out what antecedents we need to change, to learn new

stories as well as skills. People shouldn't need to beat-up each other, or worse, hurt themselves badly, in order for their own stories to be heard.

The wishes, preferences and lives of the people we serve can only be understood in context, not from a functional assessment or a report. We who listen to peoples' stories have to listen to heartbreak, anger, and a lack of opportunity, denial and oppression. Behaviour that challenges is sometimes their only language. We're lucky, because as people who know about PBS, we know how to listen. We know that listening to peoples' stories, we can learn a bit about



them. We can empathise. Their stories can change who we are, how we feel, and how we work. We are lucky.

At university, most stories I heard about behaviour spoke of the science and the clinical validity of behaviour change, not social validity. Outside university I learned to work alongside people, ask them what they needed, how to include them. I learned to see and hear people using services outside university. Some story tellers say anything apart from science is superstition, and all you need are data. Some say ABA is evil, and all you need is love. But love is insufficient, though a great beginning. You need both.

I instinctively felt listening to only one type of story – of values or of science – led to unhappy endings. Not for the storytellers, but for the people that matter most – people obliged to use services. So I began to write my own stories, which actually belonged to other people who were not being heard. One of the first was an article called *Suit You, Sir*. People resonated with the stories, the footnote jokes, and my mention of the work of Geraint Ephraim, who argued it helps us to think not of challenging behaviour but of exotic communication, because such behaviours carry messages. But often Serviceland isn't able to listen to parents or their own staff or White Papers – they get paid regardless. How the hell will Serviceland listen to people labelled as disabled?

Staff and parents usually want the same thing: to be heard and have people respect their preferences. Being compassionate means being concerned with the well-being of others. In his book on *Compassionate Leadership*, West outlines that people working or supporting others usually welcome autonomy, belonging, and being able to contribute solutions. West sets this out memorably:



It strikes me that many people using services might only dream of experiencing the same. An lone individual working compassionately in a hostile environment risks being crushed and vilified and bullied. Hence the need to create a culture that enables and encourages person-centredness for everyone involved. Simply adopting the words 'compassion' and 'kindness' without operationalising what they look like in practice, and demonstrating their achievement, will bring about the same result as *Transforming Care*: jobs for the same old faces, a series of broken promises, whitewashes. but not much else.

A few years ago, someone asked me to briefly summarise the *difference* between ABA and person-centred PBS, and why I imagined myself more ally than anything. It was nearly lunch. This is the only reason I think I answered as a I did.

Imagine that all of us that are involved in supporting people, are types of fruit. Some are oranges – let's say proponents of ABA are oranges – and some are apples – let's say those of us who use person-centred approaches before reaching for functional analysis to fix the environment are apples. Each type of fruit has varieties, just to make it more confusing. But look: we're *all* fruit. Our shared purpose is to provide nutrition.

Now imagine being a chef or cook, preparing all the different fruits for a nice dessert. Do you deliver to the person what you think is good for them? Or do you say, 'You know, I read a paper once showing oranges contain more vitamins than

apples, so in order to retain my credibility about being clinically valid, and to earn the approval of my peers, to keep my business coming in, this dessert will largely comprise oranges not apples,' even if you know full well the person who will be eating what you are preparing hates citrus?

We are there to serve the person, not ourselves. Fail to deliver what they want, what they need, what they expect, then be prepared for exotic communication. Good PBS practitioners place the person's preferences at the heart of their work. They work *with* the person, not *on* them. They are on the person's side; the person is not on their caseload. And if practitioners are not aware of what the person prefers, they discover it. They turn up, shut up and listen. This is person-centredness, this is co-production, this is being socially valid, this is kindness, compassion, partnership. This is PBS. You need apples and oranges, you need both.

When we're enjoying sublime desserts, we tend not to analyse the ratio of apples and oranges to kumquats. Rather, we enjoy the whole dish. It's only when our favourite part is missing that we begin to complain. It's only when something isn't there that we begin to communicate exotically. I think, then, in our work about behaviours that challenge, we need to remember fruit salad. What is missing to cause them such frustration or conflict? Who, as it were, has stolen their pudding?

I believe at one time BILD advertised this conferences as *Kindness, Connection, and Coproduction: Looking for the heart and soul of PBS*. Frankly, I did not realise the heart of PBS was ever lost. You simply follow the loudest beat. Then I realised BILD were right. For many people in hospitals and assessment units, the loudest beat has the same rhythm as behaviour modification. Simply rewriting care plans in a fake first person voice does not make it any less punishing no matter if you call it PBS.

The heart is often overlooked. Just like in the old days before PBS, services and hospitals and special schools recorded non-compliance, bowel movements, eating, and challenging behaviours. They did not record loneliness, choice, belonging and heartache. I guess this is because it is easier to come up with a programme when someone hurts themselves with their fists, than when someone hurts themselves with words or loneliness. Serviceland want easy solutions over difficult questions.

There's a reason we speak of heart-break, not science-break, I guess.

What we think is important may not matter to the person. And what matters to the person may be beyond our pay grade. What we *can* count, may *not* count to the person.

It is hard to listen when someone tells you that because no one hears them, they wish they were dead. Whether you're an orange or an apple, you better, if you want to be any use, become good at listening and taking people seriously. They are experts in their own lives. We do not own a person, no matter our qualification. We do not have the right to tell someone they are wrong for wishing an end to their hurt.

If they are brave to share, can you be brave enough to listen, and bold enough to do something about it, without trying to control them?

Right there is the heart of PBS: to make it that the person has a life worth living. As Beth Mount wrote, 'Loneliness is the only real disability.'

Focussing on what matters to the person, listening to their perspective, benefits them if we act. Listening always benefits us. As Gosling and Martin quote: 'You gain a better understanding of your own world and this is a gift people have given me.' Coproduction and partnership requires us to change how we think and how we work. It means we share power. For some professionals, partnership work gives them an opportunity to validate their own role, and they become territorial, rather than creating something shared. This is maybe because professionals themselves feel oppressed by the organisations they work for. Maybe they should work directly for people using services.

When thinking about partnership and co-production, let me assure you these things mean nothing unless compassion and kindness are an inherent part of the way organisations work. Indeed, compassion is at the heart of the very reason PBS came into existence. Many behaviour analysts and supporters of people grew concerned that strict applications of clinically valid technologies were missing some fundamental component that ensured the people served ended up with a better quality of life. Social validity is as vital to positive approaches as clinical validity. PBS embodies this hybrid way of working. The knack of our work isn't just about what we do, but how we go about it.

In my first book, I wrote about robotic approaches to supporting people, and compared these to human approaches. The analogy was inspired by several old-school BCBA's whose work I observed quite closely. I wrote: *'The effect of robots on humans is they make us feel unemployed, unworthy and unheard. Robots frustrate the hell out of humans. A robot finds it hard to earn trust because the metrics it uses to value humans do not count human issues: a robot may know its stuff but you might not want to marry one. It is hard for a robot to tune in to nuanced but vital human concerns. When encountering a robotic response it is the compassionate path to challenge them. It is said compassion supports our journey to understand that all humans belong to one family, but we all have family members that are tougher to get on with than others. Compassion, then, is not for the faint hearted, but for the very strong.'*

While I'm busy quoting myself, in my second book, about practice leadership, I wrote about what PBS actually is, in terms of real organisational adoption, as opposed to window dressing, and I came up with: *'It is a way of exploring the message behind behaviour and, having understood this, changing how we support an individual to improve their quality of life. Visualise PBS as the beating heart of an organisation wanting to be better. This heart has four chambers which are equally important and that need to work together: values (how it respects and enables people served to live a life of their choosing), behavioural science (the tools used to achieve its values), teams (people who use the behavioural science in a values-driven way), and leadership (people who embody the values and science, and who support the team). We keep our hearts healthy by putting them to work, and feeding the body wherein the heart lives. Think of the way the organisation communicates its intent and purpose as the valves of the heart. We aren't just a heart, but see how you go without one.'*

You see, PBS has always known where its heart is. We don't need to find it. We just need to remember why it is there, and how it guides us just as much as our heads. Without our values, we will not be inoculated against institutionalisation of the mind – where we fall into the trap of doing things to people because we believe we are qualified to decide about their stories. Compassion and listening warn us that an institution is more than a place: it is the thinking that caused people to build those places. It is institutional thinking that makes commissioners pay public money to outdated and restrictive services.

For many autistic people stuck in hospitals and assessment units, the term PBS has become, as Lovett warned, a ‘spiffy euphemism for business as usual’. People who are angry about PBS have much to be angry about. Lovett wrote of similar issues nearly thirty years ago: people can speak long and hard about diagnoses (or ‘clinical accusations’ as Herb phrased it) but not about what makes a person smile. What is recorded might not be reliable or valid to the person receiving support.

The irony of working in health and social care is that too often staff are not valued and are themselves uncared for. There is a cultural deficit of compassion and kindness. A support worker once said how tired his team were of being treated like robots by their managers. In his book on compassionate leadership, West suggests the goal of effective leadership is to create situations where people can enjoy fulfilling lives. By people, West includes those working in them. Best lives are rarely achieved by a focus on material goods, but rather belonging and recognition. Compassionate leaders attend to people – they notice suffering, ask about difficulties. They show understanding by being curious, not furious – they focus not on blame but on learning in every situations. They



empathise – show an awareness of changing situations and actively listen, tune into to feelings and concerns. Finally, they help – they direct efforts to what works best in alleviating suffering. What stories do we tell about staff or families?

If someone does not *hold* their own story, they'll hold on to whatever they can for dear life. If someone does not *tell* their own story, Serviceland will feel able to make up lies, this is why co-production is so vital. Co-production keeps us honest and safe. There's no point in fixing a behaviour if a life remains broken. Begin fixing a life by listening, but letting the person hold their own story.

I called this talk *Becoming An Ally* because many years ago I read a book by Anne Bishop with this title. Bishop writes that the world is full of oppressed people: in hierarchical societies, someone is inevitably relegated to the bottom of the pile. Bishop argues only through comprehending our privilege – and support staff are hugely privileged whilst also suffering their own oppression – can we begin to recognise the oppression of people with developmental disabilities. We need to know how oppression arose, why it continues, who is served by it. Becoming an ally means not only seeing people as equal but working in ways to make it so. Bishop wrote 'I once asked a colleague how he became an ally to women. He said: "I finally understood that I may not be a perpetrator of violence against women, but I'm a perpetuator.'" This sentence made me realise oppression is

more than something personal, it is structural.

When I was learning about person-centred planning, Simon Duffy asked us to write a plan for ourselves. Mine was fairly grandiose – to retire stupidly early, write books, be a househusband. All of which I have achieved. Simon sent us away for several weeks to begin planning with someone living in services. We all returned depressed. The focal person who agreed to my presence had the life goal of being permitted to wear his slippers in his lounge without being told off by ‘his’ staff. I cannot say whether his ambitions were maintained. You see why I choose the word oppression? You give the thinking behind Serviceland a hammer and before long, everything everyone does looks like nail.

Becoming an ally means recognising our own power, and how easy it is to misuse it, but also, how we can use it to act compassionately by including people in their own stories. John O’Brien writes that sometimes teams get things wrong, but no matter. It only matters when teams *keep* getting things wrong. Teams must learn from peoples’ responses by changing how they organise themselves.



Last year I spent a lot of time working away from home in a different country. This was pretty awful and I know I was fairly miserable and irritable. But I realised that many of the people I was working with spent no time at all at home. One evening I listened to a woman in a small service share her story. What follows is only a small part. She told me, 'They can put you in a palace, but if it's not your vision, it can feel like hell.' I was told, 'I don't want anyone to pity me. I want people to give me the ability to go forward. To be included. Maybe they don't *want* me to be like them.' She said, '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," and I was bright red as a rainbow.'

She laughed but the staff sat stony-faced. And I wondered, who there really thought of themselves as authentically dis-abled and oppressed? Maybe everyone?

A happy ending to any story only comes after lots of adventures and set backs, you see. A happy ending is not so easy, it turns out.

My journey from behaviourist to ally has taken a long while, but if you have also taken the first steps, please, do not falter. It doesn't matter if most others are

heading in the other direction, or laughing at you for facing left when they face right. Keep going. Find others like yourself. Head in a common direction, walk out to walk on. Form communities of practice rather than professions. Such communities of practice nurture people's willingness to listen and challenge institutional thinking. Often, joining a profession can come across as joining a cult. Professional self-interest is alive and unwell, and continues to contribute to the oppression of people labelled as autistic or disabled. Best be an ally.

So, what can you do? If you come across someone who has been handed a support plan that speaks of penalties or restraints more than opportunities and preferences, that bases its advice on assumptions about what is best for the person rather than exploring with the person what they need and hope for, then even if it is drawn from a functional assessment, it is not PBS. Challenge it. Challenge people who write such drivel in the same way you'd challenge a racist bigot. In your work, don't perpetuate the passivity of people using services. You are practice *leaders*, so in your work demonstrate how to include people, show



how to work in partnership, show how to be compassionate, because that is PBS. That is becoming an ally.

Our work is incomplete unless we become an ally to what is possible. Being kind is the opposite of weakness. Compassion isn't an idea, but what we do. Person-centredness isn't an approach, but our job. We must always, as Burton Blatt wrote, 'be careful.'

To end, let me quote John O'Brien: *'People with developmental disabilities come alive when careful attention is given to their stories. Person centred planning can provide social space for appreciating a person's story in a way that leads to meaningful new chapters... People trapped in the box of segregation and socially-sanctioned deprivation of opportunity need imagination almost as much as they need fresh air.'* So just imagine what you can achieve by becoming an ally.

The illustrations are from the King's Fund <https://www.kingsfund.org.uk/publications/what-is-compassionate-leadership> and used with their kind permission

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Some helpful books

Partnership, Coproduction, Compassion

Anne Bishop (2002) *Becoming An Ally: Breaking the Cycle of Oppression in People* (Second Edition), Fernwood Publishing/Zen Books: Halifax/New York [third edition was published in 2015, but only in Canada]

Burton Blatt (1987) *The Conquest of Mental Retardation*, Pro-Ed: Austin

Simon Duffy & Wendy Perez (2023) *Keys to Citizenship* (Second Edition), Centre for Welfare Reform

Paul Gilbert (2013) *The Compassionate Mind*, Constable: London

Julie Gosling & Jackie Martin (2012) *Making Partnerships with Service Users and Advocacy Groups Work: How To Grow Genuine and Respectful Relationships in Health and Social Care*, JKP: London

Michael West (2021) *Compassionate Leadership: Sustaining Wisdom, Humanity & Presence in Health and Social Care*, Swirling Leaf Press: UK

Monica C Worline & Jane E Dutton (2017) *Awakening Compassion at Work: The Quiet Power that Elevates People and Organisations*, Berrett-Koehler: Oakland

Support Strategies

Glen Dunlap, Rose Iovannone, Donald Kincaid, Kelly Wilson, Kathy Christiansen, Philip S Strain (2019) *Prevent, Teach, Reinforce: The School-Based Model of Individualised Positive Behaviour Support* (Second Edition), Paul H Brookes: Baltimore

Paula Kluth & Patrick Schwarz (2008) *Just Give Him the Whale: Twenty Ways to Use Fascinations, Areas or Expertise, and Strengths to Support Students with Autism*, Paul H Brookes: Baltimore

Lovett, H. (1996) *Learning to Listen: positive approaches and people with difficult behaviour*, London, JKP

Osgood, T. (2020) *Supporting Positive Behaviour in Intellectual Disabilities and Autism: Practical Strategies for Addressing Challenging Behaviour*, London, Jessica Kingsley

Osgood, T. (2022) *Practice Leadership in Challenging Behaviour Services for Autism and Intellectual Disabilities: Practical Strategies for Supporting People*, London, Jessica Kingsley