

# 'Still Hurting: What Jane Did Next'

## Serviceland, Commissioning & Monitoring: A Triad of Impairments

Tony Osgood

**“The ability of people with challenging behaviour to be regular members of work, school and community, resides with our ability to collaborate with them in designing effective support. Challenging behaviours are barriers to community life only if adequate support is unavailable.” (O’Neill, et al, 1990)**

It seems most people seek to avoid aversive things and it seems most people seek to be happy and to be secure in the ways that suit them. It’s what I’d like for my children; it’s what I want for myself. Is it what services deliver? Do we remember the fundamental requirement of enabling people to gain a life in our endeavours to support them? What is the point of supporting people if we fail to consider people’s rights and wishes?

I’m suggesting that while many services can rightly claim to have enabled some people with the label of intellectual or developmental disabilities to get a life, for many people with the additional label of challenging behaviour, traditional service designs has often been less than successful.

### **Where Did *That* Come From on a Friday Afternoon?**

When looking at why things go wrong (or differently than expected) there seem to be a number of ‘typicals’ that occur: one is known as Kauffman's Paradox: the less important you are to the service the more your actions are noticed and identified as causal to the difficulty. So, even though the design of the service is architecturally flawed the people at the top apportioning the blame<sup>⊗</sup> (but who designed the thing in the first place or manage it) still tend to blame the people at the bottom who actually do the work. These people at “the bottom” of the organisation often think of themselves as mushrooms.<sup>‡</sup>

To the practitioner of positive behaviour support (PBS) it’s not about blame but rather skills and capacities. For example, an uncharitable boss might report a member of staff works well only when under constant CCTV supervision and when cornered like a rat in a trap. The practitioner of PBS reports the same staff member might benefit from developing skills which help them perform their role without supervision, and what’s more, knows how to attempt to teach the person the requisite skills.

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<sup>⊗</sup> Sorry! Meant to say ‘investigation’ or ‘inquiry’

<sup>‡</sup> Go on. Think about it. I’m not spelling it out.

The practitioner of PBS looks at the whole system not just the person's behaviour in isolation and not just the skills of staff. If you ask a practitioner of person centred action or a practitioner of PBS to 'fix the person' so they cope with inadequate services *without* taking into account the environment maintaining the person's behaviour, you should hear the same response: "Go away." I think it's unethical to teach acquiescence.★

It's been said there tends to be six phases of any human services project in the UK and these can be thought of under a number of simple headings... Enthusiasm, Disillusionment, Terror, Search for the Culpable, Punishment of the Innocent, Praise and Honour for the Non-Participants. It's been long established that though everybody tends to blame the staff, wages, the person who challenges, the professionals lack of availability, communication (or lack of it), a lack of resources, turnover, inconsistency, and the ever-popular agency staff for the poor quality of service provided (when in doubt, kick an outsider really hard and divert attention!), the reality is more complex yet strangely simple. It's a management skills problem: "When pervasive problems in staff performance exist, the primary cause is ineffective supervision and management" (Reid, Parsons and Green, 1989). Often dubious provision is provided by organisations that are over managed and under led.

Root cause analysis (find out what's led to the current crisis) run by the people responsible for commissioning or providing the service that has gone wrong often involves a second typical: dancing around the real issues with the development of blamestorming techniques; having a meeting✘ discussing why it failed and who was to blame. The only certainty of the outcome of such meetings is a third 'typical': it's not them. The fourth typical is the bringing in of compliant investigators, alternatively known as pigeon managers.⌘ Hence the popular analogy found in Serviceland staff circles the world over: human services are like a tree full of big red bottomed baboons, all at different status levels in the canopy. The apes at the top look down and see a thousand grinning faces, while the apes sitting lower down see nothing but TROUBLE AHEAD.

It's important to remember that inside every service gone wrong is an ideal wondering what the hell happened to it. Let's not dispose of the ideal just because its execution(!) was poorly done. Jane's service, which I'll discuss below, is not a good example of supported living but a horrible warning of what all too easily goes wrong, but it doesn't mean supported living is wrong. Many services have delusions of adequacy and are as reflective as a Cornish tin mine on an overcast day with the electricity out. So when people point to obvious deficits in practice and design, Serviceland kicks back, trying to discredit the issue or the people rather than turn on the lights. Rather than look in the right place, they look at anywhere but their own functioning.

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★ If someone comes to me and wants to talk about Joe Bloggs who at the age of 71 is still challenging, then I'd be tempted to give Joe a medal and a 'thank you!' for not letting the system beat the crap out of him.

✘ Johnny-No-Friends? Rather chat than do something? Indecisive? Hold a meeting!

⌘ Pigeon Management : managers fly in suddenly, screech loudly and do their business over innocent bystanders before leaving after only a few moments. There are loads of these types around and they're rightly considered pests. (Sometimes it feels as if the more stupid a senior manager is the more credence and responsibility they're given).

There's an old story: George is found on his hands and knees in the street, searching the dusty gutter. A woman stops and watches him searching for a few minutes, until overcome by curiosity she asks 'What are you looking for? Do you need any help?' George looks up: 'I'm looking for my car key,' he explains. 'When did you lose it? Whereabouts?' the woman asks. 'I lost it in my house about an hour ago,' George explains, still searching. The woman looks at George long and hard: 'If you lost it in your house, why are you searching in the gutter?' 'Ah!' says George proudly, 'because there's more light here outside!'

So when the phone call finally arrived saying there were a few little difficulties in Jane's service I put the phone down and heard the echo of Noah: "a few scattered showers, indeed!" It sounded as if those responsible for providing and monitoring the placement were too busy mopping up the floor to fix the leak. And it felt that perhaps the advice of a year ago had indeed fallen upon deaf ears.

### **Serviceland: My Aching Mouth, Jane's Aching Head**

**"...professionals can have more *influence over than involvement in* a person's life. This atmosphere of remote control casts people in a negative light. This focuses planning on people's perceived deficits rather than their capacities, on what could go wrong rather than on what people need for things to go right." John O'Brien & Herb Lovett, 1992**

I made the mistake of tempting fate: during a prolonged introduction to Jane for new people coming into her life, telling people what things seem to make the world a nicer place for her from my own limited experience, and telling people they'd need to meet Jane face to face and learn to listen to what she can teach them as individuals, I foolishly said *given what we know now, given the level of resources provided, if this goes wrong, we might as well give up and take up goat farming in Andalusia*. I might as well have worn brass armour in a thunderstorm and bad-mouthed Thor whilst raising a sword. Lightning struck only a handful of months later, though the storm commenced gathering before the induction.

I was recently asked to become involved with Jane again, along with anyone else in Psychological Services who happened to be walking within a five mile radius. To Jane, I must be the New House Man, because every time I meet her something's hit the fan and we're looking for a new place to live. I was dismayed by what I was told. As people spoke at a recent review about the difficulties of managing Jane's behaviour, of keeping staff going, of the need for more psychological assessment and more medication, the room faded from view and I wondered where it had all gone wrong. The community nurse monitoring the service saying 'they're a good team because they react so fast'. The commissioner suggesting 'perhaps we have to accept we can't do this in the community'. The manager of the service suggesting physical interventions are what's needed to contain Jane, and actually she'd used them herself on Jane... The service manager on annual leave, again and again! 'Perhaps there isn't the will,' said the commissioner. I wondered why Jane wasn't at the review.□

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□ Had there been a flipchart in the room we could have played a party game: rearrange this common phrase: Lot. You. Have. The. Off. Eye. Your. Ball. Taken.

I really didn't want to be there. I saddened, and felt like the years of work of lots of good people had been squandered. The very clear views of Jane had been ignored. The behaviours described were not new (though the year old 'supported living service' said they were), and the intensity and duration wasn't unknown (though the service said they were)... and I had a flashback to December 2004, when the team I was working in predicted the inherent conflicts between what Jane required and what was being proposed would result in major conflicts in practice, in values, in listening to Jane. Those who didn't know Jane shaped the service. (I remember a nurse recommending Jane's new home have a shower rather than a bath to save time and money. We were able to say Jane preferred baths and disliked showers, and she got her bath, but oh the fuss!). I remembered the commissioner saying "You're a little negative, you're too emotionally involved." We warned the people paying for this that it probably wouldn't end well for Jane. Jane knows what she wants and how she likes things to be, and from our view, this was different from what was on offer. We tried to get the service and the commissioners to change, and they did somewhat but not enough.

At the review I heard: staff decided on where Jane shops, how she must take her shoes off when coming into her own home, the clothes she wears, where she buys the toiletries she uses, the staff who support her, how often she does things, how staff didn't feel confident enough to support Jane on holiday, the places she goes, how often she goes out... all justified because Jane's behaviour was "so out of it". I didn't recognise Jane from their description. I listened and sighed at how this very very expensive service had gone so very very very wrong for Jane in such a short time, and how Jane had become caught in the middle of disparate opinions as opposed to being kept in the centre of everyone's endeavours. I scribbled in my notebook *I am trying to have a life, only no one notices.*

No one spoke about the skills Jane has or is learning, no one mentioned her quality of life, her gifts and her potential. I looked at previous review notes and there wasn't one mention of Jane's happiness or friendships or choice or independence. The first thing mentioned was... money. *Radix malorum est Cupiditas.* And the galling bit: the service claiming adherence to supported living and positive behaviour support. It sounded as if the apparently somnambulistic providers and commissioners had found themselves suddenly fighting the person they were paid to support, restraining the person they were paid to empower; as if waking up to unexpectedly find themselves engaged in hand to hand combat, they wander about asking 'What's going on?'

I brought myself back to the meeting: the "manager of 123" (the house number) was talking about how good the staff team were considering the problems they faced, and I wondered why the manager chose to introduce herself in this way. Surely in a supported living model she should have said "I manage the people supporting Jane in her house". In less than a year most of the original staff had gone and taken their knowledge with them: the weeks of induction faded, with new staff receiving no training on autism, hearing loss, disability or self-harm. There were a lot of people working with Jane, not many people spending time with her. They were using agency staff.

The design of Jane's service was built by following off-the-peg blueprints ("everyone with autism likes this. Everyone who self-injures needs that. Everyone with hearing loss requires

one of these...”). In fact, they’d opened a franchised restaurant: a cloned outfit of reheated outdated ideas where customer care was something they’d once heard about and discarded, where serving staff and chefs thought ambiance meant ambulance, where presentation meant more than nutrition, and where the only customer was sitting quietly screaming in the corner of what had once been a life.

I pictured Jane doing what she does surrounded by floating pink bubbles with writing in them: risk assessment, support plans, care plans, physical interventions, carers, services, debriefing for staff, head injury protocol, self-harm, risk assessment, supervision, counselling, risk assessment, pathology, autism, risk assessment, colourful brochures and web site anointed service, risk assessment... Like Dumbo having hallucinations. As each bubble floated and bounced, Jane grew smaller and smaller. This was an extraordinarily (bizarre and unexpected) expensive (costly for Jane) service (provision). I remembered a phrase of John O’Brien: services by themselves are never enough.

Everyone would claim (because they genuinely see it this way) to be acting in Jane’s best interests. Yet despite a lot of people’s good intentions and efforts, despite a huge budget, the service seemed to be heading up a well established horticultural path. It was also up a famous Creek without a form of propulsion, to mix my metaphors. Restrictions increasing, behaviour increasing, exhaustion increasing, fear increasing, understanding reducing, communication reducing... Geraint Ephraim’s words of kind wisdom sprung to mind, that without conversation there is a battle of control (Ephraim, 1996). It seemed the people providing the service and the people commissioning the service were not so much helping Jane to get a life as they were inadvertently preparing her funeral.

These are not bad people, but sometimes good wishes are insufficient, sometimes people who show quite extraordinary challenging needs require extraordinary ways of thinking and doing. Professor Jim Mansell provides a story about this: he is asked to come and fix a car on the motorway and when he arrives the driver and passengers say “We want to get to London, can you fix it?” and Jim opens the bonnet to find no engine. Jim explains there’s no engine. The car users berate him: “But we really believe in London. We aspire to London. We dream of getting to London. Stop getting in our way and fix it!” For the car read an organisation. For the engine think mechanisms for learning and doing and the capacity to fix things. For London, read aspirations (‘independence’, ‘choice’, ‘user empowerment’). No matter your aspirations if you’ve no engine you go nowhere. It’s like the warning from person centred planning, told me by the wonderful Sue MacDonald: “You gotta dream... just don’t hallucinate!”

I went home and entered ‘Andalucian Goat Farming’ into Google. I was referred to a sex site. I switched it off. I fumed. I paced. I opened wine. I switched on the computer and emailed the RSPCA and then had lots more wine... fell asleep humming beloved Elbow’s *Grace Under Pressure*... the sing-a-long bit at the end.

## Serviceland: Woke Up One Morning Blues

I was driving into work one morning listening to the radio and dodging insufficiently vandalised speed cameras, ecological protesters in hand to hand combat with frazzled mothers trying to survive the 4x4 school run and screaming kids, and the shifty looking CIA types evaluating disused RAF airfields, when on the blessed Today programme someone told a story on Thought for the Day...

‘A recently married man avidly watched his beautiful wife prepare a leg of lamb for dinner. Recently married men do this a lot. The wonderful woman added rosemary and cracked black peppercorns, for she loved preparing this dish. One of the final things she did was to trim the bone of the leg of lamb: she used a large kitchen knife to chop the bone off, cutting about four centimetres away. The besotted husband asked his wife why she did this, and after thinking for a moment, waving the knife about, she told her new husband (one previous owner, only slightly tarnished) she’d always chopped off the piece of bone just before popping it into the oven. “But why?” he asked, and she thought again, frowned, wondering if he would always ask such basic questions for the next thirty years, and she told him she cut the bone “because my mother taught me to do it...” and she fell into thoughtful silence. Both a little puzzled, they phoned her mother, and asked her. The mother explained that she’d always done it that way, she’s always cut a bit of the bone off before cooking, and that her mother before her had taught her to do it that way. “Why?” asked the wife of her mother, “why did Nan teach you to cut the bone off?” Her mother paused: “I couldn’t say, dear.” The newly married couple then jumped into their car and drove to the grandmother’s house just in the next village. The newlyweds asked the elderly matriarch why she taught her daughter to cut the bone from the leg of lamb, and the grandmother explained when she was taught to cook lamb by her own mother many years before, the cooking pot was too small to fit a whole leg of lamb into...’

So much of our behaviour is like this: we do something because we’ve always done it. Without understanding that the behaviour we show and the thinking we employ originated and evolved at a different time in a different place, to meet different situations; sometimes, we are like broken records\* endlessly repeating the same thing over and over again. “The service model worked in Wessex.” “It’s an individual service. We give her what we think she wants. Therefore it’s the person that has failed when she challenges.” And so we face new situations with old behaviours and old thinking because we are creatures of conditioning and habit; doing something novel is uncomfortable and counter-intuitive: doing something we are familiar with sometimes just feels better. Even if it doesn’t work. If the rules say we do it this way then for a while we do it that way- ah, the power of rule-governed behaviour. Said another way: Old Habits Die Hard. Now this doesn’t mean an aged Bruce Willis turns up in a mucky vest and shoots people with an improbably large gun as soon as you try something new (‘OK punk, let me tell you where you can stick your innovation... I’m In Control, see? Not Simon ‘Nice Guy’ Duffy, see?’), but changing how we work with people who challenge can sometimes feel a bit like an emotional blood bath at times. We humans often resist change and sometimes instinct defies logic. We can find ourselves adopting emotionally simplistic views... OK, so it is a little like a Bruce Willis film.

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\* OK, kids, listen to Grandpa: ‘records’ were what mum and dad listened to before CDs were invented.

It's like folding your arms the wrong way. Go try this: start by folding your arms in the usual manner, but then refold them in the opposite way. Feels uncomfortable for many of us, doesn't it? (When I tried this the first time I fell into a swoon and fainted and cut my wife's lip... it's a long story). Now try folding your legs behind your ears whilst whistling Rufus Wainwright's funny and sad *Vibrate* song in a Mötörhead style (Camp Metal- I tell you, it's the next big thing) and juggling fire sticks in the middle of an oil refinery, and you get an insight into the contortion's Jane's service and Jane got themselves into. I take responsibility, because when I tried to explain to people about Jane I obviously didn't get through to them how the old approaches tend not to work with Jane: we need to give give give not take take take. Not listening to Jane was just plain dumb and I thought it was so obvious the need to keep saying it and showing how to listen was a waste of time because these people were being paid a fortune to do it right and they claimed they had the skills to listen. I thought 'OK, we've said listening and being responsive are key here, so don't bang on, don't belittle them.' Boy, was I ever wrong.

### Commissioning: So What Do You Think? Will It Fly?

Jane often can't cope very well with rigid boundaries at times of stress yet the service imposed more boundaries and costs; when Jane changed her mind the service wrote "Jane's pushing her boundaries"; when Jane became aggressive when psychologically restrained the service sought to impose physical interventions "to keep her safe". The service designed to support Jane now tries to contain her. The number of behaviour incidents are in orbit and she's angry for long long periods and she's hitting herself really hard. And other people. Oy! does she get angry. So the staff baton down the hatches, they screw down the positive opportunities: this isn't it a service it's a siege... it's Stalingrad! And Jane will wear people down because as has been said before people can't take away anything she can't take away from herself more hurtfully. Don't get into a war; everyone loses in a war. But they declared hostilities. Being asked to comment on a war zone and then getting shot at for saying "I think it's a war zone" seems odd, but it's what happens when naive questions are asked such as "Why are you limiting Jane's access to clothes?" I felt a bit like Kate Aidy.

The lost service did give me some old review notes (Jane wasn't invited to these either), and a summary of incidents (for a month). Then they gave a hunk of data (two boxes!). After detailed and careful analysis of this information I was able to conclude that apparently, from the limited amount of possibly unreliable information provided that in strictly scientific terms (forgive me, reader) we might tentatively propose the hypothesis that from the skewed data they recorded and provided, put in complex psycho speak, that functionally speaking...

# ● JANE ISN'T HAPPY! \*\*

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\*\* The bullet point means it stands out.

I truly believe, because I've seen it, that Jane can achieve a good quality of life and an understanding with people around her, and that these things lead to a reduction in conflict between her and people paid to support her to achieve a quality of life... or perhaps they're just paid to contain her, or measure behaviour, or save the commissioners money. Hmm. Hang on a mo... could be a contracting problem. What did you want the service to do, I asked? "Erm..." was the reply. Tumble weeds. A sheep bleats. "Isn't that an operational issue? If it is, it's nothing to do with commissioning... Why do you ask? You think it's maybe important?" If commissioners don't explicitly tell Serviceland what they want them to do how can they hold people to account? It's like asking a friend\*\*\* to go into Marks & Spencer with £400,000 and telling them to pick you up a little something for the weekend, you know what I like, off you go, sunshine. You really can't have a go when they come back with a gooseberry yoghurt and a fetching 'Per Una' underwear set in the wrong colour (not even your size, and when have you seen me wear suspenders anyway? This is for you isn't it? When do I wear red?\*\*\*\*) when you were really expecting solid oak furniture. As Alden Nowlan says, may God have mercy on those who need help but are too frightened to see it.

"Can you fix it?" they asked.

"Do I look like Bob the Bloody Builder?" I asked right back.

"Well actually... So what do you think, will it fly?" they ask.

"You commissioned Concord but settled for an oil tanker. I really can't see that thing flying..."

"Ah. Gosh. It does look a bit ship-like, doesn't it? Now you come to mention it. Can't think how we didn't notice it before... Oh. Erm... Any chance you guys can build a pair of wings big enough?"

"Hang on. I've got it somewhere. Let me just check my pockets. I'm sure I put my Magic Lamp somewhere. Had it a moment ago. Right by the Magic Elixir of Youth..." [Exit stage left, patting pockets, shaking head, followed by a bear].

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\*\*\* According to my children and wife, friends are people who hang around other people who are not psychological practitioners. They look out for one another. Apparently as soon as one becomes employed as a psychological practitioner one must disrobe oneself of anything remotely perceived as friends. I know this is the case because my psychological colleagues have discussed the phenomena over lonely drinks in a lonely bar called 'The Cherry Picker'. We know asking obvious questions ("Is it right to give PRN medication after she's hit her head 30 times?"), naïve questions (A Psychological Bob Newhart scene: "Gosh, he's taking his furniture out of his room, down the stairs and out the front door? He doesn't want to come back in the house? So you entice him and lock the front door? You carry him in? Gosh. Tough one. No, I have no idea what he could be telling you, really I don't. So you did what? You screwed his furniture to his bedroom floor? Well, yes, I can see you must have been shocked when he hit you for no apparent reason. Better make a psychiatry referral, I guess.") makes us as popular as the proverbial fart in a spacesuit, and having in the last 18 months been called unprofessional, the most hated people in the County, sarcastic, blackmailers, and supposedly loathed by all integrated community teams (all from commissioners and providers), I guess I have to bow to the experience of 'friendship' of my daughters and wife. What did John O'Brien write about the tensions of trying to be person centred in service structures...? There was a great line in ER recently: Obnoxious Doctor to Colleagues: "You may think I'm an asshole, but don't let that get in the way of patient care, ok guys?" Jane isn't a patient, but you get my drift.

\*\*\*\* Honestly, not me. This story relates to someone I know, Doctor.



## Commissioning & People

There are always potential conflicts of interest when one commissioning agency tends to rely upon only a handful of providers. Vested interest stuff. I'm unconvinced about market economics anyway (read 'No Logo', go watch "The Corporation") but in the industry that is Intellectual & Developmental Disabilities in the UK today, it isn't a free market anyhow.

Monitoring is a big problem for commissioners: to paraphrase Gary LaVigna, it seems those who don't know how to evaluate are commissioning those who aren't told what to do (and don't know what to do about people who don't fit what they offer anyhow) (LaVigna *et al*, 1994). In whose interest is it to say the status quo isn't working? Certainly not the interests of the major players benefiting from the status quo.

Things are not working in Jane's service (I'm not convinced she'd buy the service she's receiving. And anyone with any power over changing this discounts Jane's views on grounds of disability, so to call it 'Jane's service' is misleading). The staff may be 'working well together' (sic) but behaviour is going through the roof. Perhaps if we consider challenging behaviour as exotic communication (Ephraim, 1998) we could say Jane is currently complaining to customer service. But look here: customer service is complaining about Jane's complaining. And they're complaining about people complaining about Jane's complaining not being heard. As Clements and Martin note, the power differential comes into play here: how dare someone complain about the care we provide (Clements and Martin, 2002). If the service is 'working' we'd likely see an increase in Jane's coping and skills and quality of life, not a significant increase in her more challenging behaviours.

There is a mismatch between what Jane needs and what she is receiving from the service. This despite monitoring. Despite individual service design. Despite a provider-employed person centred planning co-ordinator. Seeing the rhetoric being valued more than the actual practice does make me once again question the ability of person centred approaches to survive service-led implementation and mechanisation (Mansell & Beadle-Brown, 2005). Watching services deliver PCP reminds me of a Transformer episode.

The rate, duration and intensity of Jane's behaviour suggest a fundamental review and evaluation of practice and outcomes is required by those responsible for the commissioning and monitoring of the service. The focus in monitoring upon behavioural problems and money spent as opposed to what staff are learning, what Jane is learning and the quality of her life, suggest fundamental flaws in design and practice. The service is so busy measuring the wrong stuff in the wrong way they forgot Jane. And the commissioners are so busy... no. Perhaps they just can't see the benefit or point of meeting and listening to Jane.

Commissioners have an impossible job in some ways, and people shout at them a lot, and because commissioners don't like being shouted out (who does?) they've no motivation to actually listen to the words- all they hear are the tones of frustration which they can dismiss or discredit ("It's just the usual suspects being angry. Bloody do-gooders! Pretend not to hear"). Commissioners are often busy not meeting people whose support they pay for.

The service try to record every challenging thing Jane does, but not communication. They record every behaviour except the skills she learns, and they tend not to record how staff interact. Dave Hingsburger (“Davie Davie you’re a hit, if you can’t help we’re in the ----)† suggests we spend so much time doing stuff to and for people with disabilities we lose the skill of being with people and meeting them face to face. His wonderful books should be required reading (Hingsburger, 1996, 1998, 1999, 2000). Such acts of mindful reflection provide an opportunity to learn.

We need to learn from our errors, from our successes. Life is not a rehearsal for Jane, for any of us. **This is it.** This is all she’ll get. Jane will never get each one of these hours back. Once these minutes are gone they are gone forever. And what a great life: what must she think of people who claim to be person focused but restrict and limit and take away her shoes when she comes into her own home? What the hell must she think of all us who have tried to work for her and failed her? She is not so much living her life as impaled upon it.

Listen to The Man: “Like other counter-perspectives on the world– those of women and economically oppressed people, for example– the experiences of people with severe handicaps challenge the basic notion that everything is controllable and the challenge is often met with redoubled effort to increase control. We promise to prevent, we promise to cure, we promise to rehabilitate, we promise to make independence as if it were a Chevrolet. And our promises have been fruitful, up to a point. If we are to move beyond that point we need the courage and the grace to learn the lessons of our collective ignorance and fallibility. There is much to learn in close attention to our errors and failings as we work to share and improve the lives of people with handicaps” (O’Brien, 1987).

I’ll copy an extract from one part of the induction I wrote for the provider in December 2004: ***“If the service design at commencement is wrong (the fit between Jane’s needs/essentials and what the service and commissioners provide) then it is likely we will see an increase in reactive strategy use, an increase in behaviour, the plateauing out of Jane’s coping skills, high staff turn over, increasing use of medication, and reduction in quality of life for Jane”*** And in less than twelve months we’ve seen a focus on reactive strategies, we’re witnessing increases in ‘challenging behaviour’, a loss of trust, communication and other skills, radical changes amongst staff, no training for new staff on topics that matter, a reliance on PRN medication, the prescribing of anti-depressants (!) and a loss of quality of life. Has anyone learned anything yet? “I’m sorry,” say the commissioners, “we were busy at the Partnership Board Meeting. We didn’t see anything.”

Jane is now described as varyingly ‘unsupportable in the community’ and ‘the most challenging individual in the County’. This is the woman who had a signed conversation with the kids about her Christmas dinner at our house; the woman with whom we shared jokes; the woman who loves clubbing and eating in restaurants and shopping and pokes fun at people. Jane’s life is the result of service and commissioning actions and thinking of yesterday.

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† ---- very serious situation we feared might come about.

Supported living is not really what's happening here because Jane is not being supported to live: she is just getting by but with a huge price. Supported living isn't just another form of service, it's a safe decent home of your own, choice, personalised assistance, and support from others who care about and respect you (O'Brien, 1993). It's not a label to avoid the increasingly ridiculous strictures and regulations of CSCI in the UK. Jane is in supported living provision in name only. But this is a service managed by a company who cite REACH standards.

The Man again: "Supported living is a simple concept in danger of being complicated until its power to help people with developmental disabilities gets lost. Its simplicity is elegant: a person with a disability who requires long term, publicly funded, organized assistance allies with an agency whose role is to arrange or provide whatever assistance is necessary for the person to live in a decent and secure home of the person's own." (O'Brien 1993). Compare this to Jane's life: restrictions imposed, agency staff... no wonder Jane became diagnosed as depressed in December 2005.

The way forward for commissioners may be to consider these things:

- Don't pay for beds or placements, pay for the service delivery of what the person desires. Base this on independent person centred planning
- Make sure you measure the right things for the person (don't measure success by budgetary savings or protocols or policies alone, try growing skills or friends or even-shock- happiness)
- Make sure you can rely on your measurement
- Move away from appearing to care only about the hours of support paid for (not the quality)
- In fact, just give the person the soddin' money. Give it up. Hand it over...

Perhaps it's just my own few experiences that colour my view of the problem around commissioning. I could be absolutely wrong and will accept corrections. Perhaps my experiences belong to me alone and everywhere else in the UK is hunky-dory. If so, drop me an email and I'll move home.

In the meantime, a couple of questions: in an expensive service why are Jane's bras and clothes drying on a radiator? Why is this occurring in a service supporting a person we know needs to not see things lying around? Why is Jane not cleaning and drying her clothes in her own tumble dryer in her own home? In such a very very expensive service with such a high profile with such a large consumables budget, why is Jane wrapping herself in a sheet on occasions? In a service with fortnightly Speech and Language Therapy involvement, with monthly monitoring by Health professionals, with one person being supported in an individual total communication ecology, why are many antecedents in the records said to be about "poor communication"?

[Goes home, turns on *Road to Nowhere* by Talking Heads, opens wine, and types into Google 'Job Opportunities in New Zealand. Yep, you guessed: gets referred to a sex site again. Emails UK Stick Insect Support Group to notify them. Falls asleep mumbling *Journal of Positive Behavior Interventions, Volume 4, Number 2, April 2002, pp118-122*']

## ServiceLand Skills

In order to support people, you need to have requisite skills in listening, in respecting, in understanding, in doing. As the old Islamic saying goes, however much you study, you don't know unless you do it, because a book laden donkey isn't a wise man. Understanding is achieved by doing. In ServiceLand, training staff tends to look a little like a tick chart: "Health & Safety- done that. Food Hygiene: completed. First Aid: sorted. Fire Safety: done. Physical Intervention: Oh yes... Okay, off you go..." No, there's no mandatory requirement for communication, why do you ask?" Managers of ServiceLand are bound by regulation and oversight to the detriment of quality. Commissioners have a thousand demands landing on their desks each day. The further away from people you travel, the less they seem to matter, the less they stay in your mind. So liberate yourselves and spend time working with people whose lives and experiences are funded by your actions and thoughts. Come sit where the humans eat.

Coaching mediators (a fancy word for people supporting other people) is a method of teaching that involves

- learning in real situations
- developing a valuing relationship between people
- creative, valued feedback
- learning through doing
- planned opportunities to engage
- support and encouragement.

Now, I don't know about you, but I've not been on many workshops or worked with many managers who took that approach when I worked in local government, the private sector or the NHS.

By actually doing the task as it should be done in a real setting, and with valued positive feedback, many people grasp what is being asked of them quickly. Done well, coaching can be a very empowering experience for everyone involved. Good coaching includes

- establishing current abilities
- agreeing objectives together
- protecting your time
- being clear
- creating hands-on opportunities
- enabling the learner to lead
- stressing that mistakes are acceptable and part of learning
- encouragement, checking concerns
- offers support, doesn't take over
- during feedback, uses self-review and reflection
- prompting the learner to the solutions prior to re-trying.

Coaching isn't always about the manager "enlightening" the lower ranks, or the specialist coming in to tell people what to do. A good coach will take into account the "learning style"

of the person. Coaching mediators enables the communication of theory within a practical context. Evaluating coaching effectiveness informs future coaching. Without reviewing what and how we are doing, we're lost!

Yet it's still too common to find managerial support in terms of 'Yep, my door is always open'. That's great, it really is, but it still says you're in your office, not showing and doing. We don't need more managers here- we need leaders and innovators willing to buck the strictures of Serviceland. Don't sell out the person's interests to further your careers, please. Always keep them central to your actions.

But to earn a good living, skilled people tend to have to go up the organisational tree and get lost in the organisational branches, and they look down from on high and wave at the people on the floor and shout down 'I won't forget you! I'm working in your best interests!' but to people at the bottom of the tree it still sounds like Baboon talk. Yet dedicated people find themselves the victims of a system which demands less time doing stuff with real people and more time doing the paperwork, because if they don't, they get shouted at by CSCI and their managers, and as we've noted, people don't like getting shouted at (particularly by people who can sack them or close the service down) so they buckle down and do what's needed to keep at least something going... and then you find that managers do good person-focused stuff in spite of, not because of, the organisation and the statutory systems.

And while I'm perhaps the first to bemoan Serviceland, and what it does to humans working in it and humans living in it, I try not to be too abusive to the front line. It's tough there. It is often the case that those people responsible for day-to-day support of the focal person may have absolutely no previous experience of being asked to help in the assessment, design and implementation of plans, which is something good practitioners of positive behaviour support try to do. We try to ask 'stakeholders' their ideas, because by listening, we learn what keeps people doing what they do, what motivates them. This is still unusual, and staff tend to be somewhat suspicious of you. Usually, someone with an "ology" qualification rolls in, often with a laptop, a nice suit and a grin, because they know they don't have to work 14 hours straight because the house is short of staff over the weekend. These 'expert visitors' pass on pearls of wisdom such as "just listen to the person", or "it sounds like you're doing everything well" (whilst staff are having the s\*\*\*†† beaten out of them seven times each hour) or, of course, the famous "gosh, that sounds dreadful! How many stitches did you have, again?" As interventionists, we often don't know what it is like because we're not there, so saying "I understand" or "I know" may not be the best tack. You need to be perceived as useful, relevant, real and credible. Mediators may not previously have had the opportunity to have their opinions considered or their questions answered. Unless you take care to help mediators understand why they're asked to do things that might well conflict with their understanding, values and training ("I was always told never to give in to the person! What are you saying? We've been wrong all these years?"), unless you invest the time in building a rapport and understanding with mediators, it's possible what you recommend may not be followed or well received (even if they nod in the right places or agree to stuff). Mediators will most certainly make mistakes. But then, who amongst us doesn't, especially when we're learning? The real nub is this: is there evidence people are really learning?

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†† soul.

While change is often inevitable (and interventions often mean changing what's occurring, what people think, for the long term) it is sometimes seen as threatening rather than an opportunity to develop new understanding and skills. Some organisations try to avoid real change by changing their appearance. Meeting superficial criteria or definitions of change and intervention in order to claim change and intervention is happening is common and is often typified by rapid changes in language, and is referred to as the infamous "bumper sticker" approach (Bartlett, 1998). Services may be focusing on such superficial achievements instead of real change benefiting people. Praill & Baldwin (1988) list mechanisms employed by organisations to avoid meaningful change. If these sound familiar, now you know what's happening...

<b>Uncoordinated and poorly implemented evaluation, based on non-objective measures</b>
<b>Use of meaningless statistics</b>
<b>Use cosmetic outcome measures</b>
<b>Jargon</b>
<b>Breakdown of interdisciplinary management structures</b>
<b>Train staff in isolation without evaluation of outcomes</b>
<b>Employ hero-innovators as change agents, to be consumed by the system</b>
<b>Procrastinate</b>
<b>Use the above 'skills' to identify staff for promotion</b>

Analysis of the organisation is vital in positive behavioural support. You need to know the readiness (motivation) and capacity (skills) of the organisation.

### **Monitoring: The Right Stuff**

'A man walks out of the wilderness (a bit like a desert) having spent 40 days and 40 nights praying up a storm. He's prayed and prayed and prayed. He's really good at it now. He's prayed so much he has repetitive prayer injury on his knees and he's twisted his swollen tongue. But boy is he angry. He prayed and prayed and prayed and you know what? There wasn't a single word, not even a cough, from God or his angels. Not a titter. Nothing. Not a burning bush (though the rash hurt a little mid-way through) nor a pillar of salt nor a voice wailing in the wilderness desert (well, Radnor Park, Folkestone), not a tablet of stone or a golden café (or was it carafe?) (he gets confused easily). Not a word. After all his efforts! So he storms out of Folkestone and is marching toward Hythe to laugh at the little trains when out of the blue and in a shower of sparks Gabriel appears, all white and glowing like a Daz advert. "You!" shouts the man, "Yes!" confirms a pleased Gabriel, because it's nice to still be recognised even after so many years in your chosen career. "You! You!" the man shouts and points a wobbly finger at the Archangel. "Yes. Yes," mirrors Gabriel, because he's recently heard of Intensive Interaction. "Forty days I was praying. Forty bloomin' days. Not a word. Night and day! Day and night. Pray pray pray! Not a hint!" "Ah," said Gabriel and looks at the birds flying overhead, before staring at the man once more. "You see, we were simply waiting for you to stop shouting at us."

I think that's the heart of the problem: we spend time talking at, around, about, and because of the person, without really listening to them. By listening I mean being present with the person one shares a little time and space with. One lady I spent some time with once visited her family abroad, and wrote on the sand of a beach "I do have a good heart". Who let her feel she might not have a good heart? Do we spend so much time talking about behaviour this, autism that, disability the other, service strictures, that we forget what it is we're supposedly doing, that we inadvertently 'pathologise' people? The things we consider worthy of measuring for monitoring purposes can say a lot about what we think is important: a doctor treating someone with a terminal disease may measure blood counts, and deterioration of physical abilities, memory losses and the like, but the person receiving treatment may measure their relationships, their happiness, their well-being. So perhaps we need to consider both objective and subjective factors when 'monitoring placements'. We need, like the man in the desert, to listen as well as demand.

Positive behaviour support to me means enabling friendship, respect, building capacity and ability and understanding with the empowering knowledge science can bring. It means working proactively with behavioural principles to deliver a life (Keenan, 2006). It does not mean restrictions, not door locks, not taking away shoes, not taking away choices. Positive behaviour support is about contributing to building status and respect. It's not denying rights in the name of best interest, without evidence that less restrictive things have been tried again and again. But in a society dominated by quick fixes, you can see the attraction for people monitoring Serviceland to receive such assurances that doing x, y and z will result in less trouble. Monitoring is not the same as commitment. It is not nodding when people throw pretty graphs across the table. It's not about saving cash. Evaluating means asking difficult questions about whether the person is getting what they want from life.

Are the people in Serviceland, are the people who commission and monitor incompetent, nasty people? Not by a long shot. These are often very dedicated people trying to do a difficult job with blunt or just the wrong instruments. They're trying to fix the car engine with prayer and hope it flies across the river. To monitor, you need to know what you're looking at and why. Ask the person: are you happy with your life? If you don't see the point of asking or meeting the person or even aren't sure how to find out, ask someone who does.

There are lessons to be learned: compliance to national standards is not the same as quality because standards are not focused on outcomes for people, not on the person's desired outcomes. Services are evaluated on 'do they' or 'do they not' meet arbitrary standards, and this shows a tendency toward rigid binary thinking- yes/no, good/bad- and life is not black and white but multicoloured. How about the following as measures...personal goals of the individual, evidence of choice growth, increasing social inclusion (if desired), relationships, rights, dignity, respect, health and well-being, security, satisfaction? (ACDD, 1993). Or how about seeing if Serviceland deliver the vague goals of Valuing People? If Serviceland enables risk taking? Remember the words of Michael Smull: "Happy and Dead are incompatible; Alive and Miserable are unacceptable" (Smull, 2003, p.121).

## A Small Hint of Doubt

I sometimes wonder (often after spending hours in meetings where clear management deficits in skills are hidden behind pathological explanations of why someone does what they do††) if the dissemination, teaching and application of behavioural technology in services have often resulted in greater control and a dimming of the humanity it aimed to serve. I wonder if behavioural approaches poorly done potentially blind not only the people receiving such incompetently applied approaches but the doers to the potential of being human, of reaching across the gap to hold the hand and acknowledge the heart of the person in distress.

Like pidgin-English spoken in some parts of the world (or pidgin-French from English tourists en route to the Ardenne- like the young couple from Berkshire asking for a toilet and inadvertently saying ‘Madam! Pay Attention! Drop Trousers With Your Permission?’), it is common to find pidgin-Behavioural speak in Serviceland, common phrases often heard but seldom understood, which on the face of things sound pseudo-believable. Common terms such as positive reinforcement, negative reinforcement, stimulus control and the like. We think we know more behavioural principles than we actually do, is my experience in services. During the induction for Jane’s staff team in January 2005, the organisation’s management organised physical intervention training and these couple of very athletic geezers showed a lot of moves, none of which, they acknowledged, would likely work with Jane, and would, one said, just make it a whole lot worse. Talk about confuse the staff. They also spent time quickly going through the theory of behavioural work because this was part of “the whole package”. They scooted through a series of interventions and afterwards I asked one of the instructors what one of the intervention principles they mentioned actually entailed- functional equivalence, I think they spoke about- and he had no idea whatsoever. Now this is a fundamentally important principle to grasp. I mean, really vital, and these guys, one of whom was responsible for the clinical work in the service, didn’t have a good grasp of this. In my experience, not accounting for functional equivalence in intended replacement behaviours is a primary common sin. ††

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†† Once people “know” why someone does something (i.e., ‘He’s just plain bad’ or ‘She lacks self-esteem’) they’ve got no reason to look for other more obvious explanations. If people place the cause of behaviour within the person (‘Autism causes challenging behaviour!’ and ‘Ah, it’s typical Tony mouthing off.’) then they don’t have to change themselves or what they do. They can just go on ‘blaming’ the person rather than considering what they’re doing.

††† Jack likes to throw staff possessions. [“Boy does it feel good AND it means staff tend to jump about AND they tend to shout AND they sometimes offer me an alternative to sitting all day doing nothing while staff hide in the kitchen away from me AND it means I can talk about my behaviour which previous psychologists have taught me is really important AND it means I got something to tell my parents!?”]. But then again so do I and I don’t get referred, but anyhow, staff were fed up having their belongings thrown out of Jack’s house (go ahead, state the obvious, I know I did and was met with blank incomprehension!), so the behaviour support manager decided to give Jack a small round rubber ball to throw instead of throwing out the window the staff’s handbags and coats and clothing (sometimes, staff were still attached to their T-shirts even). So, why do you think this was not the behaviour support manager’s finest intervention? Hmm? Follow that thought and you get to functional equivalence... you need to establish the function of the behaviour and then teach an appropriate alternative that serves the same function. Simple!



The introduction of values and person centred approaches and inclusion into much teaching of behaviour principles today bodes well for the future, and will challenge some of the prejudices that exist about behavioural work, but these things take time to influence actual practice. New teachers and mentors of people learning these approaches are emphasising the value framework within which technology must be applied. Little important issues such as consent, respect and dignity. The governing body of accreditation emphasises values in the study of people aiming to become certified as Behaviour Analysts. The importance of what is termed 'clinical governance' is crucial here- who oversees and monitors the work of interventionists. The social validity of any intervention is of paramount importance also. Interventions must be aimed at addressing socially significant behaviours in socially appropriate ways. Sharing the responsibility for designing, implementing and monitoring interventions requires us to involve everyone, and to spread the knowledge about what constitutes good behavioural practice. If people aren't familiar with the principles of behavioural work they can't often challenge poor practice.

The science of behaviour does not contradict good humane work or positive relationships, in fact it enables them; it does challenge our pathological world view, and places into a scientific context the behaviour of people. We can reject the principles of the science of behaviour if we wish, but we might as well reject gravity. Our beliefs have little to do with the operation of gravity: it still operates. Likewise behavioural science. As one web site notes, "reality is not up for a popular vote. Researchers who study behaviour did not create behavioural laws" (Sloane, accessed 2006).

We can examine challenging behaviour practices (being nice to people, intensive interaction, gentle teaching, rapport building etc), and without diminishing these account for their effectiveness using principles of behavioural science. The reality is this: there is a mountain of evidence that informed behavioural interventions can change people's lives. There are only a limited number of practitioners doing it today, but there are more people dabbling in it with varying outcomes for vulnerable people.

In Serviceland, I fear we have replaced the goals of understanding, compassionate support and enablement for individuals with the label of intellectual or development disability with organisational compliance to minimum standards and organisational survival. I know behavioural science can help us achieve the creation of value laden rhetoric. But it seems no matter what is said, however something is explained or implemented, someone without understanding or skill will interpret or twist your words into unrecognisable shapes and use the 'science' to justify restrictive dehumanising practice and thinking.

This has happened with person centred planning, with social role valorisation, with the five accomplishments, so it's bound to happen with positive behaviour support and supported living. As Lovett noted, snappy new names become euphemisms for business as usual (Lovett, 1996). So it's not surprising people reject behavioural approaches if their experiences of such technology is based on misapplication.

Currently, some people are claiming positive behavioural support as their own while carrying on just as they did before. They might change the presentation and the name but practice and thinking doesn't radically alter. Person centred planning and positive behaviour support

both require a paradigm shift not a change of clothing. As Herb Lovett noted, you can put a grass skirt on a cow but it still won't hula. For every really good example of positive behaviour support there is a bad example. And for every successful story arising from person centred planning is a big organisation trying to control the implementation.

Pretty soon in the UK there will be radical changes to how people with the label of intellectual or developmental disabilities will be supported and how that support will be paid for+. Are we good enough to be purchased by the people we support? If the support people receive today, if how you treat and spend time with the person with the label is not good enough for the person you cherish and love most in your own life then it really is not good enough for the person with the label.

I think what's happened is that people who have been trying to support Jane have misinterpreted what was taught; perhaps the teaching was insufficiently powerful, and perhaps the teaching didn't result in learning because it wasn't checked or maintained. The people thought they knew what to do anyhow and weren't willing to listen and change to accommodate alternative ways of thinking.

Perhaps we need to recognise we can all learn from the people we support, and the people we support can help us change. I've learned more from the people I've briefly met than I've ever passed on to them. Perhaps we need to sit and reflect on what the people who pay our mortgages must think of what we do in the name of behaviour support and care.

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+ Bring it on.

**I'd like to thank the following for comments on earlier drafts: Emma Osgood, Irene Walton, Maria Hurman and Peter McGill, and also to Mel Steeden for gasping and saying 'Can you say that without getting sued?' Hence my obscuration of names and services. The best bits here, they belong to Emma. The errors are all mine.**

**Your comments are welcome. Nice ones even more so. So please send your correspondence to\*:**

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**I am available for bar mitzvah's, weddings, consultations and pantomime season.**

**20<sup>th</sup> March, 2006**

**\* Just remember, it's not me that opens the post.**

**Go read immediately!**

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