"Suit you, sir?" : Challenging Behaviour in Learning Disability Services

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The Basics Bit

I work as a Behaviour Specialist (please note the capital letters). This is not because I couldn't find a proper job (as some nurse friend of mine noted), nor because being six foot five inches tall ballet was not an option, but because behaviour is really interesting, in that it often defines how people think of us. It's also interesting because challenging behaviour is often simply a problem in learning other more socially acceptable behaviours- but- and here's the *really* interesting bit (ok, so I need to get out more)- we, as service providers, as members of society- we have taught the person to challenge. Weird, eh?

I mean, perhaps not you *personally*, but someone someplace ignored an appropriate attempt to gain attention *("I'm busy- do you see how many people I have to deal with?! I'll be there in a minute. OK, a nursing minute…"),* an appropriate attempt at self determination *("It's no good refusing to put your coat on now, you should have said something at your review four months ago! Beside which, I know people with disabilities like horse riding and bowling… so stop complaining and get in the minibus!"),* and reinforced socially deemed inappropriate behaviour (*"OK, stop biting yourself/my arm/their leg/his neck/the canary! We won't go out then*" or *"No I'm going to ignore you screaming! I can't hear you! La La La! Boy, sure is quiet in here! Look, I'm not paying you any attention whatsoever. I'm staring*

manfully out of the window. OK- so I'm talking to you but that doesn't matter! Don't reinforce the bad behaviour Don't reinforce the bad behaviour Don't reinforce the bad behaviour Don't reinforce the bad behaviour… God! OK, stop, put down the sofa…"). Behaviour meets a need for the individual, however odd or inappropriate it seems to others (Carr *et al,* 1999). Problem behaviour/challenging behaviour/exotic communication/whatever we call the phenomena (Hewitt, 1998), these events are simply adaptive behaviours given the limitations of the environment, the unusual learning history and skills of the person (Durand, 1990). They're telling us somehow we're not meeting the person's needs.

We learn to behave in certain ways in order to achieve things we feel we need to get or get away from. To achieve the same goals we all by and large seek (attention, materials, affection, an extra portion of Ben & Jerry's Cherry Garcia) and to get away from things we don't like (pain, boredom, failure, responsibility, having to ask overweight team leaders for an extra portion of Ben & Jerry's Cherry Garcia), people labelled with the term learning disability have learned behaviours we think of as problematic. Because people tended not to listen to people with learning disabilities unless they did something really interesting. People tended not to respond to *"Excuse me, I'd really like some Ben & Jerry's now"* when they were busy and thought they had a God given right to limit access to things because *"We got a duty to care and you don't need no ice cream, fat boy"* (this is my mother's voice). But try throwing a table and watch people come running (I've always believed in trying out most of the behaviours people referred to the team do, to get an understanding of them… rocking, shouting, swearing are all good, but personal gratification in the communal living room is a hoot and my personal favourite). As Halle notes *"We have unwittingly taught those referred to as having disabilities… to behave in socially maladaptive ways to secure their entirely human wants and needs."* (Halle, 1994)

Being any kind of specialist means often knowing more and more about less and less. There is a danger I therefore could, by focusing on my own area of interest, forget the whole person. Professionals can easily loose sight of the person as a whole, real entity, active in their world. I know this is hard to believe, but even well-trained thoughtful and caring psychiatrists might do so. Even (heaven forefend!) warm & cuddly psychologists. We could

end simply describing the parts of the person- his or her behaviour, his or her disabilities, his or her intellect, his or her pathologies, his or her predilection for Ben & Jerry's (Lovett, 1996). We might even just describe people by what they do during the day. Often, for people with severe learning disabilities, what's on offer during the day is sometimes limited- apart from the ironically named day opportunity services (DOS). (I was once advised that my describing a DOS as more a "day opportunity-lost service" was unhelpful to promoting good relations with other professionals. But as was once noted, *"we need to stop pretending the crap smells like perfume,"* Peter Kinsella, 1999).

So, having loosely suggested that behaviour problems are often learning problems, I'm coming to the point of all this. We need to move directly and quickly to a way of thinking about challenging behaviour services that explicitly acknowledges what we know works: teaching people new behaviours & relationships should be the primary aim of service provision for people with the label of challenging behaviour. And here, I mean not just the people living in and thus funding the services, but the people working and managing and commissioning them. Let me return to Halle: "…*our goal must change from the elimination of problem behaviours to understanding their function so that we can craft an intervention designed to teach a new form of behaviour that is at least as successful in achieving the identified function as the old, more coercive form"* (Halle, 1994).

Do services for people labelled as "having" challenging behaviour (in a handbag? In a pocket? Where do they "have" this behaviour?) suit the person? It seems to me most service provision for challenging behaviour expects the person to fit the service (O'Brien & Lovett, 1996). This is off-the-peg stuff, not tailor made. Listen: if it were me living there, I'd challenge challenging behaviour services.

The Technical Bit (Go on, read it, it's not hard)

For many years now, learning disability psychiatrists have kept on prescribing stuff- some of which is good, some of which is not, but at least 25% of people with learning disabilities

receive anti-psychotics despite concerns about lack of efficacy, side-effects, tardive dyskinesia, effects on learning ability and, no less important, fears of possible litigation (Branford, 1996). Medication is *the* primary intervention for challenging behaviour in the UK. Still. Meanwhile, learning disability nurses keep running all over the shop, trying to do everything, and research psychologists have for years been studying the blindingly obvious. Experimental psychologists have not been going to many good parties but have instead discovered some interesting stuff about behaviour, but again, it's kind of obvious.

Most people are aware of the three term contingency- antecedent (A), behaviour (B), consequence (C)- model. Here's an example. Little Paddy- a small demur support worker, bravely clutching his newly acquired NVQ2- has just asked Big Frank- a towering man with whom he shares a flat in Margate- to do the washing up. Again. I mean, how many times must Paddy ask Frank not to leave his socks in the sink atop last night's Chicken Pasta Surprise (no chicken- that's the surprise) and clear up after a meal? The strained request to do the washing-up is the antecedent (A) for Frank's behaviour- throwing Paddy out the window (B). The consequence is Frank escapes Paddy's nagging (C), but for Paddy, the consequence is a fortnight in a quiet hospital bed and an aversion to asking Frank to do the washing up. A distal consequence is Paddy's purchase of rat poison and a club, but that's a different story (aggression elicits aggression).

What research (and experience) tells us is that whilst consequences to behaviour are vitally important, things called setting events often influence the selection of certain behaviours in the presence of specific antecedents. Setting events set the scene, they alter the motivation. Within setting events, you can consider two things: some are called establishing operations (EOs) and the other discriminative stimuli (S^d). As McGill summarises it: *"EOs change how much people want something; S^ds change their chances of getting it"* (McGill, 1999). S^d is an antecedent event that's become a cue signalling a specific behaviour will likely be reinforced- for example, a sign outside a specific hamburger chain tells you there are hamburgers available there. An EO in this example might well be my missing breakfast and lunch- I'm hungry. So, we can expand the three term contingency as follows: Tony has missed two meals and is hungry (EO), sees the sign outside the hamburger restaurant (S^d) (both antecedent events),

enters the shop, purchases a quarter-pounder (behaviour) *("And another one for my friend in the car. Honestly. No. He doesn't want a drink. Just the two burgers.")*, and eats, thus escaping hunger (consequence). (A distal consequence is denying to my wife I've eaten all day thus avoiding dark looks at my expanding waist).

EOs can explain why often the same S^d (say, being asked to do the washing up) often only intermittently seems to be an antecedent for Big Frank throwing Little Paddy out the Window of Social Appropriateness. One day, Frank may have slept well, he may be physically fine, and be contemplating a day off work laughing at tourists turning red on the beach. With such EOs, he is likely to be less aggressive to Little Paddy's request to do the washing up. Here, the EOs alter the aversiveness of Paddy's demand. Frank cuts Paddy a break. On the day Paddy Went Flying, Frank had slept badly, was coming down with mumps, and had a double shift at work to face (in effect, he felt *bad*), so when Paddy asked him to do the washing up, he selected the most effective behaviour he knew (throwing someone out the Velux) to escape the demand.

So, EOs are important. These can he physical wellbeing, emotional wellbeing, environmental wellbeing. If the person is unwell, emotionally isolated, in controlling, non person-centred environments being interacted with poorly… well, heavens, what would *you* expect?

So I think it would be a good beginning to ask ourselves some fundamentals here: is the life of the person who you currently find challenging a good life, some life, or no life? And how would you behave given this? This is fundamental question underpinning positive behavioural support (PBS)- an approach that aims to fix the environment (via person centred planning and person centred action based on good sound behavioural principles) and value the person enough to teach better (easier, quicker) ways to get or avoid things. *"The PBS approach refers to those interventions that involve altering deficient environmental conditions… and/or deficient behaviour repertoires… increases in positive behaviour, lifestyle change and decreases in problem behaviour define the core of PBS…"* (Carr et al., 1999).

The Neat Bit

To eliminate EOs that lead to S^d's signalling challenging behaviour, we need to think creatively perhaps about fixing the environment first. In other words, if you do what the person wishes, ensure the person gets what they need, you're creating an environment that produces lots of EOs and S^d's that signal appropriate, not challenging, behaviour. At the same time, you can teach new skills, to lessen the impact of EOs and S^ds that previously signally challenging behaviour.

And this is the good bit: if you do person centred planning right, if you create from the person's plan a person-centred environment, you're creating an environment low on problematic EOs and S^ds. In technical lingo, person centred planning and person centred action can be exercises in abolishing operations- things that eliminate the negatives from a person's life. What this boils down to, I'd like to suggest, is that behavioural science kind of shows that meeting the person's needs (through person centred action, for example) makes good solid scientific sense. (Applause, for the discovery of the obvious).

A quick guide to positive behaviour support (Koegel *et al*, 1996) and person centred action, in relation to challenging behaviour, might therefore be as follows

Step 1 What good things has the person got going for them in their life?
Step 2 Increase these good things, introduce new good things
Step 3 Make good things non-contingent (don't withhold, don't punish)
Step 4 Then come back to me and talk about challenging behaviour in six months.

The Implications Bit

It is not uncommon for services to produce (lots of!) planning documents, explicitly stating commitment to "ordinary living", "independence" or other "person-valuing" philosophies, while at the same time proposing service developments or goals inconsistent to such statements, such as large group homes and diagnosis-based services. Often people displaying challenging behaviour get grouped together. Some weeks later the wise service managers sit in a very important meeting scratching overpaid heads and doodling on expensive corporate writing pads with costly pens, wondering why John or Jane's behaviours have escalated. This is remarkably silly, and after many years of working in this area, has left me wondering who in the equation really has the learning disability.

Services are not just beds, they are not simply houses, though having a roof available can be mightily important when it's snowing. Commissioners need to grasp services as something other than bricks and mortar, a place "to put the problem". People have been moved from service to service, area to area, for years. Unless you get to the underlying difficulty, unless you realise services mean engineering social and professional support, skill building and education around the person and their relationships, you'll not resolve challenging behaviour. You (yes, you! Mr/Ms. Commissioner!) just get reinforced by moving the problem from your desk to somebody else's. Out of sight, out of mind- and there you were thinking we'd eliminated that by closing the hospitals.

Commissioners like buildings. They don't move around too much. You can calculate the electricity bills in advance. Commissioners become twitchy around people, dynamic, real and changing people. Building's seldom leap on you and demand a better support package, people do.

Working in a small peripatetic (from the Greek- to wander up and down listening with incoherent amazement at the universe) service, we get a lot of requests for help. Often these constitute a "please fix the person" plea. One person we recently worked with enjoyed leaping on a select band of (attractive) male staff, and she soon worked out how to generalise and maintain her behaviour across other staff, and indeed, many settings. Soon, she could jump on whole groups of people at a time. Many of the staff weren't even remotely

attractive. She also attended a day centre and it changed its routine. After consultation with senior managers, of course. Following the changes in her routine, she became less occupied than before. She subsequently asked to go home a lot. Staff at the day centre said *"no"*. So she hit a member of staff then jumped on her, and people came running so she jumped on them too (because hell, she was good at jumping on people) and they said *"Hey, you can't do that! Go home! Go away! Take her out in the mini-bus."* Within a few trials this young lady would get her coat on prior to hitting and jumping on staff. After being admonished, she'd then ask to go home. The routine change at the day centre was one factor of many that in the preceding 18 months had occurred:-

- two other service users had died in her service- one of whom she had been very close to for fifteen years
- staff changes: new staff coming in, older team members leaving
- new management approach to promote independence, consisting of being told to *"go fix yourself a drink"* while they had an important meeting to talk about supporting people- she liked making drinks with people, you see, and didn't want to be wholly independent
- moving into a bedroom on her own for the first time in her life
- inconsistent staff interaction: everyone doing their own thing
- medication increased to manage the problem
- relationships breaking down due to behaviour
- living in a hotel for a couple of months when the house was unusable.

The home and day centre focused on the problem being the person. She left the day service, left her home of fifteen years and spent half a year in an assessment service where she stopped jumping on people on account of them jumping on her first. The problem for the service I work in, is that this story is too common: many services expect users to be nice, constrained and compliant, even if their lives have been falling apart. They become affronted or challenged by people's behaviour. The people I work with are said to have challenging behaviour because the behaviour they display is either dangerous to themselves or others, or affront the staff. This is probably why I enjoy the work so much, because I have a lot in common with the people: I am greatly affronted by many service'. I like challenging.

Traditional success criteria (for example, a reduction of 'challenging' behaviour) are often the consequence of simply listening to people, enhancing skills, and helping people "get a life": one of Todd Risley's "secrets" (Risley, 1996). It is also at the heart of person centred planning and action. A rapprochement between values and science is hinted at, only… to be honest, I'm not sure there was ever that much difference between the two. Differences arose over the years about how both values and scientific positions have been applied. This says more about fundamentalists than the fundamentals of science and values, perhaps.

Where behavioural (or any kind of) intervention can go deeply, awfully, troublingly wrong, is when professionals get caught up in seeing things from their own point of view, not the person's. When we're not clear what we're trying to do. Nor why. When we think our opinion is more important than other's. When we do things to the person. The troubling thing is these techniques can be used despite the person's objections.

Another implication is about how we organise professional services. We can no longer hit and run. We can no longer open and close cases. Listen: *"Evidence suggests many approaches to intervention may either need to be sustained over considerable time or require permanent changes in interaction between people and those that support them… maintaining gains, achieving broader lifestyle outcomes need sustained support… Interventions need to be seen as an ongoing process rather than a time limited episode of treatment"* (Emerson, 2001).

The Final Bit

It's of no help to say *yeah well it wasn't me that taught Frank to throw rather than talk it out.* We have a collective responsibility here. We are only as proficient as the worst service, not the best. That's how history will judge us in the future: not as a generation who carried out a few pilot beacon projects (which we wrote about *ad nauseam* in journals) but as a generation high on rhetoric, low on doing. *Valuing People* (DoH, 2001) is grand- no, really!- but still poor services are commissioned daily by people who should know and expect better, paid with

public money, managed by people who could do better, and existed in by people who seldom do much better than previous generations, with front line staff who don't know better.

Some principles, to end with:

- **Behaviour** usually **happens for a** really good **reason. Behaviour** occurs in a continuum (Beware people saying *"it came out of nowhere!"*)
- The way "challenging" behaviour develops is the same as "acceptable" behaviour
- **Functional assessment can be** *really* **helpful in working out WHY & WHEN**
- **Intervention** must be based on **understanding why**
- Intervention **goals** should be **educational** not purely about stopping problem behaviour
- The reasons people do things is often complex: therefore **multi-element interventions** are useful: intervention means **changing social systems /environments**, not simply the person
- **Meaningful lifestyle changes** are the goal: intervention may require **permanent changes** in working with people
- Intervention not acknowledging **communication is usually a poor intervention. Challenging behaviour could** often be thought of as **"exotic communication"**
- **Defining behaviour** as challenging is usually a product of the behaviour's impact.
- **Challenging behaviours** range widely in their topography, as do the psychological and biological processes that underpin them.
- **Many people use challenging behaviour to get out of situations they don't like.** Doh!
- As functions of behaviour, and contexts, vary between individuals, **a "one-size fits all" approach or service** is unlikely to be of use.
- Build a **rapport** with the person. Basically, make sure you become a signal to the person for good things. If you always place demands on the person, soon you'll only have to walk in the door and trouble will start.
- Associate yourself with **good things**: find out what the person likes and get involved. Do this **non-contingently.** Don't ask the person to jump through hoops to "earn" a

reinforcer. We're not training dogs here; we're working with fellow humans. Building a rapport/ understanding /valuing interaction is ongoing. Don't try it for a couple of days and then stop.

- Through this rapport, **communication can commence**. Link communication to rapport building. The secret is to start from where the person is at.
- **Embed "programmes" and "demands" in positive interaction/rapport**. Some of the most successful interventions we've been involved with had no 'behavioural programme' bolted onto the Care Plan- they were part **of everyday interaction** and **communication**. This is why good person centred planning & practice can be so effective. To do person centred planning well is to make it **person centred active support**, and this requires not just **good values, but high skills, insight and creativity.**

A final quote: *"…we have learned to ask "Why would this person need to bang his head to get attention?" or even "Does he have so little control over his world that he needs to hurt himself or someone else to gain control?" In the context of a thorough functional analysis, such questions have helped us to use the behavioural technology in a more creative and humane manner. We exhort you to call upon your own creativity and skill in human interaction to do likewise"* (Donnellan *et al*, 1988).

Ensure challenging behaviour services suit the person.

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