

POINTS OF VIEW

BY THE BY: SEVERELY CHALLENGING BEHAVIOUR - THEM, THEM AND US

Not so long ago, I attended a conference. Half of the second day was given over entirely to the problems of disturbed mentally handicapped individuals. Politically correct language - aseptic, boring and yet exquisitely sensitive - added at least five minutes to each talk. Continual repetition of "children and adults with severe learning difficulties who challenge the services" had a curiously numbing effect. For whose benefit, ours apart, do we euphemize euphemisms? The distraught mother of a child who is trying to poke his eyeballs out certainly isn't going to feel better, or understand more, when we put yet another piece of tinsel over the problem. (There's a certain irony here, although in a wider context. A spokesperson for Personscap was quoted in one of the Sunday heavies as saying, "It is only a matter of time before even the most right-on expression becomes a term of abuse. It has been the same since people talked about village idiots, and 'learning difficulties' is no exception - children are already calling each other LDs as an insult"). But sensibilities, it turned out, were a bit selective. A lady interrupted from the floor to complain that the speaker was loading his clinical examples with males. He reddened, glistened and developed a temporary stammer. So more time was carefully, gingerly added to each talk to balance the gender effect. Another speaker with pogo-stick legs told an indignant story about a disturbed lady in an institution, and a locked door. No time for details. The upshot was that the door was eventually unlocked, and the challenging behaviour challenged no more. Keeping the door locked was a stupid practice, he repeated, eyes bulging. Ergo, nurses are stupid creatures of habit. Well-intentioned, maybe, but out of date by a long time. It was the ritual duffing-up. Many in the audience loved it.

The nursing profession has its quota of shysters, cuckoos and dingbats. So do all other professions. We cannot forget that nurses are still round-the-clock carers of some of the most disturbed individuals in the system. And in many ways they are as vulnerable as their charges. If things in a ward go wrong, a posse may arrive days later from some acronymic outpost of the Health Service, all of them strangers in tailor-made suits, all of them shooting cuffs, at least one talking urgently into a mobile phone.

The safest and most passive form of care for an unpredictably violent pocket Marciano is containment, ie. keep him in an area away from others. But this is wrong. Or so we are told. Forget the possibility, however remote, that he is terrified of others. Or that he is an extreme misanthrope. That in different circumstances he would of choice be an anchorite. Forget the next logical possibility that because he preferred being strictly alone, he reacts violently to others. Assume we devise a modest behavioural programme in which he has to spend one or two minutes in a large room with, but not near, two other men. By definition the programme will entail risks (as well as extra effort). If something goes wrong now, can you blame those nurses who want to revert to containment? When are risks too risky? You tell me. Fear of the posse will make nurses extra cautious for a very long time. If you find they do things in a certain but mysterious way, you can bet there is usually a good reason, even if it lies a year or two back.

At lunchtime, I fled the dining-room to a cupboard thoughtfully provided two miles away by the conference organisers for smokers. The only other person there was a very attractive, slightly irate, lady. Kate, Irish born, had worked as a nurse in a unit for disturbed people in England, and was now in a community post. A lady speaker at a parallel session had annoyed her by assuming that all there were "visiting professionals", not "hands-on practitioners", as if the latter were socially as well as professionally inferior and could be found living in crowded bothies, awaiting instructions. In Kate's opinion, most visiting professionals are hugely expensive jokes. They have probably attended a workshop where obliging stooges act out problems, and have gained the rest of their experience at endless case reviews. Some of these case reviews are also expensive jokes, Kate thinks.

"Say it's about Johnny or whoever and he's giving his parents and teacher a hard time. Right? Well, there could be twenty or thirty or more at the review. And you say to yourself, my God, are they all necessary? At least two don't say anything at all and you wonder if they're there by mistake, too polite to say so, that they intended to be next door at the lingerie promotion. You'll find two or three who've read everything about Johnny but have never actually seen him. Then there'll be some boring old bog trotter who talks a lot but can't come within a mile of the point".

She looked at me rather pointedly, I thought, and lit another cigarette.

"The thing that maddens me more than anything else is the unwritten rule, at least I've never seen it, that some people who should be at the review aren't: classroom assistant, guide help, nursing assistant, junior carer in a home, van driver - they all know Johnny better than I do. If Johnny's parents are there, chances are they'll be scared out of their wits by all the experience, all the expertise, all the professionalism staring at them in the face . . . Then some of these professionals visit us and give advice . . . I need someone who will actually work with us, not somebody in a Jaeger outfit and pearls who tells us about the Premack principle . . ."

Uncomfortably, I remembered a young visiting professional who called at our small Behaviour Nurse Therapy Department. He exuded aftershave and bonhomie. His advice was barmy.

I don't know whether I agree with Kate about case reviews. I don't go to many and can remember only a few excruciating ones. But I do have strong views on training.

Behaviour modification with disturbed mentally handicapped individuals is at best a craft. To get the practical hang of it you have to serve an apprenticeship. That is, you have actually to work with Johnny and his ilk. We have trainee professionals of many kinds with us on placements lasting up to three months. And guess what? A few are excellent. Some are okay, a lot are duds. One dud spent his time warily circling the room. He had a flair for being where the action wasn't. We'll come back to the duds in a minute.

Apprenticeship experience teaches you things you'll never get from texts. (I know that sounds trite. It is trite, but true nevertheless). There is for example, the client whose SQ may be 30 but whose behaviour modification quotient is four times as high - you'll have trouble catching up with him. Then there's the beautiful child, innocence shining out of dark lacustrine orbs, who stealthily unravels your complicated, sophisticated programme from the edges. And that's more frustrating than a programme which explodes in your face. Yet another seems to

exist quite happily in a reinforcer vacuum. There are times when nothing seems to work and you stand around disconsolately wondering what to try next. All Sisyphus had to do was roll a big stone up a hill.

The hardest thing I have had to learn (and I still haven't come to terms with it) is quite simply that very few individuals in any disciplines I can think of actually want to work with disturbed children and adults. Oh yes, they *profess* an interest, but preferably well away from the clients, perhaps at yet another case review down the corridor. Oh yes, as visiting professionals they'll give advice, but from a car with its engine running. So some of the duds we come across are probably smarter than we are. Maybe they know things we don't. Their arguments could go something like this:

Physically to work with a child who keeps trying to punch his jaws and bang his head off table edges involves a lot of effort and hassle, and you can get hurt. More important, you run many other risks. Mechanical restraint, properly applied, is a lot safer, is cosmetically ethical, and saves you all that effort. If a sufficient number of important people say that they are pessimistic about the boy's prognosis, you'd be well advised to join them. If on the other hand, these people would welcome behavioural intervention, then advise someone how to do it and clear off. Alternatively, refer him on to some other part of the system.

Gedye (1989) dropped a bombshell. She suggested that extreme self-injury in some individuals with temporal lobe epilepsy is *involuntary*. They just can't help it. Already in place, of course, was the strong suggestion that Lesch-Nyhan cases somehow can't help chewing their fingers, eating their lips away. Gedye's claim infuriated psychologists and others. The very notion that some self-injurious behaviours are not learned was heresy, treachery even. And yet, and yet, isn't there, for some professionals at least, a permanently secret appeal in the theory? If these behaviours are involuntary, there's no point trying behaviour modification programmes, is there? The fact that many self-injurious children are so persistent, so determined, so single-minded, so fast, so stubborn lends credence to the theory doesn't it?

The next step in the argument is easy: isn't it possible that other forms of severely disturbed behaviour are also involuntary? Epilepsy may not be a critical factor but there could be another organic component.

In my neck of the woods, the institution is still the place for severely disturbed mentally handicapped individuals. Rightly, in my view. The nurses I work with in our small department range from the good to the gifted. They most emphatically do not subscribe to Gedye's theory. I take my hat off to them. So every time they are ritually duffed up, I shall just as ritually defend them.

Reference

Gedye, A. (1989). Extreme self-injury attributed to frontal lobe seizures. *American Journal on Mental Retardation*, 94, 20-26.

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