

# *“Falling on Deaf Ears”*: Self-Harm, Self-Injury and Ourselves: Different Rules?

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## A Lot to Hurt About

There are an awful lot of people in the world (6.5 billion the week of writing). Many of these people are hurting because of one thing or another. A lot of the people hurting have ways of dealing with the hurt (for example, talking about it, doing other things, problem solving, listening to The Polyphonic Spree, etc). And there are a lot of people hurting who hurt themselves because they hurt so much. And a lot of *things* are hurt due to some people trying to understand, support and sometimes stop other people who sometimes hurt themselves because they hurt so much. Think of all the resources consumed by employing people to help other people not to hurt themselves- this hurts the people funding the people trying to help other people not to hurt themselves. Think of the amount of paper alone (articles, books, intervention plans, ethical committee minutes, training manuals and so on) that gets written upon by people wanting to help and inform the people who want to help and inform the people to not need/want/be able to hurt themselves. So there are lots of people hurting, a lot of people hurting themselves, and a lot of people hurt by being with people hurting themselves. While hearing people talk about their hurts is upsetting, watching people harm is dreadful (Fish, 2000).

We often think of self-harm as a term used commonly in mental health settings. Self-harm has been defined copiously and diversely. It broadly invokes images of behaviours resulting in harm to the person herself: the person harms herself. In many services, a tendency exists among staff to replace nouns with verbs (“Self-harmer! Cutter! Self-abuser!” staff say smoking their cigarettes) (Jones, Davies & Jenkins, 2004). Self-harming behaviours are often viewed as “caused” by emotional health difficulties (something inside the person). Often, serious self-harm is associated with ‘psychotic states’. Self-harm can include cutting yourself, burning yourself, blood-letting, hitting your self, scratching, hair pulling and the like, and has been associated with some people with borderline personality disorder, developmental disabilities or other organic conditions, as well as people with eating disorders or emotional health difficulties. In mental health circles, a number of psychological characteristics are described in people who harm themselves: people may often dislike and invalidate themselves, be sensitive to rejection, be emotionally suppressive, have poor coping

skills and have a lack of control in their lives. Self-harm is considered one result of profound emotional pain (Fox & Hawton, 2004). Following someone harming themselves, people tell us that their feelings of self-hate, anger and anxiety are “released”; many people who harm themselves speak of the act of harm as being akin to an act of taking control of their life or self-punishment. Self-harm isn’t about wanting to die, but often, about wanting to feel real and alive.

We think of self-injury as a term most often used in developmental disability circles. We can define self-injury as “any behaviour, initiated by the individual, which directly results in physical harm to that individual. Physical harm will be considered to include bruising, lacerations, bleeding, bone fractures and breakage, and other tissue damage” (Murphy & Wilson, 1985). Again, people are often defined by behaviour (“He’s an aggressor!” some will say, or “She’s a choker”<sup>\*\*</sup>). Sometimes, self-injury is thought of as ‘just something people with developmental disabilities do’, in the same way ‘not monitoring placements very intensely’ is what out of area Care Managers ‘just do’.<sup>\*\*</sup>

Self-injurious behaviour among people with developmental disabilities is relatively common and usually persistent (Hall *et al*, 2001; Murphy, 1999); whilst some specific syndromes have been identified as commonly featuring self-injurious behaviours, such conditions are rare and few (Dykens, Hodapp & Finucane, 2000; Murphy *et al* 1993). Whilst these conditions might best be considered as contributing toward the matrices of “causes” of the behaviour, they may not necessarily be the maintaining factor (Carr & McDowell, 1980; Murphy & Wilson, 1985).

But we have broadly grown to consider self-injury ‘operant’ behaviour: doing something to get or avoid something (attention, something tangible, getting away or avoiding something, self-stimulation). Tied to this, we often hear the phrase self-stimulation, where a person behaves in order to gain internal sensation (rocking, humming, head hitting, hand flapping etc). I do this a lot myself- especially in very dull meetings with very dull people (“Ok, listen to the Director talking about operational issues... gosh, how did she get her hair that colour? And at such an acute angle? And *what* is she wearing? How does she afford that car? Hey, why is it that the further away from directly working with people with developmental disabilities the higher the salary? Whoa! She’s having an earthquake... no, hang on, that’s me jiggling my leg. That feels nice. Mmm. Hey, the table is shaking. Must cut down on coffee, people are staring! Concentrate on the trite management speak! Hey, she sounds like a character from Little Britain... ‘I’m a Director, and I like Director’s things, I dress like a Director, because I am a Director’...”). I sit there humming and doodling and jiggling until poked by a colleague with a pen. “OK,” I whisper to my colleague, sometimes too loudly, “but tell her to say something *interesting*.”

\* I asked if the lady referred to in this example would leap out of the wheelchair and try to strangle people and was given a withering ‘look’- my inane grin may not have helped my enquiry

\*\* Sometimes, *everything* is viewed as the result of the initial developmental disability, including tooth decay, broken legs and unruly hair- “A broken leg? Hmm. I see. It’s because of his disability. Don’t worry, it’ll sort itself out.”

Both self-injurious and self-harm behaviours are very complex. They are caused, maintained and affected by many genetic, neuro-biological and environmental factors. Different people self-injure or self-harm in different ways for different reasons, and thus will respond to “standard” interventions differently. These behaviours may well look the same: hitting your head against a wall in a developmental disability services will be considered self-injury, in a mental health setting, the same behaviour will be considered self-harm. Today, despite the wide recognition that self-injurious and self-harming behaviours are functional for the person, progressive support and informed interventions for self-injurious behaviour is still too rare (Emerson, 2001). Interventions must be individualised to increase their effectiveness.

### The Moody Hills of Serviceland

Broadly, as discussed above, developmental disability services seem to have traditionally used the term self-injury, whereas mental health services are fond of self-harm. Well, the phrase at least. The former behaviours are often viewed as operant, the latter as pathological. Even if these behaviours look the same. People who manage and create services designed to employ people wanting to help and inform people who hurt themselves may often fall into the bondage of such terms. A person must either engage in self-injury (getting or avoiding something) or self-harm (a method of mitigating psychological distress). No cross over allowed! You mustn't self-harm and self-injure, oh no no no! It is very similar to the daily experience of people with developmental disabilities and mental health difficulties.

Historically, the incidence of mental/emotional health difficulties has seldom been recognised in people with developmental disabilities. Generic mental health services are often uneasy providing for people with developmental disabilities (Day, 1994). Service provision is often poor, if available at all (Hatton, Hastings, Vetere, 1999; Prosser, 1999). It seems as if people with developmental disabilities are not permitted to have emotional or mental health problems in the myopic eyes of serviceland (Caine & Hatton, 1999). But people with developmental disabilities are more likely than others to experience emotional health difficulties (Gravestock, 1999). A number of possible explanations have been proposed for the increased prevalence of emotional health difficulties in people with developmental disabilities:

- communication deficits
- lack of coping mechanisms and social, interpersonal and adaptive skills
- low self-esteem: experience of failure and rejection
- controlling environments and a lack of choice in environment
- organic damage (Goldberg & Huxley, 1980; Holt *et al*, 1995; Moss, 1999; O'Hara & Sperlinger, 1997).

Mental health provision often fails to consider environmental stressors, viewing emotional health as a pathological and internal state experienced by the person; developmental disability services may equally fail to consider the emotional well-being of people. The fact is, people hurt themselves in response to both environmental and internal influences. People with developmental disabilities are no different: along with

assessing what environmental factors influence such behaviours, we should consider emotional states also. Self-esteem, life and learning experiences and skills need to be considered: has the person the skills to identify and express their emotional distress? Does the person have control over their life? If not, unusual behaviours such as self-injurious and self-harming behaviours are to be expected.

The conceptual trap of holding to *either* self-harm or *either* self-injury as mutually excluding terms is obvious: thinking in self-injurious terms may lead services to forego emotional considerations, while thinking in purely self-harm terms may result in us forgetting to consider environmental influences. Such rule bound thinking hampers problem solving; it could be argued (say, by a tall, fat, bald Behaviour Specialist with a penchant for radical behaviourism, the baiting of commissioners, cooking Italian food and reading Pablo Neruda) that people and organisations holding vigorously onto either self-harm or self-injury concepts at the expense of considering what the other approach may be able to offer, are rule governed rather than contingency governed, and thus not hugely sensitive to the actual consequences experienced by people “living” among the Moody Hills of Serviceland (a strange place, almost a state of being, with a harsh tongue, a proclivity for categorising humans, a place where the interests of the individual are secondary to the interests of organisations, despite the hundred thousand Mission Statements and Value Bases reproduced on glossy websites claiming the opposite).

In Serviceland, policies are often more highly valued by those with organisational authority than outcomes of people using services. But policy alone does not deliver life-enhancement (Felce, 1999; Mansell, Hughes, McGill, 1994; O'Brien & O'Brien, 1992); policy alone does not increase service user's power in services (Bruininks *et al.*, 1981; Peter, 2000); policy does not produce significant differences in levels of problem behaviours (Emerson, 1999). Policy does not deliver meaningful outcomes for individuals, and neither does unthinking compliance to organisational strictures.

You know you've entered the Moody Hills of Serviceland by the dark glances from the hills, the cold wind sweeping away your suggestions of innovation: the territorial rules of these Moody Hills requires us to walk fixed pathways. However, good person centred behavioural/emotional support requires our first loyalty be to the person, not the organisation, and sometimes, this means wandering from the authorised pathways, trampling sometimes on the organisational pansies. Person first, policies and loyalty to organisations second! Good positive behavioural support, like person centred planning and action, is often characterised by conflict with the status quo. Good person centred planning and action, and good positive behavioural support, is all about change and growth. But services tend to inflexibility which facing change *“Predetermined services induce a reliance by staff on maintenance of the status quo... the status quo is ‘to maintain the status quo’...”* (p.3, Praill & Baldwin, 1988). *“People in organisations largely approach change with an existing set of customs, practices and politics that frequently mitigate against large scale innovation”* (p.365, McAdam, 2000). In the Moody Hills of Serviceland, challenges to existing patterns of thinking and behaving are often opposed.

Services have been limited in how they respond to individuals by conceptualising “the problem” in terms of self-injurious behaviour OR self-harm. Widening our conceptual

base can aid services to better support people: insights into why people hurt themselves should inform intervention. Using fixed models (self-harm or self-injury) to respond leaves us hidebound. As Lovett notes, our responses are often draconian and influenced by our need to stop, rather than understanding, self-harm (Lovett, 1996). Oliver *et al* (1996) found people working with others who self-injured were likely to choose a strategy to deal with the behaviour that ultimately reinforced it. Studies indicate between 75-95% of people who self-injure continue to do for a considerable time.

So think about why people might self-harm, and think about how you yourself cope with life's stresses; consider how you assert yourself in the world. Now imagine you have a small voice, fewer opportunities to learn, fewer people to listen to you. People with developmental disabilities are likely to experience high rates of abuse and control. People with developmental disabilities have a lot to hurt about and yet possess less skills to mitigate their greater burden. Think about why people with developmental disabilities might generally hurt themselves over your next cigarette, your next coffee with sugar and cream, your burger lunch, while driving a short distance you might have walked, while waiting for your tattoo appointment, or having your ear/bellybutton/eyebrow pierced\*\*\*, or over a pint or two. "Why *do* people do things that hurt themselves, eh? You got a spare fag?" Are the emotional lives and needs of people with developmental disabilities falling on deaf ears? Are their responses to emotional pain viewed as merely a by-product of disability? Phew, those Moody Hills- they can really creep up on you, can't they?

### Never Underestimate The Power of Very Stupid People in Large Groups

I was recently involved in trying to support a mental health service try to understand why a wonderful young lady with autism, learning disabilities, and communication difficulties would sometimes self-harm and self-injure. Jane (not her real name) is deaf and relies on signing and clues from the environment. She's a real observer of human life. Jane would sometimes hit her head against taps, walls, doors, windows, floors, furniture and sometimes the people who tried to stop her hitting her head against things. Jane sometimes pulled her hair out, she sometimes wanted to modify or sculpt her head and face. She found herself thrown onto the ward out of her residential service via Accident & Emergency. She stayed on the mental health ward for ten months. But the ward staff were in bondage to limiting policies, practices and thinking: self-harm only applied "to mental health users", not people with developmental disabilities. They didn't understand autism. They didn't sign. They didn't "have the skills to work with people with disabilities". They didn't know how to respond outside their traditional reactive practice: medication, restraint, punitive interventions, no therapy and level four observations- two people watching her 24 hours a day. For ten months. They didn't listen to people telling them such intrusion increased the emotional distress and thus the risk of self-harm.

\*\*\*Other body parts amenable to piercing have been omitted for the sake of decency.\*\*\*

\*\*\*\*Behave. I meant body parts such as noses.

They couldn't condone Jane harming herself or appear to try to understand why Jane wanted to hurt herself (sometimes, Jane would cry, her whole body shaking and sign to people "I want to die." Such a direct statement of hopelessness from one human to another often killed conversation dead. Such statements condemned many of us). The ward had worked with many many very unwell individuals, many of whom hurt themselves; some people had cut themselves, some people harmed or punished themselves with rituals or food or a thousand creative mechanisms or items or stratagems to inflict pain or to just feel real and alive. And once or twice, the ward had negotiated with the person who harmed themselves, and they taught the person how to hurt safely. They respected the person's choice and need. This was exceptional and rare, however. And didn't, couldn't be, applied to Jane. The ward did not recognise banging your head through a wall, ripping the flesh off your arm on a tap and rapping your forehead on a door catch thirty times in as many seconds constituted self-harm. Jane had a developmental disability so the rules of self-harm didn't, apparently, count.

They ignored her emotional distress but responded to self-harm by jumping on her and wrestling with her on the ward floor for hours at a time. In part, their adherence to the policy requiring physical intervention regardless of cost, was motivated by fear: what if Jane died hurting herself? To be honest, the most difficult thing to do is to stand aside and not physically intervene in self-harm. I remember working with Jane years before, waiting for the heart-stopping noise of dull thuds reverberating throughout the house: imagine a neighbour knocking nails into a supporting brick wall and you get the idea of the sound. The anger and fear this provoked in us cannot be over estimated. The relief at ending a shift without self-harm was immense. So I could recognise one of the motivations for staff to "do something". No one was suggesting they did nothing, only they did different things than physical interventions. We wanted them to not make the mistakes we had made before in our early attempts to understand Jane, to stop Jane. Jane had taught us long before that physical interventions resulted in more accidents, more injuries, more aggression.

An additional rationale for the manner in which the ward "managed" Jane's self-harm, may be in the way they thought about self-harm generally. People who self-harm often report the support from professionals is often judgemental and unsupportive, further exacerbating feelings of guilt and stigma and apartness. The response from services often strengthens feelings of isolation and hopelessness. People often think the person harming themselves is trying to manipulate them.

After trying to engage with the service for many months I

- a) felt like hitting my own head against the wall,
- b) wondered whether it was Jane who experienced the world through the challenge of autism, or whether the service were also someplace further along the autistic spectrum (the service were rigid in their thinking ("Well, it's because of her developmental disability..."), had limited interests ("Quick, jump on her!", drawing up injections at the beginning of shifts, waiting for her "to sabotage the shift"), they were poor social communicators ("No, I don't know how she lost two teeth last weekend, we can't find any record..."), didn't appreciate others' thoughts or feelings or ideas ("Medication, medication, medication's all you need!" and "She should know she's not allowed to hurt herself") and had little imagination. The ward had no central coherence. They perceived the world differently than neurologically typical humanity ("Don't collude with users.

Don't trust them. They're up to something"). They resisted change (but not the pizzas and free goodies supplied to them by the drug company representatives). They were echolalic ("We can't do that because of policy. We can't do that because of policy. We can't do that because of policy"). Come to think of it, most of the people living with autistic spectrum disorder I have met have less of these 'diagnostically significant' characteristics than neurologically typical people running services. Theory of mind?!?

c) wondered who had the greater learning disability, the service or Jane (Jane learned and adapted, the service didn't learn from the many two, three or four hour restraints and the administrations of Clopixol Acuphase over ten months ("Wow, Jane had two Acuphase this afternoon and she's still standing! What does the BNF say about *that*?").

The issue here was straightforward: Jane sometimes wanted to harm herself. We were trying to do things about that. Like increasing communication to and from Jane, through showing her easier ways of expressing herself. We knew, for a lot of the time, when and why such things might occur. We knew that trying to stop Jane from harming herself usually led to Jane becoming aggressive: sometimes, to stop Jane harming herself, three or four staff would restrain her on the floor. Both Jane and the staff lost dignity, sustained injuries. Jane's injuries from restraint would sometimes be horrendous: bruised and angry, injected and crying... I wonder what the people working on the ward taught Jane about people and listening? I wonder how her self-harm injuries compared to restraint injuries? She certainly didn't have bruised legs & arms, carpet burns, clothes burns or finger prints on her when she self-harmed, but she did when restrained. And that doesn't include the emotional injuries of being stopped from doing something she needed to do. Jane would usually carefully "line up" her head to the place she intended to hit: being wrestled to the ground meant she was likely to misjudge any "hit" and increase the risk of unintended serious injury. And Jane was never "sectioned", there was no legal "right" to detain her, or inject her, or restrain her, or ignore her.

But it was ward practice to use physical interventions to stop self-harm. They didn't ask Jane to not harm herself, they didn't offer alternatives, they didn't respect her right to harm herself. They just jumped on her! This was informed not by Jane's best interests, but by standard ward policy. The drive to stop self-harm, even at the cost of a loss of dignity, regular (over)use of medication, and injury to Jane and staff, was paramount. And so physical aggression increased, so Jane was watched more closely, which increased the likelihood of Jane feeling bad about herself and self-harming, which increased staff's fears and made them watch her more closely, and so on and so on. The ward were made aware such a zero-tolerance approach to self-harm only served to increase Jane's need to complete the ritual of self-harm. And being frustrated in her attempts to harm herself increased the probability of her hurting other people. Some staff learned that letting Jane harm herself safely tended to resolve incidents very quickly. They learned the self-harm was only one small component in Jane's life, and sought to listen and communicate with her. But the organisation didn't learn. Policy was blind to the actual consequences, focused as it was on policy and rules. They didn't have the skills and capacity to follow non-aversive, more respectful interventions for Jane's self-harm. The ward had the subtlety and sophistication of a small nuclear explosion in a cityscape.

There is an old teaching story: a long time ago, a man living in a small village was believed to have died. A cursory glance told people the person was dead, despite the fact that he had fallen into a faint. As he was being prepared for his burial, he came around, but was so shocked at seeing himself wrapped in a shroud and at the sounds of people mourning him in the next room, he immediately passed out in horror. When he next awoke, he was beside a grave. His grave! He sat up shouting. People screamed. "Wait!" he shouted, "don't bury me!" The crowd of mourners were horrified, they couldn't believe their eyes or ears. Here was a man certified dead, and yet he was talking and sitting up. How could this be? Even the man's wife refused to believe her eyes, and horror at such an unnatural resurrection left her speechless and angry. This was unknown, unexpected, like nothing experienced before. So they called a judge to decide what to do. The judge arrived and sought to establish the facts of the case: "You, the alleged deceased; what do you say should be done?" The shrouded man said, "I want to go home with my wife! Back to my house! I am alive!" as his wife shied in horror and the crowd murmured. The judge turned to the crowd: "And what do you say?" The crowd shouted, "He's dead! We know he's dead! This is unnatural!" to which the shrouded man screamed "Oh no I'm not! I am most clearly alive! I demand to return home with my wife!" The judge thought for a moment. "Well," he began, "we have heard what the single alleged deceased has to say, and we have heard what the fifty witnesses have testified..." and he scratched his beard. "So, it is a case of fifty against one... Better bury him."

Sometimes the status quo does not serve truth. Asking the ward to step outside of their experience and well-practiced physical interventions in favour of non-physical reactive strategies and a greater emphasis on proactive interventions was a big ask. In hindsight, we might have predicted they would decline to listen to the lessons we had learned. So they buried the advice. So followed ten months of unnecessary damage and heartache and injury.

### Learning to Listen?

"For many years the dominant psychology of learning disabilities was behavioural. Behavioural approaches were, and remain, useful. Yet, when this was the only legitimate viewpoint, it seemed as if people with learning disabilities were only allowed behaviour. It seems now that people with learning disabilities are being allowed to have thoughts" (Ephraim, 1998, p.217). Ephraim suggests there is no such thing as challenging behaviour, rather, we should consider such behaviours that challenge how we think, feel and act, as exotic communication. What Jane's self-harm seemed to be "saying" was we were not meeting her needs. We hardly needed to have studied for an 'ology' to work that out. Jane was communicating, but the ward, like services before them in the Moody Hills of Serviceland, did not have the ears or the ability to try new things.

One of the reasons for our hearing loss was our enslavement to the assumption that people with developmental disabilities self-injured, people with mental health difficulties self-harmed. Our hidebound adherence to such thinking left us blind to Jane's emotional life. We could grasp when Jane self-injured it was often about getting tangible items. Such behaviours, whilst serious in intensity, were nothing to the



intensity of self-harm, when Jane sometimes felt so distressed she felt obliged to hit herself until she was covered in blood. These intense self-harming behaviours seldom resulted in measurable pay-offs for Jane, but they tended to be followed by a huge emotional explosion: tears, hugs, cries and wailing... and Jane was not much less emotional. Jane didn't want low-level reassurance at such times, but huge hugs. One member of the staff team described Jane's self-harm as resulting in a kind of post-orgasmic relief and state of well-being.

We've learned that people working with people who hurt themselves should consider taking a functional and individual approach. An individual approach means we do not fit the person into our preferred conceptual model; rather we take what seems to be of use from any model. It requires an eclectic approach. Widening our conceptual base can aid services & people using services.

Seeing someone harm themselves is difficult and troubling. It provokes strong reactions and we often fall back to primitive instinctive responses: we wish to try to stop the person self-harming. Standing back and communicating openly requires bravery and it's hard because it's counter-intuitive. But nowhere am I advocating doing nothing, we work very hard indeed not automatically jumping on the person. Sometimes doing less is of greater value. Working out why the person self-harms is paramount. Asking the person is often useful! Recently, a number of practitioners and researchers have advocated for people facing someone harming to seek first to understand, rather than automatically respond by trying to stop self-harm (e.g., Burrow, 1994; Clarke and Whittaker, 1998; Harris, 2000). Rather than condemn the behaviour and reject the person, a non-judgemental acceptance of the person is what may be most beneficial. Staff will need a good deal of support to develop and maintain such ways of working (e.g., McAllister & Estefan, 2002). Often, self-harm is just one of the things people do and we might serve people better by not defining people by a single behaviour, no matter how confounding it appears.

This article is dedicated to Jane, who teaches many people still, to Jane's family, who seem to always be waiting for Serviceland to "get it" and "stick to it", and to Emma, with whom Jane has shared so much, and who has in turn been good enough to help me learn just a little bit more about who Jane is. Thank you.

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March 2005