

Ancient Wisdom?

What we think we know about supporting families during Positive Behaviour Support

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An Upfront Aside

This is a personal perspective on key actions (and readings) for Positive Behaviour Support (PBS) coaches and facilitators interested in fostering supportive methods when working with families.

Before becoming a lecturer at University I spent a good deal of my life working in private, voluntary and NHS services. This was often as frustrating as you might imagine. What I found most interesting (and sustaining) were idiographic solutions for individual issues of learning and service delivery, yet I was working (and to an extent represented) nomothetic paradigms.* In more straightforward terms, being part of a big system made it hard to respond to individuals. Why?

We were obliged to meet centralised goals (often set by those lacking apparent insight about *real* people** but who could recognise an easy-to-collect data set from a hundred metres – for example, a focus on the metric of the *number* of people professionals met rather than measuring *quality* or *suitability* or *outcomes* of such encounters). We had to follow rigid pathways of care (don't wander from the path, Little Red Professional), and a treatment model steeped in the tropes of the medical model (open, treat, close, repeat, open, treat, close, repeat). Add to this frustrations arising from career managers (If They Question They Shall Leave, If They Bow They Are Promoted), well, I heard (and myself contributed to) much kvetching. Paperwork was dominant (Mansell & Elliot, 2001), people requiring services almost unheard. All these things combined to often get in the way of effective work and person-centred outcomes. This is the price of working in organisations conceptualised as machines. If we think of organisations as mechanistic processes (input, process, outcome) pretty soon we all begin to resemble a cog to someone (Morgan, 1986).

* Idiographic and nomothetic describe two ways of knowing – so termed by philosopher Wilhelm Windelband – broadly individual and qualitative ways of knowing (idiographic) and broadly generalised quantitative knowing (drawn from large numbers – nomothetic. In summary, idiographic is about individuals, Nomothetic about groups of people.

** Families, kids with diagnoses of interesting behaviour, adults with disabilities, you know, *real* people

So how did I come to be part of a machine? As a family member trying to understand the behaviour and disability of a sibling, I remember thinking that once I worked formally as an employee in disability services (you know, gained status, something often lacking for families) I might have some influence. Things might change. As a support worker, I spoke with other support workers and we were pretty clear once we were *senior* support workers, we'd be able to enact the change we sought. As a *senior* support worker, the same conversations occurred. As managers, likewise. As area managers, even *more* so. In psychology services, ditto. Eventually a recognisable pattern emerged. We were often so consumed by frustration at what couldn't be done we were blindsided to what might be achieved.

Re-reading Herb Lovett's *Learning to Listen* in the late 1990s kept us acutely aware it wasn't us that were broken but the very systems intended to enable good outcomes. Community models were the bright promise to replace institutions. But institutions are not places; institutions live as thoughts and stories in community service designs and staff. Getting out of institutions does not result in better outcomes if you are still served in institutional ways. Lovett recorded a note from a personal communication with Nirje, who had observed 'hierarchies make people stupid'. But having no choice is a choice, and many people decided to walk out to walk on (Wheatley & Frieze, 2011). Choosing to listen, to do what I could, to build rapport, to be empathic, to be solution-focussed, these were also choices.

My reason for such personal revelations is merely to note that when working with parents and people using services, you will often hear the same (sometimes angry) frustrations that professionals espoused. *No one listens!* Everyone moaned about Commissioners: they kept buying the wrong things for the wrong people. Professionals are often in the firing line of angry parents and angry parents are often in the firing line of tired professionals. But professionals are not often excluded from decisions quite so readily as parents or people using services. Often, no one was listening to *anyone*. Everyone seemed preoccupied with their own legitimacy and their own voices, their own agenda.

So what if – here's the point of this aside – what if we're *all of us* in a machine, treated like cogs (largely by other bigger cogs)? Wouldn't it make sense to not treat other cogs as adversaries ('don't go that way, come this way!') but as collaborators? ('If we all turn the other way perhaps we'll get things done?')

Now, this isn't new. And it certainly isn't insightful. It's old as the hills, this art of listening, this art of crafting meaning between us. We know the more we talk the less we seem to learn or hear. The more we shut up, the more we discover. But just because we re-discover the blindingly obvious doesn't mean it's not novel, it's not revelatory.

As Will Rogers noted, good judgement comes from experience of bad judgement.

The Upside of Reading

In the early 1990s many of us encountered what was to become known as PBS: the application of behavioural technology in a socially responsible manner. For us PBS was a rebalancing of clinical validity at any cost, toward an equal emphasis on social validity.

The early PBS tracts were largely American and reminded us people we were in service to matter when it came to the design of intervention goals. The way we worked and conducted ourselves, the manner in which we applied the technology, the way we learned to listen to the hopes and aspirations of people in services and in families – all these things changed. PBS gave our growing unease at the application of behavioural technology in everyday situations a solution-shaped design. For us PBS and person centred planning (PCP) were part of a continuum. Colleagues conducted as many person centred plans as functional assessments. We co-authored as many interaction guides as behaviour support plans. We measured satisfaction as much as challenging behaviour. Mainly we modelled decent humanity and applied what we knew about what good support is, whilst avoiding what good support isn't. The person was the arbiter of quality, not centralised specifications.

In late 1996 Brookes Publishing in Baltimore had a problem with their postal service to the UK. Somehow, four copies of *Positive Behaviour Support: Including People with Difficult Behaviour in the Community* arrived. Amidst the clinically rigorous chapters and case studies of this edited volume a few things stood out – primarily the focus on family contexts in working to understand and respond to challenging behaviour – because even though it is a social construction and not a legitimate diagnosis (more a clinical accusation), challenging behaviour can hurt lives. In this book we discovered further accounts of contextual fit – making sure our collaborative suggestions fit the environment and family; we found accounts of partnership working, group action planning, teaching reciprocity. We discovered accounts of belonging, social inclusion, friendship and Todd Risley's seminal call for practitioners to begin helping people to 'get a life'. We were hugely relieved to read Don Kincaid's account of person centred planning.

In 2002 another edited volume on PBS appeared- this one focussed on families: *Families and Positive Behaviour Support: Addressing Problem Behaviour in Family Contexts*. This book further explored the accounts of partnership approaches to behavioural support and teaching new skills, amending environments and interactions. Unfortunately Paul H Brookes had their post room problems solved and only one copy was received. What struck many of us was the dedication of authors determined to summarise their learning from working in partnership with families. Family members *wrote* chapters.

In the same year *Person Centred Planning: Research, Practice & Future Directions* was published. Among the many powerful chapters Kincaid & Fox wrote about correlations and overlaps between PBS and PCP. Might PCP contribute to

abolishing operations, the social validity of PBS, enrichment of home, the collaboration between families and practitioners? Might drums make a sound? (Like Terry Pratchett's tavern *The Broken Drum*, when it comes to person centred approaches, you can't beat collaboration.)

Now all these books are almost ancient history to many students today. (There again some students don't know the legacy of Margaret Thatcher. Some don't think normalisation is a thing.) But here's a thought: there is nothing new under the sun, including the evident need of humans to keep revising history and to forget their pasts. Much of the material in these three books remains essential reading. (May they change your practice as they did ours.)

Several of us were fortunate enough to work with Jim Mansell in services (he provided a protracted induction when I worked in a Special Development Team project. Jim didn't just talk and write, Jim *did*. That's why we miss him so very much). Jim was unfortunate enough to inspire us to study with him (whether he wanted us to or not) and by dint of a short straw he taught me during formal Master's studies and during a short-lived University Affiliated Programme. In fact he asked some of us to teach – probably so he could keep a watchful eye on us. What Jim taught us was challenging: services and families are not blank canvasses. Jim taught us our job was not to prejudge any situation but rather to turn up, shut up and listen. He emphasised the need to put knowledge into service of those who required it: families, people using services, and commissioners. All the technical knowledge in the world won't help if your ears are stuffed with the fluff of your own learning.

There is a difference between knowing families and working with families. Knowing a family means you have access to tacit knowledge. Working with a family means you have access to a file. (And who conducts reliability tests on such notes?)

PBS and person centred action compliment each other, they provide a toolbox of eclectic methods to listen to the lives and views of people, not merely their discrete responses.

Families and PBS

No two families are the same and it is therefore problematic to generalise 'wants' and 'needs' without immediately thinking of exceptions ("Well, one family *I* worked with..."). There are always limitations in any research (hence the wisdom of considering a significant number of such studies or verbal accounts) and the lessons we might draw, but there are some possible summary conclusions we might use as a way to inform our practice.

Firstly, family is as families are. Forget demographics and definitions. If a group of people identify as a family - regardless of number, orientation, gender,

abilities – so be it. These things might not be your choice of situation but to be fair this really isn't about you. It may not be what you would choose to call a family but family it surely is nevertheless. Get over yourself. Being asked to attend a family is an invitation to engage our empathy as well as our knowledge: it's something of a privilege even in difficult situations.

At a workshop on Supporting Families two very experienced behaviour-support professionals working in community services were scathing about many of the families they worked with. That their negative experience contaminated their views of families of children with IDD and behaviour that challenges seemed in little doubt. Every argument offered, each piece of research, was met with a stone cold wall of cynicism built from many years of negative experiences. Now kvetching is good for the soul. Like eating, we all tend to kvetch. But kvetching so much you lose sight of the positives is unhelpful. No one enjoys hanging out with a perennial grouch. By the end of the teaching I wondered whether encountering new families while harbouring such cynical views might not predict the outcome. Some families have justification for complaining that support might easily turn out to be not so much a collaborative journey but more a judgemental burden.

Like research, no family is perfect but then again neither are professionals. How we think about families impacts our effectiveness as professionals. If we talk over families, they'll cease to speak and share. As if on an extinction programme, they might begin to yell, their sharing might fade away. So protocols and plans, how meetings are held, the ease of referrals, these are all artefacts that tell us what individuals and services *really* think of families.

Secondly, research does tend to suggest many families of children with disabilities seek information about disability, about services, about understanding and best-practice (Santelli *et al.*, 2002). (Families, from my experience, want to know *what* is happening and *what* the future might look like, too.) Santelli's work notes advice about keeping families coherent is also important. Richard Hastings's work on stresses for staff and families needs more attention (e.g., Hastings & Taunt, 2002)- as does the interest in mindfulness as an approach often helpful in supporting coping. In one study the informal supports seemed key to parental wellbeing: access to services wasn't (White & Hastings, 2004). One key point these authors make is that parental wellbeing impacted the child's behaviour.

Li-Tsang and colleagues noted that many parents of children with disabilities experience joy as well as stress. Special needs are different, they note, from problems (Li-Tsang, Yau, Yeun, 2001). These authors focussed on seeking to determine those strategies beneficial at fostering adaptive coping and constructive attitudes. Might children with disabilities in families also be acting as contributors to family cohesion? What their study suggested was a confirmation of previous investigations. Realistic positive expectations of the child seem to help, as did good level of parental education, pragmatic problem solving, and resilient personalities. Sufficient finances help. The key finding of

this small study was that parents with good adaptive skills sought out local networks of support. So one question to ask is how we as coaches and professionals contribute to such things. Often our approach and attitude inform family perceptions of services and *their* ability to cope (Bromley, *et al.*, 2004).

Thirdly, remember that no matter how skilled the professional it is doubtful the 'shared experiences' of disability or behaviour are the same as those of parents. Professional training might suggest to practitioners one interpretation of what is seen but it may not be the whole story [or even the right narrative] especially if the professional isn't good at being seen as available to *hear*. Parents may be simply tired, not sad (Green, 2007). It should be remembered that regardless of methods used "we cannot represent others in any other terms than our own" (Van Maanen, 1988, p.12). So best to share and co-construct the terms.

A cohesive blending of these points can then be made for community involvement and not a reliance on service systems. Services, as O'Brien noted, can never be enough (O'Brien, 1987). Parent to parent models offer a way of gaining support and understanding that don't necessarily rely on busy professionals. Expertise is dispersed in such models – there is no single authority. Parent to parent models can provide information and emotional support.

The emotional support provided by people who have experienced similar situations is invaluable. Emotional support might include knowing one can call on an ally who is reliable, who has 'walked the same path', who will provide practical support, who will remind partners of their ability to cope, and who accepts their partner 'warts and all'.

The 'informational support' might include knowledge shared about specialist service provision, family-focussed places and opportunities to contribute their own knowledge to others.

A network of families (the parent to parent model) is akin to a community of practice – an informal group of people sharing common interests and skills. These too provide emotional and information supports, but also a place for identities. (Being a family including a child with disabilities is often exhausting *and* joyful – being *any* family is this, too, but disabilities bring a range of additional demands, not least the requirements to bring others into the very heart of family traditions and ways of being. Belonging to a group of other families with similar experiences can help people who comprise a family to not feel so isolated. Networks or communities provide ears and shoulders.)

This has implications for how we look at family-sensitive PBS and its implementation. Having parents as practitioners or coaches may have untold benefits.

A good example of parents making all the running is the Challenging Behaviour Foundation (CBF). Started by parents, this has become a source of information, a location to gain support, and has been increasingly influential in terms of policy and research agendas. Not only do the CBF offer parents support (both informational and emotional), they offer resources to professionals, policy makers, training and a host of other functions.

In summary, there is much a coach or professional could learn by 'just hanging out with people who know'. Building into the 'process' of work such listening is one of the early innovations PBS included. Contexts and stories are data.

Training & Families

Training is often thought of as classroom-based. Training is often designed around learning goals significant to the trainer or their employer, but these may not be relevant to the different contexts experienced by families. Whilst this traditional type of training may have its place as a venue for information sharing, real training happens during work in real situations. By real training, I mean of course learning. Good learning is achieved by doing activities in real situations.

Coaching is training plus mentorship in real situations. For parents (and for most people) to comprehend PBS, rapport, peg-feeds, or anything, it helps to see these things done. Showing and doing is remembering. All too often classroom-based teaching is an exercise in forgetting. (You should come to my lectures to appreciate this fully.) Therefore if we wish to train parents in specific interventions, it makes sense to teach, do, reflect, primarily in everyday situations.

Coaches and practitioners have to be present for families. Families aren't there for professionals – I am still amazed how often I speak with families who are grateful for crumbs from the captain's table: families *are* the table *and* the captains. Professionals are there to serve not control. Professionals and coaches have to be present physically, usefully, and psychologically. They should not strive to be weird Uncle Barty who turns up only at Christmas bearing gifts and asking for a stiff brandy, but like Aunt Hazel, who calls in when she can, who responds when asked, and for whom many of the small requests that litter family life are not so small they are ignored. Being present means the lessons we pass on and the learning we gain from being present are not seen as training. The similarity to practice leadership is obvious.

Training and not doing is for many people better than real work, but may not be a good use of scarce resource or intellect. Learning through doing is key. Coaches and families can learn from each other through what we might term legitimate peripheral participation (being present). Training is vital for practitioners, competency in practice even more so; but for every BCBA with pristine

credentials, for each newly minted psychologist or nurse, I'd like to see double the numbers of ears.

Families As Resources

Rather than view families as receivers of services, we would do well if we considered families as sources of expert knowledge. In the same way those of us who work and live at the person centred action end of the continuum that PBS has become consider people with disabilities to be the expert on what they need, we might well benefit from an equivalent starting point with families.

All too often, however, we hear tales of the voices of families being silenced or ignored. It is as if the stories families tell and the knowledge they have acquired, not being certificated to University level, can therefore be dismissed. Suddenly, expert knowledge outweighs local knowledge. Such an approach is self-defeating if our goal is the amelioration of challenging behaviour and an increase in understanding of what works best (Danforth, 2000). If we make families dependent upon professionals we disable families.

When being told the news of a disability, "parents prefer professionals who show a genuine caring attitude, who encourage and allow them to talk and who show understanding of their emotional responses. Sensitivity to both informational content and parents' reactions is critical" (Jan & Girvin, 2002, p.81); such sensitivity doesn't stop once a diagnosis is made.

Not acknowledging family knowledge is a little like watching people eat in a nice restaurant. Imagine seeing tourists looking in a restaurant window. These tourists are talking loudly about what they see. They speak about how warm it looks inside. How small the portions seem. They are commenting on the behaviour of one family group – *locals* - who are talking, gesticulating, arguing, laughing. These tourists are a metaphor for professional but distanced workers - for anyone willing to categorise and make judgements about people or places without any first-hand knowledge. Whilst the tourists might say *we saw this happen, we heard that being said*, that was the limit of their knowledge. Judgements about the dishes, the aromas, the tastes, the textures, freshness cannot not be validated or reliable. Judgements of the qualities of the experience are simply projections of their own perspectives.

Unless *inside* the restaurant, eating, talking, sharing, how might any of us safely say what is really occurring? That is what families experience too often. People outside ascribing qualities and critiques of their experience. Our view as coaches and contributors to solutions is as if through the window and will be incomplete, a simplified description; our diagnoses are merely metaphors for what we think we know – or perhaps the echoing of ancient tropes.

The Nub* or Behaviours Families Might Find Helpful

For a start, **dump the doom**. Not every family is experiencing heartache or bereavement. Plenty are, but many are too busy forging new ways of being a family or too busy 'doing family' to focus on what they don't have. They're celebrating and enjoying their situation and members (Summers, Behr, Turnbull, 1989). Before any disability a child is a child in a family. The son hanging from the first floor window singing offensive versions of the Polish national anthem is neither angel nor devil. (Nor *referral*.) The boy is simply a son with a fascination for self-deprecating national anthems and a love of fresh air. They're a son first.

(We sometimes hear people mention the word 'suffer', in that the child 'suffers' from epilepsy, or they 'suffer' from Fragile-X. Ten minutes in a room with a family or advocate and the person mumbling such nonsense words may have a *completely* different perspective on suffering. Children with disabilities (perhaps children per se) are "my greatest joy and my greatest heart ache" (Myers, *et al.*, 2009). Be careful of attributions and language: words can hurt and shape the views of others.)

Eric Emerson noted psychologists could easily be more plumber, less Ivory Tower, meaning being present when needed and specific when asked (Emerson, Hatton, Bromley, Caine, 1998). This is sound advice for any coach and PBS practitioner, too. So my second point is to **be useful**. Not solely to your organisation, nor to your bank balance, but to the family. What can you bring to the party? Families usually want partners not critics. Finding a partner who listens remains, for too many families, a remarkable event: it would be grand to witness remarkable events become commonplace.

* Meaning *quintessence*, only without the hubris.**

** Being English, and of a certain age, means Winnie-the-Pooh is not so much a favourite childhood character more a guru. Example? Listen to this: "I don't see much sense in that," said Rabbit. "No," said Pooh, humbly, "there isn't. But there was going to be. When I began it. It's just that something happened along the way." Now think of the promises community supported living made at inception. Another? (This is about hubris, aka *pomposity*, aka *superiority*.) 'You can't help respecting anybody who can spell Tuesday, even if he doesn't spell it right; but spelling isn't everything. There are days when spelling Tuesday simply doesn't count.' Now think of all those times you've been tempted to insert the term *establishing operations* or *differential reinforcement* into conversation with parents. ***

*** One of the pieces of advice I give to students (who tend to ignore me because they're young and I'm old) is to *read beyond the core literature*. Hence I rediscovered the wisdom of Pooh because I didn't feel guilty at *not* reading only peer-reviewed journals and expensive academic books. It follows that to understand the import of social validity and contextual fit students shouldn't read Cooper, Heron & Heward but rather Kes Grey & Nick Sharratt's *Eat Your Peas*. In there you'll find the difference.

Language As Code. Active Listening is an interpretive act and has been widely discussed in PBS for many years. It is most often made mention of within reactive strategies. It's teaching appears less common than it's mention. In summary, to be an active listener requires us to cease being literalist and to seek what might be meant not what is said. Applying this with families might be helpful to coaches and practitioners. Language is a code.

When coaches or practitioners are asked into a family that invitation is often crouched in terms of specific behaviours. The behaviour itself may be impactful but we run the risk of falling into the disputed 'weak central coherence' schemata if we're so focussed on what is said we fail to hear what is meant. Neurologically-typicals are notorious for 'not meaning what we say and not saying what we mean' (much to the frustration of many living their lives on the spectrum we call autism). Being aware of the nuances of communication and our own responsibilities in our communication partnerships sets apart those who achieve and those who struggle to form good rapport with families.

What this also suggests is that the language we choose to use should not obfuscate or confuse people but illuminate understanding. So sheath your stimulus satiation and discriminative stimuli and speak to each in a manner the situation requires. Too often language is used to belittle the knowledge or experiences of parents. One too many *positive reinforcements* and you run the risk of becoming a signal for being shown the door – and more importantly, excluded from tacit knowledge held by family members your expensive vocabulary might alienate. Coventry is nice, but an inadvertent or even intentional use of technology-speak will mean you'll be visiting that particular city alone. Language can help you align with families.

Be honest. Sometimes behaviour is awful. It's frightening and mystifying. But it's good to know that **behaviour is lawful even when awful.** Your job is to keep reminding family members who might be at the raggedy edge due to sleep deprivation and sneers from neighbours that this is something they can work out and work through. The last thing to do, though, is to downplay the awfulness. Don't tell family members to just 'buck up' or cheerfully to 'work through it'. Don't tell them the attributions about their daughter hitting herself are merely 'a social construction'. You have to be honest in acknowledging that the crap doesn't smell like perfume. It stinks. But... **working together means finding solutions.**

Don't be a hero. Be a host. This is a tricky one. Who doesn't want to be a hero? But as Will Rogers is said to have noted, being a hero is the shortest-lived profession on earth. I enjoy interdependence. Sure, I *could* live alone and write pastiches of Great Russian Novels (they all die in the snow, you know) but being in a family and being loved is far more fun than independence, at least for me. We practitioners might do well to remember it isn't us up at 3am trying to implement a stimulus control programme for a kid with suddenly five arms, six legs and the ability to spit through the eye of a needle at seventeen metres.

Listening to these tales means our analytical expertise may not be of prime import ('Let me just read up on that for you in the *Journal of Applied Behaviour Analysis*... Here it is. Look. You see what you did wrong?').* How can you **support the family to learn, reflect, and grow?** Heroes are fine on the cinema screen but in real life enablers and team players tend to trump most crises.

Come Down From The Cross We Could Use The Wood. This line from Tom Waits seems sound advice – it's easy to blame ourselves when people don't listen, when our carefully crafted plans head South for a while, and when people give us short-shrift for genuine efforts. Rather than bemoan, gnash teeth or condemn, get your own support. No one is an island (though plenty of people are a bit rugged and prone to strong wind) so **get yourself support**. Everyone seems to kvetch about everyone else – that's fine, but don't do it to yourself. I heard a story (I think from a David Pitonyak talk**) of one person advising another to 'treat others how you would want to be treated yourself' but *another* person noted most people treat themselves terribly – always blaming themselves, never getting enough family-time, working all hours. You're allowed to **get sad but then give it back**. Work out how to avoid feeling like that in future. The bottom line is PBS and ABA make rocket science seem simple. Humans are complicated! Fear and uncertainty (and performance anxiety) are old friends to those supporting people to understand challenging behaviour. So cut yourself a break.

Don't Be Reductionist, Be Expansionist. In PBS we're *allowed* (nay, expected) to think systemically to some degree. During your exploring (assessment) of situations don't simply focus on target behaviours to reduce, plan to increase family-enhancing behaviours and accomplishments. Whilst the child may be the focus, family members are equally important (**allies bring about change**). Once you've nailed the definitions of the issue, nail the contexts, too. You never 'treat' a single behaviour, you work with a repertoire and family. You will find yourself being a source of information – about marriage guidance, about stress reduction, about education, about history and futures, about love. Often challenging behaviour is merely a symptom.

Reducing behaviours, increasing others, are both simple *and* complex: what PBS strives for is a far greater complexity. This sometimes freaks people out. PBS aims to look beyond the challenging behaviour to lifestyles and futures. PBS is focussed on robust science but also hope. PBS looks at behaviour, but also the accomplishments of extra-ordinary lives.

* Will Rogers: 'An ignorant person is someone who doesn't know what you just read'.

** I might be mistaken here. However, I tend to attribute everything *good* and *insightful* in this wounded world to David Pitonyak – who remains a source of inspiration.

Love is a key feature in families and we overlook it at our peril. But love is never simple or elegant or prone to formulation. Love often features contradictions and fears. Being a parent often involves incompatible objectives and states. “Parents who want simultaneously to love and heal their children are old hands at finessing the fact that caring requires that we believe incompatible things at the same time. That is, parents can accept the value and importance of their child’s obsessions and the beauty of their different ways of experiencing the world around them, even as they work to free them from restrictions...” (Silverman, 2012, p.235). This means agreed plans can change suddenly. **Learn to dance.**

In summary, then,

- Build partnerships with families and other professionals: work to achieve cohesion
- Respect family-centred principles through your exploring and your doing
- Support the family to voice a future that is meaningful for them
- Repeat the mantra: this problem behaviour is just a learning issue, so let’s get teaching alternatives
- Communication is everything – for the child, for the family, for you
- Functional assessment is essential to understand functions: a questionnaire often won’t cut it. Get in there and look. Just hang out with people who know
- Every child is an individual and every support plan is too. Don’t cut and paste
- Ensure the plan is collaborative and fits well with reality. Social validity matters as much as clinical validity
- Align plans with everyday life. Make them part of the family
- Be there, be present, be useful. Don’t assess then disappear, review and critique. Be available
- Check things are on course. Adjust, amend, learn: is this still what the family need, what works for the family?
- You’re there to serve not direct

The above bullet points are of course Ancient History. These are derived from a remarkable chapter written by Lucyshyn, Horner, Dunlap, Albin and Ben way back in 2002 (Lucyshyn, *et al.*, 2002). Before iPhones, already. That *old*. Can we remember to remember?

Alternatively, there is a simpler method than memorising Ancient Wisdom (no matter how good it is): the best method might be to turn up, shut up, and listen, as Jim advised. It’s easier to ask families what they want from you and if they cannot say, actively listen and offer an interpretation. Often, each member wants different things. *That’s* the moment you begin to craft coherence and clarity (Bromley, 2008).

The above principles are not new but ancient. If history teaches us anything it is people struggle to learn from history. How can we avoid being forgetful? Perhaps we embed what we know in what we do. Thus Ancient Wisdom becomes

everyday practice. For example, if we belittle the subjective experience of people we support, we may simply be writing ourselves a warrant to do what we please. Because our voices have more authority as our wisdom is drawn from nomothetic science, whereas theirs is simply subjective.

Adopting a blind adherence to principles that served us well in ancient times is itself an error – if evolutionary psychology teaches us anything, it is that patterns of old behaviours are often as useful as the appendix (think xenophobia – when *that* bursts open you sure notice it, even in democratic societies). Science necessarily challenges old tropes – that’s essential. But as we rush to capture research funding to replicate studies or discover new things, we might stand a risk of forgetting useful older things.

(Some of us are sufficiently old to remember our teachers warning a parent that *sparing the rod spoils the child*. We may have *wanted* to reassure our parents *that* particular perspective was nothing more than a painful *lie*! But we knew few listen to mouthy or sarcastic ten year olds in English primary education. Now many subscribe to it’s opposite through evidence: *using the rod spoils the child and doesn’t particularly help the person doing the hitting*. And yet we see authoritarian politicians dominate elections in many places. So one thing is worth considering though: “*It is not God who is authoritarian, but us*” (Blaug, 2000, p.96).)

Now, the above perspectives may seem common sense (remember, common sense is not a protocol, it is not so common it shouldn’t be considered a super power), but common sense is merely, as Jim Mansell taught us, clinical intuition. To gain this remarkable power one has to merely practice PBS and person centred approaches time and time again, and reflect on what didn’t work, what did, and how to do more of the latter, less of the former. Aristotle said we become excellent at what we practice. For a dead philosopher he continues to have a point. The more experience we gain and the more we learn from listening to people whose lives have been devalued, the more we listen to family members whose words have been too often ignored, the more we learn to talk and walk gently.

And Then Comes Leadership

Leadership comes *after* having invested in listening to families. Families are likely to listen to the advice of coaches and practitioners if they have been heard themselves and if sufficient rapport has been banked.

In reality, leadership is not fixed and is not associated with one person. The concept of **dispersed leadership** comes closest to the model that seems best to work in family situations: at different time, different individual’s describe the vision and direction to which all members align with to follow and work

towards; as situations alter, different people's leaderships skills drawn from their particular knowledge – specific to that situation – come to the fore.

Leadership is granted by the group not imposed. What keeps a leader temporarily relevant are 'willing followers'. As any manager will testify, leadership is fundamentally important but vastly different from management. Whilst organisations adopt hierarchical models of management, functional families may not. What works for organisations may not be efficient in families.

It is ultimately futile to assume leadership is granted due to your qualifications, certification or appointment, or indeed your gender and age. If only *you* have the final say on 'all things behavioural' you've simply created a benevolent enslavement. All that might happen is a prompt-dependency hampering the family.

An additional hazard is found in Ancient Wisdom: Dewey suggested that those with special privileges often acquire **myopia in terms of cognition** (Dewey, 1988). Whilst I am not arguing coaches and practitioners adopt the Roman model that saw triumphant parading Caesars being followed by slaves whispering *remember you are mortal* (Blaug, 2010), it is interesting to note that even within the excesses of Rome some thought had been given to the human tendency to imagine ourselves all powerful. But those in leadership positions need even more to learn to listen in order to remain relevant and not corrupted. Corruption here implies the *old* meaning, namely "*the general failure to orient to the common good, a crisis of moral judgement and an aggrandised and hubristic distortion of individual thinking*" (Blaug, 2010, p.2).

Sutton uses the American vernacular to provide a warning of the effects of too much leadership and not sufficient listening. He's a Stanford professor and has earned certain latitude in language: he warns of adopting 'an asshole' persona (Sutton, 2010, 2011). Sutton's work might be expressed simply: though most of us are born possessing one, there is need for us to resist *becoming* one. Sutton suggests organisations and pressured situations often result in such a persona developing: the litmus test, Sutton argues, is to see if the suspect licks up, kicks down. Does she or he contribute to the growth of peers and shoulders responsibility for creating shared solutions?

Leadership is an identity we clothe ourselves in (or find ourselves so dressed) but like all identities, these change. Wenger argues identity is a *developing* sense of belonging some place with some people (Wenger, 1998, p.72-85). Identity is "*a pivot between the social and the individual*" which avoids "a simplistic individual-society dichotomy without doing away with the distinction" (ibid, p.145). For Wenger an identity is a constant practice, produced "*as a lived experience of participation in specific communities*" (ibid, p.153). Because we are members of multiple communities of practice or social groups, our identity is not fixed (coach, mother, daughter, colleague, friend) but nuanced and many, attuning to

different situations; we are, in effect, chameleons. (A staunch radical behaviourist may use mentalistic terms frequently if conditions allow.)

Garfinkel suggest humans can be organisationally 'incarnate' (Garfinkel, 1967) while Ahrne suggest people that join social groupings or organisations might become half-human centaurs, absorbing and embodying the dominant identity roles of organisations (Ahrne, 1994). Our identities then are forged by contexts. Our roles inform what we do and how we do it and whom we think are; our roles and places in social groups and organisations contribute to "making up people" (Hacking, 1995).

This implies we can each craft an enabling leadership style more easily if we experience being enabled ourselves. If we experience bullying management, authoritarian figures cruelly hurtful, nobody should be in the least surprised as to its effect on culture and identity. (Culture can be defined in traditionally *broad* anthropological terms, as comprising "*the ideas, beliefs and knowledge that characterise a particular group of people*" (Fetterman, 2010, p.16). Culture is how families do things and who they think they are. There are benefits for coaches from taking ethnographic methods with families.)

Identity is something crafted in the doing of work, in the exchanges of relationships, in places. Wenger argues identity "*is a layering of events of participation and reification by which our experience and its social interpretation inform each other. As we encounter our effects upon the world and develop our relations with others, these layers build upon each other to produce our identity as a very complex interweaving of participative experience and reification projections*" (Wenger, 1998, p.151). Social groups combine with a sense of self to oblige us to write ourselves each day, often using shared tropes (Giddens, 1991; Linde, 1993).

Leadership in families requires each of the leaders to challenge people and say *enough talk, who is going to do what?* There is a story associated with Jean Vanier told by people who know him: following one inspirational speech on belonging and renewal of L'Arche, Vanier called leaders of communities to a meeting where he slammed his fist on the table: "So what are we going to *do?*" Leaders know when to stop talking and start doing.

Leaders construct meaning and direction from existing knowledge others posses. They give voice to what is already there, and if need be, ask demanding questions.

What Counts?

Working with families has taught many of us to speak less, so it feels right to stop writing – you must be bored by all the footnotes – but it has also taught plenty of us to speak from within different paradigms and tropes, and to respect those we

don't know enough about. We know the science of behaviour is a fundamental starting point, but we know humans have different understandings that can enrich our work. There are different paths to the same end.

My experience of families and disability and behaviour comes from *my* story. Dismissing this experience as unreliable because it is not part of a robust research project tells you much about the nomothetic and idiographic views. My experiences also come from being a practitioner. This has obliged me to find the human in the science, and love amidst objective formulations, whether these are peer-reviewed or not. Because objective is subjective: values and narrative inform the data we select. *My* lessons arise from my working for change *alongside* families and students. It comes from making mistakes and not following my own learning then remembering to do a quickstep to avoid Sutton's warning.

What we count might not count to families. What matters to families might not matter to the metrics of effectiveness our employers seek. Our role then is to support by listening those requiring access to our experience, and to educate those responsible for designing provision and services. Because current metrics of efficient service delivery don't account for love.

David Pitonyak asks us to think about this: if, when you get home, the person you are expecting isn't there – if your parents, boyfriend, girlfriend, flatmates, husband, wife, partner, children aren't there – if your family is *gone* – and instead there is a stranger sitting at your table, David suggests the chances are you'd be pretty taken aback, not a little upset. There might be challenging behaviour. *Where is the person I love?* you might holler. The stranger answers *don't worry, I'm an agency nurse; we have you covered.* How do you *feel*, David wants to know. How do you *react*?

Philip Larkin wrote a powerfully quiet poem called *The Mower*; we find Larkin sombre but moved by small things.* Difficult to measure synapses make me wonder if the hedgehog in the poem, and its untimely fate, represent more than a favourite garden creature's demise causing the poet to wonder at the fragility of precious lives.

The small things a family seeks are not small things to them. The small reductions signed off by commissioners are not small things to families. Austerity has wrought a path of hurt through families. This is inevitable when we think services are the only answer to the needs of families. Our approach to taking time to listen to families can add salt to the wound or not. That's up to us in large measure. It's helpful to reflect, as Larkin says, while there is still time.

* <http://www.wussu.com/poems/pltm.htm>

We're always seeking summaries, or 'take aways', key points to hold. But simple summaries invariably end up elegantly wrong because they are not nuanced to contexts. But broadly, coaches and practitioners will benefit from listening carefully – without prejudice – to families. Parking what you know because what you know may not be what families need. What you know can fill your ears with fluff to such a degree you will not be able to hear what is said and what is meant by the code of language. Leadership tends to follow listening.

The benefits of PBS are many: contextually-sensitive use of technology can bring clarity to complex situations. You can, as a practitioner or coach, be exactly what the family need, or precisely what they don't. There are many powerful examples of the positive impact on family and friendships PBS can, at its best, enable (e.g., Fleisher, Ballard-Krishnan & Benito, 2015). But let's not be zealots for PBS. Let us be honest. There are examples of awfulness that *claim* to be PBS (in *hospitals*, in *units*, in community work) that Ancient Wisdom (and books) might suggest bear the same similarity to PBS as pornography does to love. We have to remember that values as much as science were the founding principles and remain the primary methods of PBS.

Challenging behaviour is not wholly about behaviour. Listening to families* can widen our options when seeking to understand and respond to behaviour that is impactful. These may include work on stories about who the child is and what family means. Often, a challenging behaviour is both operant phenomena easily reduced to contingency formulation *and* a symptom of an unquiet life, an unheard complaint or an unmeasured joy. Challenging behaviour is a call to arms to teach new ways of doing, new ways of being, and a reminder for us to remember what we've forgotten we know. Challenging behaviour has multiple meanings.

Behaviour matters, but lives matter more. Responses matter but accomplishments matter more. Our knowledge matters, but service matters more.

* Winnie-the-Pooh on last time? "If the person you are talking to doesn't appear to be listening, be patient. It may simply be that he has a small piece of fluff in his ear," explained Pooh. Now think of tired parents not listening to you- the fifteenth professional they've encountered in as many weeks. Imagine the sheer density of the fluff likely to accrue in the ears of parents who feel alone and unheard.

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