"Never mind the quality, feel the width!" Person Centred Planning Implementation & Developmental Disability Services

A polemic of unease

Tony Osgood, Behaviour Specialist,
Positive Behaviour Support Team,
East Kent Community NHS & Social Care Partnership Trust,
Laurel House, 41 Old Dover Road, Canterbury, Kent CT1 3HH

Abstract:

The recent White Paper *Valuing People* recommends adoption of person centred planning in developmental disability services. This paper suggests there is a difficulty in larger organisations applying such principles and leading implementation: the family of approaches now known as person-centred planning are about people, not organisations. Developmental disability service organisations often function by viewing service users as a population- some homogenous whole- collections of people with defining deficits requiring professional intervention. Whereas person centred planning is focused upon people, gifts and community.

The paper suggests existing services have failed to learn the lessons of past "innovations": without a clear understanding of why previous value and practice initiatives have failed to be effectively implemented or maintained, services are likely to poorly apply, support and maintain the paradigm-challenging themes underpinning person centred planning. It is suggested organisations may soon be found to adopt the language, but not the practice, of person centred planning.

Learning from History?

"We have historically been more effective in providing people for services than services for people... " (John O'Brien & Herb Lovett, 1992)

In 1999, a Senior Manager in Social Services stopped me in an office corridor and asked if I would contribute to a working group (this was an occupational hazard, even for people innocently delivering sandwiches to the building). This particular working group was to examine empowerment in developmental disability services provided by the local authority. *"We need to get a grip on empowerment,"* the manager explained. *"We've been working on it a while,"* he added. Within a number of organisations, I had laboured uneasily on empowerment. This unease was partly due to the nature of working groups, which often a) did not work, b) did not act as a group, and co-incidentally, c) produced few meaningful changes to organisational practice (after a while it began to dawn on me such an outcome might have been the intent). A more fundamental source of unease arose from the nature of professionals' control & power in disability services: I wondered who we were to give power without first understanding our own motivations.

I explained to the Senior Manager how I had concluded that to truly empower a service user, organisations had to essentially change- we had to become person orientated. We had to listen. Empowerment working groups were not the answer, person-centred action & attitudes might be. He said *"But we want something realistic. We've looked at person-centred planning and it's just not realistic"* before wandering into his office to draw up an empowerment policy to pass down to the people he managed.

During early 2001, I attended a brief seminar by Lynne Seagle. Senior Managers were present, all enjoying stories about person-centred approaches in the United States. I noticed the Senior Manager from two years previous sounding forth on the topic- how he felt person-centred planning was *"the way forward",* and *"had done for years."* He explained how he intended to *"roll it out across Social Services."*

There *is* a reason for this early aside. Person-centred planning has gained an increasingly high profile in the UK: people flock to conferences and seminars. Organisations, even the change-fatigued NHS and Social Services, buzz and bubble with person-centred terminology- if not action. *Valuing People* (Department of Health, 2001) places person-centred planning centre stage in service delivery for people with developmental disabilities. But will services bring into being the vision through the pathways highlighted in the implementation guidance (DoH, 2002)? Is Government's advice based on research outcomes or on anecdotes? Are anecdotes a rationale for national policy? I ask as a warm and cuddly individual committed to person-centred approaches, caught betwixt the world of faces and numbers (O'Brien, 2002).

I am uneasy about the recommendation to generalise person centred planning without clarity about how to turn person centred *planning* into person centred *action* in large service systems. Person centred planning is an idiographic qualitative approach. Large services are nomothetic quantitative beasts, lumbering heavily, dealing with conceptions of groups of people as homogenous classifications. PCP developed within 'communities of practices', not formal institutionalised organisations such as the NHS or Social Services, and in a culture different from the United Kingdom. How do we generalise bespoke tailored provision in large services used only to providing off-the-peg solutions?

Changing words is easy (Praill & Baldwin, 1988): claiming adherence to person centred planning is something any individual or organisation might do. Who judges the quality of person centred planning? Standard definitions and criteria of what does and does not constitute person centred will simply lead to unthinking compliance, not innovation or quality- quality defined by subjective outcomes for people. I have seen some appalling practices and mismanaged services heralded as person centred. Organisations are currently tempted to wonder *what do we do now that we could claim is person centred, to* *avoid meaningful changes, to appear as responding to the policy demands of Valuing People*? If services focus on changing language without changing actions, relationships, finances, functions and structures, person centred planning may go the way of other innovations: lost in a mire of organisational cognitive dissonance, a battleground of professional interests. *"New names and phrases always run the risk of becoming spiffy euphemisms for 'business as usual'"* (Lovett, 1996 p.xiii). It is essential to gather qualitative (people's stories) and quantitative (generalised) information to see whether person centred approaches are being applied in ways that makes a difference to people. Both research approaches have their benefits and deficits, but when combined, such data-stories can help us reflect, learn and distribute the myriad ways of listening & doing (Holburn & Vietze, 2002). But what do we know so far about what works? Smaller, flatter, less-hierarchical and less professionally qualified organisations find responsiveness and person centred planning easier. And one size fits no-one. Hearing stories of success should not encourage us to repeat verbatim the formula. The formula may be for a totally different context and disease. Don't put pile cream on acne! Person centred planning and action is an art, not a science, and not a short cut. How can such an approach survive in a system that teaches managers that plagiarism saves time, that creative thinking is unsupported, that focuses on developing managers rather than leaders.

The generalisation of person centred planning is fraught with dangers that may 'discredit' the family of approaches that constitute it (O'Brien & Lovett, 1992). History suggests normalisation ideology has often been poorly applied (Mansell *et al.* 1987; Emerson, 1992; Tyne, 1992; Wolfensberger, 1983). *"Like other efforts for social change, person-centered planning has been used and misused, complicated and simplified, lengthened and shortened, trivialized, legalized and lionized"* (O'Brien & O'Brien, 2000). As Lovett noted, nothing-named remains unchanged (Lovett, 1996).

It is easy for organisations to simply adopt the stance of person-centred planning when no demanding meaningful outcome measures are required: *"Although valuable, planning is* *not sufficient. There must be distinct assistance that can be made available to implement the plans. Without the commitment of resources and personal effort, the planning process can end up as little more than a vacuous gesture"* (Dunlap & Fox, 1996, p.44).

If organisations have really adopted normalisation principles, or the Five Accomplishments (O'Brien, 1987) as many claim, I wish to know why so many people I've met and worked with are living & working in (and brutalised by) such controlling, institutionalised and poor situations? In ecologies and with barren lifestyles most of us ourselves would not choose to inhabit (Risley, 1996; Durand, 1990). Why are so many staff poorly trained and supported in organisations brandishing *Investors in People* status? Why is service delivery and practice often just so poor? Why are so many lives disabled by services claiming adherence to "valuing" principles? Value base and mission statement do not a quality service make.

I've learned, very slowly, to simply not listen wholly to managers, but to people receiving services, families and direct care staff. I compare service language to service action. Are those large services now leaping ungracefully, haphazardly & maladroitly toward person-centred stances really putting values into action, or writing just another bloody mission statement? A balance needs to be struck between vague value statements, and the operationalisation of skills and knowledge to really apply such values. As McGill notes *"If one mistake is to conceptualise our work with individuals in an overly clinical fashion, surely another is to forget that the process of supporting a person with learning disabilities may require technical knowledge, skills and methods of a high order"* (McGill, 1998).

Mansell suggests *"the poorest community services appear no better… than the institutions they were designed to replace"* partly due to *"unclear goals and lack of direction"* with *"little guidance on interpretation of... principles"* in services where *"the home leader… becomes an administrator"*. He notes *"it is as if the hard lessons learned* *in the institutional scandals of the 1960s have been forgotten"* (Mansell, 1996). The reality seems to be, regardless of what mission statements proclaim, that services are largely inefficient & wasteful (Emerson, 2001), not only in resources, but in putting values into action (Allan, 1992; Kinsella, 2000; Wolfensberger, 1980). The-beatings-will-cease-once-morale-improves ideology of many service managers is required to be replaced by learning organisation ways of thinking & doing.

I fear person-centred planning could easily go the way of other innovations in "service-land" (Sanderson, 2002): enshrined on paper not in practice, in organisations that use the language but stumble when taking steps. I'm worried organisations are simply changing the words to current practice: *"Much of what is being done represents no real change in practice. It is business as usual masquerading as being person centred"* (Smull, 1996).

So two years ago I was wrong: empowerment *per se*, wasn't wrong. It's what organisations do when implementing such ideas. Services are doomed to repeat the mistakes of poor application of past innovation because people who create, commission, manage, work in, and impose service models, have not consistently nor clearly learned from history. [1] And so, the perversion of good practice and values continues. Eagles soar high, but weasels don't get sucked into jet engines…

Service Led Implementation

"…we have established services for *what* people are not, rather than for *who* they are." (Lovett, 1996)

I recently attended a strategy meeting on implementing person-centred planning in a local authority. I'm not sure how I ended up there- but *carpe diem*! The language of person-centred planning was in evidence, and people were enthusiastic with frothy words. The question of where to begin person-centred planning was raised: answers included “more resources”, “more care managers”, “more training”-all important issues perhaps, but all focused on the needs of the organisation. Few suggested listening to what people currently being failed by services were already telling us. Few suggested looking at where (and why) person-centred approaches have been successful: smaller organisations, flatter committed management structures, smaller steps, slowly learning, growing in responsiveness. Senior managers sought a single model to “roll out” across the whole county, at the cheapest price. They wanted, above all, to control the process, to minimise the organisational risk. They wished to eliminate ambiguity and retain organisational control.

Yet person centred paradigms are often ambiguous for organisations: such processes highlight tensions between the individual and organisation, and create uncertainty for managers. Person centred planning arose in different culture, from a *real* disappointment with conventional approaches, growing at the angry chaotic creative community edges of no or poor traditional service options & provision; person centred planning demands flexibility of resources and roles, it demands ambiguity when compared to current practice. Can large human services be flexible in the enforcement of systems, and fit to the person’s unique needs? I’ve had to learn and embrace a blurring of who I am and what I do in relation to my “professional” role.

There is a real danger service led implementation of person-centred planning will not affect organisational functioning: larger organisations are usually bureaucratic and often haven’t established or acknowledged why current claimed practice paradigms fail to be fully implemented or maintained, even if they recognise such flaws. How easy is it for staff to implement person centred approaches when they are poorly paid, often not valued, and receive poor guidance and training on implementing, in meaningful ways, policy innovation? Organisations are rarely staff orientated. What hope for large organisation to become ‘user’ orientated, when users have smaller voices than the small voices of staff?

If initiating or implementing change is problematic, maintaining innovation is challenging to "second generation" services (Felce, 1991). Once innovators move on to new challenges, once the consultant leaves for her new task, how can service systems alone continue the vision? It's easier for organisations to blame service users, external consultants or specialists, the model, the resources, *anything!* than the lack of skills within management. Finger pointing is easy when *"those who don't know how to manage are managing those who don't know what to do"* (LaVigna *et al.* 1994).

Management is often apparently not *that* interested in quality of life of service users, focusing on financial security and uniformity- certainty and control. Acknowledging individual variation among "consumers" (sic) creates uncertainty and ambiguity, and muddies the clear water for administrators. Organisations have been obliged to focus on budgets as a primary function: quality outcomes are secondary. When presenting their results, organisations display turnover, potency, efficacy, and penurious management systems. Not the life stories of 'users'. Structures & criteria need to acknowledge people with developmental disabilities are not a homogenous whole (Felce & Emerson, 2001; Schreibman, 2000), that each person has their own preferences and the organisation's bottom line is not the only rationale.

When not thinking in profit terms, organisations focus on protecting themselves from liability. In the UK, what are the legal consequences for managers and executives whose services fail to deliver a quality of life for 'users' so commonly claimed in brochures and mission or value statements? What are the benefits of promoting independence for organisations when income depends on disability? The voiceless remain, at the dawn of the new century, hidden way behind the balance sheets and organisational audits, lost in powerful ideologies (Tyne, 1992). Organisations fudge 'user' and quality outcomes.

"The way a service works before intervention is… functional for someone…" (Mansell, McGill and Emerson, 1994). "*The failure of change to match rhetoric"* (p.286, Felce,

1991) is partially accounted for by services not being explicitly designed to achieve defined outcomes. Services *“evolved in a… haphazard way…* [not] *as a response to a specific rationale”* (p.3, Praill & Baldwin, 1978).

O’Brien suggests we need to acknowledge our failings and ignorance-

> *“We promise to prevent, we promise to cure, we promise to rehabilitate, we promise to make independence as if it were a Chevrolet. And our promises have been fruitful, up to a point. If we are to move beyond that point we need the courage and the grace to learn the lessons of our collective ignorance and fallibility. There is much to learn in close attention to our errors and failings as we work to share and improve the lives of people with handicaps”* (O’Brien, 1987b)

Then we might move forward in our learning through listening. Organisations have often got the manuals and the theory down pat: application and honesty is a problem. This is a potential nexus of conflict, for person centred planning is not about organisations, it is about people.

I remain to be convinced large organisations can “do” person centred planning in any meaningful wholesale way (partly due to it being difficult to define operationally), without massive changes in structure, financing, values and interaction with direct support staff and users. Services, focusing on their own needs (implementing person centred planning in line with *Valuing People*) may be tempted to adopt a model of planning wholesale, which simply demonstrates their lack of understanding the individual approach of person centred planning. Person centred planning evolved through creative collaboration. That creatively challenged boundaries of practices and thinking.
The themes of person centred planning are reasonably clear

- Listening to the focus person or their representatives
- identifying preferences of the person and core values
- addressing the very real issues disability presents
- developing a vision of a desirable future
- mobilisation community resources (Allard, 1996).

We need to define success and quality: I would suggest this would need to be achieved in conjunction with the focus person. This implies each individual's definition might be different. There is plenty of room for dilemma and ambiguity in this situation. From my experience, some common themes are likely to emerge: understanding, collaboration, listening and problem solving. In effect, a move toward interdependence (Sailor, 1996).

What is good to know is that better people than I have voiced this fear of the debasement of person centred planning (O'Brien & Lovett, 1992), and the obstacles to implementation are clearly acknowledged (Kinsella, 2000; Holburn & Vietze, 1999; O'Brien, O'Brien & Mount, 1997). It is encouraging that outcomes of person-centred planning are being examined (Holburn *et al.* 2000; Hagnar *et al.* 1996), and though the potential "fad-trap" of the initial burst of enthusiasm followed by a steady decline in direction and development (O'Brien et al, 1997) is worrying, it is not unique to person centred innovations.

My fear about the "roll out" of person centred planning is just that: *my* fear. That this is something I cannot control is a cause of tension, because it challenges me as a practitioner. But for many decades now professionals have tried to control services and systems and we've not maintained or generalised that many good results. Person centred planning is a welcome challenge to service and clinical control. I'm becoming used to working at the edges of my competence: fortunately there are plenty of helpful people living & working in services tolerant of my lack of knowledge who have been able to give me advice or often forceful feedback. Exotic communication (Ephraim, 1998) is a remarkably powerful teacher.

Increasingly, management in community services is becoming administration-focused. One cannot, however well qualified, lead from an office. Nor can one write person centred policies or plans from ivory towers. To begin to try and apply some degree of person centred thinking, not managers but leaders are not needed by organisations.

Leaders engage the approach within organisational systems by working with real people and real puzzles in real places. Leaders are dynamic, responsive to the ambiguity arising from person centred work. Leadership means getting emotions, minds and resources all focused to make progress on problems, involving people with different views to invent creative solutions. Leaders aid unique teams to create unique solutions for unique individuals. Administrators would perhaps try to avoid such ambiguous creativity, simply reaching for hefty policy statements (O'Brien, 1987b).

My fears for the future of person centred planning are partly drawn from service and professional failures of yesterday- not applying what we know. Person centred planning means action planning. The underpinning approach, as well as the various tools, demands we commit to people, not time-limited cases. Eric Emerson recently noted *"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).

My anxiety arises from the challenges of changing not only what I do, how I organise my "cases", but also my need to change how I think. In light of the general ambition to move toward the approach, it is perhaps salutary to listen to the person credited with helping to develop essential lifestyle plans. *"Person centred planning should be done with everyone only where there is the willingness to make the investments and changes necessary... we should not make the promise unless we believe we can keep it"* (Smull, 1996). Recommending person-centred planning for everyone illustrates, I would suggest, how poorly it is understood by those in control of policy.

For services to begin wanting to facilitate person centred practice, they will need to learn and not condemn, surrender power and professional interest, and listen (Iles, 2003). Such listening implies a conversation, a partnership. Services are ironically designated: for many people, services do not serve, but subjugate. Services are never enough to meet people's needs (O'Brien, 1987), yet these services and professionals are striding into the future implementing person centred planning. Person centred planning challenges the thinking & practices of professionals (products of often stagnant training regimes reformulated, but inherited from, medical and institutional ways of doing).

Conclusions?

Larger human service organisations are often quantitative- promoting centralised & generalised models or systems of working which like to measure *outcomes* in order to justify their continued financial existence. However, person centred planning is a qualitative *process*: it challenges traditional roles and responses to the needs and hopes of people using services. The general "rolling out" of person-centred approaches, without insight from examination of implementation difficulties with previous "innovations", without understanding why maintenance of quality delivery systems & approaches is problematic, raises the probability of poor implementation, dooming us to repeat historical mistakes.

Person centred approaches may become discredited if organisations fail to recognise implementation-management and current culture are obstacles to change. Fitting poorly understood person-centred planning techniques into existing service structures is likely to not result in fundamental change. It is suggested services need to concentrate not so much upon person centred *planning* but person centred *action*. If services aren't able to do it well, to collaborate in making meaningful changes in the lives of people, they should not use person-centred language.

Services should stop posturing, writing implausible, imprecise and indistinct mission statements; they must cease lying to the people they are paid to serve. The people who, in effect, pay our mortgages. Services could do worse than openly and clearly measure lifestyle outcomes, both good and bad, for the people they were intended to serve, and learn from these outcomes.

Research is helpful in examining meaningful outcomes in services claiming adherence to person centred planning. Such research should present successes as well as critiques, and might provide test-beds able to question service mission statements. Such measures might include

- the degrees & methods of interaction & involvement at planning meetings between the focus person and service staff or others (e.g., Carnaby, 1997, 1999)
- the means to turn person centred *planning* into *action*, for example, through person-centred active support models (Emerson, 1999) or total quality management procedures (e.g., LaVigna *et al,* 1994)
- qualitative outcomes of individual's experience of effective person centred action planning against socially valid criteria and values (e.g. Five Accomplishments)
- participation & influence of users in services (Simons, 1999)
- a comparison with data collected from services claiming adherence to other paradigms (e.g., Hatton *et al,*1995).

Presentations of qualitative and quantitative 'research' with and by people with developmental disabilities are essential in both academic and more accessible journals: but assessments, 'treatments' and 'case studies' need to consider the narratives of the focus person, not just behaviours and pathologies. What I'd like to see more of, are not so much "case studies", as real stories. This would help my own understanding and inform my attempts in trying to work in person centred ways.

The challenge ahead for services are twofold: to understand they cannot control or take the lead in implementing person-centred planning, and that they should not focus resources on language, but action. We are all responsible to ensuring our walk matches our talk.

Why is person centred planning important? In 2003…

Barbara has a bad reputation- people coming into the house she shares with four men are warned *"She'll have you*". In her bedroom her clothes are locked away. Mind you, so is her bedroom door. She loves clothes, but access is restricted, controlled by staff with controlling paradigms (*"This* is *a challenging behaviour unit, you know!*") so Barbara has learned to urinate to get a change of clothes. She spends hours in a dressing gown so *"she doesn't win":* as staff say *"Don't worry, we're covered, it's in the care plan"*. Staff shout at her. Care Plans are approved by a senior nurse manager.

Jane is allowed a cup of tea at breakfast, 11am, lunchtime, 3pm and dinnertime. With medication. Staff justify this *"Because she obsesses about drink"*. Let me get this right: a woman with few activities and little control is obsessed about the one predictable item in her life? Heavens! Because she does little else, with few quality interactions, has no life? Whoa! It seems to me this is more about power & control, and that nursing jobs are defined and justified by the problems exhibited by Jane right now. Challenging behaviour or self-determination? Maladaptive behaviour or complaining? Perhaps Jane doesn't even like tea: perhaps she's trying to instigate a conversation?

George has autism. And learning disabilities. And a file as big as a barge. And a bigger reputation. And a heart breaking smile. He hurtled into a behaviour assessment unit. A functional assessment was completed (this makes no sense since many of the variables influencing his behaviour in this specialised setting were not present in other environments, but hey, there you go…). George has been assessed and a service specification was written. We made sure it was a good one. We even asked people who loved George where they thought he'd be happiest, and how people needed to support him best. We found a service in 2001 and this would have cost around £2,500 per week. This was ignored and George was placed miles from home in an inappropriate place. We shouted, we hollered. We were ignored. What do clinicians know about the financial constraints facing Care Management? A few months later George was admitted under the Mental Heath Act (it's easier to claim the person is ill than to admit our own actions failed someone). His new service (which bears an uncanny resemblance to what was suggested some years ago) is individual but will cost over £7,000 a week.

Bob had a series of seizures and collapsed underneath a radiator. Staff, who are paid to check on him hourly, found him in the morning. He was badly burned. He lived with 18 other people with 3 staff on a shift. But it's by the seaside! He's nearly blind and had nothing to do during the day. His Care Manager saw him once a year. We hollered! We found a service with one other person: Bob's a lot happier. The original service still has 18 people (it's cheap, and sometimes, people go out as much as twice a week).

Del wears arm splints because a decade ago he hurt himself by trying to swallow his hand (no one tried to work out why, they just wanted to stop him). People know if you spend time with him he often doesn't hurt himself, *"sometimes for whole shifts"*. Splints are still used. There aren't enough staff. The solution arm splints offer has the potential for resolving fiscal dilemmas, as much as for avoiding behaviour problems. It is cheaper to the service in resource terms and easier for staff to rely on splints than alternative approaches. Let me repeat: Del wears splints even though the service know if you do things with Del, he tends not to put his hand in his mouth.

Jack has a condition that causes him to focus on eating, needing structure and routine, and being listened to (no, not just being a human or a behaviour specialist, not that condition, something different from that!). He's sometimes teased by staff about not having food for dinner, and not having money to go shopping. He's being moved in a couple of weeks and hasn't chosen where. "He's a problem"- being restrained 100's of times over the last few months.

Fred asks staff about what's happening. A lot. It can get tiresome for staff. But there are no schedules, no way of knowing, and staff don't want to tell Fred about what few plans there are to do stuff in case he *"becomes obsessed".* In case he knows? Now if someone told me once in ten days what I was doing tomorrow, I think I'd get obsessed! The other day a senior support worker got fed up with Fred asking if he could go out in the bus the next day, and she said "You know what we always say, Fred: *'Wait and see what tomorrow brings'* " Fred looked at the senior support worker, and Fred said "But tomorrow never comes".

Notes from history

[1] Soranus of Ephesus lived in Rome between 110 & 130 BC: considered the father of gynaecology and paediatrics, he was also concerned with the rearing of children and interested in the care and treatment of the "excluded", and violently opposed the then current treatment. "*The physicians prescribe placing all patients in darkness without ascertaining whether the absence of light is in some cases irritating, without ascertaining whether or not this measure adds another burden to the affected. Rather than being themselves disposed to cure their patients, they seem to be in a state of delirium; they compare their patients to ferocious beasts whom they would subdue by the deprivation of food and by the torments of thirst. Misled without doubt by this error, they advise that patients be cruelly chained, forgetting that their limbs might be injured or broken and that it is more suitable and much easier to restrain the sick by the hands of men than by weights of often harmful iron. They even advise bodily injury, like the use of a whip, as if such measures could force a return to reason; such treatment is deplorable and aggravates the patient's condition. It stains the body and limbs with blood- a sad spectacle indeed for the patient to contemplate... They have the patient fall asleep by use of the poppy; but this provokes a drowsiness and morbid torpor instead of good sleep; they rub the patient's head with oil of rose, wild thyme or castor oil, thus exciting the very organ they seek to quiet. They use cold applications; they use irritant clysters and by means of acid injections. They produce no other results than dysentry."* Celsus (first century AD): *"When the patient has said or done anything wrong, he must be chastised by hunger, chains and fetters. He must be made to attend and learn something that he may remember, for thus it will happen that by degrees he will be led to consider what he is doing"* (Scheerenberger, 1983). Sound familiar?

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