CHAPTER 4

Managing the Tensions between the Interests of Organisations and Service Users

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INTRODUCTION

> We have historically been more efficient in providing people for services than services for people… (O'Brien and Lovett 1992, p.9)

The context to arguments over the organisational implementation of person centred planning (PCP) and action is the lives of people using services and there are examples in this chapter illustrating why person centred planning and action are vital to underpin changes in power and power relationships between services and service users.

As person centred planning has gained an increasingly high profile in the UK, many organisations are awash with person-centred language. *Valuing People* (Department of Health 2001) places PCP centre stage in service delivery for people with learning disabilities. The implementation guidance (Department of Health 2002) suggests there are two elements – PCP and person-centred approaches – meaning that services, in their systems and practice, should be responsive to individuals. However, are learning disability services *en masse* able to implement such innovation meaningfully, particularly when PCP ideologies fundamentally challenge conventional systems and traditional thinking? Moreover, PCP has been considered 'mindful', in that it requires openness to new ideas and perspectives, and involves creating new ways of doing and being. This compares to the relative mindlessness of old rigid ways of thinking and acting, precluding new events, and operating from a single perspective. The question

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'what happens when a radical mindful concept such as PCP is thrown into the mindless mainstream?' (O'Brien, O'Brien and Mount 1997) needs to be asked. There is clearly a risk that services will unwittingly debase person centred planning. This chapter identifies major potential obstacles for larger organisations when implementing PCP and will argue that this family of approaches is primarily about people, rather than organisations.

IMPLEMENTING PCP

The recommendation to generalise PCP without clarity about how to turn person centred *planning* into person-centred *action* in large service systems is potentially problematic, as PCP is an idiographic qualitative process. Large disability services in the UK are in the main nomothetic quantitative systems, dealing with conceptions of groups of people as homogenous classifications (O'Brien 2002). Person centred planning originated from the voluntary commitment of people toward a fellow human, and we need to consider if and how organisations can legislate for ways in which poorly paid employees are to empower service users. Services focusing on their own needs, such as implementing PCP in line with *Valuing People*, may be tempted to adopt a wholesale model of planning. This simply demonstrates a lack of understanding about the individual approach required by PCP and its emphasis on creative collaboration and the challenging of boundaries around both practice and thinking.

According to Allard (1996), the themes of person centred planning are reasonably clear:

- Listening to the focus person or their representatives.
- Identifying the person's preferences and core values.
- Addressing the very real issues that disability presents.
- Developing a vision of a desirable future.
- Mobilising community resources.

How might large providers respond?

PCP developed within 'communities of practices', rather than formal 'institutionalised' organisations such as NHS trusts or social services departments, and in a culture different from that prevailing in services in the UK. We are faced with the challenge of generalising bespoke tailored provisions to large services familiar only with providing off-the-peg solutions. Learning disability service organisations often function by viewing service users as a population – a homogenous whole or collection of people with defining deficits requiring professional intervention. PCP, on the other hand, focuses on people, gifts and community (O'Brien and Lovett 1992).

Case study: Barbara

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 and her bedroom door is locked. She loves clothes, but access is restricted, controlled by staff with controlling paradigms (e.g. 'This is a challenging behaviour unit, you know!'). Barbara has learned to urinate in order to get a change of clothes. She spends hours in a dressing gown. 'She doesn't win,' staff say. 'Don't worry, we're covered, it's in the care plan.' Staff shout at her. Recently, the provider of the service changed the name of their recording system. Barbara no longer has an Individual Service Plan – as the format has altered slightly it is now called a PCP. The content, however, remains largely unchanged.

QUALITY VS. QUANTITY?

The requirement on services to produce so many plans by such-and-such a date may possibly encourage a greater emphasis on planning rather than outcomes, encouraging organisations to focus on the breadth rather than the quality of implementation. The greater the number of plans, the higher the kudos of achieving a quantitative target. Fewer, higher quality plans leading to better outcomes for individuals may not attract the same kudos. Plans are easier to deliver and complete than person-centred action and improvements in quality of life. It is easier to complete a plan than change how organisations and those who work in them operate. Rather than measuring the number of plans started or completed, the emphasis needs to be switched to the number and types of goals set in plans, and their achievement. We need also to appreciate the complexity and quality of many of these goals; if we are obliged to produce numbers, perhaps we should measure how many people are happier as a result of their plans, or perhaps how many new friendships people have developed, even what new skills have been learnt and what new attributes have been acquired. Counting the number of people with plans is easier than establishing the quality of PCP and the actions which follow. There is also the thorny issue of rationing of scarce resources. There is a sense of thinking where 'better everyone get a little' (namely a plan), than 'a few get a lot' (namely achieving the goals). Services may rightly be concerned with equality and equity in coverage, but this brings with it the risk that PCP becomes just another service tool – a sure way to disenfranchise users.

ISSUES FOR ORGANISATIONS

Changing the language, not the action

Changing organisational appearance is relatively easy (Praill and Baldwin 1988) and claiming adherence to PCP is something any individual or organisation is able to demonstrate. Existing planning formats are being modified to incorporate the language of PCP and person-centredness. Some organisations are issuing pro-forma person-centred plans, with staff and service users, where able, simply filling in the gaps. Yet such practice is not what was intended when trying to give the individual a real voice, leading to wider questions about who judges the quality of PCP and with what credentials. Standard definitions and criteria of what does and does not constitute PCP may simply lead to unthinking compliance, rather than innovation in practice and user involvement and quality outcomes for people. One possibility is that organisations may soon be found to adopt the language and appearance of person-centredness without the action inherently demanded by PCP.

> 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 and Fox 1996, p.44)

If services focus on changing language without changing actions, relationships, finances, functions and structures, PCP is likely to go the way of other innovations, lost in a mire of organisational cognitive dissonance and 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).

Reflecting on ideology and its impact

The generalisation of PCP is fraught with dangers that may 'discredit' the family of approaches that constitute it (O'Brien and Lovett 1992). For example, experience suggests normalisation ideology has often been poorly applied (Emerson 1992; Mansell *et al.* 1987; 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 and O'Brien 2000, p.2). As Lovett noted, nothing named remains unchanged (Lovett 1996). To establish whether PCP is improving things for people and changing organisations, it is essential to gather qualitative and quantitative information. 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 and doing (Holburn and Vietze 2002).

Existing services have often failed to wholly learn the lessons of past innovations, as the quality of life of many people with learning disabilities using some services remains some distance from what experience and research, as well as values, suggest might be achieved. Without a clear understanding of why previous value and practice initiatives have failed to be implemented or maintained effectively, services are likely to poorly apply, support and maintain the paradigm-challenging themes underpinning PCP, diluting its aspirations and ultimately leading to it being discredited. Larger organisations are likely to resist the changes in thinking and functioning required by PCP and may seek to adopt superficial aspects of the person-centred movement, by focusing on plans, not action (Carnaby 1997, 1999).

For example, if organisations have really adopted normalisation principles, or the Five Accomplishments (O'Brien 1987a), we can ask why so many people are living and working in (and are arguably brutalised by) such controlling and institutionalised regimes, in ecologies and with barren lifestyles few of us would choose to inhabit (Durand 1990; Risley 1996). Ericsson and Mansell (1996) suggest 'the poorest community services appear no better…than the institutions they were designed to replace' (p.15), partly due to 'unclear goals and lack of direction' with 'little guidance on interpretation of…principles' (Mansell 1996, p.55) in services where 'the home leader…becomes an administrator' (p.56). Mansell notes 'it is as if the hard lessons learned in the institutional scandals of the 1960s have been forgotten'. The reality seems to be, regardless of what mission statements may proclaim, that 'serviceland' (Sanderson 2002) is often inefficient and wasteful (Emerson 2001), not only in resources, but in putting values into action (Allen 1999; Kinsella 2000; Wolfensberger 1980). 'Much of what is being done represents no real change in practice. It is business as usual masquerading as being person centred' (Smull 1996, p.1).

The risk of 'service-led' vs. 'person-led' services

Services seem doomed to repeat the mistakes of failing or poor application of past innovations because people who create, commission, manage, work in and impose service models may not consistently or clearly have learnt from experience why individualisation has failed in the past. Larger human service organisations often gravitate toward promoting centralised and generalised systems of working. PCP is a dynamic *process* for individuals, challenging 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 or understanding why maintenance of quality is problematic, simply raises the probability of failure and the repeat of historical mistakes.

Case study: Del

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 as there are not enough staff. The solution – arm splints – offers the potential for resolving fiscal dilemmas, as much as for avoiding behaviour problems. It is more economical for the service in resource terms and easier for staff in terms of competence to rely on splints than alternative approaches. Again, it needs to be stated that Del wears splints even though the service know if you do things with Del he tends not to put his hand in his mouth. He has a pro-forma PCP, with standardised sections, completed by nurses and support workers, but it's difficult to recognise Del as anything other than a collection of medical and behavioural problems.

At a strategy meeting in a local authority, people were enthusiastic, but when the question of where to begin implementing PCP was raised, answers included we need 'more resources', 'more care managers', 'more training' and so on. All these things are important, but all focus on the needs of the organisation, rather than users. Senior managers sought a single model to roll out across the whole authority, at the cheapest price. They wanted, above all, to control the process and to minimise the organisational risks, eliminating ambiguity and retaining organisational control, but in the process stifling innovation. There were few suggestions about listening to what people currently failed by services were already saying and few suggested looking at where (and why) person-centred approaches have been successful – for example, smaller organisations, with flatter management structures, where change is implemented in smaller steps, with the organisation slowly learning and growing in responsiveness.

Person-centred paradigms are often ambiguous for organisations, as they highlight tensions between the individual and the organisation and create uncertainties for managers. PCP arose in a different culture, from a *real* disappointment with conventional approaches, growing at the angry chaotic creative community edges of no or poor traditional service options and provisions. PCP consequently demands flexibility of resources and roles, and creates ambiguity compared to current practices.

There is a real danger that service-led implementation of PCP will not affect organisational functioning as larger organisations are usually bureaucratic and

Case study: The NHS campus

Imagine a campus with four bungalows, next to a special needs school. It stands on an old hospital site. The bungalows house between five and seven people and all have one respite bed. This means that there are a lot of people, all with learning disabilities and complex health needs, in one place. The bungalows are called homes but are classified as a hospital in law. This means little food is prepared in the bungalows, with most meals arriving from another hospital some 15 miles away. As food is ordered in advance, you cannot change your mind about what food you want to eat the next day and, anyway, most of the wheelchair users living in the bungalows tend not to be able to use the kitchen areas due to their poor design (even though the bungalows are 'purpose built'!). In 2003 the commissioners decided to try out Essential Lifestyle Planning (ELP) with 12 service users. They felt this would challenge practice and perhaps identify who might be able to move into different settings, such as supported living and smaller community group homes. Many were trained in ELP facilitation (all being employed by the NHS), consuming significant resources. The outcome for one individual was that he is woken with a radio alarm, rather than staff with medication, and most of the 12 plans have not resulted in any meaningful changes or outcomes. Some of the campus staff apparently opposed the planning and the commissioner has now called in an external organisation to take over the planning, at further cost, without identifying or doing anything to address the culture that stopped ELPs from being completed or actioned in the first place.

often have established or acknowledged why current claimed practice paradigms fail to be fully implemented or maintained. It is consequently difficult for staff to implement person-centred approaches when they are poorly paid, often not valued, and receive poor guidance and training on implementation. Few organisations are staff orientated and in most the voice of service users is less evident than the voice of staff.

Quality of life and the management of risk

Management often seems uninterested in the quality of life of service users, seemingly focusing on financial security and uniformity in creating certainty and control. Acknowledging individual variation among 'consumers' creates uncertainty and ambiguity, and muddies the clear water for administrators.

Organisations have been obliged to focus on budgets as a primary function, with quality outcomes secondary. When presenting their results, organisations display turnover, potency, efficacy, and penurious management systems, not the life stories of 'users'. This is simply because these are the normative standards by which services are judged. However, standards, structures and criteria need to acknowledge that people with learning disabilities are not a homogenous whole (Felce and Emerson 2001; Felce *et al.* 1999; Hatton *et al.* 1995; Schreibman 2000), and that each person has his or her own preferences, which come before the organisation's interests.

When managing risk, organisations focus on protecting themselves from liability, yet in relative terms there are few legal consequences for managers and executives whose services fail to deliver a quality of life for users so commonly claimed in brochures and their mission or value statements. Compare this to the consequences of financial overspend, and the pressures and distortions on services are apparent. What are the benefits of promoting independence for organisations when income depends on disability and why promote PCP when this may increase uncertainty and thus risk? 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, and it is salutary to remember: 'The way a service works before intervention is…functional for someone' (Mansell, McGill and Emerson 1994). 'The failure of change to match rhetoric' (Felce 1991, p.286) is partially accounted for by services not being explicitly designed to achieve defined service user outcomes. Services 'evolved in a…haphazard way…[not] as a response to a specific rationale' (Praill and Baldwin 1988, p.3). O'Brien suggests we need to acknowledge our failings and ignorance in providing services for people with learning disabilities:

> 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, p.24)

We need to redefine success and quality not simply in terms of the numbers of people 'served' by having a plan, or financial outcomes, but by including the outcomes for people and such success criteria need to be developed in conjunction with a focus on the person. However, this also implies each individual's definition of success might be different, leaving plenty of room for dilemma and ambiguity, although it seems likely that some common themes may emerge.

Case study: Martin

Martin lived at home with his mother and his sister. He was largely cared for by his mother who, as she grew older, found it more difficult to care for him. Martin and his family were offered respite care in a residential home where, eventually, Martin asked to go and live, and he was able to do more of the things he loved. He continued to stay with his mother for weekends and other visits. After a time, structures, staff and regulations changed within the home and Martin's lifestyle changed. He became increasingly unhappy with his situation and expressed this by becoming physically and verbally aggressive towards other people. Unfortunately, this became a pattern in Martin's life and the rhythm of his life was changed. Things he loved were taken away, people didn't listen to him or realise how important his lifestyle was to him and he lost respect. His sexuality, dress, language and preferences were also lost and Martin ended up with a severe reputation. *He* became a problem, with the people who did not listen to him not subject to such categorisation.

At around about the fourth move, a community nurse who Martin liked was asked to come and help discuss with him how he would like his life to be. They discussed the problems of finding his ideal place to live and what that ideal place might be like. The community nurse felt that a new way of looking at the issues Martin faced should be used at the next planning meeting. Stakeholders were invited and the information that Martin and the nurse had gathered over the previous few weeks was used to develop a PATH.[1] This clearly stated what Martin wanted out of life, namely a bungalow, a couple of people to live with, a girlfriend, a particular local radio, time, space to be who he was and dress as he wished, and support when he needed it. The stakeholders present agreed to the plan and, by planning, promises were implied. It was decided that this was the way forward for planning Martin's care. Since this meeting, however, Martin has moved a further three times and is still waiting for his ideal place to live, as he was promised, with the move following the plan being the antithesis of his dream. His behaviour deteriorated again and although Martin still has his PATH, his hopes and dreams, they haven't changed much as no one in authority followed them through.

The dominance of administrative procedures

Management in services seems to be becoming increasingly administration-focused, although an obvious response is that one cannot lead from an office. Nor can one write person-centred policies or plans from ivory towers. To begin to apply some degree of person-centred thinking, leaders not managers are needed. Leaders are dynamic, responsive to the ambiguity arising from person-centred work and involve people with different views to invent creative solutions. They also aid teams to create unique solutions for individuals. Conversely, administrators would perhaps try to avoid such ambiguous creativity, simply reaching for policy statements (O'Brien 1987b). The underpinning approach of PCP and action, as well as its tools, demands that we commit to people, not time-limited cases. Services will need to reconceptualise their roles and reorganise. 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' (Emerson 2001, p.148); so, maintaining gains and achieving broader lifestyle outcomes needs sustained support: 'Interventions need to be seen as an ongoing process rather than a time limited episode of treatment' (Emerson 2001, p.148).

Those responsible for funding Martin's care, and commissioning the plan, might wish to consider Michael Smull's view:

> Learning how people want to live and then doing nothing with the information is a form of abuse. A good plan not only clarifies what each individual wants but creates the perception that those who participated in the planning will do something about it. Planning should only occur where there is commitment to implement. (Smull 2000a, p.75)

Case study: Fred

Fred asks staff about what's happening. He asks this frequently and it can get tiresome for staff. But there are no schedules, prompts, landmarks or ways of Fred knowing, and staff are reluctant to tell Fred about the few plans there are in case he 'becomes obsessed' – or rather in case he knows. 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 said, 'But tomorrow never comes.'

Commissioning people to do the plan without enabling them to follow through is simply not sufficient in terms of social validity. It allows commissioners to say that they have started person centred planning, but little else other than endangering the credibility of PCP itself.

CONCLUDING COMMENTS

Services are never enough to meet people's needs (O'Brien 1987a), yet disability services and professionals are striding into the future claiming to adopt PCP. Many have voiced the fear of the debasement of PCP and the obstacles to implementation are clearly acknowledged (Holburn and Vietze 1999; Kinsella 2000; O'Brien, O'Brien and Mount 1997). It is encouraging that outcomes of PCP are being examined (Hagner, Helm and Butterworth 1996; Holburn *et al.* 2000), and though the potential 'fad-trap' of the initial burst of enthusiasm followed by a steady decline in direction and development is worrying, it is not unique to person-centred innovations.

For many decades now professionals have tried to control services and systems and we have not maintained or generalised that many good results, making PCP a welcome challenge to service and clinical control. Services wanting to facilitate person-centred practice will need to learn and not condemn, surrender power and professional interest, and listen to the sometimes challenging and humbling experiences of service users (Iles 2003). Such listening implies a conversation and a partnership but currently many services are ironically designated, as for many users they do not serve, they subjugate.

Recommending person centred planning for everyone illustrates, I would suggest, how poorly it is understood by those in control of policy. Rather than the wholesale adoption of approved planning methods across services, service leaders would do well in listening to the advice of the originators of PCP and action, and the experience of people charged with introducing it – start small, learn, respond, change and grow (Butkins *et al.* 2002; O'Brien and Lovett 1992; Sanderson 2002; Smull 1998, 2000b; Smull and Lakin 2002). 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, p.3)

A graphical analogy provided by O'Brien and Lovett suggests PCP might be conceptualised as circular or oval (adaptable), whereas service systems are square and rigid, sometimes triangular (O'Brien and Lovett 1992). Larger organisations adopting PCP approaches without radically changing how they think and

act may simply be attempting to literally square the circle. Soon, in the United Kingdom, it is probable that a thousand squares will be claiming to be spherical.

NOTE

1   PATH is a style of PCP.

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