

Title page

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Policy and practice in intellectual disability services**

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Abstract

This critical review considers the nature and importance of person-centred planning in the context of current British policy and service development in intellectual disability. The difference between person-centred planning and other kinds of individual planning is discussed. The scale of the task of implementing person-centred planning as a national policy initiative is considered. The limited evidence base for person-centred planning is reviewed and the reasons for the failure of previous attempts at individual planning are analysed. The assumption that person-centred services will be produced by a new kind of individual planning is questioned. Finally, consideration is given to what would be necessary to make services more person-centred, including changes in power relations, funding arrangements and in staff training and supervision.

Introduction

What is person-centred planning?

Person-centred planning is an approach to organising assistance to people with intellectual disabilities. Developed over nearly thirty years in the United States of America, it has recently assumed particular importance in England because it forms a central component of the 2001 White Paper *Valuing people*.

Person-centred planning is represented by a family of approaches and techniques which share certain characteristics (O'Brien and O'Brien, 2000). It is individualised, in that it is intended to reflect the unique circumstances of the individual person with intellectual disabilities both in assessing and in organising what should be done. It shares this focus with other approaches to individualised planning adopted in intellectual disability services, such as individual programme plans (Accreditation Council on Services for Mentally Retarded and Other Developmentally Disabled Persons, 1983; Blunden, 1980; Houts and Scott, 1975; Jenkins *et al.*, 1988) or individual service plans (Brost *et al.*, 1982; Emerson *et al.*, 1987), as well as with case management methods adopted across many client groups (Challis and Davies, 1986).

In distinction to these methods, however, person-centred planning emphasises three other characteristics found wanting in them. First, it aims to consider aspirations and capacities expressed by the service user or those speaking on their behalf, rather than needs and deficiencies. This emphasis on the authority of the service user's voice reflects dissatisfaction with the perceived failure of professionals to attend to what matters most to service users, the extent to which services are seen to constrain or impose goals (Crocker, 1990; O'Brien and Lovett, 1992) and the observation that services sometimes create artificial hurdles between goals in an inappropriate 'readiness model' (Wilcox and Bellamy, 1987) or 'developmental continuum' (Taylor, 1988).

Second, person-centred planning attempts to include and mobilise the individual's family and wider social network, as well as to use resources from the system of statutory services. This partly reflects the special interest that family and friends have:

“Often it is family members who know the person best. They care about the person in a way that is different from everyone else and they will probably be involved in supporting the individual for the rest of their lives. They often bring huge commitment, energy and knowledge to the table.”

(Sanderson, 2000)

The implication is that families in particular have a stake in the arrangements made to support an individual with intellectual disabilities in a way that service employees do not.

Mobilising the service user’s social network is also intended to broaden and deepen the range of resources available to help them; indeed for some authors there is the suggestion that services are part of the problem more than they are part of the solution (O'Brien and Lovett, 1992, p13). The social network is seen as a richer source of imagination, creativity and resources than the service system, not least in the area of forming and maintaining social relationships, where intellectual disability services are seen as weak (Emerson and Hatton, 1994).

The third distinctive characteristic of person-centred planning is that it emphasises providing the support required to achieve goals, rather than limiting goals to what services typically can manage.

“Person centred planning assumes that people with disabilities are ready to do whatever they want as long as they are adequately supported. The ‘readiness model’ is replaced with the ‘support model’ which acknowledges that everyone needs support and some people need more support than others.”

(Sanderson, 2000)

Taken together, these three characteristics are presented as making a fundamental break with previous methods of individual planning:

“It is not simply a collection of new techniques for planning to replace Individual Programme Planning. It is based on a completely different way of seeing and working with people with disabilities, which is fundamentally about sharing power and community inclusion.”

(Sanderson, 2000)

Why is person-centred planning important?

Person-centred planning has been increasingly fashionable in intellectual disability services but it has assumed particular importance since its adoption as a primary vehicle for change by the 2001 White Paper *Valuing people*.

The White Paper identifies person-centred planning as central to delivering the Government’s four key principles (rights, independence, choice and inclusion) and a high priority for management attention and resources.

“Given the importance of person-centred planning as a tool for achieving change, we will make supporting its implementation one of the priorities for the Learning Disability Development Fund and the Implementation Support Team.”

(Department of Health, 2001b, p50)

Guidance issued subsequently (Department of Health, 2001a) is intended to create a large-scale programme of training and implementation. The White Paper sets out an ambitious programme of targets for the introduction of person-centred planning (numbers, unless otherwise indicated, from *Valuing People* (Department of Health, 2001b)):

By April 2002:

- ◆ Learning Disability Partnership Boards to agree a local framework

By 2003 “specific priorities” for:

- ◆ People still living in long-stay hospitals (about 1500 people)
- ◆ Young people moving from children’s to adult services (number not known)

By 2004 “significant progress” for:

- ◆ People using large day centres (about 50,000 people)
- ◆ People living in the family home with carers aged over 70 (about 29,000 people (Mencap, 2002))
- ◆ People living on NHS residential campuses (about 1500 people)

The scale of the task

This is an extremely ambitious target for public policy, and not just because of the number of people involved. The population of people with intellectual disabilities include many individuals with very severe problems, which are likely to hinder or impede the development and maintenance of relationships with other people, making the maintenance of effective person-centred planning difficult. For example, a recent study of adults in residential care (Mansell *et al.*, 2002) found that 43% had major communication difficulties, 63% had impaired social interaction and 35% had severe challenging behaviour. Each of these, alone and in combination with others, presents substantial difficulties. For example, there is evidence that staff often mis-judge the receptive language ability of people with intellectual disabilities (Bradshaw, 2001; McConkey, Morris and Purcell, 1999; Purcell, Morris and McConkey, 1999), a common error being to rely too heavily on verbal communication. Thus, in presenting and discussing options in the context of a person-centred planning meeting, staff (and perhaps others too) risk failing to explain possible courses of action adequately. Similarly, the extent to which people with intellectual disabilities can understand choices and decisions is often limited and requires careful assessment (Arscott, Dagnan and Kroese, 1999; Murphy and Clare, 1995). The nature of the difficulties experienced by the individual service user may also interfere with person-centred planning. For example, aggression or self-injurious behaviour often result in negative emotional consequences for staff (Emerson and Hatton, 2000; Hastings, 1995), which may make it more difficult to empathise with the individual or to identify feasible means to achieve their goals.

None of these characteristics is, in itself, insuperable, and individual case illustrations (eg O'Brien and Mount, 1989) show that irrespective of the level of intellectual disability or the nature of additional problems, people with intellectual disabilities can

have close personal relationships; but the studies cited indicate the scale of the difficulty to be overcome.

It is, therefore, not surprising that many people with intellectual disabilities are extremely socially isolated. Studies of people in residential settings, for example, often show low levels of contact from other staff and other residents, particularly for people with severe and profound intellectual disabilities (Emerson and Hatton, 1994; Felce and Perry, 1995; Mansell, 1994). Studies of the social networks of people with intellectual disabilities show that they are often extremely restricted and dominated by family and staff. Cambridge *et al* (2001) found that, on average, people living in the community twelve years after deinstitutionalisation had very limited social networks compared to the wider population. They found that only 19% of members of these networks were unrelated to intellectual disability services. Robertson *et al* (2001) found even smaller networks. Forrester-Jones *et al* (submitted) found that people with mild or moderate intellectual disabilities attending a supported employment programme had networks averaging less than 50 people and nearly two-thirds of network members were staff, family or other service users. Building the 'circle of support' required around an individual to undertake person-centred planning is therefore likely to be difficult for many people in the White Paper target groups.

A third reservation about the scale of the task implied in the White Paper is the general difficulty in modern society of developing and sustaining relationships of the kind required. The language of person-centred planning is the language of reciprocity, mutual interdependence and community. However, community, in the sense of the closely knit, mutually supportive neighbourhood or village exemplified in sociological studies (eg Bulmer, 1986; Young and Willmott, 1986), is scarcer in reality than it is in rhetoric. In practice it is family, and overwhelmingly women, who undertake the role of helping people with substantial needs (Dalley, 1988). If tradition and duty are less important than they might once have been in recruiting and sustaining a 'circle of support', then other sources of motivation are important. As Bulmer (1987) points out, the most convincing general explanation of the nature of caring relationships is reciprocity. What sustains and nurtures helping relationships among people who are not kin is a sense of exchange and balance in the relationship. Here, people with very substantial disabilities face a particular problem, in that they may have great difficulty

maintaining the sense of balance required in the relationship. Qureshi, Challis and Davies (1989) note the importance of payment to community care helpers as a way of enabling recipients of care to feel that this balance is maintained. The difficulty of recruiting citizen advocates for people with intellectual disabilities perhaps reflects this as well as purely practical problems.

Assessing the policy initiative

There is now no serious alternative to the principle that services should be tailored to individual needs, circumstances and wants. It is hard to remember a time when services for people with learning disabilities were not expected to be individualised. But in the 1960s, in Britain and North America, custodial care, depersonalisation, block treatment and rigidity of routine were the norm. People did not have their own clothes; their possessions were taken away, or lost, or destroyed, or stolen by staff. There was no expectation of change and therefore no need to plan anything (Blatt and Kaplan, 1966; Morris, 1969).

Individualisation of service organisation has been accompanied by the development of assessment and planning tools, from early work on goal planning (Houts and Scott, 1975) through to care management (Challis and Davies, 1986). However, it has also been accompanied by the investment of much greater resources in service provision and by new, smaller-scale services in the community (Mansell and Ericsson, 1996). Greater individualisation in practice may, therefore, be the result of a number of different aspects of the great changes in service provision, acting alone or in combination. It may owe at least as much, for example, to changes in the kinds of services provided and the associated changed attitudes of staff as it does to particular methods of planning.

Assessment of the weight given to person-centred planning in the 2001 White Paper *Valuing people* therefore requires evaluation of the contribution made by planning systems as distinct from other changes in service organisation (ie answering the question “are individual plans effective?”). If person-centred planning is not likely to deliver the benefits required in terms of individualising services and driving their redevelopment, then its adoption as a central plank of the policy seems problematic. In particular, the diversion of large amounts of time, effort and money into switching

from existing planning systems to person-centred planning may not be justified if this turns out to be 'more of the same'.

Are individual plans effective?

As Kinsella (2000) points out, there is almost no evidence of the effectiveness of person-centred planning compared to other approaches. What evidence there is largely comprises individual case studies referred to in the course of commentaries on the process and its desirability (eg Certo *et al.*, 1997; Department of Health, 2001a; Everson and Reid, 1997; O'Brien and Mount, 1989). A systematic review by Rudkin and Rowe (1999) found no statistically significant outcome differences with good statistical power for people receiving person-centred planning.

Despite the lack of an evidence base, there are studies of other forms of individualised planning which share some characteristics with person-centred planning. These include studies of individual programme plans in intellectual disability services, studies of care management arrangements and studies of the individualised planning process in special educational needs.

The first observation from these studies is that in practice individual planning only reaches a minority of service users. An inspection of day services by the British Social Services Inspectorate (1989) found that only 25% of service users had an individual programme plan on file. Felce *et al* (1998) report that during the implementation of the All-Wales Strategy for intellectual disability services the highest level of individual plan coverage achieved was only 33% of service users. Problems in resourcing the level of individual planning required are also evident in special education, where despite a legal mandate, half of education authorities fail to achieve the 18-week target for production of a plan (Audit Commission, 1998), and in care management, where failure to hold effective reviews have been identified as a common problem area (Challis, 1999).

Where individual plans are created, they are often a paper exercise. The Social Services Inspectorate (1989) found evidence that plans were in case notes but not

necessarily used. Radcliffe and Hegarty (2001) found that in two and three cases out of eight they studied in 1998 and 1999 individual plan goals were not translated into the daily programme of support to service users. Cambridge (1999) suggests that administrative interests predominate in care management assessment, with evidence of standard assessments that do not address the particular needs of people with intellectual disabilities (Challis, 1999).

There is also evidence from several larger-scale evaluations that individual plans are not well-connected to the real lives of people using services.

Shaddock (1991) found serious deficiencies in the planning process in 50 plans drawn from group homes for people with developmental disabilities. Clients, relatives, and advocates were often not present when goals were set. Long-term goals were often omitted. Typically, goals and objectives were not written in specific measurable terms, criteria were not stated, and the conditions under which the behaviour should occur were omitted. Cummins *et al* (1994) found that 19% of plans for 199 people had no review date and 30% of meetings were not attended by any family, friends or advocates of the individual service user. In a later study, Cummins *et al* (1996) analyzed 163 plans from 11 community living support services. The average level of presentation was poor. Only 14% offered any criterion for evaluating performance objectives, the average number of skill-building objectives was 3.25 per plan, and only 39% of plans were current. Conroy, Beadle-Brown and Mansell (submitted) compared 18 people who had functional individual programme plans with 18 who did not and found no difference between the groups in satisfaction, observed levels of engagement or records of participation in activity. Stancliffe *et al* (1999) evaluated plan objectives for 126 adults with mental retardation living in institutional or community settings and found no significant change in outcomes associated with having an objective. Miner and Bates (1997) found that participation in person-centred planning increased the extent to which parents or guardians contributed to individual educational planning or transition planning meetings. These families perceived that meetings were more favourable and almost all rated person-centred planning as valuable and effective, although there was no difference in their satisfaction with the meeting.

Thus, case studies suggest that person-centred planning can be valuable and may change the perception of participants. There are no good-quality, systematic evaluations of person-centred planning, but since person-centred planning shares many characteristics with previous attempts at individual planning evidence from these is relevant. This evidence suggests that when implemented on a large scale, there are problems with coverage, quality and outcomes. In order to achieve greater individualisation of service organisation and delivery, it may therefore be helpful to analyse why earlier attempts at individual planning appear to have failed.

Why do individual plans fail?

Resource constraints

A recurrent theme in reviews of care management is that an important factor shaping the operation of such individualised planning systems is the need for service organisations to control expenditure (Challis, 1999). In the absence of effective financial information systems enabling devolved budgets, the freedom for care managers to design individually tailored arrangements is likely to be constrained. This appears to be achieved through the introduction of waiting lists, the use of standardised procedures for assessment (*prix fixe* rather than *à la carte*), the bureaucratisation of management processes and the reservation of funding decisions to higher-level managers removed from direct contact with service users.

An important factor in the British context may be that, unlike the United States of America, individualised service plans are not legally mandated. The scope for redress if aspirations are ignored or subverted is therefore very limited. Even in British special education, where there is a legally enforceable right to a plan, delay and a restricted range of options appear to have been used to ration resources. Administrative culture may therefore be as important as legal entitlement in promoting meaningful individual planning.

If cost control does intrude in this way the implication is that simply changing the style of planning, from whatever went before to person-centred planning, is unlikely to make any difference. It would be expected that, if person-centred planning became at all widespread, mechanisms would be developed to constrain it within financial limits.

One particular risk that person-centred planning presents in this respect is that it explicitly embraces the idea that informal care is important and possibly even preferable to formal service provision. Thus it opens up the possibility for service agencies to define activities, which they would previously have funded as now the responsibility of the 'circle of support'. There is some evidence from the care management literature of emotional support and counselling not being provided even though identified as areas of need in their own right (Challis, 1999), which might reflect rationing judgments that some kinds of services are not to be provided by the formal sector.

This suggests the possibility, therefore, that the failure of individual planning is not primarily due to lack of understanding or to the particular kind of planning approach used, but a by-product of the need for public agencies to control their budgets. In this sense, failure may be functional; it may serve the purpose of the organisations involved.

Implementation gap

A second feature evident in evaluation of individual plans is what might be called the *implementation gap* – the failure to carry through plans into practice. Although the evidence is limited because so few studies have addressed outcomes – real changes in the lives of the people with intellectual disabilities studied – there are sufficient grounds in the literature cited to be concerned that person-centred planning (or any other kind of individual planning) is largely a paper exercise.

The explanation for this is implicit in the White Paper *Valuing people* is that there is insufficient understanding (and so the appropriate reform is more training in how to do person-centred planning). The alternative formulation given above is that lack of resources prevents implementation and undermines the motivation to take planning seriously. In addition, there is a further aspect of individual planning which may help explain its limitations in practice; that is, the relationship between objective setting and the skills and daily practice of staff providing support.

There is extensive evidence that front-line staff working with people with intellectual disabilities, especially people with severe and profound intellectual disabilities, typically provide little in the way of facilitative assistance to support engagement in

meaningful activity at home and in the community (Emerson and Hatton, 1994; Perry and Felce, 2003). In consequence, levels of engagement are low, with related evidence that people do not continue to develop and grow in competence in adult life (Cambridge *et al.*, 2001) and have restricted social networks and relationships. Only a small proportion of these staff are trained (Ward, 1999), and recent Government initiatives acknowledge this and include attempts to substantially increase training (Department of Health, 2001c, 2002). Therefore, if individual plan goals are developed which involve providing skilled support to the individual (for example, in accessing unfamiliar places and situations, or in coping with much higher levels of stress and demand) it is likely that staff will not be able to provide sufficiently skilled help for people with more complex needs.

Thus, where goals have resource implications – moving from a residential home to supported living, for example – expenditure constraints may prevent their achievement. Where they are concerned with changing individual experience without major new resources – such as helping a person with severely challenging behaviour to shop more independently – skill shortages among staff may do so. Both situations are likely to lead to individual planning becoming a paper exercise with little impact on real life. In a sense, staff working through these processes in services are once again in the grip of a ‘readiness’ model, not for the client but for the service - “we are waiting until the person gets a new home/job/we get training/policy changes/we are reorganised”. In this situation, individualised planning becomes a kind of displacement activity, using staff energy, time and resources but not making any difference to people’s lives.

Is a new kind of planning going to change this? Is pushing investment into training lots of people to make individual planning person-centred the best use of resources?

What would it take to make services more person-centred?

The implication of this analysis is that making British services more person-centred will not result from attempts to achieve the widespread introduction of a new model of individual planning. Rather, it directs attention to the way services are funded and to the skills staff have.

The first area in which change is needed to address the balance of power that diminishes the potency of individual aspirations in public planning processes is to strengthen the hand of the individual service user against social services departments in determining the goals and implementation of any individual plan. There are several ways, which are not mutually exclusive, in which this might be achieved:

- (i) Person-centred planning could be given legal weight, as is the case in some other countries. This might be based on legal entitlement to fair, humane and effective treatment based on a constitution or on human rights legislation. This would allow individual service users to challenge failure to provide services to help them achieve what they want and to test the decisions of public agencies in terms of their reasonableness. As British special education experience shows, legal entitlements are not everything; but in those countries where they exist there is evidence of them being used to secure improved services.
- (ii) Funding decisions could be decoupled from individual planning by replacing local budgets managed to a fixed level, with social security entitlements based on assessed status. This would give service users with disabilities of a set degree an absolute entitlement to a particular level of funding; it would re-focus individual planning arrangements in social services departments on the content of the plan and on helping people achieve better lives, instead of on rationing.
- (iii) More use could be made of direct payments and user-controlled trusts/independent living trusts for people with severe intellectual disabilities as well as those with more mild disabilities. This would potentially empower service users in achieving their individual plan, providing more security and consistency of service (in that once agreed, it is harder for a direct payment to be taken away or reduced in amount without evidence of mismanagement of the direct payment). However, for this to happen, local authorities need to be more open to the possibility of trust-managed direct payments.
- (iv) National policy could set the expectation that personal goals and plans would be resourced and achieved, instead of maintaining an equivocal stance that

asserts on the one hand that person-centredness is a high priority but avoids, on the other, holding local social services departments to account for its delivery.

- (v) Performance management by government could focus not on numbers of plans produced, but on the quality of the plans and the extent to which they are implemented. The focus of policy implementation and monitoring could shift from person-centred *planning* to person-centred *action*. This would be likely to require a shift from a rationalist policy implementation framework, in which implementation is treated as a largely mechanical process, to focus on what Wenger and Snyder (2000), cited in O'Brien and O'Brien (2000), call communities of practice - "groups of people informally bound together by shared expertise and a passion for a joint enterprise". The development of such communities, with evidence of real effects in the lives of the people they serve, would be a higher priority than extent or coverage of plans.

This directs attention to the quality of work of staff providing support and advice to people with intellectual disabilities and their families. Whatever national policy says, it is these staff who make it a reality or not. Here too there are several steps that could be taken to make services more person-centred:

- (i) Training in the goals of service provision could emphasise action that makes a tangible difference in the daily lives of people with intellectual disabilities as a priority, and distinguish this from action, which is consistent with appropriate values but does not actually lead to change. This is likely to require a balance to be struck between relatively ordinary and more special activities. Ordinary, even mundane activities, which occur frequently and do not necessarily require great resources to change, (but from which many people with intellectual disabilities are excluded through lack of appropriate staff support) may be important opportunities for personal growth, development and empowerment. The kind of dramatic, difficult, expensive activities which are often identified as important (because of the belief that they will transform expectations about individual people with intellectual disabilities) do not necessarily have much impact beyond the event itself.

- (ii) Staff training could focus more on ways of facilitating real change for people with intellectual disabilities, instead of on individual planning systems. For staff with care management responsibilities, these would include brokerage skills. For those providing or managing direct support to individual, these would be likely to include approaches such as active support (Felce, Jones and Lowe, 2000) and positive behaviour support (Kincaid and Fox, 2000). These approaches help staff develop skills to facilitate greater participation in activities and relationships by people with complex needs.
- (iii) The supervision and monitoring of the quality of support provided by staff to the people they serve could focus on real changes in the everyday lives of people rather than on plans and planning.

These changes would be entirely consistent with the aspiration of proponents of person-centred planning, that it should be a process of “continual listening, and learning; focussed on what is important to someone now, and for the future; and acting upon this in alliance with their family and friends” in which “having meetings, involving the person and making the plan is not the outcome. The outcome is to help the person to get a better life on her own terms” (Sanderson, 2000). They also reflect the concern of some (Black, 2000) that making person-centred planning a prescription in national policy is unlikely to produce the changes wanted in the lives of individual people with intellectual disabilities. As O'Brien and O'Brien (2000) point out,

“agencies that want to benefit from person-centered planning often act as if person-centered planning were a sort of tool box of techniques which staff could be trained to use in workshops by studying protocols, hearing about ideas, and perhaps trying out a technique or even two for homework. Such context-free training no doubt teaches something, but we think it deprives learners of the kinds of social supports for inventive action that were available to the people who developed the first approaches to person-centered planning.”

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