Risks and opportunities of personal plans and budgets
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Introduction
In this presentation, I want to set out some of the risks as well as the opportunities of greater personalisation. In this, I will draw on some of our recent work looking at the introduction of person-centred planning following the 2001 White Paper *Valuing people* (Mansell and Beadle-Brown, 2004). The general background against which my comments are framed is one in which greater individualisation of services is already a well-embedded principle; almost all large institutions for people with intellectual disabilities have been closed; large day centres are beginning to be turned into resource bases which organise individualised programmes of work, education and leisure activity. Most people with intellectual disabilities who leave their family home now live in small group homes of 3-6 people. These changes have, in general, brought many benefits to people with intellectual disabilities. But not enough has changed and this has led to renewed interest in person-centred planning and personal budgets as a way of improving services.

Origins of personalisation in the British context
The pathway followed by services to reach the current point, where personalisation of services is regarded as central, began with attempts to introduce individualised goal plans (Houts and Scott, 1975) to structure therapeutic intervention by staff. Soon these developed into more comprehensive individual programme plans (Accreditation Council on Services for Mentally Retarded and Other Developmentally Disabled Persons, 1983; Blunden, 1980; Jenkins et al., 1988) or individual service plans (Brost et al., 1982; Emerson et al., 1987). These later approaches to planning were comprehensive both in that they focused on all aspects of the individuals life, and in that they included service design and organisation as well as care practices. In their latest iteration, these are now person-centred plans (O'Brien and O'Brien, 2000).

Person-centred planning emphasises three additional characteristics found wanting in earlier planning approaches. 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).

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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 knowledge of and interest in the individual that family and friends have, so 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 p6)

These changes essentially apply to the administrative processes of care. Alongside them, there has been a parallel of increasingly individualised funding. In Britain, this has two distinct roots. First, as institutions began to be closed in favour of community-based housing and support, a mechanism had to be created to transfer funds from the organisation providing the institution to the many different organisations providing community services so that there would be an effective incentive for them to set up new services. At the beginning of the 1980s, ‘dowry’ payments were invented to do this. Regional authorities funded community service organisations with a fixed amount for every individual they resettled from the institution (Mansell and Ericsson, 1996). The regional authorities managed the transitional costs of institutional closure. Although eventually subsumed in the general system of allocating public resources for care, the dowry system created a service culture of focusing on individuals and the resources available to support them, rather than on services and organisations.

The second root of current interest in personalised budgeting came from studies of the efficiency of residential care, particularly for older people (Challis and Davies, 1986; Davies and Challis, 1986). This showed that there were many people receiving residential care at public expense who had lower support needs than people living on their own in the community. A model of case management was developed from American experience, which showed better outcomes and lower costs if care managers were given budgets with which to support informal and domiciliary care of people at risk of admission to residential care. This model was adopted throughout the UK after 1989 (Department of Health, 1989).
Both these developments in individualising funding left the money in the hands of professionals. However, an important third influence on policy has concerned giving resources directly to disabled people (what are now called ‘direct payments’) so that they can organise their own services, blending and selecting components as they wish (Beadle-Brown, 2002). Although promoted as an extremely important development, the take-up of direct payments has been rather low (Commission for Social Care Inspection, 2004; Department of Health, 2004).

The opportunities presented by personalisation
What is it that people seek from the increased personalisation of services and funding?

First, it is clear that a prime concern is *individualisation*. Personalisation is intended to make services more finely tailored to the needs and wishes of the people who use them. A constant criticism of existing services is that what they provide is determined by the needs and characteristics of the service not the person. This happens at the level of selecting which services are provide to an individual. For example, a recent British report gives this example:

“When the social worker came to see me she said she would assess me for whether I would qualify for direct payments or home care services. Actually what I wanted was to go to college to do an IT course so I could get a job. And I need help to do that.”

(Great Britain Prime Minister's Strategy Unit, 2005 p64)

Once services are selected, lack of individualisation is also reflected in the way the person is treated. For example, a residential home may have policies and practices which suit most people but which cause problems for particular individuals. In England, for example, regulations were recently introduced to require everyone in a residential home to be given their own bedroom; and then it was immediately discovered that some people who had shared rooms for many years wanted to continue to do so.

Personalisation is also about *responsiveness*. People’s needs and wishes change over time and one of the opportunities that personalisation presents is that services can be adapted as needed to reflect these changes. This also applies at a broader level – for example, people who need more support may have to move to a different residential home – and at an everyday level, in terms of shaping activities and help from staff to fit round individual wishes.

The third opportunity presented by personalisation is *control*. Individualisation and responsiveness could, perhaps, be provided by organisations which themselves assess and direct the form and content of services they provide. What proponents of personalisation seek is that the individual should be able to control services. This reflects the belief that people using services are often best-placed to work out what help they need (Great Britain Prime Minister's Strategy Unit, 2005 p71) but also that they can be more effective than service agencies at managing and directing their own package of services.
Individualisation, responsiveness and control are benefits experienced by individuals. Personalisation also offers benefits to society. Principally, it offers the prospect of **effectiveness**, **efficiency** and **sustainability**.

Effectiveness of public services is increased if personalisation leads to better targeting of need (because self-assessment is more accurate) and more effective interventions (because they are directed by the individual themselves). Insofar as increased effectiveness entails less waste (through not providing services that people do not need) and lower needs (through preventative intervention) it will increase efficiency, allowing more people to be served or better services to be provided. And because personalisation permits the better integration of formal and informal care (that is, of care provided by service agencies and care provided by members of the family and neighbourhood) it ought to lead to services that are more sustainable over the long term, because of the sense of commitment of family and friends, secure in the knowledge that their efforts are supported.

**The risks of personalisation**

In our recent work on person-centred planning (Mansell and Beadle-Brown, 2004), we pointed out that the scale of the proposed implementation was extremely demanding. By now, ‘significant progress’ is supposed to have been made in introducing person-centred plans for over 80,000 people.

The guidance that has been issued (Department of Health, 2001a, b) emphasises that planning must be a creative process in which the individual person with intellectual disabilities must be fully involved and that a ‘circle of support’ made up of family and friends has a central role to play. This is a substantial task given the degree of disability of many people receiving services. For example, a recent study of adults in residential care (Mansell et al., 2002), we 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 the 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; Forrester-Jones et al., 2004; Robertson et al., 2001). 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.

Against this background, the experience of previous attempts to introduce individualised planning is instructive. 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. Plans may be in case notes but not necessarily used to shape the daily programme of support to service users (Radcliffe and Hegarty, 2001; Social Services Inspectorate, 1989). Cambridge (1999) suggests that administrative interests predominate in care management assessment, and there is evidence of standard assessments that do not address the particular needs of people with intellectual disabilities (Challis, 1999). We also see, in the development of direct payments to disabled people, the development of bureaucratic rules designed to protect public agencies from risk rather than support people to lead the kind of lives they want (Commission for Social Care Inspection, 2004). For example, I recently met a man and wife, both disabled, who were told that they were expected to keep separate receipts for their and their children’s food and clothing, so that the public authorities could be sure that their direct payments were being used for them and not their children. I am pleased to say that they declined to do this.

The first risk of personalisation must therefore be that it is administratively unfeasible. In the face of the scale of the task, practices are likely rapidly to become standardised and focused on form-filling rather than real change in people’s lives. The complexities of individual disabilities and the social isolation of many people with intellectual disabilities make it more likely that the central distinguishing characteristics of person-centred planning are overlooked.

A second risk of embracing personalisation as the basis for service organisation is whether the required range of services is available from which people can construct their own individual package of care. Most British experience to date is of people with physical disabilities using resources to employ personal assistants – people
without professional training, directed by their employer to help as required. Extending personalisation will mean finding people with the qualifications, skills and resources to provide much more intensive services to people who are not themselves able to organise and direct them. There is evidence from British experience of creating a market in social care services that it is difficult to create and sustain a sufficiently wide range of services, especially for people with the most complex needs. In this situation, individual choice and control is constrained to what is available.

Similarly, we do not know whether there are enough interested people to play the role of helping the most intellectually disabled people organise their care and whether such arrangements provide a sufficiently robust defence against their self-interest and low expectations.

Finally, there is the political risk of blurring individual entitlement to service. I said earlier that a key feature of person-centred planning was the emphasis on blending the contribution of formal services and the practical support and help of family and friends. If this is driven by the wishes of the individual, choosing which services they need to support rather than replace the help they get from family and friends, then perhaps it leads to better quality of service and greater efficiency.

But suppose that it begins to be driven by the state? The language of person-centred planning is the language of reciprocity, mutual interdependence and community. However one should ask why these policies prove attractive to neoconservative and liberal governments at a time when the policy imperatives are to constrain welfare expenditure. There must be the risk that personalisation inadvertently opens the door to redefining the responsibilities of the disabled person and their family so that more of the support required falls to them. 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. Thus personalisation could lead to a shift in the costs of care - costs including finance but also including the cost of lost opportunities, lower quality of life and lost years of life - back from the community to the individual person, their family and friends.

This may be particularly likely if personalisation leads to what the Norwegian researcher Sandvin calls ‘de-differentiation’. De-differentiation is the loss of special, separate policies and service structures for people with intellectual disabilities and their replacement by general policies and structures. De-differentiation is the consequence both of the active belief in intellectual disability – for example in the normalisation literature - that specialist services are bound to be discriminatory, and of the spread of deinstitutionalisation to other client groups so that implementation issues are addressed as part of the general modernisation of social care.

De-differentiation involves the replacement of specialist models tailored to the needs of people with intellectual disabilities with generic models which have to apply to other client groups. So, for example, the invention of regulatory systems, occupational health and safety arrangements and other mechanisms that apply to all services inevitably impose constraints based on assumptions that may not be relevant in
intellectual disability. The consequences of de-differentiation include greater competition for priority for resources and a lack of recognition of special issues. In a sense, reform and improvement opportunities in intellectual disability services are increasingly in competition with those in other sectors, at a time when understanding of the specific issues and problems of intellectual disability grows less.

Ironically, in this context, personalisation might lead to less opportunity, because the special needs of people are no longer visible at the group level, where competition for resources is played out.

**Safeguarding personalisation**

Thus, personalisation offers the prospect of great benefits, but also some risks which could undermine it. The task, therefore, is to work to safeguard the true intentions of personalisation in a context which may not be particularly supportive.

Broadly speaking, I suggest that safeguarding personalisation will require three areas of activity outside and in addition to the system of person-centred planning. The first of these is the development of a framework of enforceable entitlements to services. At the heart of the process of personalisation is the question of power. Personalisation is not just a series of convenient changes in administrative process; for it to work, personal needs and aspirations have to be listened to and acted upon. Power will not be readily given up by existing vested interests and so we can expect a struggle ahead.

Enforceable entitlement is likely to mean both, on the one hand, laws and regulations that express a right to a personal budget and the help and advice to effectively use it; and, on the other, social solidarity so that attitudes towards and perceptions of disabled people support the level of public resources required.

Social solidarity will also be needed at a much more local level. ‘Circles of support’ and personal assistants in great numbers are going to be needed. There is no evidence that they are forthcoming in a situation where disability is treated as a private tragedy rather than as part of community diversity. So the second area of activity required is going to be ‘community development’ – locality-based social work that builds the sense of shared values, social responsibility and local commitment to supporting disabled members of the community. I guess that in our kind of society we should expect that families will continue to be the most important advocates for and supporters of disabled people; but effective personalisation requires the support in principle of taxpayers and the goodwill and practical help of many members of the public.

The third area of intervention required will be work by the public administration to stimulate the development of a much wider range of models of service and assistance. Personal plans and personal budgets are no use at all if the only things you can buy are more of the same. Britain’s experience of more individualised arrangements managed not by the disabled person themselves but on their behalf by a care manager has not been promising in this respect. However, this may be because care managers are more likely to buy traditional patterns of service and because innovation is stifled by budget constraints. It may be that disabled people themselves, or their families and representatives, will do better. Either way, there is an important job to do for government. This may involve directly encouraging new kinds of service through, for
example, providing financial incentives, training and help to start new organisations. It will certainly involve developing the necessary infrastructure – for example, through the training of sufficient people to be skilled personal assistants, advisors and specialists for people with complex needs and the revision of regulatory frameworks which create perverse incentives to provide the wrong kind of service.

**Conclusion**
The language of personalisation has current political potency. It sounds like (to use Ingrid Körner’s words) the realisation of ‘our dreams’. However, as I have tried to show, the rhetoric conceals some ambiguity about motives. People with intellectual disabilities and their supporters see the opportunity for better quality of life; government may see the opportunity to save money and reduce the public profile of the issue. There are risks to be managed. These risks are not going to be addressed by the tools of person-centred planning – by doing it in this way or that way. They require strategic action by public authorities in other domains.

**References**


