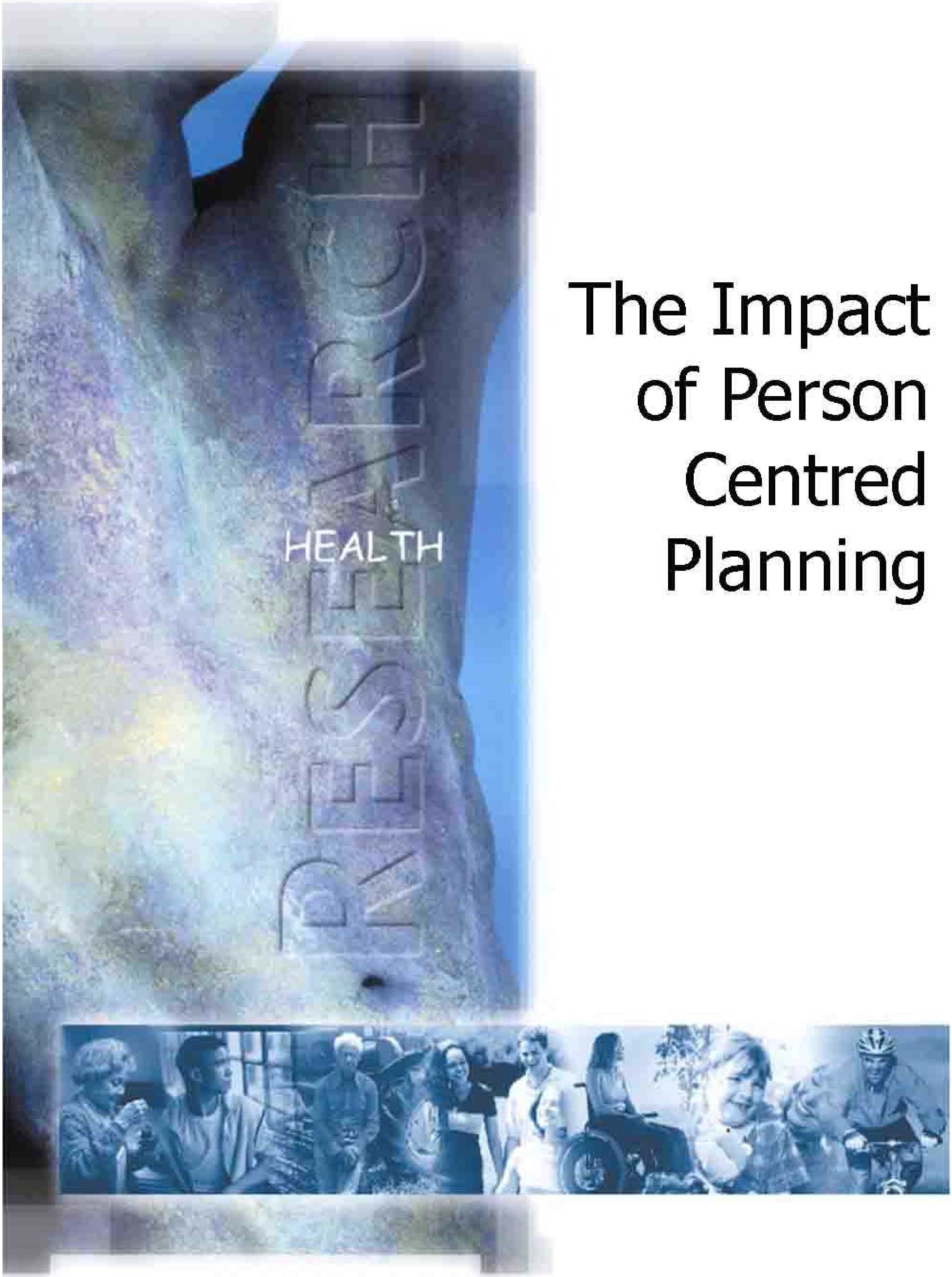
The Impact of Person Centred Planning



The Impact of Person Centred Planning

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We would like to thanks all the people in the four sites who worked to make person centred planning a reality for so many people, and who also put up with our unending questions.

Contents

Summary

Background

In 2001 the Department of Health published a new White Paper (*Valuing People*) that set out a strategy for the development and delivery of health and social care services for people with learning disabilities in England. A central component of this new strategy was to require Learning Disability Partnership Boards to introduce person centred planning (PCP) as a means of increasing the extent to which supports were tailored to the needs and aspirations of people with learning disabilities. The White Paper expectations were translated into 'section seven' guidance in LAC (2001) 23 and good practice guidance published in 2002 as *Planning with People – Towards Person Centred Approaches*.

At the same time the Department of Health launched the Learning Disability Research Initiative. This was a policy related programme of research that sought to commission a range of research projects addressing issues relevant to the new policies laid out in *Valuing People*. Our project was commissioned by the Department of Health under the Learning Disability Research Initiative. Additional funding for the project was provided by the Foundation for People with Learning Disabilities.

The main reasons for commissioning the project were that there was, at that time, no robust evidence either of the impact of introducing PCP or of those factors which may either facilitate or impede the introduction and effectiveness of PCP.

Thus the mains aims of our project were to:

- Evaluate the impact of the introduction of PCP on
    - the life experiences of people with learning disabilities
    - the nature and costs of supports provided to people with learning disabilities.
- Identify personal, contextual and organisational factors which appear to either facilitate or impede the introduction and effectiveness of PCP

The Project

In order to pursue these aims, our project was comprised of four distinct, but related, components.

First, we undertook development work with organisations in four localities in England. The selection of localities was based on two main factors.

- That the organisations within the localities showed evidence of a commitment to implement PCP in order to enhance the life experiences of people with learning

disabilities. That is, we attempted to exclude localities whose primary commitment appeared to be to implement PCP in order to fulfil organisational obligations and requirements. We evaluated the commitment of organisations through local knowledge of members of the research team and discussion with key managers in candidate organisations.
- That the sites, in combination, would provide a high degree of diversity with regard to the characteristics of communities and participants. Thus, for example, we sought to include localities that varied with respect to level of affluence, urban/rural location and the ethnic mix in the communities served.

The essential aim of the development work was to provide additional support to local organisations to help them develop robust policies procedures and practices to implement PCP. The nature of the development work and the conclusions drawn by the external consultants who undertook the development work are presented in Chapter 2.

The evaluation side of the project involved three related components that addressed distinct questions. They were:

- What impact does the introduction of PCP have on the life experiences of people with learning disabilities?
- What costs are associated with the introduction of PCP?
- What organisational factors impede or facilitate the introduction and effectiveness of PCP?

We addressed the first question by attempting to follow over a two year period each of the first 25 people in each site who participated in the PCP process. In Chapter 3 we describe the characteristics of the people who participated and present results relating to the efficacy and effectiveness of PCP in improving the life circumstances of people with learning disabilities.

We addressed the second question by documenting the costs associated with developing and implementing PCP in each of the four sites and by determining the impact of the introduction of PCP on the costs of supports for the first 25 people in each site who participated in the PCP process. We present the results of these analyses in Chapter 4.

We addressed the third question by undertaking interviews with managers and practitioners in each of the four sites, reviewing documentation and attending meetings. A detailed description of the approach taken and results of this organisational-level analysis are presented in Chapter 5.

Summary of Results

Person Centred Planning Leads to Improved Life Experiences for People with Learning Disabilities

The results of the evaluation clearly indicated that the introduction of PCP had a positive benefit on the life experiences of people with learning disabilities. Even when we employed the more conservative ‘intent to treat’ analyses to evaluate effectiveness (rather than efficacy), PCP was associated with benefits in the areas of:

- community involvement
- contact with friends
- contact with family
- choice.

These positive benefits are consistent with the comments made by the participants themselves, claims made by advocates of PCP and the results of the very small number of previous studies that have sought to formally evaluate the impact of PCP. They also support the current emphasis within health and social care policy current UK on using PCP to improve the life chances of people with learning disabilities.

The Benefits of Person Centred Planning Vary Across Areas of Life, People and Contexts

While the results of our evaluation indicated that PCP was both efficacious and effective, they also suggested that the impact of PCP varied markedly across the domains of ‘quality of life’ we investigated, across people and across the contexts in which people were living.

Across Areas of Life

While PCP was associated with benefits in some domains of ‘quality of life’, it had no apparent impact on others (e.g., more inclusive social networks, employment, physical, activity, medication) and there were three areas (risks, physical health, emotional and behavioural needs) where there was evidence of change in a ‘negative’ direction.

This pattern of results (benefits in the number and variety of community-based and non-inclusive social activities, but no change in ‘stronger’ markers of social inclusion) mirrors that of research that has evaluated the impact of deinstitutionalisation. This similarity suggests that, rather than representing a radical departure from previous practices, PCP builds on the existing capacity of services and supports. In other words, PCP may be best considered an evolutionary step in the long-standing trend towards the increasing individualisation of supports and services.

Across People

Our analyses of factors that were associated with the uptake and efficacy of PCP highlighted the importance of a number of characteristics of people with learning disabilities.

- *People with mental health or emotional or behavioural problems* were less likely to receive a plan and less likely to benefit of they did receive a plan in the areas of size of social networks, contact with friends, contact with family, choice, hours per week of scheduled activity and (depending on the measure used) number of community activities.
- *People with autism* were less likely to receive a plan.
- *Women* were more likely to benefit in the areas of number of community activities and choice. *Men* were more likely to benefit in the areas of number of hours per week of scheduled activity and contact with friends.
- *People with more health problems* were less likely to receive a plan, but if they did were more likely to benefit in the areas of contact with friends.
- *People with restricted mobility* were less likely to receive a plan, but if the did were more likely to benefit in the areas of contact with family, hours per week of scheduled activity and number of community activities.

These results, and in particular those relating to mental health and autism, indicate some powerful inequalities in the extent to which people are likely to receive a person centred plan and, if they do, the level of benefits they can expect. Similar inequalities have previously been reported in a wide range of studies on supported accommodation and the general life experiences of people with learning disabilities in England.

Across Contexts

Similarly, a range of contextual factors appeared to be associated with whether people were more or less likely to receive a PCP and, if they did, the likelihood that they would benefit.

- The *existence of more person centred ways of working prior to the introduction of PCP* was associated (perhaps unsurprisingly) with increased chances of getting PCP. It was also associated with *increased* chances of benefiting in the areas of hours per week of scheduled activity and choice, but with *decreased* chances of benefiting in the areas of size of social networks, number of community-based activities and contacts with family. These apparently contradictory results may reflect the success of pre-existing IP systems in addressing the latter three areas, thus leaving less scope for further improvements following the introduction of PCP.
- *Having a care manager* was associated with benefits in the areas of: size of social network; number of community-based activities; choice; and contact with family. It was associated with reduced benefits in the area of contact with friends.
- Similarly, *living nearer to one's family* was associated with increased chances of getting PCP. It was, however, also associated with *decreased* chances of

benefiting in the areas of contact with family, contact with friends and hours per week of schedules activity. Again, these results could reflect higher rates of such activities prior to the implementation of PCP, thus leaving less scope for additional improvements.
- *Living in a less affluent area* was associated with benefits in two areas: size of social networks and choice. These results do need to be interpreted with some caution as the more affluent areas in our study were also very rural areas which would be expected to offer fewer opportunities for social activities.

When these analyses were restricted to people in supported accommodation a number of factors appeared to be associated with the chances of getting a plan and the benefits derived for those people who did get plans.

- The probability of getting a plan was associated with possible indicators of leadership, stability of the staff team and, as above, evidence of the prior existence of person centred approaches.
- However, factors associated with the chances of benefiting in particular areas were often indicators of what would be commonly taken to be poorer quality services (e.g., not having a tenancy, poorer internal planning systems, more institutional practices). As above, it is possible that these are simply indicators of increased capacity to benefit (in that the ‘better’ services have less room for improvement).

The analysis of variability highlighted the potential importance of a number of factors associated with the *process* of PCP.

- Indicators of the *commitment of facilitators* to PCP was the most powerful predictor of whether people would get a plan and was also related to increased chances of benefiting in the areas of: choice; contact with friends; hours per week of scheduled activity; and size of social networks.
- Indicators of the *personal involvement of the focus person* with learning disabilities (e.g., in directing their own meetings) was associated with increased benefits in the areas of: size of social network; contact with friends; and choice.
- The *identity and role of facilitators* was associated with increased benefits in a number of areas. First, facilitators for whom facilitation was part of their formal job role were more likely to deliver plans and appeared to deliver greater benefits in the areas of size of social networks; hours per week of scheduled activity. Facilitators who were managers within services were associated with greater benefits in the areas of: size of social networks; choice; and community activities. Having a facilitators who was a members of support staff, however, was associated with benefits in one area (size of social networks), but disadvantages in three (community activities, contact with friends, contact with families).

The Introduction of PCP was Not Associated with Any Change in the Costs of Supports to Participants

The direct training and implementation costs per participant were

- £658 if these were calculated across all 93 participants (i.e., including those participants to whom the ‘intervention’ was not delivered) or
- £941 if they were calculated across the 65 participants to whom the ‘intervention’ (delivery of a plan) was delivered.

However, these costs are likely to fall over time as local capacity is built and training is carried out by external trainers but undertaken in house.

For the full sample, the average weekly service package cost per participant before the implementation of PCP was £1,326. By the end of the study this had risen by 2.2% to £1,356. This increase was not statistically significant. For the sub-sample for whom it was possible to develop and sustain a plan, the average weekly service package cost per participant before the implementation of PCP was £1,366. By the end of the study this had risen by 1.6% to £1,388. This increase was not statistically significant. The group for whom a plan was developed and sustained did not differ in their use of services either at the beginning or end of the study from those for whom it was not possible to develop and sustain a plan. Accommodation and associated care costs made up the bulk (88 per cent) of the costs.

Strengths & Limitations of the Study

As with all research studies, the results need to be considered in the context of the strengths and limitations of the study. We consider the main strengths of the study to be:

- the use of multiple methods (informant completed questionnaires, qualitative interviews with participants, organisational analysis);
- the comprehensive range of outcomes and processes addressed, including costs;
- the relatively large sample size and time-span over which data were collected.

To date, this study represents the largest most comprehensive evaluation of the costs and impact of PCP to be undertaken anywhere in the world.

The study does, of course, also have some limitations. We consider the two most important of these to relate to the time-span of the study and the confidence with which one can generalise the results to other organisations in England who are attempting to implement PCP in the early 21st Century.

While, as noted above, the two-year time-span over which the study was undertaken compares well with previous research, it was only sufficient to evaluate the short and (to an extent) medium-term impact of PCP. This is problematic given the difficulties known to be associated with attaining certain key outcomes (e.g., inclusive social relationships, paid employment) in the short-term.

The confidence with which one can generalise the results to other organisations in England who are attempting to implement PCP in the early 21st Century is dependent on the representativeness of the participants, the organisations and the broader policy context within which the organisations were operating.

- We did not employ any inclusion or exclusion criteria to select the participants. They were the first 25 people per site who were 'enrolled' in the local PCP process. As reported in the chapter '*The Impact of Person Centred Planning on the Life Experiences of People with Learning Disabilities*', they were a very diverse group whose abilities and needs covered the full range of those the needs and abilities of people with learning disabilities. We were not aware of any attempt within the four sites to select participants who may have been 'easier' to work with or whose situation may have suggested the opportunity for better outcomes. As such we are reasonably confident that the results could be generalised to other potential participants.
- The organisations were, as reported, originally selected on the basis of their apparent commitment to implement PCP in order to enhance the life experiences of people with learning disabilities. That is, we attempted to exclude localities whose primary commitment appeared to be to implement PCP in order to fulfil organisational obligations and requirements. It is important to note that we did not seek to recruit organisations who evidenced a very strong commitment and capacity to implement PCP. Rather, we sought to exclude organisations whose commitment was based solely on compliance with policy directives. This clearly raises a question regarding the representativeness of the participating organisations. It is not possible to provide a definitive answer to this question. However, we have no reason to believe that the localities selected were untypical of those authorities that are committed to implementing PCP to improve the life chances of people with learning disabilities.
- Finally, it must be kept in mind that the study was undertaken in the early stages of the implementation of PCP in English services. It was in light of this that we undertook development work with the participating organisations. This clearly raises a question regarding the representativeness of the policy and practice context within which the participating organisations were operating. Again, while it is not possible to provide a definitive answer to this question, it is our judgement that the four participating localities operating in policy and practice contexts that are not dissimilar to those faced by similar organisations in England today.

Implications for Policy and Practice

The results indicated that PCP, while being largely cost neutral, is both efficacious and effective in improving the life experiences of people with learning disabilities. It has also indicated that some people are more likely than others to experience the benefits of PCP and that the benefits associated with PCP may not extend into certain areas of peoples' lives without additional action. The results also identified some organisational characteristics that appeared to facilitate or hinder the introduction and efficacy of PCP. The task for the future is twofold.

- First, we need to develop policy and practice to ensure that as many people as possible gain access to the types of benefits that appear to be associated with PCP. This must involve directly addressing the types of inequalities in both access and efficacy that we have described in this project.
- Second, we need to learn more about the conditions under which PCP may have an impact on a broader range of outcomes. This would appear to be particularly important with regard to outcomes central to the social exclusion (e.g., employment, inclusive social networks) and positive health; outcomes that are central to the broader sweep of health and social care policy for adults in England.

These twin tasks will require action on a number of fronts. Specifically, they will require that services:

- maintain and enhance investment in PCP as an important component of service improvement
- develop robust procedures for ensuring and monitoring equity of access to and the impact of PCP
- ensure that services have the capacity for delivering person centred results
- continue learning about the conditions under which PCP delivers the maximum benefits for people with learning disabilities

Maintain and Enhance Investment in PCP

The results indicated that PCP leads to improvements in the life experiences of people with learning disabilities. PCP also reflects the core values of empowerment and personalisation that underlie contemporary approaches to health and social care in England. Indeed, there can be little doubt that the continued evolution of procedures to improve the ways in which supports can be tailored to the needs and aspirations of people with learning disabilities will constitute a core task for those commissioning and providing services and supports.

In order to help maintain and enhance the current levels of investment in PCP we recommend that the Department of Health develops a clear strategic plan for supporting the development of PCP. This should include plans for financially supporting development activities in the period following any termination of the Learning Disability Development Fund.

We also recommend that the Department of Health issue new guidance to Local Authorities and Primary Care Trusts on the implementation of PCP. Much has happened and been learned since *Planning with People* was issued in 2002. We recommend that this guidance should:

- Summarise current knowledge on the organisational context, policies and specific procedures that enhance the impact of PCP and reduce inequalities in access to PCP, with useful examples;
- Stress the importance of viewing PCP as one component in the development of polices and procedures to support person-centred action. As such, the guidance should also summarise current knowledge on effective policies and practices in the use of individualised budgets and service brokerage, providing examples and models;
- Highlight the need to tailor local approaches to local contexts. In order to do this, we suggest that the guidance includes a simple guide that would enable local commissioners and providers to develop a strategic approach to developing capacity that is sensitive to local concerns;
- Clarify the role of care management and specialist professionals in respect of person centred planning.

We also recommend that the Department of Health through SHAs seeks to ensure that professional training courses are equipping professional social and health care staff to work in person centred ways and have a familiarity with PCP. Similarly, training courses for first line and middle managers should equip them to use person centred thinking throughout their work, rather than person centred planning as an ‘add on’ to their responsibilities.

Develop Systems for Monitoring the Delivery and Impact of PCP

The results of the research that, while effective, the impact of PCP varies considerably across people, contexts and life domains. As a result, it will be important to develop simple robust approaches to monitoring equity of access to PCP and the impact of PCP.

Monitoring equity requires information to be collected on access to PCP in such a way that it can be linked to indicators of potential inequalities associated with geographic locality, social context (e.g., level of neighbourhood deprivation) and the characteristics of consumers (e.g., gender, age, ethnicity, support needs). At present, very few government returns allow for such comparisons to be made. It is recommended that the Council for Social Care Improvement (CSCI) consider the development of a standard approach for recording social context and the characteristics of service users that could be applied at local and national levels.

We also recommend that CSCI consider the development of one simple performance indicator through which access to PCP could be monitored. It is, of course, important that the any such indicator is defined in a manner which encourages the development of effective practice, rather than compliance with procedural requirements which can promote perverse incentives.

More important, however, is the need to develop robust procedures for monitoring the *outcomes* associated with PCP and other social care ‘interventions’. In this context we very much welcome the current commitment of the Department of Health to focus on the development of programme of work to develop measures of the outcome of social care for adults.

Ensure That Services Have the Capacity and Systems for Delivering Person Centred Results

The impact of PCP will always be dependent on the capacity of support services to deliver person centred solutions or action. Indeed, the constraints placed on the potential of PCP by local difficulties in developing and sustaining person centred solutions was one of the themes of our development work and organisational analysis.

We believe that the proposals laid out by the Department of Health in *Independence, Well-Being and Choice* (and in particular the proposal to make the use of individualised budgets central to the development of social care for adults in England) will significantly improve the ability of local services to deliver person centred action. For all to benefit, however, we believe that person centred planning and individualised budgets will need to be complemented by the kinds of support brokerage assistance upon which the Green Paper invites consultation. Attention will also need to be paid to developments in commissioning and provider services to ensure that they become increasingly responsive to what person centred planning tells services about people’s preferences. We recommend that the new guidance suggested above includes advice on better linkage between person centred planning and service commissioning and delivery systems, both micro and strategic.

To develop local capacity for change, services will need to invest in leadership in person centred planning, build the capacity of first line managers to use person centred thinking and planning, and find effective ways to support facilitators and link learning from planning to organisational change. It would be helpful for new guidance to produce examples and models to support organisations in developing their local capacity.

Continue Learning about the Conditions under Which PCP Delivers the Maximum Benefits for People with Learning Disabilities

The results of our research suggest that that PCP represents a positive step in the direction of delivering individualised support to enhance the quality of life of people with learning disabilities. It is not, however, a panacea. Neither does it appear to represent a radical departure with previous practice. The latter point is important.

If PCP is accepted as making a fundamental departure from previous practice then, by definition, evidence and experience related to previous ways of working (and why they failed) becomes irrelevant. If, however, PCP is considered an evolutionary step then such learning becomes highly relevant. This is not just a matter of semantics. Change within services for people with learning disabilities is often represented in a manner that denies the possibility of historical continuity. New models are often represented as providing ‘radical departures’ or ‘paradigm shifts’. Such an approach serves to discount prior experience and evidence, rather than build upon it. We believe that the evolution of services and supports for people with learning disabilities will be best served by the development of open minded organisations that have a desire to learn from past experience along with a willingness to embrace change and new ideas.

Final Comments

The results of this project have indicated that PCP is both efficacious and effective in improving the life experiences of people with learning disabilities, benefits that come without significant additional service costs. It has also, however, indicated that some people are more likely than others to experience the benefits of PCP and that the benefits associated with PCP do not extend into certain areas of peoples’ lives. The research has also identified some organisational factors that need to be attended to, for successful implementation. The task for the future is twofold.

- First, we need to develop policy and practice to ensure that as many people as possible gain access to the types of benefits that appear to be associated with PCP. This must involve directly addressing the types of inequalities in both access and efficacy that we have described in this project.
- Second, we need to learn more about the conditions under which PCP may have an impact on a broader range of outcomes. This would appear to be particularly important with regard to outcomes central to the social exclusion (e.g., employment, inclusive social networks) and positive health; outcomes that are central to the broader sweep of health and social care policy for adults in England.

Introduction

Eric Emerson, Martin Routledge, Janet Robertson, Helen Sanderson, Barbara McIntosh, Paul Swift, Theresa Joyce, Peter Oakes, Christine Towers, Chris Hatton, Renee Romeo & Martin Knapp

In this section we will present information on the background to the project. This will include information on the:

- commissioning and aims of the project
- policy context within which the project was undertaken
- evidence that already existed on the impact of person centred planning.

Background

In 2001 the Department of Health published a new White Paper (*Valuing People*) that set out a strategy for the development and delivery of health and social care services for people with learning disabilities in England.[1] A central component of this new strategy was to require Learning Disability Partnership Boards to introduce person centred planning (PCP) as a means of increasing the extent to which supports were tailored to the needs and aspirations of people with learning disabilities. A more detailed discussion of this policy context is provided below.

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At the same time the Department of Health launched the Learning Disability Research Initiative. This was a policy related programme of research that sought to commission a range of research projects addressing issues relevant to the new policies laid out in *Valuing People*. Our project was commissioned by the Department of Health under the Learning Disability Research Initiative. Additional funding for the project was provided by the Foundation for People with Learning Disabilities.

The main reasons for commissioning the project were that there was, at that time, little or no robust evidence either of the impact of introducing PCP or of those factors which may either facilitate or impede the introduction and effectiveness of PCP. A detailed summary of the existing evidence-base is provided below.

Thus the mains aims of our project were to:

- Evaluate the impact of the introduction of PCP on
    - the life experiences of people with learning disabilities
    - the nature and costs of supports provided to people with learning disabilities.
- Identify personal, contextual and organisational factors which appear to either facilitate or impede the introduction and effectiveness of PCP

In the following sections we will:

- Introduce the ideas and techniques that comprise PCP;
- Describe key aspects of the policy context within which PCP operates;
- Review the existing evidence-base relating to the impact of PCP
- Provide an overview of our research project

What is Person Centred Planning?

The past three decades has seen an increasing trend toward individualisation or personalisation in the design of services and supports for people with learning disabilities. Early manifestations of this trend were apparent in the development of Individual Programme Plans and the use of person-centred approaches to planning supports for people who challenged services.[2] More recently, person centred approaches have come to strongly influence innovation in the provision of supported accommodation[3 4] and the design and delivery of vocational, educational and recreational supports.[5 6]

PCP as a specific approach originated in North America in the late 1980s.[7-9] The development of PCP was influenced by a number of factors including dissatisfaction with the impact of Individual Programme Plans[10 11] and broader ideological developments reflected in theories of normalisation and social role valorisation,[12-16] the ‘five accomplishments’,[9] and the inclusion and disability movements.

A number of different approaches to PCP have evolved. These include Essential Lifestyle Planning,[17] Individual Service Design,[18] Personal Futures Planning,[7] MAPs[19] and PATH.[20] The different styles of PCP are used to answer the questions, ‘Who are you and who are we in your life?’ and ‘What can we do together to achieve a better life for you now and in the future?’.[18] They differ in the way in which information is gathered and whether the primary emphasis is placed on the detail of day-to-day life or on developing longer-term plans for the future.[18]

The Policy Context

PCP received its first English policy endorsement in *Valuing People*.[1] The White Paper expectations were translated into ‘section seven’ guidance in LAC (2001) 23 and good practice guidance published in 2002 as *Planning with People – Towards Person Centred Approaches*.[21]

Partnership Boards were expected to drive the development of person centred approaches within services and to start to make PCP available, with specific priority groups listed along with timescales by which substantial progress was expected with these groups. Boards were to produce frameworks for the development of PCP by April 2002. These frameworks were evaluated by the Valuing People Support Team and detailed feedback provided to Boards.

Some Key Features of the Department of Health Guidance

Approach

Because of the nature of the innovation, the guidance did not provide a detailed blueprint for local implementation. It presented PCP as a set of technologies which could be of use in delivering on *Valuing People* objectives in the context of other key activities to be undertaken by local services and systems. In respect of local implementation, it started from the position that Partnership Boards should take a learning approach, while suggesting some features for incorporation into local frameworks.

PCP was placed in the context of the *Valuing People* principles of rights, independence, choice and inclusion. It was seen as a means by which people, their families, professionals and service managers could discover what is important to people with learning disabilities as a basis for action to advance the achievement of the *Valuing People* principles for individuals.

> *When we use the term "person centred", we mean activities which are based upon what is important to a person from their own perspective and which contribute to their full inclusion in society. Person centred planning discovers and acts on what is important to a person. Person centred approaches design and deliver services and supports based on what is important to a person. Hence person centred planning can promote person centred approaches*

The main styles of PCP were outlined and shared key features described in the guidance.

Implementation

Planning with People suggested that Partnership Boards set up PCP implementation groups to develop and oversee local frameworks. Frameworks that should aim:

1. To offer increasing opportunities for people and their families to plan and to have the supports and services that they receive designed around what is important to them now and in the future
2. To provide a way that commissioners and providers (specialist and non-specialist) can learn how their services and systems need to change in order to respond positively to the aspirations of people with learning disabilities and their families. Boards should give an explicit commitment in their frameworks to report and act on this learning

To achieve these aims, it was proposed local Boards:

1. Undertake initial identification of what is working and not working well in respect of the ability of the local service system to deliver person centred approaches; including PCP, and plan phased action for improvement. Based upon this review the implementation group should:
2. Develop and deliver a local programme for training, development and support including:

    a. An introductory overview of person centred approaches and planning, including for people with learning disabilities and their families
    b. An ongoing training and learning process for people facilitating and implementing person centred plans
3. Support service development projects in *Valuing People* priority areas by integrating, implementing and learning from PCP
4. Work with strategic commissioning, care management, specialist professionals and provider services to build person centred approaches; including the use of PCP support and respond to initiatives from self-advocates, families and provider agencies

The guidance provided advice in respect of appropriate roles and activities for commissioners, providers and professionals. It aimed to encourage the integration of/connection to PCP within the regular activity of each to support the changes required by *Valuing People*. Particular attention was paid to the provision of information and assistance to people and their families so that they could play a major role in planning for themselves – sometimes independently of services.

Limits of person centred planning

The guidance sought to discourage ideas that PCP could be a panacea or that it should be imposed by services:

> [PCP should not become] …*an end in itself. For some individuals, person centred planning can be a powerful instrument to achieve the life they want to lead. However, many people will make changes without person centred planning, through the support of their families, allies and creative service staff. Person centred planning must never become compulsory for individuals and the completion of large numbers of plans must not be a measure of success for service agencies. There are serious risks in focussing on achieving plans rather than changing lives*

The guidance stressed strongly that PCP on its own, however well done, could not deliver White Paper objectives.

> *Person centred planning…cannot substitute for quality leadership, adequate resources efficiently used, skilled and energised staff or service development work and system changes*

It also warned of the need to proceed carefully with an innovation in the early stages of system wide implementation:

> *Experience suggests that it is better to introduce person centred planning gradually. Trying to create lots of person centred plans for everyone quickly is likely to lead to lots of plans but little positive change in people's lives*

A "depth and breadth" strategy was proposed which would allow learning about PCP through doing it and learning from the initially small but growing number of plans.

Context for Implementation

A number of features of the context can be identified, including:

- A lack of experience and understanding of PCP within English learning disability services. PCP had been implemented on a very small scale prior to the White Paper. *Valuing People* recognised the scale of the challenge when it stated 'Development of a person centred approach requires real changes to organisational culture and practice'. The authors of the guidance, and the Valuing People National Director identified significant implementation obstacles linked to what they saw as "counter cultural" features of PCP as a complex innovation in learning disability services. They predicted an uneven adoption, especially in the early years of implementation.[22]
- Availability of only modest implementation support assistance. This has mainly been made up of a programme of work led by the Valuing People Support Team which has primarily taken the form of some training capacity building, good practice networks and learning sets and commissioning of further more detailed guidance resources and tools. These have covered areas such as person centred approaches to providing services, commissioning and care management, support for self-advocates and families leading planning and auditing progress
- Relative absence of significant performance management levers or monitoring of progress. These have been limited largely to questions in the SSI (now CSCI) bi-annual Delivery and Improvement Statement covering some of the *Valuing People* priority groups for PCP. Other levers typically used to drive policy implementation are largely absent. For example, there has not been a significant targeting of government directed training resources made available to local authorities. PCP has been a priority for the Learning Disability Development Fund (LDDF), but Partnership Boards can decide amongst a list of priorities for use of this relatively small resource

Despite these limiting factors, it is clear that thousands of people are involved in PCP work across the country.[23] For example, four of the main specialist development agencies estimate they have trained about seven thousand PCP facilitators. This is likely to be a significant underestimate of the national total. There are at least sixty PCP co-ordinators working with Partnership Boards. We are seeing a small but apparently increasing number of initiatives in support of families and self-advocates leading planning. Many of these people and groups come together to share their learning and offer mutual support in regional and national networks. A significant level of concern has been reported to the National Director for *Valuing People* about the sustainability of funding for these local efforts, as they are seen as highly dependent on the temporary funding from the LDDF.

The Future?

The early stage of the innovation as a system level intervention means that there is inevitably much to learn. Few would question that the services and supports that people are entitled to should be based upon what is important to them from their own perspective. Most would agree that there need to be effective methods in place to find out and act on what is important to people. Most would also agree that services have not been good enough in this respect to date.

Important questions remain about how best to do this, what it takes to do it well, how to best link hearing what is important to individuals to service and system change. This research, alongside the serious implementation efforts of many people across the country, will hopefully provide more guidance for the efforts of those involved in this work.

Developing policy context

It will be important to use the learning from the research in the context of current policy initiatives to promote better lives for people with disabilities who use adult social care. People who use services (and their carers) have increasingly clear expectations that they should be able to lead and direct their own care/support. This is seen as a crucial means by which people can take their place as full citizens.

These expectations have begun to drive health and social care policy in the direction of choice, control and "personalised" care/support. The Prime Minister's Strategy Unit has just published *Improving the Life Chances of Disabled People*[24], which puts the shift towards "independent living" at the centre of government policy for disabled people, including people with mental health problems.

In particular, proposals to "personalise" supports and services and individualise budgets incorporate "co-design" as an important feature.[24 25] Charles Leadbetter, in the Demos pamphlet *Personalisation through Participation*[25] states:

> *Personalisation through participation makes the connection between the individual and the collective by allowing users a more direct, informed and creative say in rewriting the script by which the service they use is designed, planned, delivered and evaluated.*

Leadbetter sets out a number of steps towards personalisation: intimate consultation; expanded choice; enhanced voice; partnership provision; advocacy; co-production; funding.

Two of these steps can be seen to be of particular importance to developing policy on disability.

- *Co-production*: users who are more involved in shaping the service they receive should be expected to become more active and responsible in helping to deliver the service: involved patients are more likely to attend clinics, students to do homework. Personalisation should create more involved, responsible users.

- *Funding*: should follow the choices that users make and in some cases – (such as) direct payments to disabled people to assemble their own care packages – funding should be put in the hands of users themselves, to buy services with the advice of professionals.

So, it seems likely that shifting in the direction of personalised support will require the development of approaches whereby people using services co-design them and have significantly greater influence over the use of allocated resources than at present. PCP is likely to play an important part in supporting this co-design and the shifts towards greater choice and control. For example, the Valuing People Support Team, in association with Mencap are sponsoring a set of pilots in six local authority areas called *In Control*. Some of the key elements of the model are:

- Assessment using a transparent resource allocation process: This is intended to lead to quick assessment and people being told up front and early what resources they are entitled to
- Making a plan: The support plan to use the resources is developed by the person/their friends and family. There is a simple guide to support planning that people can use to make sure the plan will work for them. They can get (usually independent) support with this if they want it. This may be funded and provided in a range of ways
- Getting the plan agreed: The plan has to be agreed by the care manager. There is a guide to a good support plan, to show that people are meeting the assessed needs in the plan. If the support plan is good it will be agreed.
- Money for support: Once the plan has been agreed the money will be allocated to the person. It can be used in different ways including:
    - Using a direct payment
    - Using an agent to manage the money
    - Through a trust
    - Using an individual support fund arrangement with a provider
    - Asking a care manager to commission a service using the plan
- Organising support. A form of support brokerage may be used if the person wants and needs it to use the money to deliver the plan
- The support is then delivered according to the plan, using whichever of the arrangements suits best
- The person is accountable back to the care manager, representing the commissioner to show that the resources allocated are being used to meet the assessed needs. Importantly the level of monitoring is commensurate with level of risk and resources allocated. It should be as non-intrusive as possible to avoid reducing creativity and flexibility

Clearly, if a model such as this is more widely adopted, the potential role for PCP is significant in preparing a support plan to use the resources that people are allocated and to integrate use of services with a person’s natural supports. Adoption of this type of model would also indicate the need to invest in skills and awareness for PCP in some key groups – including people with learning disabilities and families and people occupying support broker roles – in addition to professional staff. It also has implications for commissioners and providers. Commissioners will need to increasingly individualise their specifications and have clear expectations of providers in respect of methods for delivering personalised services. Service providers will need to develop their ability to deliver supports that reflect individual aspirations. PCP is likely to need to play a significant role in these developments.

The trends towards empowerment and personalisation are central to *Independence, Well-Being and Choice,* the recent Green Paper on the future of social care for adults in England.[26]

Conclusion

The developing context, both learning disability specific and broader health and social care policy is in the direction of increased personalisation, choice and control for people using services and supports.[23 26] This shift will require means by which people are able to more powerfully co-design and control the supports they use. PCP may be able to offer an important contribution to this. This makes it increasingly important to develop effective approaches for the use of PCP in different contexts. The learning from the current research will hopefully make an important contribution to this.

The Evidence Base: What is Already Known about the Impact of Person Centred Planning?

Over the past decade, numerous position papers have outlined the potential benefits of PCP in terms of enhancing the quality of life of, and quality of supports provided to, people with learning disabilities.[27 28] There have, however, been few attempts to formally evaluate the benefits and costs associated with the adoption of PCP.

Indeed, a systematic review of the evidence for lifestyle planning approaches (including PCP) published in 1999 included only five studies (involving a total of 108 participants) which reported any outcome data for any form of lifestyle planning.[29] The authors concluded that: '*There is no quantitative evidence to support the use of lifestyle planning in general or in any individual form*' (p.366).

Since that time, very few studies have been reported that sought to formally evaluate the impact or outcomes associated with PCP. [30-33] As noted by Steve Holburn and colleagues in 2004[30], research evaluating quality of life outcomes as a result of PCP have tended to employ qualitative research designs. Those quantitative studies that have been reported have tended to examine elements of the PCP process (e.g., participation in and satisfaction with meetings, effectiveness of training)[34-37] rather than evaluating the efficacy of PCP per se. While these qualitative studies may provide a rich description and source of ideas about the possible impact of PCP,[11 31 38] they cannot be accepted as credible evidence of either efficacy or effectiveness.

More robust support for the effectiveness on PCP has only appeared more recently. Holburn and colleagues conducted a longitudinal study of the impact of PCP for a group of 19 people living in an institutional setting in the US[30]. This group were compared with 18 matched peers who received conventional Individual Service Planning (ISP). The results of this study indicated that PCP hastened the move to community settings (18 of the PCP group moving to the community, compared to only 5 in the contrast group) and that quality of life indicators in the areas of autonomy, choice-making, daily activities, relationships and satisfaction improved more for the PCP group than the contrast group. One limitation of this study, however, is that no information was collected on the cost of the intervention. Information on outcomes and costs are essential for the development of evidence-based policy and practice.[39 40]

A number of studies have described difficulties that may be associated with the implementation of PCP. These have included: goals remaining unmet[38 41 42]; goals being limited to options previously available to service users[41 42]; failure to address goals in more ambitious or contentious areas such as sexuality[41 42]; and goals not corresponding with preferences assessed by alternative means[43]. For example, Hagner and colleagues reported the results of a qualitative study of the outcomes of PCP for 6 people. Their results pointed to an indirect, tenuous relationship between planning and outcomes and that, after 6 months of PCP, only a few planned outcomes had been achieved and several participants felt that “not much had happened”(p.167).[38] Similarly, Dumas and colleagues interviewed 13 people who had participated in PCP, reporting that, although needs and desires were identified, in many instances plans were not implemented because of a lack of viable service or support solutions. Further, they reported that most participants seemed to believe that they were limited to existing models of service delivery rather than being able to gain access to individualised services and supports.

In summary, despite the existence of a considerable amount of literature advocating the use of PCP, very little quantitative evidence exists with regard to the effectiveness of PCP in improving quality of life related outcomes for people with learning disabilities. Furthermore, there is no information available on the likely costs of implementing PCP on the sort of scale advocated by *Valuing People*.

An Overview of the Project

As noted above, the mains aims of our project were to:

- Evaluate the impact of the introduction of PCP on
  - the life experiences of people with learning disabilities
  - the nature and costs of supports provided to people with learning disabilities.
- Identify personal, contextual and organisational factors which appear to either facilitate or impede the introduction and effectiveness of PCP

In order to pursue these aims, our project was comprised of four distinct, but related, components.

First, we undertook development work with organisations in four localities in England. The selection of localities was based on two main factors.

- That the organisations within the localities showed evidence of a commitment to implement PCP in order to enhance the life experiences of people with learning disabilities. That is, we attempted to exclude localities whose primary commitment appeared to be to implement PCP in order to fulfil organisational obligations and requirements. We evaluated the commitment of organisations through local knowledge of members of the research team and discussion with key managers in candidate organisations.
- That the sites, in combination, would provide a high degree of diversity with regard to the characteristics of communities and participants. Thus, for example, we sought to include localities that varied with respect to level of affluence, urban/rural location and the ethnic mix in the communities served.

The essential aim of the development work was to provide additional support to local organisations to help them develop robust policies procedures and practices to implement PCP. The nature of the development work and the conclusions drawn by the external consultants who undertook the development work are presented in Chapter 2.

Some key characteristics of the four sites are summarised in the following table.

Table 1: Selected Characteristics of the Participating Sites	
Site A	Site A is an inner London borough with a population of approximately a quarter of a million people. One third of the population are from black and minority ethnic groups. The 2001 census shows an older age profile for those living in the borough, a higher rate of unemployment, and significantly lower levels of home and vehicle ownership compared to national averages. While Site A contains many deprived neighbourhoods, it does not have the extreme contrasts of poverty and wealth found in many other London boroughs.
Site B	Site B is a large rural area in the south of England. The overwhelmingly white population of between 150 and 200,000 is concentrated in dormitory towns, resorts and a couple of market towns. The area is characterised by general affluence with associated pressure on the housing market.
Site C	Site C is a metropolitan borough in the North of England. Compared with England as a whole, Site C has a higher proportion of younger people and a lower proportion of older people within its 200,000m plus population. One tenth of the population describe themselves as Asian or British Asian, most having a Pakistani heritage. The towns in Site C were built upon the success of the textile and other manufacturing industries that declined in the middle of the last century. As a consequence site C ranks as one of the 25th most deprived districts in England.
Site D	Site D is another metropolitan borough in the north of England. In most respects the demographic profile of 200,000 plus people who live there conforms to national trends, but the effects of severe economic recession and the loss of traditional industries in the 1970s and 1980s are reflected in the high rates of long term unemployment amongst men over the age of 50 and the localities place amongst the 10% most materially deprived areas of the UK.

The evaluation side of the project involved three related components that addressed distinct questions. They were:

- What impact does the introduction of PCP have on the life experiences of people with learning disabilities?
- What costs are associated with the introduction of PCP?
- What organisational factors impede or facilitate the introduction and effectiveness of PCP?

We addressed the first question by attempting to follow over a two year period each of the first 25 people in each site who participated in the PCP process. In Chapter 3 we describe the characteristics of the people who participated and present results relating to the efficacy and effectiveness of PCP in improving the life circumstances of people with learning disabilities.

We addressed the second question by documenting the costs associated with developing and implementing PCP in each of the four sites and by determining the impact of the introduction of PCP on the costs of supports for the first 25 people in each site who participated in the PCP process. We present the results of these analyses in Chapter 4.

We addressed the third question by undertaking interviews with managers and practitioners in each of the four sites, reviewing documentation and observing meetings. A detailed description of the approach taken and results of this organisational-level analysis are presented in Chapter 5.

Finally, in Chapter 6 we provide a summary of the results of this project and draw out implications for policy and practice.

Supporting the Development of Person Centred Planning

Barbara McIntosh & Helen Sanderson

Introduction

In this section we will describe the methods used to implement person-centred planning in the four sites and highlight some of the key issues which we believe need to be dealt with in order to implement it effectively. We will describe the training and other initiatives provided for managers, staff, those who use services and their families. We will also share some of the lessons we learned while undertaking the development work across the four sites. These are, of course, our personal views. We will focus on person centred working with the 93 people who participated in the project, 65 (70%) of whom had a person centred plan that was developed and maintained.

The key aims of the implementation phase were to assist staff, families and self advocates to understand and use person centred approaches to improve each person's quality of life. There was some variation across the four sites in the type of training and tools used, but the aim was the same – for people to be supported to be contributing members of their communities and to have fulfilling lives. A central aim of the development phase was the training of facilitators who were residential workers, day centre staff, paid advocates, parents, and siblings.

Implementing Change

Our experience of implementing Individual Programme Planning (IPP) in the past illustrates how implementing a new approach to planning is difficult. Nearly 10 years after the introduction of IPPs, an inspection found that in thirteen local authorities, seventy five per cent of people did not have an IPP recorded in their file[44]. It is clear that putting a new approach into practice is not the simple process it first appears.

Implementing PCP not only requires technical training in styles of planning, but also challenges the way power is used in services. Early learning from the implementation of PCP in the UK (described in *People Plans and Practicalities*)[45] suggests that for successful implementation of PCP we need:

- to inform people
- to build capacity to help people make plans
- to promote person centred change more widely throughout the organisation and create a favourable context to help peoples plans become a reality
- to learn from plans and blocks to influence organisational change

- to build a network of practitioners to support and develop learning about planning and implementing plans
- to support new developments to help services to change

For this to happen we require leadership, and an influential.

Leadership

In the course of the implementation phase, it became clear that powerful leadership can come from families and self advocates, as well as paid staff. In one site we saw leadership from families in changing their own family situation. In another site we saw senior managers skilfully negotiate resources for five posts to work exclusively on person centred approaches. The same authority had leaders who agreed to devolve flexible funding to day centres to provide individual funding to help make people's plans happen. In the sites we learnt that close collaboration with key senior staff was essential to achieve good outcomes for disabled people. As external trainers it was important to be in touch with the organisational culture, strengths and weaknesses. Knowing these factors helped us to have an impact with the training initiatives.

We had some very committed managers whose enthusiasm and partnership made a significant contribution. We recognised that first line managers have a significant role to plan in ensuring that plans are implemented. Where first line managers showed leadership we saw rotas written to reflect what was important to people as described in their person centred plans, managers using team meetings and supervision to reflect with staff on what was working and not working about implementing the plans. Without this leadership, PCP was seen as something 'extra' to the real work, and not the real work itself.

Influential Implementation Group

Having an implementation group does not, of course, guarantee success. The implementation group in one site struggled to lead, as it was a group with some energy but competing commitments. Families and self-advocates were not involved, and therefore could not help the group keep its focus and commitment. In two other sites the implementation groups helped to stay focused on outcomes for people and to consider the changes needed within their own organisations to promote person centred working. In one site each member of the implementation group was paired with a facilitator to offer support, information and increase positive change.

In the development process we were only able to concentrate on three of the six elements we believe to be required (see Table 2). We focussed on building capacity, promoting PCP more widely and linking learning to organisational change. We had some influence on the involvement of leaders, and little influence on the make up of the implementation group.

Table 2: The Development Process

What is necessary	What the research was able to influence
1. To inform people	No - Only people affected by the research
2. To build capacity to help people make plans	Yes – through facilitator training and support
3. To promote person centred change more widely throughout the organisation and creating a favourable context to help peoples plans become a reality	Attempted this to a limited extent through the involvement of first line managers and running sessions for community teams and community organisations
4. To learn from plans and blocks to influence organisational change	Yes – to work with the implementation group and senior managers to do this
5. To build a community of practice to support and develop learning about planning and implementing plans	Partially - A facilitator buddy group was established in one site.
6. To support new developments to help services to change	Partially- some influence on this where it emerged from the implementation group

The Development Process

We will now describe the three areas that we were able to address in the development process.

Building Capacity to Help People Make Plans

Facilitator Training

Across the sites core material and awareness training included:

- the key principles of person centred working
- the policy framework for person centred working (Valuing People)
- the values base
- the historical context of person centred working and what we have learnt from elsewhere
- communication styles and communication support for people with non verbal communication
- Health Action Planning as part of person centred working
- An overview and more detailed focus on some of the tool (essential lifestyle planning, MAPS, PATHS, Personal Futures Planning, The Personal Planning Book)

Key elements of the training

1. Begin with awareness training for everyone involved
2. Encourage self advocates where possible to choose their facilitator
3. Support people to work out what is important to and important for the person
4. Ensure that families and facilitators keep the person central to the whole process
5. Think carefully about who could be facilitators, for example in two sites Circle of Support members (including self advocates) were active participants in the training
6. Explore ways of people leading their own plans, for example in two sites parallel activities were provided for some sessions for self advocates who found the pace too fast in the main training sessions
7. Using a systems approach offer training to first line managers of the facilitators
8. Use in house resources. Strategic managers and Community team members were involved as participants and trainers for some sessions e.g. , session on helping people with complex needs express their hopes and desires was run by the speech and language therapist
9. Listen to the requests of participants. In some sites facilitators requested specific sessions linked to people's goals or unique needs: for example supported housing, Direct Payments, Understanding Autism.
10. Problem solving. Provide ongoing support through individual coaching, and action learning sets.
11. Link learning to organisational change. Use action learning sets to explore what is working/ not working with people and act on these through the implementation group
12. Developing relationships, community connections and community inclusion Once facilitators feel comfortable and have begun to learn what is important to the person, and what support they want, introduce these concepts
13. Continue to support facilitators and managers though action learning sets and individual sessions
14. Stay focussed on outcomes. Later introduce another style of planning that has a future focus

Examples of Additional Topics Covered During the Training

As the goals and priorities of individuals emerged, support and training sessions were designed to build special knowledge and expertise to achieve the person's goals.

- *Autism*: Several facilitators working with people with autism asked for help in identifying the person's goals and hopes. An external expert was brought in for one session
- *Housing*: a specialist was commissioned to run one session on housing and supported living. This was in response to parents whose wanted to know more

about options and in response to several people who wanted to leave their current accommodation.

- *Community Capacity Building*: Many people expressed the wish to participate in work, leisure, volunteering, and friendship. Key players from the community were invited to be part of a session to work on making these goals a reality (e.g., managers of local leisure centres and employment experts).
- *Direct payments and the Independent Living Fund*: Several people wanted to have more flexible individual packages of funding. Information and support in making it happen were provided by in house managers.
- *People with complex needs*: A trainer with particular skills gave one session in two sites. Meeting the needs of people with high support needs was a frequent topic in the "blocks and barriers to be overcome" section of each training session.
- *Risk and innovation*: Facilitators who were front line support workers (especially those working for the Local Authority) frequently perceived themselves as disempowered. Workers from advocacy services or well managed Voluntary Sector organisations appeared more confident with risk and innovation.
- Time was spent in numerous sessions to find more unique person centred solutions rather than service based solutions. One young woman with complex needs was helped to access the Independent Living Fund .She was supported to hire local college students to support her in activities for her own age group rather than use a respite unit.

Facilitators within Organisations

Lessons from the implementation sites suggest that organisations should initially identify those staff who clearly demonstrate person centred values and continually seek ways to improve how they translate these into practice. The rationale for this is that these are the people who will be most able to begin to put planning into practice, begin to create learning for the organisation and hopefully positive stories that can inspire and enthuse others. They can then offer extra support to the next wave of planners.

Although we offered guidance on who would make the best facilitators, we could not strongly influence the sites' decisions on who to invite to facilitators training. In all four sites, there had already been some training programmes and therefore where there were people who had already participated in training. In one site there was an existing buddy group for facilitators, in another site there was a pre-existing implementation group. In another site there had previously been training in person centred working. This project built on and consolidated the previous work while offering training to new staff.

Our reflections on choosing the first facilitators within organisations

- To initially chose the ‘naturals’ within the service.
- To invite people to join rather than demand it.
- To invite parents to facilitate or co-facilitate with a member of staff
- To invite people who are in a position to make changes in the person’s life.
- Avoid isolating new facilitators by only selecting one person from each locality or team. There are benefits in having a few facilitators in one area to support each other.
- Have an internal expert/champion as well as external support for facilitators during the training process
- Train internal staff to facilitate action-learning sets to support new facilitators in their learning and build in house resources
- Offer facilitators individual sessions with the trainer to review progress and problem solve .The presence of line managers during these sessions promotes problem solving and tackling goals together.
- Training can only offer a starting point, facilitators need ongoing support
- support and time to plan and to implement plans
- Managers need to rota in extra time for staff to work in a person centred way
- Facilitators should be committed, enthusiastic and volunteer to undertake training. This may ensure that they are optimistic and encouraging to the next generation of facilitators.
- Remember that facilitators may see themselves as disempowered as part of a large bureaucracy) and need time and encouragement to build confidence and skill
- Seek facilitators from advocacy and User led organisations as the values of person centred working are often central to their way of working

Family Members and Self Advocates as Facilitators

The sites differed in the extent to which families were involved in directly leading planning. In one of the sites there were five families working with their family member to lead planning. All had positive outcomes while valuing the input of local staff to help access resources and services. Co-facilitation involving a staff member and a family member working together was reported by families to be helpful. They also enjoyed learning from and supporting one another as families.

At another site there had been intensive efforts in supporting families to plan. There was a weekly drop in for families and carers who were developing a plan. This took place at the carers centre, where there is an experienced facilitator to help problem solve. The facilitator was also part of the implementation group and where appropriate and with permission she kept the group informed of what the successes and blockages were for the families. There was an IT suite at the carers centre, and an IT tutor (also a parent) to help with word processing, scanning in photos or whatever families wanted. Because of this pre-existing investment in supporting families, in this site the development work focussed on supporting staff facilitators to lead planning.

In two sites they were unable to find families who wanted to act as facilitators at that time. Since then, one site has invested in supporting a family member as a PCP co-ordinator.

Where self advocates and families want to lead their own planning, we need to learn how to respond, support and sometimes simply keep out of the way. This shifts power and creates tension. We are learning from families about PCP and listening to how people want training and supports designed and delivered. In one site several parents worked as co-facilitators choosing a member of staff to work with. They felt that accessing resources and services was made easier with the knowledge held by staff.

There is much skill and talent amongst family members to act as facilitators or co-facilitate with members of staff. The lessons are to think flexibly about how to best achieve the goals and aspirations of the person. Pooling the skills and knowledge of staff and families can be a powerful way to meet these needs and also addresses the power imbalance.

Young people in transition and their parents may be particularly responsive to leading their own planning. Leaving school and negotiating access to adult services can be frightening. Parents are not always given information about the choices and services that are available. In this project families learned about the options available enabling them to seek entry to residential college, apply for direct payments/Independent Living Fund and look for supported living rather than residential care.

We believe that the benefits of people and families leading their own planning include:

- It provides an effective process during Transition into adult services when there is tension and concern about changing systems and potential loss of information about the person
- It offers strong opportunities to ensure that the issues of prime concern to the person or family are centre stage
- It promotes more creative PCP – when people plan for themselves they are less likely to limit themselves to those things they think are likely to be made available from state funded agencies. Many families and self advocates have argued that this kind of planning needs to be separated out from formal assessment for service eligibility. In this way the anticipation of limited resources does not limit thinking.
- It offers a greater possibility of discovering and using resources outside of service agencies, such as family, friends and community resources
- It engages sisters and brothers, friends and other social contacts where services have no contact

Supporting Facilitators

Training is a beginning, but not enough. Extensive support is required for people to begin to act on this information. PCP requires new skills, new knowledge and new ways of thinking. To achieve this requires mentoring and coaching. Both managers and practitioners can underestimate how difficult it is to change practice. Many managers state, that it is important to get their staff to ‘own’ a new way of working and that it is necessary to be clear what is required of them. They may think that this is enough. Some managers underestimate the difficulties involved in changing what people do.

In one site they invested in supporting facilitators after the training, and in another site, facilitators were invited to join a pre-existing buddy group. In one site facilitators were supported by the PCP co-ordinator in between the training sessions. And in another site the voluntary organisation that had 10 people involved in the pilot supported people in supervision to work in a person centred way, provided staff cover to free up people to attend training, re-wrote their business plan and re-organised their structure to ensure a stronger person centred culture.

In one site the appointment of a PCP co-ordinator and later four regional PCP workers created a strong and effective force for change through the support of facilitators involved in the research and training of new facilitators.

Training self advocates, families and staff in PCP is the start, but without an equal investment in support change runs out of steam. In one site several facilitators were from the Citizen Advocacy service. They were ‘naturals’ in acting as facilitators. They showed confidence and flair in helping people make real and positive changes. Their underlying values appeared to be a strong factor in achieving change with people.

> *“Those who treat person centred planning simply as a technique and those who fail to provide for their own development and support will offer little benefit to the people they plan with”* John O’Brien and Herb Lovett[46]

For successful implementation of person centred planning we need:

- In-depth training for facilitators
- Ongoing formal and informal support for facilitators
- Investment in families and people with learning disabilities leading planning
- To introduce opportunities for other community members to facilitate plans
- Think carefully about the support needed to ensure plans are implemented, and that we learn from person centred plans about how organisations need to change

Learning From Plans and Blocks to Influence Organisational Change

All the steering/implementation groups were supported to oversee the training and support programmes and to actively take learning from plans to influence organisational change.

The implementation group in one site used a process of content analysis from what was ‘working’ and ‘not working’ in peoples lives as described by their plans. They then agreed actions to begin to address what was not working for people. Incorporating people’s hopes and aspirations into the organisational design became an increasingly important issue for planners across all the sites.

In one site two people who had lived in long stay hospital declared a goal to leave hospital sooner than the system had planned and to live together. They chose three senior NHS managers for their Circle of Support. They were supported by the NHS managers to rent a flat through the ordinary rental market and moved to their new flat in the community after 5 months. The blocks had been large bureaucratic organisational issues and reliance on service systems rather than person centred systems.

What emerged from an early session in one site was a group of seven people who wanted to move from their existing accommodation. The PCP consultant and the steering group established a sub group to work out how to get changes for those individuals.
At first the group simply considered how they could better utilise ‘vacancies’ across the agencies. They reported this back at the next steering group meeting, and as they had not been successful in making changes for people, the consultants suggested bringing in external facilitators to work out how people could move on.

In one site managers were supported to think about what was blocking the outcomes from people’s plans, by using elements from *Shaping the Future*[47]. As part of the programme, the managers and facilitators came together to identify blocks and enable people to problem solve next steps together. The managers met together with a consultant and used the *Shaping the Future* format to identify what was preventing people from moving forward. The consultant then facilitated a discussion to identify the themes from this, to share with the implementation group. The facilitators and managers then worked with the consultant to map where they were now in supporting plan and implementation, and what they needed to do next.

What others difficulties were there?

- Initial scepticism from families about the ability of Social Services to deliver improvements in the quality of care held them back from signing up to the project.
- Organisational change and high staff and manager turnover caused delays in getting started and keeping going .
- Concern from families that this was another trend and that it would not be sustained caused some resistance early in the training sessions.

- Mental health problems and anxiety experienced by two people caused them to feel pressurized when asked questions about a better future. One person withdrew from the project as a result.

Lessons from this are that organisations need to have a structured way to take learning from person centred plans to influence organisational change. There also needs to be ways of learning what the difficulties and blockages are to planning, and then to work on what can be changed.

To Promote Person Centred Change More Widely Throughout the Organisation and Creating a Favourable Context to Help Peoples Plans Become a Reality

That person centred working should be a fundamental driver in all organisations is a long term goal of learning disability policy. *Valuing People* asks that all organisations use PCP to help improve the lives of individuals and in turn improve the way organisations work. Culture change in the UK is slow but we have learnt that we need to provide development support to organisations so the entire culture is person centred.

The following initiatives were part of the training offered across the 4 sites.

- In each site Community Teams were involved in looking at how they worked in relation to PCP. In the Northern sites much emphasis was placed on developing person centred teams while in the Southern sites the focus was on the role the community team might play to ensure person centred goals were realized.
- Care managers were initially sceptical about person centred working and were clear that they could not act as facilitators. At the end of the project care managers were more accepting of the concept of person centeredness but some remained unclear about their role. Some suggested that the crisis nature of their work made it difficult to see how they could develop lasting supportive relationships with self advocates.
- Mentoring to experienced staff to train others to undertake person centred working. This is key to develop capacity and skill.
- Supporting senior strategic managers to manage culture change and receive the goals of PCP which in turn should change the design of the organisation (e.g., most self advocates stated in their plan that they wanted to participate in community activities). Managers in one site then suggested that community bridge builders should be employed to assist one person at a time to accomplish their goals.
- Action Learning Sets for facilitators. In all the sites long term groups were established after the project to continue the learning of experienced facilitators and to support new ones after their initial training.
- Working with managers to understand their role in implementing plans and developing person centred teams. A few of the first line managers of the facilitators were trained in ways to implement plans, and how to apply the principles of PCP to the way they managed and supported their teams. This concept is known as creating ‘person centred teams’. This training was separate

from the facilitators training, and then both facilitators and managers came together to look at how the plan for the focus person could be implemented.

Our reflections on creating a Person Centred Culture and Person Centred Teams

- The whole organisation needs to work in a person centred way and believe in and express these values
- For person centred planning to be truly effective, managers need to mirror the same principles in the way they support and work with staff – person centred teams
- The culture of well managed voluntary sector organisations including an advocacy organisation in two sites provided a better environment for PCP to flourish than the Local Authority
- Increased creativity, sensible risk taking and community capacity building within local authority culture will promote the development of person centred working.
- Person centred team training focussed on these ideas and some teams began work on their own ‘person centred team plan’.
- Managers are more likely to keep plans ‘alive’ and make a difference in peoples lives if the plans become part of ‘the way we do things here’ and are part of team meetings, supervision, and affect the way the rota is written.

Conclusions

The experience of implementing person centred working across the four sites leads us to a range of conclusions.

- Person centred working challenges the way our organisations function and the roles played by staff, managers and families. It asks front line staff to take on a more powerful role and to be determined in finding solutions outside of traditional boundaries. It asks that we use public resources in a different way to maximize the outcome for each person.
- Training initiatives will be needed that are long term and continuous to ensure users, staff and families have the fundamental skills to improve individual’s lives and create necessary culture changes within services.
- Person centred working will be more effective if it is in collaboration with other initiatives. Individualized funding, building the capacity of communities to include people, greater engagement with person centred care management and increasing choice in the nature and number of services will all help.
- The flexible monitoring of PCP from national bodies such as CSCI and The Healthcare Commission needs further consideration and development.
- Of great importance is the continuous investment in financial and human terms to develop and train staff and families to carry out this important task.

The Impact of Person Centred Planning on the Life Experiences of People with Learning Disabilities

Janet Robertson, Eric Emerson, Peter Oakes, Chris Hatton Johan Elliott & Emma Krijnen-Kemp

The central aim of the project was to evaluate the impact of PCP on the life experiences of people with learning disabilities.

The Approach to Evaluation

In order to evaluate the impact of PCP we attempted to collect information on the life experiences over two years for 100 people with learning disabilities. In each site we sought consent (see below) from the first 25 people with learning disabilities for whom an attempt was made to develop a person centred plan. Overall, 93 people with learning disabilities gave consent and participated in the project.

We began to collect information on each person as soon as they gave consent (i.e., before a plan was developed) and continued to collect information about their life experiences every three months for two years (or until the project ended). We (correctly) assumed that there would be ‘natural’ variation within and across sites in the speed with which plans were developed. As a result of this variation, we expected that there would also be variation between participants in the length of time over which we collected information on their life experiences before the implementation of a PCP. We collected information on the life experiences of each participant every three months regardless of whether or not the person’s plan had been completed. Our plan was to use this information to determine what changes were occurring in people’s lives prior to the implementation of PCP (i.e., during a ‘baseline’ phase). Once we knew this, we could estimate whether any changes we saw following the implementation of PCP could be attributed to PCP or to other extraneous factors associated with the passage of time.[48]

For a variety of reasons, it did not prove possible to develop and maintain PCPs for each of the 93 people. Overall, PCPs were developed and maintained for 65 (70%) participants. This gave us the opportunity to distinguish between the efficacy and effectiveness of PCP in our analyses. It also gave us an opportunity to attempt to identify organisation, situational and personal factors that impeded or facilitated the implementation of PCP.

Consent

Wherever possible, written informed consent was obtained from each participant. We took care to ensure that potential participants clearly understood the implications of their involvement and that: (1) they could withdraw their consent at any time; (2) refusal or withdrawal of consent would have no impact upon the support they received; and (3) they would still be able to take part in PCP even if they did not give consent for involvement in the research element of the study.

However, some potential participants were unable to give informed consent due to the severity of their intellectual impairments. In these cases, agreement for participation was obtained from either: (1) the user's independent advocate; or (2) the closest family member who was in regular contact with the person.

Information Collected

The information we collected was based on measures employed in a recent Department of Health funded study on supported accommodation[49 50] and audit materials that had been used on by nine Local Authorities in England.[51-53] Most of this information was collected from a key informant who knew the participant well (e.g., the person's keyworker).

However, when participants were able and willing, they were interviewed using a questionnaire designed specifically for this study (the My Life interview) which was adapted from an interview schedule used in one of our previous studies.[54] These interviews were conducted every six months.

Every three months we collected information from key informants on:

- current scheduled day activities
- physical activity using items from the Health Survey for England[55]
- community based activity using the extended version of the Index of Community Involvement (ICI)[49-51 56 57]
- social networks using the Social Network Map[58 59]
- contact with family and friends
- use of hospital based services
- health checks
- community based service receipt using the Client Service Receipt Inventory (CSRI)[39 60 61]
- PCP activities.

Every six months, we collected all of the above and we also collected information from key informants on:

- health problems
- medication receipt
- the person's behavioural and emotional strengths and difficulties using the Strengths and Difficulties Questionnaire (SDQ)[62]
- risks, accidents and injuries using an adapted version of the Risks Scale[49 50]
- changes in choice.

For participants who lived with an informal carer, we collected information from the carer every six months on:

- staff support and professional input in the home
- satisfaction with current arrangements
- involvement in planning
- barriers to goals set for the participant being met
- impact of PCP for the person.

Information was also collected from PCP facilitators on a six monthly basis commencing six months after the first data collection point. A self-completion questionnaire was used to collect information on:

- facilitator characteristics (age, gender, relationship to participant)
- the reported impact of PCP for the participant
- barriers to goals set for the participant being met
- attitudes towards PCP
- organisational barriers to PCP
- commitment to PCP
- perceived self-efficacy.

Factor analyses were conducted on four of the scales included in the questionnaire (barriers to PCP for focus person; general views regarding PCP; organisational barriers to PCP; and commitment to PCP). The results of these factor analyses are presented in the Appendix.

Background data collection. At the start of the project we collected information on all of the above as well as a range of background information including:

- age, gender and ethnicity
- ability and additional impairments using Part 1 of the Adaptive Behavior Scale – Residential and Community, 2nd Edition (ABS)[63]
- psychiatric status using the PAS-ADD Checklist[64 65]
- syndromes associated with learning disabilities
- challenging behaviour using the Learning Disabilities Casemix Scale (LDCS)[66]
- residential history (for those living in support accommodation only)
- existing arrangements for individual planning.

In addition, the participant’s postcode was used to derive a measure of neighbourhood deprivation: the English Index of Multiple Deprivation.[67]

For those living in supported accommodation, background information was also collected on:

- the structural and procedural characteristics of service provision including size, structure, location of the facility and staffing arrangements (Residential Services Setting Questionnaire)[68]
- internal planning procedures including arrangements for individual planning, managing staff and monitoring the quality of provision (Residential Working Practices Scale)[69]
- the social climate of residences with regard to the extent to which the setting embodied the cardinal features of 'total institutions'(block treatment, depersonalisation, rigidity of routines, and social distance (Group Home Management Interview: GHMI)[56 57 70]

Copies of all the questionnaires are available on request by email from Janet Robertson (j.m.robertson@lancaster.ac.uk).

Procedure

For each participant we identified a key informant who knew them well (e.g., keyworker, informal carer, advocate). We collected information from the key informant using a combination of self-completion questionnaires and structured interviews. Research staff visited each participant's home or day service to complete questionnaires and conduct structured interviews with the key informant. We took a flexible approach to data collection. For example, some key informants, especially where their first language was not English, preferred to complete all questionnaires by interview. For some participants, it was necessary to visit more than one key informant. In some instances it was not possible to collect all the information as participants occasionally requested that particular people not be approached (e.g. residential staff, family). The schedule of data collection in described in the following table.

Table 3: Schedule of Data Collection

Initial Visit	Background information; 'Every three months …' data; 'Every six months ..' data
Visit 2	Three months after initial visit. 'Every three months …' data
Visit 3	Three months after visit 2 'Every six months …' data
Visit 4	Three months after visit 3. 'Every three months …' data
Visit 5	Three months after visit 4. 'Every six months …' data
	The above cycle was repeated until
Final Visit	Background information; 'Every three months …' data; 'Every six months ..' data

The average time between the first and final visit was 1.5 years (range 0.4 to 2.0 years).

The Participants

Participants for the study were the first cohort of people, selected by the participating sites, to participate in PCP. In total, 93 people (from a target of 100) took part in the study from four sites: 25 in Site A; 20 in Site B; 24 in Site C; and 24 in Site D. In this section we will present information on the characteristics of participants at the start of the study. We used non-parametric statistical tests in order to see whether there were any significant differences in the characteristics of participants between the four sites[1]. Those areas in which we did find a significant difference are indicated with an * in the following tables. Further information regarding these differences is presented by site in the Appendix.

Age, Gender & Ethnicity

Table 4 provides summary information on the age, gender and ethnicity of participants.

Table 4: Age Gender and Ethnicity

Age (years)	
average age (and standard deviation)*	40.25 (12.4)
range	16-86
Gender	
% men	61%
Ethnicity	
Asian (Indian)	-
Asian (Pakistani)	3%
Asian (Bangladeshi)	-
Asian (East African)	-
Asian (Chinese)	-
Asian (Other)	-
Black (Caribbean)	2%
Black (African)	2%
Black (Other)	-
Mixed Race	1%
White	91%

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[1] Kruskal-Wallis was used for ordinal variables and Chi Square was used for dichotomous variables.

Abilities and Additional Impairments

We used Part 1 of the Adaptive Behavior Scale[63] to collect information on the overall severity of participants' learning disability, and to identify additional physical and sensory impairments or disabilities. This information is summarised in Table 5.

Overall, the adaptive behaviour of participants represented the full range shown by people with learning disabilities (the ABS possible total score ranges from 0 to 323).

Table 5: Needs and Abilities

Abilities	
Total ABS Score (and standard deviation)	179.9 (78.9)
Range	10 - 310
Individual domain scores ...	
Independent functioning	69.8 (32.6)
Physical development	18.8 (5.7)
Economic activity	5.1 (6.1)
Language development	22.2 (13.2)
Number and time	5.4 (4.6)
Domestic activity	10.9 (8.2)
Vocational activity	5.5 (4.3)
Self-direction*	15.5 (7.0)
Responsibility*	6.7 (3.0)
Socialization*	18.9 (6.1)
% users reported to have....	
... visual impairment*	8%
... hearing impairment	7%
... dual sensory impairment*	3%
% users reported to have....	
...no medication and no seizures	65%
...seizures controlled by medication	13%
... seizures less than monthly	6%
... one or more seizures per month	15%
% users reported to have toilet accidents....	
...never	48%
...at night only	8%
...occasionally during day	29%
... frequently during day	16%

Health Needs

Information was collected from informants regarding specific conditions or syndromes associated with learning disabilities. Of the people who participated: 14% were reported to have Downs syndrome, 13% were reported to have Autistic Spectrum Disorder; 6% were reported to have Cerebral Palsy.

We also collected information on whether the participant had suffered from a range of possible medical conditions and ailments within the last 12 months. This information is summarised in Table 6.

Table 6: Reported Health Needs Over the Previous Year

Percentage of participants reported to have had problems in the following areas ...	
Circulation and Breathing:	
...bronchitis	3%
...difficulty breathing	3%
...troublesome cough	4%
...asthma	9%
...emphysema	0%
...cyanosis	4%
...Oedema	1%
Digestion and Elimination:	
...recurring stomach trouble or indigestion	4%
... Frequent constipation	18%
... frequent loose motions	9%
... poor bladder control	26%
... poor bowel control	12%
Heart:	
... angina	1%
... high blood pressure	5%
... heart attack	1%
... heart murmur	2%
... abnormal heart rhythm	1%
Other health problems:	
... diabetes	2%
... arthritis	3%
... rheumatism	1%
... sciatica, lumbago, recurring backache	1%
... persistent skin trouble	22%
... pressure sores or bed sores	4%
... piles	3%
... foot trouble	7%
... varicose veins	2%
... persistent trouble with teeth mouth or gums	4%
...no health problems	23%
...1 to 4 health problems	64%
...5 or more health problems	13%
Mean number of health problems*	2.2
Range	0 - 11

Mental Health, Emotional and Behavioural Needs

We used the Learning Disability Casemix Scale[66] to provide a quantitative measure of the severity of participants’ challenging behaviour. The total score on the Casemix Scale is categorised as representing severe, moderate or no challenging behaviour. We also used the Strength and Difficulties Questionnaire[62] to summarise the participants’ emotional and behavioural needs. Finally, we collected information from informants on whether participants had any known diagnoses of psychiatric problems and used the PAS-ADD Checklist[64 65] to screen for the potential presence of psychiatric disorders. The information from these three measures is summarised in Table 7.

Table 7: Mental Health, Emotional and Behavioural Needs	
Challenging behaviour	
Average total score on the LD Casemix Scale (& s.d.)	4.2 (5.3)
Range	0 - 20
% classified as having ..	
No challenging behaviour	77%
Moderate challenging behaviour	14%
Severe challenging behaviour	9%
Strengths and Difficulties	
Average total score on the SDQ (& s.d.)*	8.4 (6.7)
Range	0 – 25
Reported psychiatric diagnoses	
Total (%)	16%
% with know diagnosis of ...	
... schizophrenia	2%
... other psychoses	3%
...depression	8%
... manic depression	2%
... anxiety	1%
... dementia	1%
Average total PAS-ADD score (& s.d.)	1.8 (4.5)
Range	0 – 23
% reaching the criterion for possible psychiatric disorder	10%

Current Living Arrangements

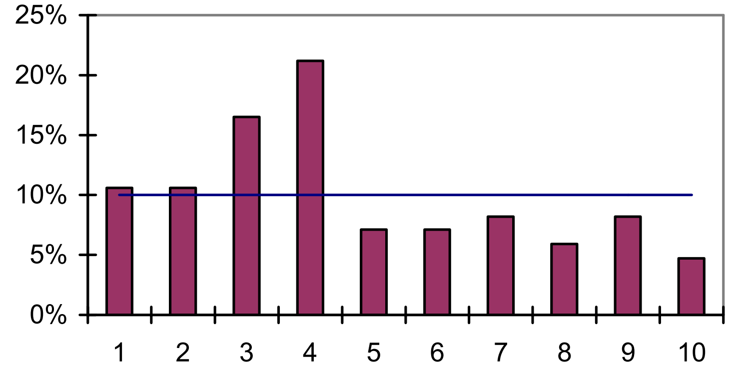
We collected information on where people were living. For people living in supported accommodation, we collected additional on when they had moved into their current residence, their residential history in the past 10 years, and when they had first moved away from their family home. This information is summarised in Table 8.

We also used peoples' postcodes to link to the English Indices of Deprivation 2004[67] in order to evaluate the level of deprivation of the neighbourhoods that people were living in. This information is summarised in Figure 1. Approximately 10% of the population of England lives in each of the 10 bands of deprivation shown in Figure 1. The Figure shows that, while participants were more likely than we would expect to live in moderately deprived areas, some also lived in affluent areas.

Table 8: Current Living Arrangements and Residential History

Current residence (n=93)	
Group home*	62%
Living with informal carer*	27%
LBHU*	7%
Independent Living*	3%
Respite	1%
For people living in some form of supported accommodation ….	
Average age (& s.d.) when left home	23.1 (14.5)
Range	0.8 – 54.6
Residential history over last 10 years	
Average years in current setting (& s.d.)	7.6 (6.1)
Range	0.1 – 30.7
% who have lived in NHS Hospitals*	38%
Average number of moves (& s.d.)	0.9 (0.9)
Range	0-4
Previous living arrangements: % who moved from a ...	
... children's home	1%
... residential children's home	1%
... respite care	3%
...residential or village community*	5%
… hostel	6%
... family or foster family home	20%
... group home	28%
... NHS hospital ward*	29%

Figure 1: % Participants Living in Areas of Very High (1) to Very Low (10) Deprivation



The Impact of Person Centred Planning

In this section we will present the results of statistical analyses conducted on the outcome data we collected over the course of participants' involvement in the study. As we described above, our study did not include a comparison or control group. Instead we aimed to collect information for each person at several different points in time prior to and following the implementation of PCP.

The first issue we needed to consider in the analysis was whether any changes we saw over time could be attributed to the introduction of PCP, or whether they may be due to other factors associated with the passage of time per se (e.g., a general improvement in the quality of supports over time). To do this we first evaluated what changes were occurring in peoples' lives prior to the introduction of PCP. The results of these analyses (given in detail below) suggested that very little was changing. This meant that we could be more confident that any changes we saw following the introduction of PCP could be attributed to this specific intervention than to other factors.

In the second stage of the analysis (presented in detail below) we assessed whether the introduction of PCP was associated with change in different areas of peoples' lives. We found positive change in six main areas:

- social networks
- contact with family
- contact with friends
- community involvement
- scheduled day activities
- choice.

In the third stage of the analysis we attempted to identify factors (e.g., characteristics of the participant, situational factors) that were associated with PCP having a greater or lesser impact.

Change Prior to the Implementation of PCP

We used two approaches to assess whether or not change was evident in key outcome areas prior to the implementation of PCP. First, we analysed the data for all participants which had been collected prior to the development of individual PCPs to see if any changes were evident over time. Second, for the 28 people for whom an individual PCP was not developed within the timescale of the project, we made comparisons between the first and last data collection points.

Data collected prior to PCP implementation

Data was classified as pre- or post-PCP based on responses to the question "Does this person have a current Person Centred Plan which has been used or reviewed in the last 6 months?". This question was asked at each data collection round. From the total sample of 93 participants no pre-PCP data was available for one person (their PCP had already been developed) and only one pre-PCP round of data collection was available for 36 participants (their PCP being developed after the first round of data collection). For the remaining 56 participants we had information from two or more pre-PCP rounds of data collection. Due to missing data we had usable information from two pre-PCP rounds of data collection for 41 participants and for three pre-PCP rounds of data collection for 30 of these 41 participants. We used these two sets of data to evaluate the extent of change that was occurring prior to the introduction of PCP.

Our analysis of the two rounds of data collected for 41 participants indicated that there were no statistically significant differences at the p<.05 level for any of the measures. These comparisons were restricted to measures collected on a three-monthly basis. These results suggest that there was little evidence of change over time prior to the implementation of PCP on any of the measures of outcome.

Our analysis of the three rounds of data collected for 30 participants indicated that there were no statistically significant differences at the p<.05 level for:

- all categories of community based service receipt (eg physiotherapy, social workers, GP);
- all categories of hospital based service receipt (eg outpatient appointments, inpatient days);
- physical activity levels as defined in the Health Survey for England;
- number and variety of activities as measured by the Index of Community Involvement (standard version);
- total number of people in social network, having a member of family in the social network, having someone who is not family, staff or another person with learning disabilities in the social network;
- hours per week of scheduled day activities;
- having received a particular category of day activity (e.g., day centre, voluntary work, adult education);
- level of contact with family;
- all categories of medication receipt (eg hypnotics, anti-depressants, anti-epileptics);
- total score on the SDQ and on all SDQ subscales;
- existence of all health problems;
- evidence of risk for all risk categories.

The following changes were found to be significant at the p<.05 level:

- Increase in total number of activities on extended ICI (Friedman 11.784, df=2, p<.01). The mean for round three (57) was significantly higher than that for round one (mean 38; Z=3.363, n=29, p<.001) and round two (mean 39; Z 2.765, n=20, p<.01).
- Increase in variety of activities on extended ICI (Friedman 6.961, df=2, p<.05). The mean for round 3 (9.2) was significantly higher than that for round two (mean

7.7; Z=2.286, n=21, p<.05), but not significantly higher than the mean for round one (8.4).
- Increase in total number of visits to, from, or with friends (Friedman 9.387, df=2, p<.01). The mean for round 3 (11.8) was significantly higher than that for round two (mean 8.0; Z=2.310, n=21, p<.05), but not significantly higher than the mean for round one (9.6).

Again, these results suggest that there was little evidence of change over time prior to the implementation of PCP on our measures of outcome.

Change for those without a plan

Participants were classed as not having had a plan developed within the timescale of the project if the answer to the question “Does this person have a current Person Centred Plan which has been used or reviewed in the last 6 months?” was “no” for all data collection points. For these participants (n=28) comparisons were made between the first and last data collection points on each of the outcome areas on which the impact of PCP was subsequently assessed. Only two statistically significant results were found. By the end of the project, those people who did not have a PCP:

- showed a 34% decrease in the extent of reported ‘peer problems’ on the SDQ (Z=1.988, n=25, p<.05);
- showed a 23% decrease in the total number of people in their social network (Z=3.236, n=27, p<.001).

In addition, there were three non-significant associations of note:

- an 81% increase in the number of visits to, from or with friends (Z=1.933, n=25, p<.1);
- a 2.4 increase in the odds of receiving chiropody (McNemar p<.1, n=27)
- a 2.9 increase in the odds of having more choice (p>.1).

Summary

We found very little evidence of positive change occurring in peoples’ lives prior to or in the absence of the implementation of PCP. While the data collected prior to the implementation of PCP did show some positive changes, it is notable that they did not show evidence of gradual improvement over time, rather the positive changes tended to occur at the third round of data collection. It is possible that these changes reflected activity associated with the development of a PCP.

The Impact of Implementing PCP

In this section we will look at the impact of implementing PCP. In view of the very small number of changes evident prior to the implementation of PCP, we undertook simple pre/post comparisons to test for the impact of PCP (using the first round of data collection as the ‘pre’ measure). This enabled us to increase the power of the analyses by maximising sample size.

We addressed two main questions.

- Is PCP efficacious?
- Is PCP effective?

Efficacy looks at the impact of an intervention for those people who receive it. It is the traditional way of evaluating impact. The efficacy analyses were, therefore, restricted to those 65 people for whom a plan was developed. For this group three questions were asked:

- Was there any impact? To do this the ‘pre’ indicator was compared with the final data collection point. This does mean that the length of time that PCP has been implemented varies across participants. It does, however, give the maximum amount of time available (within the constraints of the project) for PCP to have an impact.
- Was there an immediate impact? To do this the ‘pre’ indicator was compared with the first data collection point following the implementation of PCP (3-6 months). It is useful in identifying ‘quick wins’.
- Was there evidence of ongoing impact? To do this the first data collection point following the implementation of PCP (3-6 months) was compared with the final data collection point. This series of analyses indicates whether PCP has an ongoing impact in improving peoples’ lives.

Effectiveness looks at the impact of an intervention for all people for whom it was supposed to be implemented. It is becoming increasingly used in order to determine the population level benefits of interventions. The effectiveness analyses, therefore, included all 93 participants, whether or not they actually had a plan. For this group, comparisons were made between the ‘pre’ indicator and the final data collection point.

The following table provides a summary of statistically significant changes, trends and moderate effects found during the analysis. We decided report trends and non-significant (but moderate) effects for several reasons. This study is the first formal evaluation of PCP to be undertaken in the UK and the largest formal evaluation to be undertaken anywhere in the world. It is, however, still rather ‘underpowered’, in that the overall sample size is quite modest and the sample sizes for some comparisons (e.g., the ongoing impact of PCP) is decidedly small. The main result of the modest sample size is that ‘real’ effects of a modest size may not be ‘statistically’ significant. They may, however, be highly relevant to policy and practice.

In the following table:

✓ indicates a statistically significant change (p<.05) in a positive direction
✕ indicates a statistically significant change (p<.05) in a negative direction
?+ indicates a statistical trend (p<.1) in a positive direction
?- indicates a statistical trend (p<.1) in a negative direction
??+ indicates an effect in a positive direction where p>.1 but odds ratio is >1.5 for categorical data or % change in scores is >50%
??- indicates an effect in a negative direction where p>.1 but odds ratio is >1.5 for categorical data or % change in scores is >50%
A blank cell indicates no evidence of change

The level of statistical significance is indicated by *= p<.05; **=p<.01; ***p<.001

For each change noted, the magnitude of the effect is noted using odds ratios for categorical data, and percent change for ordinal data. The odds ratio is a simple measure of effect size that indicates how much more likely the odds are of something happening following the implementation of PCP. Thus for example, an odds ratio of 2.0 indicates that the odds of this event or activity happening doubled following the implementation of PCP.

In order to aid interpretation of the magnitude of these changes pre/post mean or % values are given in the Appendix (Table 35) for all variables in which a significant difference is reported for the ‘efficacious at all’ comparisons.

Table 9: Summary of the Impact of PCP

		Is it Efficacious?			Is it Effective?
Domain	Variable	At All (1st v final round of data collection)	Immediately (1st v next round of data collection following PCP)	Continuing Change (1st round of data collection following PCP v final round of data collection))	At All (1st v final round of data collection)
Social Network	Size of person's social network	✓** 52%		✓*** 67%	
	Family member in social network				
	Inclusive social network (contains at least one person who is not staff, family or other people with learning disabilities)				
Contact with Family	Level of contact with family	?+ 17%	✓* 33%		?+ 17%
	Number of visits to/from/with family	?+ 19%			✓* 18%
	Has active contact with family	?+ 2.0	?+ 2.1		?+ 1.8
	Has active contact & family in social network	✓* 2.4			✓* 2.0
Contact with Friends	Level of contact with friends	✓** 40%	✓** 30%		✓** 28%
	Number of visits to/from/with friends	?+ 28%		✓*** 62%	✓* 37%
	Has active contact with friends	✓* 2.2	✓* 2.0		✓* 1.8
Community Involvement	ICI total number of activities	✓*** 30%		✓*** 35%	✓*** 26%
	ICI number of different activities	✓*** 25%		✓*** 27%	✓*** 19%
	ICI (extended) total number of activities	✓*** 35%		✓*** 38%	✓*** 27%
	ICI (extended) number of different activities	✓*** 24%		✓*** 20%	✓*** 19%

Table 9: Summary of the Impact of PCP

		At All (1st v final round of data collection)	Immediately (1st v next round of data collection following PCP)	Continuing Change (1st round of data collection following PCP v final round of data collection))	At All (1st v final round of data collection)
Scheduled Day Activities	Hrs p week scheduled day activity	✓* 33%		✓* 35%	
	ATC/Day Centre			✓* 1.6	
	Voluntary work				
	Adult education				
	Social club				
	Recreational activities	??+ 1.8			
	One to one		?+ 1.7		
Choice	Choice improved in preceding 6 months	✓** 2.8	✓* 2.6		✓** 2.8
Community based service receipt (Having received service is preceding 3 months ......)	Number of service contacts				
	Variety of service contacts				
	Psychiatrist				
	Psychologist				
	GP				
	Community psychiatric nurse				
	LD nurse				
	Other community nurse		??+ 1.6	??- 0.5	
	Community mental health team				
	Health care assistant				

Table 9: Summary of the Impact of PCP								
	At All (1st v final round of data collection)		Immediately (1st v next round of data collection following PCP)		Continuing Change (1st round of data collection following PCP v final round of data collection))		At All (1st v final round of data collection)	
Speech therapist								
Physiotherapist			??+	1.9				
Occupational Therapist	?+	2.8			✓*	3.4	?+	2.4
Art/drama/music therapist	??+	2.2			??+	2.1		
Alternative therapist					??+	1.9		
Social worker/care manager								
Social work assistant								
Home help/home care worker								
Advocate/counsellor	??+	2.9			??+	3.0	??+	2.8
Dentist	??+	1.7	??+	2.0				
Optician	?+	2.5					??+	1.8
Audiologist								
Chiropodist	??+	1.6					✓*	1.8
Employment services/job centre								

Table 9: Summary of the Impact of PCP

		At All (1st v final round of data collection)	Immediately (1st v next round of data collection following PCP)	Continuing Change (1st round of data collection following PCP v final round of data collection))	At All (1st v final round of data collection)
Hospital based service receipt	Having used in preceding 3 months				
	Psychiatric intensive care ward				
	Acute psychiatric ward				
	Psychiatric rehabilitation ward				
	General medical ward				
	Other specialities				
	Psychiatric outpatient visit				
	Other outpatient visit				
	Day hospital				
	A&E department				
Physical activity	Activity level (none, low, medium, high)				
	Person inactive using HSE criteria				
Current Medication receipt	Hypnotics				
	Anxiolytics				
	Antidepressants				
	Anti-psychotics				
	Anti-epileptics				
	Anti-parkinsonism				

Table 9: Summary of the Impact of PCP					
		At All (1st v final round of data collection)	Immediately (1st v next round of data collection following PCP)	Continuing Change (1st round of data collection following PCP v final round of data collection))	At All (1st v final round of data collection)
Health problems	Having had various health problems				
	Number of health problems			x** 67%	
Strengths and Difficulties	SDQ Emotional subscale total	?- 50%	x* 38%		
	SDQ Conduct problems subscale total				
	SDQ Hyperactivity subscale total	x* 37%		x* 35%	x* 30%
	SDQ Peer Problems subscale total				
	SDQ Prosocial subscale total	?- 14%		?- 15%	x* 13%
	SDQ total difficulties score	?- 32%			
	SDQ total impact score	??- 58%			
	SDQ Caseness category				
Risk	Risk in or out of home or from traffic	??- 1.5		?- 6.6	
	Risk physical or sexual abuse				
	Risk financial or material abuse				
	Risk psychological abuse				
	Any risk, accident, verbal abuse, vandalism or crime				

Summary

In contrast to the very limited number of changes evident prior to the implementation of PCP, we found statistically significant changes in a number of key outcome areas.

Comparing baseline and final data points (i.e., looking at whether PCP was efficacious at all), PCP was associated with participants having a:

- 52% increase in size of social networks;
- 2.4 times greater chance of having active contact with family and a member of family in their social network;
- 40% increase in level of contact with friends;
- 2.2 times greater chance of having active contact with friends;
- 30% increase in number of activities measured by the ICI (standard);
- 25% increase in the variety of activities measured by the ICI (standard);
- 35% increase in the number of activities measured by the ICI (extended version);
- 24% increase in the variety of activities measured by the ICI (extended version);
- 33% increase in hours per week of scheduled day activities;
- 2.8 times greater chance of having more choice.

In addition to these statistically significant outcomes, there were also a number of areas where non-significant effects were evident. Again, comparing baseline and final data points (i.e., looking at whether PCP was efficacious at all), PCP was associated with participants having a:

- 17% increase in level of contact with family;
- 19% increase in number of active visits to, from or with family;
- 2.0 times greater chance of having had active contact with family members;
- 28% increase in number of visits to from or with friends;
- 1.8 times greater chance of having scheduled recreational day activities.

There were also non-significant increases in receipt of some services with participants being more likely to have seen an Occupational Therapist, an art, drama or music therapist, an advocate, a dentist, an optician and a chiropodist.

There were, however, other areas where change was in a negative direction.

- There was a significant increase (37%) in scores on the SDQ hyperactivity subscale and non-significant increases on: the SDQ emotional problems subscale (50%); the SDQ total difficulties score (32%); the SDQ total impact score (58%); and a decrease on the SDQ prosocial subscale (14%).
- Participants were also 1.5 times more likely to be perceived to be at risk in or out of the home or from traffic.

- Finally, when comparing the first data point post-PCP with the last data point post-PCP (i.e., looking for evidence of continuing change) there was a 67% increase in the number of health problems reported.

In conclusion, the main areas where PCP was found to be efficacious were:

- social networks
- community involvement
- scheduled day services
- contact with friends
- contact with family
- choice.

Not surprisingly, the evidence of effectiveness is slightly more limited at these analyses included information on participants for whom it was not possible to develop and maintain a plan. Nevertheless, the results did indicate that PCP was effective in the following four areas:

- community involvement
- contact with friends
- contact with family
- choice.

While PCP appeared to be both efficacious and effective it was clear from the fieldwork and data that it had a greater impact for some people than for others. In the following section we consider the factors that are associated with positive outcome in each of the six areas in which PCP was considered to be efficacious as well as factors that are associated with having a PCP developed successfully in the first place.

Predicting the Outcomes of PCP

We took two approaches to identifying factors that were associated with the impact of PCP. First, we made a series of simple bivariate comparisons between successful outcomes in each of the six areas and a range of variables associated with:

- participant characteristics;
- service support;
- setting characteristics;
- facilitator characteristics and views;
- family characteristics.

Potential predictor variables were taken from the ‘pre’ data point (first round of data collection), with the exception of variables relating to facilitator views which were taken from the final questionnaire completed by the facilitator in order to maximise the sample size. Chi square was used to identify significant associations for dichotomous variables and Mann Whitney for ordinal data.

Second, variables found to be significantly associated with dependent variables (defined as p<.05) were entered in a forward stepwise fashion (conditional model; criterion for entry and exit 0.01 and 0.05 respectively) into a multivariate logistic regression model to identify the unique contribution made by particular factors once the effects of other factors in the model had been taken into account. Variables which were relevant to only a sub-sample of participants (for example, setting variables relevant only to those living in supported accommodation) or variables where missing data meant that over 10% of cases were missing were excluded from multivariate analyses in order to maintain adequate sample sizes.

These two approaches were also used to identify factors that predicted whether it had proved possible to develop a PCP for the participants within the timescale of the project.

Analyses to identify associations with whether or not the person had a plan were conducted on the whole sample. Analyses to identify associations with the six main areas where PCP was found to have an impact were conducted using the subsample of those who had a plan only.

Bivariate associations are reported for:

- statistically significant results (p<.05);
- statistical trends (p<.1);
- and moderate effects where p>.1 but odds ratios were >1.5. For ordinal predictor variables, odds ratios were calculated by performing a high/low median split on scores for the relevant sample (i.e., the whole sample for associations with who got a plan, and the subsample of those who did get a plan for all associations with outcomes). Odds ratios were also calculated for ordinal data where p>.1 but there was a greater than 50% difference in scores. Resulting odds ratios of greater than 1.5 are reported.

In the following tables the notation is:

*=p<.05; **=p<.01; ***=p<.001; $^{?}$=p<.1; and blank if p>.1
UC=unable to compute (i.e., a cell value of 0 makes computation of odds ratio impossible).

These results do need to be viewed with a certain amount of caution. One particular problem is small sample sizes which result from:

- information being restricted to a subset of the overall sample (for example, setting characteristics for those in supported accommodation);
- the low occurrence of particular potential predictors;
- missing data due to the problems inherent in collecting a large amount of information over an extended period of time.

In some cases, low occurrence of potential predictors made the calculation of bivariate associations with outcomes impossible. For participant characteristics, this applied to:

- mental health problems on the PAS-ADD;
- autism (with the exception of associations with who got a plan);
- impaired vision;
- impaired hearing;
- dual sensory impairments.

For facilitator characteristics this applied to:

- having a facilitator who was a family member;
- having a facilitator who was an advocate.

For informal carer characteristics this applied to:

- how much time the carer spent caring for the person; and whether the carer was in paid employment.

In other cases, small sample sizes meant that although significant bivariate associations were found, variables could not be entered into multivariate analyses due to the number of missing cases. This makes interpretation of the multivariate analyses difficult as potential predictors have been excluded. Indeed, for improved family contact small sample sizes meant that it was not possible to perform any multivariate analysis despite the existence of significant bivariate associations.

Having a Person Centred Plan

Factors associated with having a PCP are shown below in Table 10.

Table 10: Bivariate Predictors of Having a PCP	
Factor	Odds Ratio
Facilitator has higher personal commitment to PCP**	12.2
Person has a keyworker**	5.7
Been involved in the study for longer***	5.5
Fewer health problems**	3.7
Person had a current IPP at baseline**	3.7
Person had less days off activities eg due to illness*	3.7
Facilitator has more contact with person?	2.9
Not having autism?	2.8
Facilitator has less hostility to PCP?	2.1
Not reaching criterion for mental health problems on the PAS-ADD	2.1
Less problems on the SQD emotional subscale?	1.9
Prior residence not being a hospital	1.8
Not having a known psychiatric disorder	1.7
Living nearer to family	1.7
Less impact on the SDQ impact subscale	1.6
Less problems on the SDQ peer problems subscale*	1.5
Not having impaired mobility	1.5
Facilitator is facilitator to more people*	UC
For those in supported accommodation only	
Higher senior staff ratio**	5.9
Better procedures for staff support of residents*	4.3
Greater active support of residents ***	4.1
Better procedures for individual planning at baseline**	3.6
Better procedures for activity planning at baseline*	3.5
Less staff turnover?	3.3
Person does not hold a tenancy*	3.1
More staff training*	2.9
Greater service user involvement?	2.8
Better procedures for assessment and teaching at baseline*	2.7
More rigidity of routines?	2.3

The following variables were included in the multivariate analysis (n=78): number of health problems at baseline; score on the SDQ peer problems subscale; having a keyworker; having an IPP at baseline; time off normal activities due to (e.g., illness or injury); total time involved in the study. The following variables were associated with having a PCP (Nagelkerke $R^2 = 0.46$):

- being involved in the study for longer (Wald = 13.9, $p<.001$);
- having a keyworker at baseline (Wald = 4.6, $p<.05$).

At each data collection round, where the person did not have a person centred plan informants were asked to give the main reasons why the plan had not been completed. Reasons given for non-completion of a plan were grouped into themes with the following themes being identified:

- In the process of being done (e.g., being quality checked; being written up; information collection being done).
- Facilitator issues (e.g., facilitator left; no facilitator).
- Health issues (e.g., participant ill health or injury).
- Time (e.g., not enough time to do planning).
- Staffing issues (e.g., staff shortages).
- Difficulty arranging meetings (e.g., people not turning up to meetings; cancelled meetings).
- Difficulty setting up circle of support (e.g., unable to find people to be in circle).
- Difficulty engaging focus person in the process (e.g., person not interested; person did not turn up to meeting).
- Family attitudes (e.g., family cannot see the point; dropped out as felt goals unrealistic).
- Focus person has new circumstances (e.g., new home; new staff team).
- Communication problems between supporters and focus person.

The following table gives the percent of those for whom each theme was identified at all during the course of the project (i.e. theme occurred at any data collection round). This data is only for those who did not receive a plan during the timescale of the project (n=28).

By far the most common reason for the failure of PCP to be implemented was problems related to facilitators (64%). Of those without a plan, 57% were noted to still be involved in the process of having a plan developed.

Table 11: Reported Barriers to Developing a PCP	
Theme	% for which theme identified at all
Facilitator issues	64%
In process of being done	57%
Time	25%
Staffing issues	18%
Health issues	7%
Difficulty arranging meetings	7%
Difficulty engaging participant in process	7%
Family attitudes	4%
Participant new circumstances	4%
Participant communication problems	4%
Difficulty setting up circle	0%

Having an Improved Social Network

Having an improved social network was defined as there being more people in the person's social network at the final data collection round than at baseline. Bivariate associations with having an improved social network are shown below in Table 12.

Table 12: Bivariate Predictors of Having a Wider Social Network

Factor	Odds Ratio
Focus person directs meetings more**	6.1
Less barriers from service providers*	4.6
Having a smaller social network at baseline*	4.2
Not having active contact with family and family in social network at baseline*	3.4
Less community and service barriers to PCP?	3.2
Facilitating is part of paid job of facilitator	2.8
Living in less affluent areas*	2.7
Facilitator is a member of management staff	2.6
Being in the study for longer?	2.5
Living with an informal carer	2.5
Prior residence not being a hospital	2.5
Less impact on the SDQ impact subscale?	2.4
Facilitator expresses more belief in people having a right to PCP?	2.4
Not having a known psychiatric disorder	2.1
Focus person seen as not being a barriers to PCP?	2.0
Having a known care manager	1.9
Not living in a group home	1.8
Not having a keyworker	1.8
Facilitator is a member of support staff	1.6
For those in supported accommodation only	
More social distance*	3.3

Two variables were included in the multivariate analysis (n=58): size of social network at baseline; and index of deprivation. Both variables were in the equation (Nagelkerke R^2 square .221) with an increased social network being associated with:

- a smaller social network at baseline (Wald = 5.6, p<.05);
- and living in areas with an index of deprivation indicative of less affluent areas (Wald = 4.0, p<.05).

Increased Community Involvement

Increased community involvement was defined as having a total score on the standard ICI which was greater at the final data collection round than at baseline. Bivariate associations with increased community involvement are shown below in Table 13.

Table 13: Bivariate Predictors of Having Increased Community Involvement

Factor	Odds Ratio
Focus person less seen to be a barrier to PCP**	5.3
Reported to have a psychiatric disorder	4.1
Facilitator not being a member of support staff*	3.7
Lower score for community involvement*	2.8
Not having a keyworker	2.6
Being female	2.4
Having a known care manager	2.3
Not having an IPP	2.3
Having impaired mobility	2.2
Living with an informal carer	2.1
Not having active contact with family and family in social network	1.9
Facilitator being management staff	1.9
More problems on the SDQ emotional subscale	1.7
Less problems on the SDQ conduct problems subscale*	1.4
For those in supported accommodation only	
Senior staff not having a relevant qualification	2.1

The following variables were included in the multivariate analysis (n=65): total ICI (standard version) score at baseline; score on the SDQ conduct problems subscale; and facilitator being a member of support staff. The only variable in the equation (Nagelkerke $R^2 = 0.166$) was total ICI (standard version) score at baseline with lower scores being associated with an increased score at follow up (Wald = 6.2, $p<.05$).

Increased Scheduled Day Activities

The number of hours per week that people have scheduled day activities is important as previous research has suggested that it is a key determinant of the satisfaction people with learning disabilities express about their day activity.[54] Increased day activity was defined as having more hours per week of scheduled day activities at the final round of data collection than at the first. Bivariate associations with increased scheduled day activities are given below in Table 14.

Table 14: Bivariate Predictors of Having an Increased Number Hours of Scheduled Day Activity per Week

Factor	Odds Ratio
Less challenging behaviour***	10.2
Having a circle of support?	6.9
Emotional & behavioural problems have less impact (SDQ subscale)*	3.7
Facilitating is part of paid work for facilitator	3.7
Having a keyworker	3.5
Fewer emotional problems (SDQ subscale)*	3.4
Facilitator has less calculative commitment to PCP**	3.1
Fewer emotional & behavioural problems (SDQ total scale)**	2.8
Living further from family?	2.7
Fewer problems with hyperactivity (SDQ subscale)*	2.6
Being male?	2.4
Less problems on the SDQ peer problems subscale*	2.4
Previous residence being a hospital	2.2
Facilitator is not an “other” worker eg community nurse, day service staff	2.2
Having less scheduled day service hours**	2.1
Not having active contact with family and family in social network	2.1
Not living with an informal carer	1.8
Having impaired mobility	1.8
Less organisational barriers to facilitation*	1.8
Facilitator has higher personal commitment to PCP?	1.8
Living in a group home	1.6
More prosocial (SDQ subscale)*	1.5
For those in supported accommodation only	
Lower overall staff ratios?	3.4
Less staff turnover*	3.3
More block treatment*	2.8
Person not holding a tenancy	2.6
Senior staff having a relevant qualification	2.5

The following variables were included in the multivariate analysis (n=51): hours of scheduled day service hours at baseline; total score on the LD Casemix challenging behaviour scale; total score on the SDQ; score on the SDQ emotional problems subscale; score on the SDQ hyperactivity subscale; score on the SDQ peer problems subscale; score on the SDQ prosocial subscale; score on the SDQ impact subscale; and facilitator ratings of organisation barriers to effective facilitation. Variables in the equation (Nagelkerke R^2 = 0.382) associated with increased day service hours were:

- lower total score on the LD Casemix challenging behaviour scale (Wald = 8.3, p<.01);
- and having less scheduled day service hours at baseline (Wald = 6.3, p<.05).

Improved Contact with Friends

Improved contact with friends was defined as: level of contact with friends went up; OR number of visits to from or with friends went up; OR active contact with friends changed from "no" to "yes". Bivariate associations with improved contact with friends are given below in Table 15.

Table 15: Bivariate Predictors of Having Increased Contact with Friends

Factor	Odds Ratio
Fewer problems with hyperactivity (SDQ subscale)**	6.3
More prosocial (SDQ subscale)***	4.7
Having more health problems*	3.7
Fewer conduct problems (SDQ subscale)*	3.4
Living further from family	3.3
Fewer emotional & behavioural problems (SDQ total scale)**	3.1
Facilitator expresses more belief in peoples' right to PCP?	3.1
More facilitation of communication in meetings?	3.0
Fewer peer problems (SDQ subscale)?	2.7
Not having a care manager?	2.5
Prior residence not being a hospital ward	2.4
Not having active contact with friends at baseline	2.1
Not living with an informal carer	2.1
Not having active contact with family and family in social network	2.1
Being more able?	2.0
Facilitator not being a member of support staff	1.8
Being male	1.8
For those in supported accommodation only	
Less sophisticated procedures for individual planning*	7.5
More social distance?	3.7
Not having senior staff with a nursing qualification	2.1

The following variables were included in the multivariate analysis (n=54): number of health problems at baseline; total score on the SDQ scale; score on the SDQ conduct problems subscale; score on the SDQ hyperactivity subscale; and score on the SDQ prosocial subscale. Variables in the equation (Nagelkerke $R^2 = 0.493$) associated with improved contact with friends were:

- having more health problems at baseline (Wald = 7.7, $p<.01$);
- lower scores on the SDQ hyperactivity subscale (Wald = 4.4, $p<.05$);
- and higher scores on the SDQ prosocial subscale (Wald = 2.9, $p<.1$).

Improved Contact with Family

Improved contact with family was defined as:

- level of family contact went up OR
- number of visits to from or with family went up OR
- active contact went from “no” to “yes” OR
- active contact & having family in the social network went from “no” to “yes”.

Those living at home were excluded from these analyses. Bivariate associations with improved family contact are given below in Table 16.

Table 16: Bivariate Predictors of Having Increased Contact with Family Members

Factor	Odds Ratio
More facilitation of communication in meetings*	7.2
Having impaired mobility	4.7
Living further from family*	4.4
Fewer problems with hyperactivity (SDQ subscale)	3.7
More prosocial (SDQ subscale)?	3.5
Focus person directs meetings more?	3.2
Fewer peer problems (SDQ subscale)*	3.0
Having a care manager	2.8
Not having active contact with family at baseline	2.2
Not living in a group home	2.2
Not having an IPP at baseline	1.9
Facilitator not being support staff	1.7
Not having a known psychiatric disorder	1.6
Previous residence being a hospital ward	1.6
For those in supported accommodation only	
Less sophisticated procedures for individual planning**	9.0
More block treatment?	2.9
Senior staff having a relevant qualification	1.6
Person not holding a tenancy	1.6

Only one variable, score on the SDQ peer problems subscale, fitted the criteria for inclusion in multivariate analysis. This variable was not found to be a significant predictor using logistic regression (n=41).

Improved Choice

Improved choice was defined as having had choice improved in the last 6 months at either the first data collection point post-PCP or at the final data collection point. Bivariate associations with improved choice are given below in Table 17.

Table 17: Bivariate Predictors of Having Increased Choice

Factor	Odds Ratio
Fewer community and service barriers to PCP***	13.2
Less accessible local facilities*	9.4
Focus person less likely to be seen as a barrier to PCP?	6.9
Facilitating being part of paid job for facilitator?	5.6
Less staff-related barriers to PCP**	5.4
Living in more deprived areas?	4.5
Focus person directs meetings more?	3.6
Not having active contact with family and family in social network	3.3
Less advocacy and resource barriers to PCP?	2.8
Higher facilitator agreement that PCP works for all*	2.8
Living in a group home	2.7
Facilitator being a member of support staff	2.2
Having a keyworker	2.1
Facilitator being a member of management staff	1.9
Being female	1.8
Having a known care manager	1.7
Emotional & behavioural problems have less impact (SDQ subscale)?	1.4
For those in supported accommodation only	
Senior staff not having a nursing qualification	2.4
Senior staff not having a relevant qualification	2.2

The following variables were included in the multivariate analysis (n=44): access to local facilities; index of multiple deprivation; facilitator agreement with principle PCP works for everyone; and facilitator reported staff barriers to PCP. The only variable in the equation (Nagelkerke $R^2 = 0.271$) was facilitator reported staff barriers to PCP with less reported barriers being associated with improved choice (Wald = 6.2, $p<.05$).

The Views of the Participants

An important part of evaluation was to listen to the views expressed by the people with learning disabilities who took part. To do this we developed a semi structured interview called My Life. The interview had two main aims: to gather the views of participants about the PCP process itself; and to record how people saw their lives before and after PCP.

The opportunity to take part in a My Life interview was offered to all participants who had some verbal communication, every six months throughout the project. A total of 55 people gave at least one My Life interview. A total of 65 interviews were given either before the PCP process had begun or during its early stages. There were 70 interviews after PCP was fully established or at the end of the project.

The purpose here was to listen to the views of the participants in the project as they relate to the central research questions of the project as a whole. With that in mind, interview content was transcribed and sorted in order to articulate views of the PCP process itself and to gain insight into the impact of PCP in the words of the people who were its focus. This was not intended to be a formal qualitative study. It was not about defining the construct of PCP or producing a formal qualitative evaluation of the PCP process.

This section begins with an analysis of the interviews given before PCP or during its early stages. These tend to reflect the ideas that people had about their lives at that time. These findings are followed by the interviews given after the PCP process was well underway or at the end of the study. There is a good deal more information here. First, it gives an opportunity to explore the experience of PCP itself. It then moves on to give some insight into the changes that have or have not taken place in the lives of the individuals who took part.

Life before PCP – Everyday Hopes and Concerns

As might be expected the hopes and concerns expressed in the early interviews were, in large part, the important everyday things that matter to us all.

The question that people responded to with information about their lives was entitled “and finally”. Here individuals were asked about the three things that would most like to see change in their lives and also mention anything that is important and that had not been mentioned elsewhere. In reviewing the answers to these questions seven main themes emerged from the material.

Relationships

‘Seeing mum’
‘Get engaged and then get married’

Perhaps the most important area for people related to their relationships, both in terms of family contact and hopes for new relationships in the future.

Basics

These include the issues related to where people lived, employment, going to college and day services. Participants were concerned to see changes in what be understood as the basic framework of their lives.

Health

> ‘I want some help to get my leg better’

There were very few mentions of physical health issues at this stage.

Holidays

> ‘Go to *Centre Parks* with M, S and G’

The places mentioned varied from Wales to America and the means of transport from car to cruise ship. Often though it appeared that it was the people to go with who mattered most.

Things to do

> ‘Do shows’
> ‘Do classes’
> ‘Seaside’
> ‘Sailing’
> ‘Theatre’

When talking about hopes for the future the longest list of single items were activities. The sense here is that these are simply things that people like to do and would like to do more of.

Food

> ‘Tea’
> ‘Chocolates’
> ‘Vegetable pie’

Again these were given as one-word answers that are self-explanatory.

Personality

> ‘Freedom’
> ‘Respect’

Two people talked about hopes and concern for what might be described as self expression.

The Person Centred Planning Process

In discussing their experience of the PCP process, participants gave some important insights that have been organised into 9 themes.

Standards

The interview included a set of specific questions that implied a series of standards for conducting PCP meetings. Answers suggested that participants experienced PCP meetings as they should be.

‘I choose where to have the meetings.’
‘I choose when to meet.’
‘I choose who to invite and send out the invites.’
‘I invite people myself.’
‘People who I have never met do not come to the meetings.’
‘I feel able to say what I want.’
‘I am listened to properly.’
‘I understand what people say at the meetings.’
‘The meetings talk about what is important to me, and about going to the theatre.’
‘People say what they will do to make things happen for me.’
‘I am involved in writing my plan. I make up the minutes with …..’
‘I get a copy of my plan.’
‘Things happen for me like they are supposed to after the meetings’

Variations

There were some differences from the standards, but these weren’t necessarily negative. This is clearly a different process for different people and the following quotes illustrate some of the differences.

‘I go to my planning meetings - sometimes they are here or at the office.’
‘I don't know who chooses where to have the meetings - I think it's the bosses.’
‘I don't choose who to invite, or invite people myself.’
‘I know some of the people who come to the meetings.’
‘Sometimes I understand what people say at the meetings.’
‘At the meetings, people ask me things and I tell them.’
‘I talk about how the meeting went with someone. They tell me all kinds of things.’
‘I get a copy of my plan in a way I understand it - I don't know where I've put it now.’
‘Planning is making things better for me.’
‘Sometimes the bosses are there - we talk about what's going on and any changes.’
‘The meeting where I got a copy of my plan was at …..’
‘I've no idea when the next meeting is.’
‘We talk about my money and they tell me how much I've got.’
‘Before the meetings I talk to J. The meetings are usually held at my sister's house. J chooses this. I choose who to invite and I invite them.’
‘My social worker is coming to the next meeting (to help with moving house). I have not met her yet. The meetings sometimes talk about what is important to me.’
‘After the meeting I talk with F and J - they write the plan. I keep a copy in my locker at the centre.’

Mixture of experiences

Following from the theme of variation, there were a number of comments combining the positive with the unclear and the uncertain.

‘I don't really feel comfortable with the meetings. ‘
‘I don't know if I go to the meetings - I can't remember.’
‘I don't remember if I go to planning meetings ‘
‘I liked the meeting, but I want my family to come to the next one, so I will invite them next time.’
‘Janet wanted to come but I didn't know her so I didn't invite her. ‘
‘I got a bit bored with the meetings.’
‘I think the plan is making my life better - I like having a go with the iron.’
‘I want the meeting the way it is next time, but with my family there.

Understanding what is going on

Some people talked about the struggle to understand meetings

M didn't have a PCP plan in the house. He said he was frightened of going to the PCP days in case he said something wrong

R. had told one of the circle members that he was talking too fast and she couldn't understand what he was saying

Talking about things that matter

A number of people reflected on how PCP got to grips with the issues that were important to them and with a sense of realism!

‘The main thing we talk about is our wedding and going to Disneyland for our honeymoon - this is what is important to me. We do talk about things after the meeting’
‘I would like to live in a mansion, to win the lottery and take S to the Caribbean!’

Important people

Some people were important to the process, but it wasn’t clear if they were the facilitator

‘M. and R share the meeting’
‘There are quite a few people in the circle - M, G, M, L, S and M. I asked people to join.’

Getting started and keeping going

There were a number of comments that suggested it is difficult to get the process started and difficult to maintain. In one case this isn’t necessarily a negative thing.

‘I haven't had any PCP ones yet ‘
‘I go to planning meetings, but it's a bit long ago to remember’
‘M was doing my plan with me, but I don't know who's doing it now. I don't know what's happening with it.’
‘I enjoyed the meetings I had with M.’
‘I think my plan is good so far and I would like to carry on with it ‘
‘I saw A (facilitator) at the buffet the other day, but haven't seen her much apart from that. ‘

Materials

‘J. has a PCP file with pictures in. ‘
‘I'm not sure whether I get a copy of my plan.’

Only very sparse mention was made of materials used.

Outcomes

‘Lots of things have got better with planning’
‘Things happen for me like they are supposed to after the meetings - it takes time’
‘I'm not sure if my meetings are any use or making things any better’

There are many people who agreed that PCP made a difference. Other comments ranged from ambivalence to satisfaction.

Changes

In considering the material over the overall period of analysis, there were a number of points about change.

Changes over time

‘I like to colour, draw pictures of spiders and listen to the radio.’
‘I help around the house.’
‘I like to go to the local pub for a pint of lager.’

First there were interviews at the end of the study that gave far richer information than those carried out in the earlier stages. Here are some examples of richer information that did not appear in the earlier interviews.

Changes Achieved

Some people talked about substantial changes in their lives.

‘We live in a privately rented flat and have a nice landlord who lives a few doors away. I went to pay the rent this evening.’
‘I wasn't sure about the flat when I first saw it, but we have done a lot of work on it. We've painted it and bought lots of things for it. I had saved money up when I was in hospital and had bought the TV and furniture with savings.’
‘I like to be able to look out of the window into the street.’
‘I have a job 3 days a week - Monday, Thursday and Friday from 9am to 2.30pm. I work as a paper and postman at … hospital. I love my job and don't want to change anything about it. R goes with me once every few months’
‘I live at … it's above the Post Office and near the other shops.’
‘I live with my fiancé M, we moved here from hospital about a year ago.’
‘I like living here and want to live here for good. We have gradually done the flat up as we want it, we have painted it and bought furniture.’
‘I like where the flat is, I like being near the shops. I don't like the children who hang about outside. I like the local pub and we are friendly with our neighbours.’
‘Our flat is rented from a private landlord.’
‘I like the staff who support us - John is a good friend and helps us out, everyone helps us.’
‘I used to have a voluntary job in a charity shop but left that a long time ago.’
‘I am going to help at the local church - wash up the cups in the café kitchen. I am waiting to hear about it, it might be in the mornings, or at the weekend. I would like to get a job, it would be lovely to get the job at the church.’

Maintaining good things

A number of people talked about the ways they enjoyed their lives and wanted to keep these the same. This also would be a role for PCP. There were some examples of people whose lives were already rich and enjoyable making small changes to keep things interesting.

> ‘I live with the same people as before, except M has moved out.’
> ‘I like the house I live in.’
> ‘I like the people I live with.’
> ‘I like the staff that support me at home.’
> ‘I like where my home is.’
> ‘I can't think of any thing I'd like to change about my home’

Changes to come

There continue to be a number of hopes for the future and changes that really need to take place.

> ‘I would like to do Cook and Eat in September.’
> ‘I would like to go to classes with S.’
> ‘I would like support from 2 staff to learn new things - one for my brother.’

Conclusion

In considering the words of the people themselves, it is appears that PCP has had an impact in some of their lives. The experience has been relevant to the hopes and concerns that people share with others in the community. In some instances important and positive outcomes were already being seen. Perhaps unsurprisingly, the details of the process in terms of paperwork and indeed facilitation are not as important as the fact that people who take decisions and control resources might have found a way to listen to the people who are affected by the decisions and intended to be the recipients of the resources.

The Economic Impact of Person Centred Planning

Renee Romeo & Martin Knapp

In this section of the report, we concentrate on some results from the evaluation undertaken by the Centre for the Economics of Mental Health. The aim of the economic section was to evaluate the direct and indirect costs associated with the systematic introduction of Person Centred Planning.

Methodology

From an economic perspective, PCP can be considered an investment. Costs are incurred in the short-term in the expectation that there will be improvements in social and economic function in later life. Putting PCP into practice requires (among other things) running development and training sessions among various groups on its principles and application.

The training cost estimation exercise adapted from established economic principles followed four stages:

- Describe the training process
- Measure each element associated with the training
- Value the implications of each of these elements
- Calculate the unit cost of training, and cost per trainee

The information underlying the training cost estimation associated with implementing PCP was gathered through focused discussions held between the consultant trainers and one of the researchers. Consultants described the way the training was delivered. This included the various elements of the training and how it was delivered, including the time spent by the trainer, location of the training (the training space used), the average number and hours of staff who attended from different professions and roles.

The choice of a unit of measurement for each element of the training and the way in which it is calculated is integral to the overall costing exercise. Participants in the training session were involved in the sessions at various times over the course of the two years. For a paid facilitator, it was appropriate to use the cost per hour so that this unit could be multiplied by the time spent in each training session, which was usually no less than one hour.

We then collected information on the cost implications of the elements (resources) associated with the training. These elements included salary and on-costs, clerical support, relevant share of the capital and maintenance of buildings and equipment and the management of the department and other training related expenses such as catering, stationery. The cost of training self-advocates, families, friends, paid support staff and front line managerial staff includes their salary as well as additional cost to the employer such as national insurance contributions. Data on the salaries and related cost for families and friends, who were unpaid facilitators, was not available. We therefore estimated their costs based on the cost of paid facilitation. Training across the sites was undertaken in a variety of settings, in some cases a nominal rent was paid for the facility basis and in other areas use of the facility was provided ‘free’ of charge. To ensure that capital was consistently employed across all sites we replaced information on rental of facilities with standardised estimates. Capital costs based on new build and land requirements for a local authority training room were used. Local authorities may consider using existing facilities, whose facilities can be presently valued, based a rate of 3.5 per cent over 60 years. The rate reflects the fact that expenditure or benefits in the future are worth less than if they were incurred now.

To calculate the cost per trainee of attending a PCP training programme geared towards understanding, owning and implementing the principles of PCP, the average costs of each of the elements was calculated and these cost summed to give an average cost for implementing PCP.

Additional information on implementation sessions provided at two of the sites was excluded to maintain consistency. For example, two of the sites held implementation sessions with the steering group, which initially involved the PCP research steering team and was subsequently merged with the local implementation group. Salary related cost for the research steering team and the implementation group were excluded from the calculations

The financial arrangements surrounding funding for PCP activities and training, changes in accounting and budgetary procedures are strategic to the implementation process. However, these arrangements which obtain at the strategic level will be discussed in the following section and will not be included in the direct implementation costs.

Training and support took place over a period of two years from March 2001/2002 to March 2002/2003. The training took place for twenty days at each of the sites. Costs associated with these training days were estimated for the period 2003/2004.

Interventions have an *indirect* impact on the package of services provided as part of their care. A diverse range of mainstream services can be affected, such as day activities, hospital (inpatient and outpatient), primary care, mental health services, social care, and aids and adaptations to assist with daily living.

In order to evaluate these indirect costs implications of PCP, three issues will be considered:

- The accommodation and service-based costs prior to the implementation of PCP, and whether or not there were differences in costs between those who had a plan and those who did not have a plan developed.

- The accommodation and service-based costs following the implementation of PCP and whether there were differences in cost for those who had a plan and those who did not have a plan.
- We will then look at associations between a range of potential predictors and service-based costs post PCP implementation.

Data Collection

Alongside the collection of lifestyle outcomes described earlier, information on the use of all hospital and community services was collected for each participant using a revised version of the Client Service Receipt Inventory (CSRI).[60 61] Briefly, the CSRI is a semi-structured interview designed to collect cost-related data including service utilisation and socio-demographic information on household composition, employment status, receipt of social security benefits, and other income. For all participants in supported accommodation *The Residential Services Setting Questionnaire*[68] was used to record information about the managing agency arrangements and staffing levels.

Agencies responsible for providing accommodation and support were contacted and asked to provide information that would allow estimation of facility-specific costs. Researchers identified the point of contact for finance data at the agencies responsible for providing accommodation and support. A letter of introduction was sent to each of the organisations participating in the study, which set out the aims of the economic component and outlined the areas where information would be needed.

An attempt was made by the Centre for the Economics of Mental Health (CEMH) researcher to visit each of the residential facilities. However, information on service users living in their own home or homes rented from a private landlords or housing association was obtained from organisations providing outreach services and by researchers who were involved in outcome assessments.

Obtaining and estimating facility-specific costs provided by each organisation raised some difficulties. In certain forms of supported settings, residents share housing facilities and receive outreach support at various times during the week. Residents may do their own shopping with some support from staff. In these living settings, housing-related support and outreach support are usually contracted out to several agencies. Therefore, it is difficult to coordinate the necessary account information and to gain access to the people able to provide and interpret the data. Constraints on the researcher’s time and the time between the two data collection points meant that everyone of these arrangements could not be investigated in detail. However, data on facilities for which we did not have information were estimated based on similar facilities.

Cost Estimation

The approach used to estimate the direct and indirect costs associated with the introduction of Person Centred Planning (PCP) uses established principles of costing in general and costing of services in particular.[60 71]

For each service used by each participant a unit cost must be estimated. In turn, these unit costs (per day, per contact, etc.) are multiplied by the amount of use each person has made of that service. This allows calculation of the costs of supporting each participant. In this study, we take a public sector perspective including costs to the health service, and social services; thus, the costs of care provided by informal caregivers have not been estimated.

All unit costs are based on 2003/2004 price levels (the time period for service and other data collection) and where possible nationally applicable costs have been taken from a well-established compendium.[72] For services not included in that volume, unit costs were estimated specifically for this study. The methodology employed is equivalent to that used in the Netten and Curtis volume[72] providing estimates of the long-run marginal opportunity costs, thus including allowances for capital costs and overheads. Opportunity costs mean that resources reflect their next best alternative use rather than the amount spent. Marginal cost is the additional cost incurred by adding one more service user or one more unit of service. Short-run average revenue costs (the recurrent operating expenses of a service) plus appropriate capital and overheads costs are close to long-run marginal costs for most services and form the basis of the estimation.

The total cost therefore includes the cost of services received as part of the accommodation plus the cost of a range of routinely provided services. Costs were estimated for two discrete time-periods:

- The three months prior to baseline interview (pre-implementation of PCP)
- The three months prior to the final visit (post PCP implementation)

Data analysis

To look at cost differentials between those for whom a plan was developed and those without a plan, Mann-Whitney U-test was used. Costs were not normally distributed so the non-parametric test, which does not make assumptions about the distribution, is more appropriate than say a t-test. Cost analyses are reported at the 5 per cent level of significance. The arithmetic mean values and standard deviations are reported in the tables.

To look at associations between the range of potential predictors and costs after the implementation of PCP for those who had a plan, multivariate analysis was used. All potential predictor variables were entered into multivariate regression analyses, with total cost as dependent variable, to identify associations with costs, and then sequentially removed. The regressor with the smallest partial correlation with the dependent variable was considered first for removal if it met the criterion for removal (0.05). After the first variable was removed, the regressor remaining in the equation with the smallest partial correlation was considered until there were no variables in the equation to satisfy the removal.

Participant characteristics were also examined in linear and non-linear forms, to derive a cost prediction equation. This was done to maximise the predictive powers of the estimated equation whilst ensuring the statistical significance of individual coefficients. The best fitting equation has been summarised.

Results

The training has been described in an earlier section of this report. Briefly, the implementation of PCP took place in three main phases over the two-year period.

- Focus on what is important to the person with a learning disability
- Focus on learning more about people's relations and connections to the community
- Focus on future aspirations

Direct Costs

Training was provided to both the facilitators and the managers. Facilitators consisted of paid outreach support staff, self advocates, unpaid volunteers such as friends and family members. In two of the sites, there were a few self-advocates. In two other sites, all facilitators were paid members of staff and there were no family members or self-advocates involved in the training. On average, there were sixteen facilitators at each of the sites involved in the training. Support sessions were also provided to both facilitators and managers in two of the four sites. This enabled the facilitators and managers to meet with the trainer to review progress and plan next steps.

At each of the phases, implementation sessions were held with the implementation steering group. This group consisted mainly of the PCP research team. Each facilitator was asked to provide a summary of what was working and not working in the person's life from the facilitator's perspective. The group then did a content analysis on a sample of issues that arose from this. This provided a summary of the main themes that were working well and the areas that required organisational change. The group then developed an action plan from this. The cost associated with the implementation is research-related costs and is not include in the overall cost estimation.

As seen in Table 18, the average cost of building the capacity of families, friends, paid support and front line staff was £15,297 per site with a range of £13,996 to £16,500. Costs varied depending on the time spent by facilitators and managers in the sessions. The cost of the trainer contributes three quarters (75 per cent) of the overall costs for each site. The use of facilities or office space to hold the training sessions represents a small proportion of the overall costs. Training materials were not used consistently over all the sites. The estimated cost of a training pack for facilitators used at two of the sites was given at £19.99. Insufficient information on the consultants' expenses was held and was not included in the cost estimation.

Table: 18: Training and support cost

	Total direct Input	No in receipt of training	Unit cost (£)	Minimum cost per site	Maximum cost per site	Average cost per site
Consultation costs:						
Trainer (days)	20	22	575±	£11,000	£12,000	£11,500
Staff costs						
¥Facilitators (hours)	92*	16	19	£1,605	£1,900	£1,748
Managers (hours)	77§	6	26	£1,391	£2,600	£2,002
Total staff cost				£2,996	£4,500	£3,750
Other costs						
Capital				-	-	£47
Total cost				£13,996	£16,500	£15,297

± Trainee cost range from £550 - £600 per day. Each session consists of between 5 –8 hours direct input

* Facilitators spent 84.5 – 100 hours in training

¥ Facilitators consisted of paid staff, self-advocates and unpaid volunteers such as friends and family members. There were few self-advocates in the sessions, and the cost of time spent in the training sessions by self-advocates was not measured. The cost of volunteer time provided by friends and family members was estimated using the cost of paid facilitator.

§ Managers spent 53.5 – 100 hours in training. This includes individual support and group training sessions.

These training and implementation costs translate into a cost per participant of

- £658 if calculated across all 93 participants (i.e., including those participants to whom the ‘intervention’ was not delivered) or
- £941 if calculated across the 65 participants to whom the ‘intervention’ (delivery of a plan) was delivered.

Pre-Implementation Costs

Before we use the methods described previously for the cost analysis we will describe the socio-demographic characteristics of the participants for which service use data were collected before PCP.

Of the 93 people with learning disabilities who gave consent and participated in the project before the implementation of PCP, we received service use data on 86 participants. The majority of the participants were men (64 per cent), and white (86 per cent). At the time of interview, 70 per cent lived in staffed accommodation such as an inpatient ward a locally based hospital unit or a staffed group home. Seventy eight per cent were unemployed or unable to work. Participants who were employed did voluntary work.

In order to estimate the total cost of care received prior to the implementation of PCP, we need to look at the services provided as part of the accommodation facility and services received externally.

Accommodation costs refer to the cost to all agencies of providing services to the individual setting whether it is on a full-time or on a part-time basis. These services may be provided by a number of agencies with responsibility for aspects related to accommodation. It should be noted that when we discuss accommodation costs we are also referring to the contribution of the client to the cost of housing-related support.

From the providing agencies perspective, services provided in the community may be included in the provision of accommodation. However, we have separated these from the overall cost of accommodation and discussed these separately in a subsequent section (non-accommodation based service).

Every attempt was made to consider and estimate all the elements associated with providing accommodation and the associated care and support within the settings before the introduction of PCP and after implementation. Yet, we must be aware of those costs that are not as easily quantifiable. We have therefore sought not to include in the estimation the transaction costs for health and local social services departments, including higher-ranking support and related overheads. As is known, there are cost implications associated with senior level planning and development and the purchase and monitoring of these services. It may even be hypothesised that the more individual the package of housing and support the more time is invested in its development. However, these estimates are often excluded from the analysis of costs.

Accommodation costs for residential settings and those in supported living setting (individualised care) were calculated from four categories of information: direct staffing in the setting, non-staffing costs within the setting (heating, light provision), administrative or professional staff working across the whole site and central office overheads. All capital costs were annuitised over an expected 60-year life span at a discount rate of 3.5 per cent. Ten per cent of the annual figure was added as an estimate of the replacement of fixtures and fittings. This is consistent with other studies conducted in this area. The total accommodation costs were derived using the following:

Client contribution: Such contributions might be linked to pocket money for the purchase of personal items or any proportion of rent payment meeting bricks and mortar costs.

Direct staffing costs: These were the total costs of staffing the individual setting. They included support workers based in each house where a study client was resident, and the apportioned input from senior care staff and others (such as domestic staff) whose time would be divided between several different settings.

Direct non-staffing: These included food, heat and lights, and water rates and council tax, routine maintenance and small items of household equipment, where provision was the responsibility of the provider organisation or where provision was contracted out to a housing association or housing agency.

Agency overheads: These were central office costs, apportioned across all facilities managed by the parent organisation.

Capital: This item covers the opportunity costs of building, fixtures and fitting and vehicles based at the setting. It also takes into consideration the concern that properties lose value over time.

Client contributions: These are the out-of-pocket expenses incurred by the service user for personal and household expenses. These can include cash contributions to the maintenance of the garden, food, travel, clothing and shoes and small household supplies.

Data were also collected on all services received by the study participants external to the accommodation facility at two time points: before the implementation of PCP for a retrospective period of three months and after implementation of PCP for the same period. A three-month retrospective period is long enough to allow inclusion of most commonly used services and short enough to reduce the problems of recall.

Services are likely to span a diverse range of mainstream services such as daytime activities, hospital services (inpatient and outpatient services), and community based services with professionals in primary care, mental health services, social care and the aids and adaptations used by study participants to assist with daily living.

In order to take a comprehensive look at the total pre-implementation costs we need to include both the accommodation and the component non-accommodation costs. The complete service package cost is detailed after the component costs for those with a plan relative to those who did not have a place developed have been explored. Mean costs are quoted for the accommodation facility, which includes all the components mentioned previously including any costs met by the client. Non-accommodation services costs are also defined by their mean and have been divided into service-related categories described above.

Accommodation costs

The following tables provide a summary of various elements of the service package received before the implementation of PCP. We will present the distribution of the costs for the sample of 86 participants before the introduction of PCP and go on to explore the distribution of accommodation costs for those who went on to have a plan developed and those who did not go on to have a plan developed.

In order to explore the distribution of the accommodation costs, Table 19 gives details of the mean costs for the full sample and then for those who went on to have a plan developed and those for whom a plan was not developed. The weekly accommodation cost per resident was £1,179. This cost varied between £191 and £3,365, with the staffing costs being the main contributor to the overall cost of accommodation. The mean cost appeared to vary for those who had a plan (£1,224) and those who did not (£1,055), although the difference in mean costs was not statistically significant.

Before the implementation of PCP, approximately 70 per cent of the participants for whom we have information on services were resident in a staffed facility. The majority of these facilities were housing clusters, linked but dispersed. This is in contrast to the number of people who lived in unstaffed accommodation. Twenty one per cent of the participants lived in flats owned by the person or family or in privately rented flats, while almost 9 per cent lived in flats or houses rented from a housing association.

Table 19: Average weekly cost of accommodation

	Full sample (n=86) Average weekly cost	Plan (n=63) Average weekly cost	No Plan (n=23) Average weekly cost	Test of statistical significance
Accommodation cost	1179	1224	1055	n.s.
Range	191-3365	576-3367	191-1304	
Standard deviation	499	556	263	

Non-accommodation based service costs

Using the methods descried above, the following sections explore the cost of services used, looking in turn at daytime activities, hospital-based services, community-based services and aids and adaptations. We will then go on to analyse these costs components for those people for whom a plan was developed and those for whom it was not developed.

Table 20 presents the non-accommodation based services received by the sample of participants prior to the implementation of PCP. Daytime activities were the highest contributor to costs (84 per cent). This is mainly due to the use of day centre facilities, which have traditionally been the mainstay of leisure activities of persons with a learning disability.

Table 20: Total services costs: average weekly non-accommodation based cost prior to implementation of PCP

	No. Using	(%)	Average weekly cost	(SD)
Day-time activities	72	(84%)	125	(126)
Hospital based services	22	(26%)	5	(21)
Community based services	74	(86%)	17	(32)
Aids and adaptations	7	(8%)	0	(1)
Total non-accommodation based cost			147	(133)

Daytime activities

Daytime activities are summarised in Table 21, where the utilisation rates and the average cost per week are shown those for those person who did and did not have a plan. As can be seen, day centre use made up the majority of the cost of day activities (69 per cent for those who had a plan and 89 per cent for those who did not.

Table 21: Daytime activities: Percentage of service users using services and average weekly cost

	Plan (n=63)		No Plan (n=23)		Test of statistical significance
	No. Using (%)	Average weekly cost (SD)	No. Using (%)	Average weekly cost (SD)	
Day centre	43%	81 (112)	56%	127 (121)	n.s.
Adult education	30%	25 (77)	13%	2 (6)	n.s.
Voluntary work	3%	0 (0)	0%	0(0)	n.s.
Drop-in/social club	38%	2 (3)	26%	3(6)	n.s.
Recreation	14%	2 (6)	17%	1 (2)	n.s.
Other day activities	16%	2 (8)	4%	1 (4)	n.s.
One to one activities	33%	6 (123)	39%	9 (21)	n.s.
Total		118(128)		143 (121)	n.s.

Few service users in each of the groups were employed before the implementation of PCP. Only 3 per cent of service users who had a plan developed were in some form of employment, compared to no one in the other group. This is in part due to the higher percentage of service users (over 57 per cent) who were either unable to work, retired or pensioned or a student.

Day services made up the bulk of the service-based costs. However, these costs did not differ between those who did and those who did not have a plan developed.

Hospital services

Table 22 provides details of the percentage of service users in the two groups who used inpatient, outpatient, day hospital and accident and emergency services and the cost per week of those services.

Generally, moderate use was made of all categories of hospital services and this is reflected in the average weekly costs. The most widely used of all hospital-based services was attendance at outpatient services (24 per cent for those who had a plan developed and 13 per cent for those who did not have a plan developed). Again, the component and total average weekly hospital cost did not differ between the groups.

Table 22: Hospital services: Percentage of service users using the service and average weekly cost

	Plan (n=63)		No Plan (n=23)		Test of statistical significance
	No. Using (%)	Average weekly cost (SD)	No. Using (%)	Average weekly cost (SD)	
General medical ward	3%	1(5)	0%	0(0)	n.s.
Psychiatric outpatient ward	8%	1 (6)	0%	0 (1)	n.s.
Other outpatient ward	16%	6(23)	13%	1 (2)	n.s.
Day hospital	2%	0 (1)	0%	0 (0)	n.s.
Accident and emergency	6%	0 (2)	4%	1 (2)	n.s.
Total		8 (24)		2 (2)	n.s.

Community-based services

Table 23 presents the utilisation rates for community-based services used by both groups prior to the implementation of PCP. Service users made contact with a variety of community-based professionals. The most widely used community-based service was the GP (46 per cent for those had a plan developed and 39 per cent for those who did not). Interestingly, 30 per cent of service users who did not have a plan developed made use of an employment service such as the job centre compared to those who had a plan developed (22 per cent). This is in the context of those in employment in both of the groups (3 per cent for those who had a plan developed and no one in the group who did not have a plan developed).

Table 23: Community based services: Percentage of service users using services and average weekly cost

	Plan (n=63)		No Plan (n=23)		Test of statistical significance
	No. Using (%)	Average weekly cost (SD)	No. Using (%)	Average weekly cost (SD)	
Psychiatrist	8%	0 (1)	4%	0 (0)	n.s.
Clinical psychologist	2%	0 (0)	0%	0 (0)	n.s.
General practitioner	46%	2 (3)	39%	1 (1)	n.s.
Learning disability nurse	10%	1 (8)	4%	0 (1)	n.s.
Other community nurse	8%	0 (0)	26%	0 (1)	p<0.01
Speech and language therapist	11%	1 (2)	13%	0 (0)	n.s.
Physiotherapist	10%	1 (7)	4%	5 (15)	n.s.
Occupational therapist	6%	0 (2)	4%	1 (4)	n.s.
Alternative therapist	19%	2 (6)	13%	1 (2)	n.s.
Art therapist	5%	0 (1)	9%	1 (5)	n.s.
Social worker	10%	0 (1)	4%	0 (1)	n.s.
Home help	3%	6 (33)	0%	0 (0)	n.s.
Counsellor	3%	1 (1)	4%	0 (0)	n.s.
Dentist	33%	1 (1)	26%	0 (0)	n.s.
Optician	11%	0 (0)	9%	0 (0)	n.s.
Chiropodist	22%	0 (0)	30%	1 (3)	n.s.
Employment service	22%	1 (3)	30%	3 (6)	n.s.
Dietician	2%	0 (0)	0%	0 (0)	n.s.
Dermatologist	2%	0 (0)	0%	0 (0)	n.s.
Relaxation therapist	0%	0 (0)	4%	0 (1)	n.s.
Housing officer	0%	0 (0)	4%	2 (9)	n.s.
Respite care	0%	0 (0)	4%	3 (12)	n.s.
Support worker	2%	1 (4)	0%	0 (0)	n.s.
Total community based services		17 (36)		18 (22)	n.s.

However, across all categories of community-based services there were no significant differences between the two groups.

Aids and adaptations

Table 24 shows the percentage of service users who received specialist aids and adaptations during the three months prior to the implementation of PCP. Across the full sample 93 per cent of service, users did not use any aids or adaptations. Specialised aids and adaptations included an adjustable chair, shower chair, handrails, bath lifts/ hoists, step stool and wheel chair.

Aids and adaptations made a very small contribution to the total cost. There were no significant differences in the average weekly cost for persons who had a plan developed and for those who did not.

Table 24: Aids and adaptations: Percentage of service users using the service and average weekly cost

	Plan (n=63)		No Plan (n=23)		Test of statistical significance
	No. Using (%)	Average weekly cost	No. Using (%)	Average weekly cost	
Average cost	8%	0	9%	0	n.s.
Range		0 to 3		0 to 4	
Standard deviation		0		1	

Total service package cost before implementation of PCP

In order to look at the overall impact of PCP on services, we need to combine all the accommodation and non-accommodation-based services used before its implementation. Pre-implementation service package costs will give a description of the distribution of costs by categories and we can then explore the influences for those who had a plan relative to those who did not. In Table 25, average weekly costs are shown for all service users in their residential setting and outreach support and non-accommodation-based services categorised by service (day time activities, hospital services, community-based services and aids and adaptations). Costs are also compared for those for whom a plan was developed and was not.

Accommodation and support made up over 88 per cent of the total cost of the service package across the full sample. A similar picture emerged in sub-group analyses. For service, users for whom a plan was developed, accommodation-related support made up 90 per cent of all costs, and for service users who did not have a plan developed 88 per cent. However, no significant differences were found between the groups for accommodation and support.

There were no significant differences in the components of non-accommodation service costs between the groups. In other words, the groups for whom a plan and developed and those for whom it was not developed do not differ in their use of services before implementation.

Table 25: Total services package: average weekly cost of accommodation and non-accommodation cost by group prior to implementation of PCP.

	Full sample (n=86) Average weekly cost (SD)	Plan (n=63) Average weekly cost (SD)	No Plan (n=23) Average weekly cost (SD)	Test of statistical significance
Accommodation cost				
Total accommodation cost	1179 (499)	1224 (556)	1055 (263)	n.s.
Non-accommodation costs				n.s.
Day-time activities	125 (126)	118 (128)	143 (121)	n.s.
Hospital	5 (21)	8 (24)	2 (2)	n.s.
Community based	17 (32)	17 (36)	18 (22)	n.s.
Aids and adaptations	0(0)	0 (0)	0 (1)	n.s.
Total cost	1326 (508)	1366 (557)	1215 (328)	n.s.

Post-implementation Costs

In order to assess whether the implementation of PCP had an effect on accommodation and services used, data were collected on their location and services accessed as part of the accommodation facility and external to it. To maintain consistency with the data collection before the implementation of PCP a three-month data collection period was used.

Non-accommodation services after the implementation of PCP included the same range of services before the implementation of PCP. Services included: daytime activities, hospital services (inpatient and outpatient services), and community-based services with professionals in primary care, mental health services, social care and the aids and adaptations used by study participants to assist with daily living.

After the implementation of PCP, comprehensive data were collected on 77 service users across the demonstration sites. This represents 89 per cent of the services users for whom accommodation and service data were collected at baseline interview.

Before we estimate the costs after the implementation of PCP, we must also look at the characteristics of the sample to see whether there were any significant changes over the research period.

At final data collection, there was little change in the socio-demographic characteristics of the sample shown (see table 10. Sixty one per cent of the participants were males, and 86 per cent white; 23 per cent lived independently with outreach support.

Accommodation costs

The following tables provide a summary of various elements of the service package received after the implementation of PCP across the four demonstration sites.

In order to explore the distribution of the accommodation costs, Table 26 gives details of the mean costs for those who went on to have a plan developed and for those for whom a plan was not developed. The weekly accommodation cost per resident was £1,196 across the sample. This cost varied between £191 and £3,421, with the staffing costs as the main contributor to the overall cost of accommodation. There was little difference in the mean costs for those for whom a plan was developed (£1,220) and those for whom a plan was not developed (£1,117). This difference was not statistically significant.

Table 26: Average weekly cost of accommodation

	Full sample (n=77) Average weekly cost	Plan (n=59) Average weekly cost	No Plan (n=18) Average weekly cost	Test of statistical significance
Accommodation cost	1196	1220	1118	n.s.
Range	191 - 3422	191 - 3422	885 - 1261	
Standard deviation	526	594	160	

Non-accommodation based service costs

Daytime activities

After PCP implementation, day activities continued to be the most widely used of all services. The activities are summarised in Table 27, where the utilisation rates and the average cost per week for those for whom a plan was developed was not are shown. As can be seen, day centre use made up the majority of the cost of day activities yet again (47 per cent for those who had a plan developed and 50 per cent for those who did not have a plan developed). More service users were involved in recreation activities, day activities and one-to-one activities such as going to the pub or for a walk. Only service users for whom a plan was developed (3 per cent) were in voluntary work, though the hours spent in employment increased.

There were no significant differences in the total cost of day activities for people who did and did not have a plan. There were also no significant differences between the two groups when components of day activities were analysed.

Table 27: Daytime activities: Percentage of service users using the service and average weekly cost

	Plan (n=59)		No Plan (n=18)		Test of statistical significance
	No. Using (%)	Average weekly cost (SD)	No. Using (%)	Average weekly cost (SD)	
Day centre	47%	71(89)	50%	69 (78)	n.s.
Adult education	24%	0 (1)	5%	0 (1)	n.s.
Voluntary work	3%	2 (10)	0%	0 (0)	n.s.
Drop-in/social club	42%	12 (22)	11%	2 (6)	n.s.
Recreation	46%	11 (24)	50%	6 (7)	n.s.
Other day activities	24%	7 (21)	33%	7 (12)	n.s.
One to one activities	34%	47 (124)	50%	33 (90)	n.s.
Total		149 (137)		117 (130)	n.s.

Hospital services

Table 28 summarises the utilisation rates and weekly costs for service users in both of the groups. As stated previously costs are indicated as means across the two groups, whether or not people used the service, so there is some flattening out of the mean.

Little use was made of inpatient, outpatient, day hospital and accident and emergency services. After PCP implementation, only four persons made use of accident and emergency services and only three persons in either group made use of outpatient services for a general medical condition in a three-month period. The poor uptake of services is not surprising given that empirical evidence suggests there are unrecognised health needs in people with a learning disability. Only 26 per cent (22 service users) of all participants had a routine health check in the last three months of the study period.

Poor uptake of services is reflected in the weekly average hospital costs. The total weekly cost of hospital service was approximately £3 for both groups.

Table 28: Hospital services: Percentage of service users using the service and average weekly cost

	Plan (n=59)		No Plan (n=18)		Test of statistical significance
	No. Using (%)	Average weekly cost (SD)	No. Using (%)	Average weekly cost (SD)	
General medical ward	2%	1 (5)	5%	2 (9)	n.s.
Other inpatient ward	3%	1(8)	0%	0 (0)	n.s.
Psychiatric outpatient ward	8%	0 (1)	5%	0 (1)	n.s.
Other outpatient ward	19%	0 (1)	17%	0 (1)	n.s.
Day hospital	2%	0 (0)	34%	0 (0)	n.s.
Accident and emergency	7%	0 (1)	0%	0 (0)	n.s.
Total		3 (10)		3 (10)	n.s.

Community-based services

Table 29 shows the percentage of service users who made contact with community-based services and the weekly cost of community-based services. As laid out previously, costs are indicated as averages across the two groups, whether or not people used the service. Contact was made with a variety of community-based service professionals, however in general there was moderate use made of services. The most widely used of all services was the GP (49 per cent for those for whom a plan was developed and 50 per cent for those for whom a plan was not developed). Dental services were also used by 47 per cent for those who had a plan and 39 per cent for those who did not, while chiropody services were used by 35 per cent for those who had a plan and 44 per cent for those who did not. ‘Other community services’ included behavioural support worker, manicurist and dietician. Together six persons used these services.

The contribution of these component services to the total community-based service costs was not large. In fact, the average weekly cost of community-based services for those who had a plan was £16 and £13 for those without a plan. The difference in cost between the two groups was not significant.

Table 29: Community based services: Percentage of service users using the service and average weekly cost					
	Plan (n=59)		No Plan (n=18)		Test of statistical significance
	No. Using (%)	Average weekly cost (SD)	No. Using (%)	Average weekly cost (SD)	
Psychiatrist	2%	0 (0)	22%	0 (1)	p<0.01
Clinical psychologist	3%	0 (0)	0%	0 (0)	n.s.
General practitioner	49%	1 (2)	50%	1 (1)	n.s.
Community psychiatric nurse	2%	0 (0)	0%	0 (0)	n.s.
Learning disability nurse	10%	2 (10)	0%	0 (0)	n.s.
Other community nurse	8%	3 (18)	5%	0 (1)	n.s.
Community mental health team	3%	0 (1)	0%	0 (0)	n.s.
Speech and language therapist	8%	0 (1)	11%	1 (2)	n.s.
Physiotherapist	10%	1 (7)	11%	3 (9)	n.s.
Occupational therapist	15%	1 (6)	5%	0 (2)	n.s.
Alternative therapist	13%	2 (5)	28%	3 (6)	n.s.
Art therapist	10%	1 (4)	5%	1 (3)	n.s.
Social worker	17%	0 (1)	11%	0 (1)	n.s.
Home help	0%	0 (0)	5%	3 (14)	n.s.
Counsellor	13%	2 (10)	0%	0 (0)	n.s.
Dentist	47%	0 (0)	39%	0 (0)	n.s.
Optician	22%	0 (0)	11%	0 (0)	n.s.
Audiologist	5%	0 (0)	0%	0 (0)	n.s.
Chiropodist	35%	0 (0)	44%	0 (0)	n.s.
Employment service	3%	0 (1)	0%	0 (0)	n.s.
Other community services	8%	0 (1)	5%	0 (0)	n.s.
Total community-based services		16 (26)		13 (18)	n.s.

Aids and adaptations

Table 30 shows the percentage of clients who received specialist aids and adaptations and the average weekly costs, standard deviation and minimum and maximum costs. The types of aids did not change from those used before the implementation of PCP. These included wheelchairs, shower chair, handrails, step stool and jacuzzi bath. The cost of aids and adaptations contributed very little to the total cost. There was no difference in the cost of aids and adaptations between the groups.

Table 30: Aids and adaptations: Percentage of service users using the service and average weekly cost

	Plan (n=59)		No Plan (n=18)		Test of statistical significance
	No. Using (%)	Weekly cost	No. Using (%)	Weekly cost	
Average	5%	0	5%	1	n.s.
Range		0 to 3		0 to 12	
Standard deviation		0		3	

Total service package cost after implementation of PCP

The baseline service package costs before PCP was assessed above, by combining all the accommodation and non-accommodation based services. A consistent approach was taken in assessing the post implementation service package costs. We summarised the distribution of costs by categories and explored the influences for those who did relative to those who did not have a plan. In Table 31, average weekly costs are shown for all service users in their residential setting and outreach support given and non-accommodation based services categorised by service such as day time activities, hospital services, community based services and aids and adaptations by the two groups.

The average weekly service package cost per participant increased to from £1,326 before the implementation of PCP to £1,356. Accommodation and associated care costs made up the bulk (88 per cent) of the costs. For service users who had a plan developed accommodation cost made up 88 per cent of the total cost, and similarly for those who did not have a plan (89 per cent). The second largest contributor to the total cost was daytime activities. When these two categories were added, they made up 99 per cent of the total service package costs for those for whom a plan was developed and 99 per cent for those without a plan.

There were no differences between the groups in the component costs (of accommodation and related support, daytime activities, hospital services, community based services and aids and adaptations) as shown in Table 31.

Table 31: Service packages: Average weekly cost of service packages by sub-groups at follow-up

	Full sample (n=77) Average weekly cost (SD)	Plan (n=59) Average weekly cost (SD)	No Plan (n=18) Average weekly cost (SD)	Test of statistical significance
Accommodation	1196 (526)	1220 (594)	1118 (160)	n.s.
Day-time activity	142 (135)	149 (137)	117 (130)	n.s.
Hospital	3 (10)	3 (10)	3 (10)	n.s.
Community based services	15 (24)	16 (26)	13 (18)	n.s.
Aids and adaptations	0 (0)	0 (0)	1 (3)	n.s.
Total service package cost	1356 (531)	1388 (594)	1252 (203)	n.s.

Longitudinal analysis: Before and After PCP implementation

There were no significant differences in the cost of support either at the beginning or end of the study between people for whom a plan was or was not developed and sustained.

Longitudinal analyses were carried out to compare the cost before and after the implementation of PCP. This comparison revealed non-significant differences in the overall service package costs over the period of the study both for the full sample and for the sub-sample of people for whom a plan was developed and sustained.

Cost Prediction

PCP did appear to increase costs marginally after implementation; it was also clear from the effectiveness analyses that it had a greater impact for some people than for others. In the following sections, we consider the factors that are associated with costs of the full sample, whether the person had a plan developed or not. Then we go on to identify associations with costs after the implementation of PCP only for those who had a plan developed.

To identify the factors associated with the cost of implementing PCP a couple of multivariate analyses were used. The first used the data collected on individuals as a possible predictor and the second examined variables associated with:

- participant characteristics
- facilitator characteristics and views
- family characteristics and

- changes in successful outcomes such as community involvement, contact with friends, family, and choice.

Analyses to identify associations with costs associated with PCP for those who had a plan (only) were conducted using the above approach.

The ‘best’ estimates of the set of relationships between characteristics of the participant and costs are summarised in Table 32. Participant characteristics explained 63 per cent of the variation in the costs of accommodation and non-accommodation based support (shown by equation 1). Including variables associated with PCP in the set of potential explanatory factors did not add to the explanatory power of the analysis (shown in equation 2).

Turning to the pre-implementation characteristics, the costs of service packages were significantly associated with having a diagnosed psychiatric disorder, previously living in a hospital, employment status and ethnicity. Those who previously lived in a hospital before entering the study incurred higher costs compared to those who previously did not live in a hospital; costs were higher for participants with a psychiatric diagnosis. Participants who were employed incurred greater costs than those who were not employed. We would perhaps expect that participants who were unemployed would incur more cost since they would be the ones with a higher level of disability and would therefore use more services. Persons who are able to work were in employment and were perhaps more active than other participants and vocal in their need for services after the introduction of PCP. There was also a strong association between ethnicity and costs of service packages. People from black and ethnic minorities had higher costs.

Areas where PCP was found to be efficacious were also included in multivariate analyses with costs. However there were cases where variables could not be entered into the multivariate analyses because of missing data. This takes away from the interpretation of the analysis since potential predictors were excluded. The results are in equation 2.

Only one such variable was significant: people who were educated up to primary (1) secondary (24) or tertiary education (5) incurred higher costs than those who were educated in vocation courses.

Table 32 Cost Prediction equations for total accommodation and non-accommodation costs (77 observations)

	Equation 1			Equation 2		
Explanatory variables	β coefficient	(95% confidence interval)	P-value	β coefficient	(95% confidence interval)	P-value
Constant	1991	(-235 to 4217)	0.07	552	(-1917 to 3022)	0.65
Psychiatric diagnosis: n=10 (relative to no psychiatric diagnosis: n=66)	572	(77 to 1066)	0.03	1223	(713 to 1733)	0.00
Previously lived in hospital: n=15 (relative to did not previously live in hospital: n=43)	477	(100 to 854)	0.02			
Employed: n= 7 (relative to not employed: n=57)	438	(-5 to 881)	0.05			
White: n=66 (relative to non-white: n=7)	-1693	(-2404 to -983)	0.00	-589	(-1155 to -23))	0.04
Education: other general: n=2 § (relative to other: n=30)				-365	(-723 to -5)	0.05
	R2 = 0.81 adjusted R2 = 0.63			R2 = 0.69 adjusted R2 = 0.50		
	N=38			N=38		

§ Dichotomous ‘dummy’ variable, taking the value ‘1’ if the condition is satisfied and ‘0’ otherwise.

For those persons for whom a plan was developed, the only variable associated with costs was: ethnicity. None of the facilitator or carer characteristics or changes in outcomes in the six domains was significant: social networks, community involvement, contact with friends, family, and choice. There was a large degree of missing data for factors after the implementation of PCP, which reduced the predictive ability of the equation estimated.

Table 33 Cost Prediction equations for total accommodation and non-accommodation costs - PCP implementation successful only (59 observations)

Explanatory variables	β coefficient	(95% confidence interval)	Equation P-value
Constant	1319	(-2211 to 4850)	0.42
White: n=53 (relative to non-white: n=6)	-1833	(-3059 to -608)	0.01
			R2 = 0.88, adjusted R2 = 0.67 N=30

§ Dichotomous ‘dummy’ variable, taking the value ‘1’ if the condition is satisfied and ‘0’ otherwise.

SDQ; Strengths and difficulties score

Summary

The average cost of training paid facilitators, front line staff, members of the family and friends was £15,297 per site. These trainee costs varied depending on the time spent by facilitators (both paid and unpaid) and managers in the training session. It is important to note that the cost of the trainer contributes 75 per cent of the overall costs for each participant. However, these costs are likely to fall over time as local capacity is built and training is carried out by external trainers but undertaken in house.

These training and implementation costs translate into a cost per participant of

- £658 if calculated across all 93 participants (i.e., including those participants to whom the ‘intervention’ was not delivered) or
- £941 if calculated across the 65 participants to whom the ‘intervention’ (delivery of a plan) was delivered.

For the full sample, the average weekly service package cost per participant before the implementation of PCP was £1,326. By the end of the study this had risen by 2.2% to £1,356. This increase was not statistically significant. For the sub-sample for whom it was possible to develop and sustain a plan, the average weekly service package cost per participant before the implementation of PCP was £1,366. By the end of the study this had risen by 1.6% to £1,388. This increase was not statistically significant. The group for whom a plan was developed and sustained did not differ in their use of services either at the beginning or end of the study from those for whom it was not possible to develop and sustain a plan. Accommodation and associated care costs made up the bulk (88 per cent) of the costs.

The finding suggests that the total service package costs were marginally but not significantly higher after the implementation of PCP. It was therefore be inferred that PCP does not lead to a significant change in the cost of service packages.

The multivariate analyses suggest that demographic and psychiatric factors influence service package costs while shifts in domains such as social networks, community involvement, and contact with friends, family and choice have no impact. Further, that the cost of service packages is in some respects responding to the increased awareness of needs (through an increase in day activities over time), facilitated by the implementation of PCP.

Organisational Factors Influencing the Effectiveness of Person Centred Planning

Paul Swift

The project has explored whether PCP makes a difference to the lives of a group of individuals. A critical adjunct to this work is an analysis of the demands placed upon the organisations that support PCP, the factors that either help or hinder them in their efforts to implement government policy, and the lessons that can be drawn from their engagement with the project. This chapter is about the necessary, but not in themselves sufficient, conditions that are required to make PCP work.

Relatively little research effort has thus far been expended on questions of the organisational frameworks within which person centred technologies and approaches flourish. This may be explained partly by the relative absence of a role for welfare support services in the development of person-centred planning in the US, indeed some have argued that this was precisely why the US proved such a fertile breeding ground for concepts of person-centredness and self-determination. In the UK however, formalising PCP as, *inter alia*, an instrument for the delivery of publicly funded care places agencies and organisations at the heart of local implementation strategies.[73] In addition, traditional methods for evaluating organisational (and policy) development are largely antithetical to concepts predicated on individual choice, dreams, wishes, and desires. In this sense PCP marks a radical departure in social policy and we, as evaluators are struggling to keep up.

Yet it takes no great leap of the imagination to suppose that it is precisely at the point where individual aspirations and organisational pragmatics intersect that PCP is most likely to fail. Peter Kinsella[73] points out that PCP is ‘frequently seen as a tool to aid quality improvement, care planning, resource allocation and staff planning, it has become a darling of services’ resulting in ‘a bureaucratic and mechanical approach’ which ‘indicates a superficial understanding of PCP; a desire to be seen to be doing the right thing and a continuing obsession with a mechanical approach to change that belies the necessary changes in culture and attitude’. Still, PCP opens up a number of possibilities for statutory services. On the one hand it may be helpful, providing a mechanism by which they may be sensitized to the needs and wishes of the people who use their services, although this does not imply that services will take account of the messages they receive. Indeed, John O’Brien & Connie O’Brien caution about the limits of PCP, arguing that it ‘belongs to the politics of community and disability. It is not a way to avoid conflict about the investment of public resources.’[74]

Our organisational analysis looked at what services at the four sites did to ensure that PCP happened. As has already been noted in chapter 1, PCP is a complex innovation in learning disability services, requiring significant changes to established organisational cultures and practices. As the project began we were aware of the potential impact of person centred planning upon (amongst other things):

- The way direct care staff work
- The relationship between organisations, the users of their services and the families of those users.
- The style of management adopted in services.
- The roles played by care managers in the PCP process.
- The types of services bought using public money.
- Who provides services, and possibly in different ways from the past.
- How services are planned at a strategic level.

Models for evaluating similarly complex policy initiatives suggested we therefore explore issues of context, policy, organisational capacity and stakeholder response[75] [76] [77] in relation to their impact both upon the structure of organisations (how they are configured) and upon the way they go about their work (the process of 'cultural' change). A template for data collection was designed to expose those factors that either helped or hindered the implementation of PCP in these respects. Following meetings with the lead officers for PCP at each of the four sites and a review of the Valuing People Guidance and local documents relating to PCP, a set of potential factors were distilled which would form the basis for subsequent interviews and group discussions:

- The clarity of national and local strategies for PCP amongst managers and groups of staff.
- The extent of understanding of the respective responsibilities for making sure PCP happened.
- The specific local contexts in which organisations operated.
- The degree of compulsion/discretion experienced by organisations and individual agents in implementing the policy.
- The presence or otherwise of incentives for implementing PCP.
- Anticipation of the problems that might be entailed in implementing PCP.
- Commitment to the principles and values associated with PCP.
- Leadership for the initiative.
- Resources available to make it happen.
- How the quality of both processes and outcomes associated with PCP are monitored.

Two further related factors were also identified, concerning the local strategic infrastructures to PCP. Firstly, the style and nature of working between organisations since there is some evidence that a general culture of joint working in localities is a predictor of success for specific policy initiatives. [78] Secondly, interviews with the chairs of Partnership Boards and commissioners, conducted as part of the Strategies For Change Project[79] (another study funded as part of the Valuing People Research Initiative), hinted at as yet unrealized local aspirations for using person centred planning in strategic decision-making and the potential implications for organisations supporting people with a learning disability. Accordingly we used documentary sources, such as Joint Investment Plans, s31 Health Act partnership arrangements, service audits, inspection reports and local strategy papers to compile a history of partnership working between agencies at each site, while Joint Investment Plans (JIPs) were evaluated for evidence that they were informed by a person-centred approach; that action plans for PCP were in place; that mechanisms existed to ensure that PCP could influence strategic decision-making and planning; that priorities for PCP were clearly stated; and that quality assurance mechanisms were in place.

The delegated roles and tasks associated with PCP were explored at each site through interviews with key informants, documentary analysis and observation of meetings. The tasks included the establishment of implementation group, the drafting of frameworks and plans, and the identification of resources dedicated to the development of PCP. Key roles were associated with strategic leadership for implementation (accountable to the Partnership Board), frontline coordination of the process of PCP across the locality, training, advocacy, and information and communication. The analysis of local infrastructures also included chosen approaches to PCP (the 'tools' adopted), systems for managing information about person centred plans (including those for aggregating data), and mechanisms for quality assurance.

Semi-structured interviews with senior managers were used to detail the existing and planned configuration of organisations directly involved with PCP, including the policy-making procedures, service capacity, line management structures and stated service philosophies. We explored the styles of assessment and care management employed at the four sites, how they related to the introduction of PCP, and to what extent this changed during the course of the project. Special attention was paid to the development of community learning disability teams following the review of their role and functions demanded by *Valuing People*. As the project progressed we gauged how responsive service managers had been to the demands of service users and commissioners expressed through PCP.

A series of interviews were conducted with a selection of first and second line managers in the principal organisations charged with delivering PCP. The purpose of these interviews was to ascertain the clarity or otherwise of the particular formulations for PCP employed in their locality, their perceived ability to implement it, and the implications of PCP for the management function within their organisation.

Group discussions were held with a selection of care managers, community teams and frontline support workers to explore their understanding of the concept of PCP, their experience of it (as facilitators, members of circles, named persons and so on), how it fitted with their respective roles, and whether it had altered the way they approached their work. A variety of techniques (according to the communication needs of individuals and opportunities to convene group discussions) were used to elicit the views of self-advocates, families, advocates and facilitators about the local infrastructure to PCP and the organisational responses to their own involvement in it.

All of the interview material was analysed thematically, firstly to chart the evolution of organisational responses to the requirements of PCP, secondly, by comparing data across sites, to build predictive organisational indicators of successful implementation, and thirdly to identify key factors that help and hinder organisational change.

Amongst the many tasks that *Valuing People* laid at the door of the nascent Learning Disability Partnership Boards was a responsibility to ensure that PCP was implemented locally. The early signs were that most Partnership Boards struggled to find an effective modus operandi let alone tackle the massive agenda contained within the White Paper.[79] The practical work of implementation came to be expedited through small working groups focusing on specific objectives, led by people with specialist knowledge or interests, and reporting back to a parent Board. Government guidance on PCP worked with this realistic grain by proposing the establishment of implementation groups charged with developing a framework and action plans.

Initial findings from our fieldwork sites confirmed the wisdom of such an approach, since Partnership Board members were, and in many cases remained, unclear about the detail of PCP and regarded the outcomes of individual plans as unimportant to their strategic remit, at least during the initial phase of their existence. As the bodies responsible for strategic change in the commissioning and delivery of services, and for the practice of professional specialists, Boards were clearly some way short of the position where PCP would ‘play a significant role in assisting [them] to bring about the necessary shifts in culture and practice so that people can lead the lives they want within their communities.’[21]

Against this background, the Partnership Boards at each of the project sites set about creating an infrastructure to support PCP in their respective areas. This comprised a local framework to guide the process, a group to oversee implementation of the policy, a strategy for training and staff development, dedicated personnel to support implementation, the production of accessible information about PCP, systems for collating and analyzing the information generated by individual plans, and mechanisms for assuring quality in local systems.

The guidance outlined three key principles for establishing implementation groups.[21] First, membership should comprise a range of ‘stakeholders’, people who are likely to have a role to play in PCP, including people with learning disabilities, their families and representatives of children’s services. Second, they should draw upon specialist knowledge and expertise about PCP if this is not already present. Third, groups should be chaired by people of seniority and influence.

Implementation groups were asked to review local services’ ability to deliver person centred approaches, including the roles and tasks undertaken by care managers, health professional and service providers, and to produce an action plan based upon the findings. The guidance advocated a “depth and breadth” approach to implementation whereby an investment in ‘high quality training and support’ is complemented by a breadth approach which ‘offers larger numbers of people practical ways that they can start to improve how they listen and respond to people in ways that are consistent with Valuing People’.[21]

Groups were also encouraged to promulgate the principles and practice of PCP and to institute means for evaluating the effectiveness of it.

The early stages of the project witnessed a degree of adaptability applied to the governance of PCP across the fieldwork sites. In Site B, for example, the existence of distinctive localities within a large rural county, each with their own Primary Care Trusts, community learning disability teams, and second tier local authorities, led to the creation of a network of local implementation groups acting as ‘mini-partnership boards’. In another area the implementation group visualised their role as a ‘final say’ or coordination group, with most of the substantive work being done in member organisations and smaller groups to spread discussion about PCP. This was deemed the most suitable arrangement for a locality within which a multiplicity of service providers had already instituted PCP. The chairperson of a neighbouring Partnership Board (not involved in the project) described the Board as “just another bloody meeting” lacking an executive function, from which members “drifted away looking bored and dispirited”. Mindful of his obligation to produce a framework and action plan, but keen to avoid a proliferation of meetings in a compact authority, he alighted upon the solution of running full Board meetings as workshops facilitated on a rota basis by members each designated with a lead responsibility for implementing an aspect of *Valuing People*. This had the effect of revitalising the Board and providing members with a sense of purpose.

The reality confronting the implementation groups in the project sites was that they were entering uncharted waters. One group member described it as “having to think outside the box”, while the members of another group felt compelled to acknowledge that “there is a great deal of uncertainty about the best way forward. We are not yet at the starting line, we should address ourselves to the question of how we get there.” Indeed, early meetings were dominated by some surprisingly fundamental discussions both about PCP as a concept, their role in relation to it as well as a degree of ignorance about the current state of play within the locality. At the end of one meeting the chairperson asked members to reflect on their progress:

> *“It was good that no one tried to say what person centred planning is. I worry that there is someone out there with a grand plan… I hope we never get to that stage”*
>
> *“It feels scary and chaotic, but that is good. We have got to embrace the challenge”.*
>
> *“At the next meeting perhaps we should hear about things that are going on at present.”*

Groups also recognised that PCP was unlikely to make a significant difference to the lives of people with learning disabilities in the short-term: one member described their task as laying the foundations for a fundamental change to the way that services are planned and provided. For PCP to work, implementation groups needed to start on a small scale and be realistic in what they could achieve in the early years. A favoured tactic within the wider strategy of change was the identification of ‘quick wins’ and early successes to demonstrate the possibilities of PCP to a wider, and often more sceptical, audience.

Similarly, the influence of those various described as “champions”, “ambassadors”, “enthusiasts” and “leaders” for PCP appears to be axiomatic to successful implementation. The fact that champions tend to self-motivated was reflected in the varying degrees of success experienced by the implementation groups in identifying champions within member organisations. Furthermore, the influence that champions were able to exert was commensurate with their status within an organisation rather than the depth of their passion for PCP. The third ingredient to this leadership mix was the amount of dedicated time available to people with leadership roles for PCP.

Within most of the provider services across the four sites, leadership for PCP was vested in relatively junior members of staff who assumed the role by virtue of a particular interest in the subject, experience or attendance at training events. Provider services at three of the sites had made commitments to release staff from other activities to promote PCP within their organisations, although the extent to which they were able to do so was invariably determined by other priorities.

Leadership for implementation more widely was vested in different places at each of the four sites. At three (A, B and C), the leadership role was taken on by a senior officer in conjunction with his or her existing duties, while in Site D the lead officer was a dedicated appointment. The strengths and weaknesses of both approaches were apparent from an early stage in the project. Although the senior posts had the potential to convey messages about PCP to influential forums, the time available to attend to their duties were heavily circumscribed by other tasks, while the focus of the ‘Planning With People Coordinator’ in Site D remained rooted in practical details of developing planning tools, producing information, training staff and recruiting participants to the project.

Site B alone of all the sites made significant changes to its dedicated support for PCP during the lifetime of the project. The aim was to create a structure that would both support local efforts to make PCP work, while providing a linkage to strategic issues of commissioning and service development. A senior nurse already heavily involved in PCP was appointed to the post of commissioning manager with responsibility for leading a team of local coordinators (one of whom covered the project site). Their job descriptions (see appendix) set out in some detail the tasks they were expected to carry out. The team has become a powerful hub for all activity about PCP in the County and the assertive advocacy of the commissioning manager ensures that senior managers in local authority departments, PCTs and health trusts are reminded of their responsibilities to support it.

Implementation groups also began to identify an agenda for the future development of PCP within their localities. All of the groups were keen to ensure that vulnerable sections of the learning disabled population were identified at an early stage so that they could be included in line with the Government priorities. However, this aspiration has been undermined by poor information systems (“we simply don’t know who is out there or where they are"), the variable quality of inter- and intra-organisational cooperation, and resistance from some service users and carers to becoming involved in PCP.

Valuing People makes much of the need for services and organisations to change if PCP is to work. Studies have also tentatively suggested that structural changes, such as the decentralisation of services or the use of a single support team across residential and day services, can facilitate person centred practices.[32 80] Others highlight the importance of systems to communicate clearly what PCP is about, why change is required and why risk-taking is an essential part to putting plans into place.[81 82] Indeed, it is worth pausing here to consider just what it was that organisations were being asked to implement since a Scottish study found that a lack of knowledge about the principles and practices of PCP hindered its implementation in educational settings.[83] The guidance defines PCP as 'a process for continual listening and learning, focused on what is important to someone now and for the future, and acting upon this in alliance with family and friends. This listening and learning is used to understand a person's capacities and choices. PCP is a basis for problem solving and negotiation to mobilise the resources necessary to pursue the person's aspirations. These resources may be obtained from a person's personal network, from service agencies or from a range of non-specialist and non-service sources'.[21] Interestingly, the guidance includes examples of what PCP is not – assessment & care management, a service review or a replacement for other forms of planning - although PCP may contribute to these activities. Nor is it only for 'people who are easy to work with', or and end in itself.

The guidance distinguishes PCP, which 'discovers and acts on what is important to a person', from person centred approaches, which 'design and deliver services and supports based on what is important to a person'.[21] The guidance goes on, 'person centred approaches look to mainstream services and community resources for assistance and do not limit themselves to what is available within specialist learning disability services. They work to build a person centred organisational culture.' This might be bolstered by the application of person centred approaches to Best Value Reviews whereby 'a review should start from the perspective of what people want from their lives, and not the way in which services have traditionally been organised by public authorities… The whole approach is based upon looking outwards beyond the constraints of traditional services towards making links with other provision, networking with other key stakeholders and working towards targets that are essentially focused on individuals' needs and wishes rather than on (aggregate) service performances'.[84] The focus of such reviews should therefore be upon the core objectives set out in *Valuing People*.

In the fieldwork sites we found a good deal of uncertainty about what was meant by PCP, especially in the early stages of the project. The principal ingredients of this uncertainty were ignorance, neglect and resistance in varying measures. At one end of this scale, staff at all levels struggled to makes sense of the concept in relation to their role and how it was likely to be affected by it. Many found it easier to say what PCP was not, assessment and care management being most frequently mentioned, or to distinguish person centred practice – the deployment of a repertoire of knowledge, skills and values – from the process of planning. For many direct care staff, notions of helping people achieve their dreams and aspirations seemed impossibly stratospheric to the perceptions of their own influence. Others felt they lacked the skills required for the task, couldn't accommodate it within their traditional way of working, or simply complained that "it is not part of my job".

PCP was neglected by staff at all levels within organisations either because they believed it had nothing to do with them or because they supposed it was unlikely to be sustained. In some places neglect shaded into an active resistance that took several forms. First, an insistence that current practices and procedures were already person centred; this sometimes led to the 'tippex' solution, whereby existing individual plans were simply re-labelled with the 'PCP' badge. Second, there was a belief that the national and local policies were unrealistic and unachievable and therefore could be safely ignored. Third, the transatlantic provenance of PCP and the way that it had been presented to a British audience grated with some: a care manager summed up the sentiments expressed by many when he dismissed 'PCP' as "a 'buzz word' which strikes cynicism in me straight away".

Black also identified a number of barriers to implementation within organisations.[82] These were present to a greater or lesser degree within organisations across all of the sites. The first hurdle was that key people might not perceive that there is a problem that needs to be addressed by a person centred approach. There may be low expectations of what might be possible through PCP, coupled with a lack of imagination about how things might tackled differently than before, including the use of non-specialist resources. Added to this might be a desire for the simplicity and predictability of established models of care compared to the apparent complexity of individualised service designs. And change carries costs and risks, so that the people affected by it have to be convinced that the benefits will make the investment in PCP worthwhile.

Black talks about the problem of 'distraction' whereby the sustained effort involved in achieving the organisational changes implied by PCP is subordinated to dealing with crises and short term objectives. Staff may lack the experience in collaborating with others to achieve change for an individual. They may be undermined inflexibility in resource investments, often in the form of money and staff being aligned to building rather than individuals.

We also witnessed the drag caused by typical practice by care staff evolving at a slower pace than good practice. This means that policy makers were confronted with resistance from a service culture in which 'good plans on paper are considered more important than good lives,' blame takes precedence over accountability, people at the centre of plans are not consulted, and organisations are in a chronic state of crisis.[85]

While there was undoubtedly a degree of cultural drag evident in all of the fieldwork sites, the interplay of what we might call the 'supply-push' factors for PCP was more complex. Some factors, such as the training, development and information generated by the project, were influential in this equation (and are reported in Chapter 2), as were the infrastructures to PCP described earlier in this chapter. However, a key 'supply-push' factor was the opportunity to initiate PCP as part of the reconfiguration of services demanded by *Valuing People*. The Government set down specific targets for the implementation of PCP for people moving from long-stay hospitals and young people moving from children's to adult services by 2003. By 2004 significant progress was expected to be seen for people using large day centres, people living at home with older family carers, and people living in NHS residential campuses.

The sites varied in their approach to the opportunities presented by overhauling transition arrangements, reviewing community teams, modernising day services and reprovisioning large-scale residential services. Care managers in Site A found transition planning to be a problematic process because colleagues in children's services tended to work with parents and rarely engaged in long-term planning. They also resented being cast as 'the people who pick up the pieces' for young people and their families used to a better level of support than that on offer to adults with learning disabilities in the locality. For the team, the problems of transition boiled down to a clash of cultures and a lack of resources: while they could appreciate the value of an approach that encouraged dreaming, their focus remained firmly on the relationship between assessed needs and the means to meet those needs.

The two northern sites placed PCP at the heart of their respective modernisation programmes for day services and reported some modest successes in altering commissioning policy as a result. Yet Site A, despite detailing a care manager to review the lifestyle options of 200 users of day services in the area did not link this exercise to the work being undertaken in the project. Similarly, Site B had allocated a significant portion of its care management resources to work on plans for the people living in the four campus-style settings. Progress remained painfully slow with little evidence that the process was being driven by PCP, as care managers and commissioners wrestled with the 'big picture problems' of finding alternative community facilities for such a large group of people.

Another potentially significant supply-side factor has been the introduction of health facilitation and health action planning. *Valuing People* states that health action plans 'will form part of PCP' (para. 6.15), and while we found several examples of health action plans being initiated as a result of PCP, all too often health action planning was regarded as a separate process by health professionals and frontline staff. In other words, the obligation upon services to offer health action plans was not translated into a broader promotion of PCP.

These supply-push factors were complemented by more or less tangible demand-pull factors. One would expect the investment in training, development and infrastructure to stimulate a demand for PCP at all of the sites, however other subsidiary factors appear to have determined the degree and direction of this demand. In one area, care managers believed that the demonstration of successful outcomes by self-advocates were key to convincing others, including families and paid staff, of the benefits of PCP:

> *"the whole thing would take off, it would gather momentum because if you had say more able people who have been through the process and found it empowering, you then have a self advocacy group who then could provide support for people who would be a bit perhaps sceptical about what it is all about because they could then say look I am taking control of my life and this is where I have got to with it. Do you see what I mean? Once it has been proven that it works, and then perhaps people will go with it.*

Frontline care staff may be required to undertake a variety of roles in relation to PCP, but most importantly they often assume primary responsibility for ensuring that PCP happens. In Site C the Service Manager acknowledged the high, and sometimes unrealistic, expectations placed upon PCP coordinators, a role usually undertaken by staff who are not well rewarded:

> *"They have to think conceptually, to act with insight when they came to do caring rather than enabling. Not all can do facilitation, so the good ones are the ones who are likely to get promoted and move on. We need to get staff to 'unlearn' the way they have done things in the past. Trying to get them to move on from thinking that traditional services are the only way of providing support for people. We need very capable, confident people to take on the role."*

Across the four sites there were structural impediments to professionals working together around PCP. In Site C the progress of the project coincided with slow and disjointed progress towards a formal partnership arrangement between the Primary Care Trust and the Local Authority, typified by the lead officer's comment that co-location of the health and social work teams was more likely to happen because the social work team base had been condemned as unfit for use that than any planned integration. Health and social care professionals continue to be separated by geography, parallel lines of management and different governance arrangements. However, both health and social care teams there expressed optimism about the likely impact of PCP upon the way they go about work. In particular, health professionals envisaged a future in which professionals would increasingly come together as teams around the needs of an individual. They appreciated training which had emphasised the need to model PCP through their own management practices (person centred teams), but felt that the absence of a comprehensive training strategy that included all stakeholders was an impediment to sustained change in this direction.

A recent review of Site A's community teams rejected an integrated management structure as 'an unnecessary complication', while Site B has also retained separate health and social care team structures. Site D has opted for a decentralised patch approach that managers and practitioners there hoped would stimulate greater multi-disciplinary working, but there was not much evidence that this was linked to PCP.

A Scottish study found that the lack of good multidisciplinary working reduced the effectiveness of PCP.[86] Guidance about the role of a 'named person' makes clear that care managers and other professionals need to work in a more person centred approach, using an individual's person centred plan as the starting point for professional assessments and service design. The 'named person' has a key role to play in maintaining the link between an individual, the facilitator or coordinator of their plan, and those responsible for arranging and providing services. While there were examples of professionals working together in response to individual plans, at none of the sites was multidisciplinary working or the named person role sufficiently embedded in typical practice to make an impact on PCP.

The overriding concern for care managers across the sites was one of conflict, both about their accountability and about their proper relationship to service users, circles of support and the planning process. The issue of accountability boiled down to an acknowledgement of "our core business" (care management) which entailed tasks, such as the gatekeeping of resources, that could not easily be reconciled with some of the tasks associated with PCP. For most, it was a question of striking "a balance of intrusion and input – some people are happy with us just doing the bit they need us to". This care manager summed up the sentiments expressed by colleagues at each of the four sites:

> *"'We need to have a huge change in the way that we work and I think all of us would say that we want to work and we try to work in a person centred planning way but the processes that we have within Care Management are not person centred as such because they are about needs and it is about resources and the way the resources are then allocated."*

In Site A, care manager involvement in PCP was minimal because of the time constraints of their role. As the project progressed a few care managers did play a more active role in some person centred plans. One care manager pointed out what she regarded as an anomaly – that people already receiving a good deal of support (including care management) were more likely to have a PCP. She wasn't sure this was fair, a point echoed by counterparts in Sites B and C. The research project had given some service users a "high profile" within the service when powerful people had been enlisted to achieve significant change in their lives. Whilst none begrudged the individuals such positive outcomes, the process by which had been achieved not only offended the care managers' sense of social justice for the wider learning disabled population, but also raised questions about the realism of such an approach. While the research project had made care managers more aware of PCP, they expressed irritation that it had overshadowed their own "good news stories" of working with people in a person-centred way through individualised packages of care, supported tenancies, individual day services, Direct Payments and the Independent Living Fund.

One way for care managers to become more involved with PCP is to assume the role of facilitator to a person's plan. Although some believed the two roles could be reconciled, most preferred not to assume the mantle of facilitator, preferring instead to work in partnership with others. One described how a circle helped him get to know service user with specific communication difficulties, which previously he would not have had time to do. Another viewed his relationship with a circle as "very much task-oriented… they keep me on my toes" and while he could envisage situations where this might become burdensome, it had so far served to strengthen his negotiating position within the local authority. He summarised his role as being "to frame what people's desires are, within risk management and meeting need, so that you can apply for resources." In Site A only a few care managers reported being in contact with the facilitators of a PCP, but supposed that facilitation should be based upon a good personal relationship, and might be akin to advocacy in that it could ensure the focus person's views were heeded by service providers. This suggested a potential conflict of role according to some: "if we did facilitation, we would call it social work", before adding that "although we are called social workers, what we do is care management".

Uncertainty about their proper role was exacerbated in some areas by what care managers regarded as an unnecessary reliance upon them for leadership in the PCP process. This was related to what care managers perceived to be a substantial and enduring barrier to the successful implementation of PCP: the sheer scale of the task set for them by national and local policy makers. In Site B there was a significant group of individuals supported by families and circle of support to leads their own plans, while the other areas relied largely upon frontline day and residential care staff to support individuals. In all areas, care managers felt the weight of expectation to contribute to the plans of people falling within the priorities set out in national guidance, but the extent of that contribution varied. In Site B, for example, care managers told us about their attempts to get care staff to take on day-to-day responsibilities for making plans work:

> *"but they can feel disempowered. We are acting as gatekeepers, but they could do a lot of the work we do. We often double up on our time. They have got access to computer records so could do more, but they see care management function as separate. We wonder if they think all our work is with people who they know – most of our caseloads aren't."*

By having to deal with the sorts of practical issues, care managers were diverted from what one described as the crucial role in helping services to change their culture. For example, in residential services, one person suggested:

> *"we may need to be taking on a role to ensure that that [cultural change] happens. So it is perhaps a facilitating role rather than a monitoring role. In terms of people's lives changing, that could be very small but very meaningful thing to people: they way they get up in the morning, when they have shower… it is those little things that can be missed but can actually make a real difference to people… That then is the responsibility of the residential provider."*

The most commonly cited obstacles to care managers becoming more engaged in PCP or feeling able to work in person centred ways with individuals related to the bureaucratic strictures of their employing agencies. There were several elements to this. First, the weight of their caseloads invariably meant that they had limited time to spend with any one individual. Second, eligibility criteria under *Fair Access to Care*[87] determined that priority for care management services was given to people with the most immediate needs and ran counter to the ethos of long-term planning. Third, the infrastructure to assessment and care management (the assessment processes, local authority financial requirements and data recording systems) were not conducive to a person centred approach. Finally, care managers complained about the “dead hand of management” that too often frustrated attempts to find innovative solutions to the problems thrown up by PCP.

Kinsella suggests that ‘endemic incompetence’ amongst qualified professional staff and managers of care services is also a significant barrier to proper implementation of PCP, manifested in management practices within the public sector that tend to stifle innovation and creativity.[73] Care managers had their own perspective on the role of line managers in supporting PCP. All teams recognised the potential for PCP to improve both the efficiency and effectiveness of services in their areas. In Site B the care management team regarded their involvement in PCP as important preventative work, but feared that senior managers lacked the vision to invest time & resources in it now, to reduce expenditure on crises at a later date.

The personal implications of engagement in PCP were also considered. Care managers in Site B found attendance at circle meetings time-consuming and often taking place outside of normal working hours. Some had experienced a dilemma between a commitment to supporting the individual in such a person centred way and the limitations placed upon their ability to do so: “if we are to take part, we need to be supported to get a balance. We already work really hard, and need our time off!”

Similarly, frontline care staff looked to managers to provide them with the necessary support to carry out their roles in PCP and to work in person centred ways. The key issues for these staff were managers who: motivate and value them (modelling how they should work with the people they support), provide them with a vision for the sort of service they would be delivering in the future (this included describing what PCP is all about), supported them in risk-taking (and fostered a non-punitive culture), and kept the work ‘fresh’ by encouraging innovation. Training, mentoring and dedicated time were required to make this happen for staff. One organisation in Site A provided an example of how this was put into practice.

An independent review in 1999/2000 recommended that PCP be used to provide a baseline of needs for service development. Having struggled to find creative solutions to the problems of people with complex needs, the outcomes subsequently achieved created an “infectious enthusiasm” amongst the staff for PCP. They came to appreciate the adaptability of PCP compared to previous paper-based planning systems.

Some concerns remained for a minority of staff about:

- ☐ The ability of the people they support to take an active part.
- ☐ Their own ability to do it well.
- ☐ The implications for their role as support staff.
- ☐ The loss of influence over the things that people do.
- ☐ Changes to established ways of working and thinking about problems.
- ☐ Fear of blame and failure around risk-taking.

Key supports to PCP within the organisation were quality action teams (though still dominated by staff they planned to stimulate greater service user involvement) training and staff development, person centred management that engenders a culture of openness. Circles of support were described as “mini-pressure groups” agitating for change.

The impact of PCP was felt in two ways. On a day-to-day level, staff timetabling had become more flexible to allow people to receive intensive support as they began to access community facilities and activities, tailing off as they coped more on their own or found other sources of support. At a strategic level, PCP became the means by which people could move into their own homes with the organisation’s support.

Staff at day centres in Site C described the impact of PCP in terms of improving the working atmosphere even if the outcomes for individuals were limited. Their frustrations centred on the difficulties experienced in working with colleagues from other services. Plans were alleged to have been undermined by the relative lack of time and training for PCP available to staff in supported living services, while plans for people supported by a voluntary sector provider were more successful because the organisation had displayed commitment to the process. This echoed a complaint articulated by frontline staff at all of the sites: what changes that had been achieved were due to things that they could influence, usually within their own organisation. Actions that required agreement spanning organisational boundaries were less likely to produce a successful outcome, the chief reason being that colleagues in other services did not invest PCP with the same priority.

Frontline staff in each of the sites also provided examples of resistance to PCP from the families of people with a plan. We need to be careful about overstating this since many families were also regarded as allies in PCP. At one extreme, in Site C, day services staff had supported a young woman to think about living independently and getting a job. However, her family held strong beliefs about their daughter getting married and eventually persuaded her to withdraw from the project. At the other end of the scale, staff complained about the benign neglect of a person’s plan by their family carers. Frontline workers were generally philosophical about the role of families, accepting that their attitudes might be slow to change. For some this had an impact upon their morale which was then cited as a reason for doubting the long-term possibility for PCP to effect change in people’s lives. It was noticeable however, that where the minds of families had been changed as a result of something achieved through PCP, the morale of care staff was lifted.

In some instances where families were hard to engage, or where the person had no family to engage, independent citizen advocacy provided an important bulwark to PCP. There was some form of advocacy service at each of the sites, but Advocacy in Site B was by far the most actively engaged in PCP. The director of the service was the PCP lead for a neighbouring authority and several advocacy workers acted as facilitators for people in the project. While the advocacy service debated with itself about the proper role for advocacy in PCP, asking if they were properly funded for the task, there was little doubt that they provided a unique voice within PCP. By virtue of their status and the experience of individual workers, advocates were able to support people to develop their plans independently of their principle supporting agency as well as challenging those agencies to respond in appropriate ways. In doing so, there was a balance to be struck between encouraging people with a plan to be more ambitious and assertive in their dealing with support agencies, while acknowledging their desire for stability in their lives.

The outcomes achieved for people through PCP fell within the personal and social domains and were not, except in a few instances, related to decisions made by strategic commissioners. Care managers were held to be the catalyst for individuals requiring significant public resources to put their plans into action. Strategic commissioners at the fieldwork sites believed that although PCP had alerted them to the possibilities for commissioning services in different ways, three principal barriers to them doing so remained. First, they lacked information about the demands being generated through PCP. This was ascribed in part to the tension between person centred approaches and assessment and care management processes designed to standardise and aggregate information. Second, commissioners were struggling identify individual sources of funding within budgets dominated by block contracts. Third, the capacity of local social care markets to deliver new and flexible services was limited. Commissioners were optimistic that substantial progress could be achieved in each of these areas, but doubted that PCP alone could deliver it. They suggested clarifying and strengthening the role of care managers in relation to PCP, increasing the use of direct payments and individualised funding, and greater investment in alternative services, especially beyond the public sector.

Conclusions

The trajectory of implementation across the sites followed a familiar pattern: a steep upward curve denoting early enthusiasm and optimism gave way, after 6-9 months, to a plateau characterised by uncertainty about the next steps. This led to a bout of reflection and a reassessment of the support required to sustain implementation in the longer term. There are encouraging signs that this gentler trajectory of implementation will underpin a further expansion of PCP in the four localities. Key issues for sustainability are:

- Political and strategic leadership for PCP was generally poor. There was only limited evidence that PCP informed strategic planning.
- Implementation groups worked hard to produce frameworks and action plans, but the roll-out of these has been slow. There was some prioritisation of effort, but the extent to which this was translated into practice varied. Quality assurance was at an early stage of development.
- Throughout the project there remained a lack of clarity about what PCP means in theory and in practice. This was a drag to the sort of cultural change in organisations envisaged by the government. While there is a gradual sedimentation of ideas about PCP, there is no discernable pattern to this and the influence is as much from external factors as from the project. Knowledge about what was happening locally in relation to implementation was also uneven.

- Dedicated staff were an important driver for implementation, but their roles varied. At a relatively junior level the roles of ‘coordinator’; ‘problems-solver’; the ‘signposter’ and ‘information-hub’ were widely appreciated. Only in Site B was this supplemented by an influential senior role designed to promulgate PCP. The existence of this role also made it more likely that information about, and generated by, individual plans would impact upon strategic decision-makers.
- We observed different styles of training and different models of support for PCP across the sites. These essentially fall into two categories, both addressing the need to utilise resources within what has been termed the ‘breadth and depth’ approach to training & support. There is a general acceptance that as many staff, carers, users as possible need to be familiar with the principles of person-centredness for organisational culture to change. There appears to be a debate, however about the degree of targeting that is required in supplying the depth training & support given the high turnover of frontline care staff in some organisations.
- A heavy burden is placed upon frontline care staff and families to deliver good outcomes for people, yet they often feel their powerlessness and lack of influence prevents them from doing so. First tier managers can be crucial to either helping or hindering staff pursue plans.
- The impact of PCP upon the commissioning process has thus far been marginal. An increasing number of good outcomes for individuals can produce ‘ripple’ effects upon staff morale and the local capacity to meet needs in a flexible way. However, tight and shifting eligibility criteria means that people do not always qualify for public support.

- Care managers are not always sensitised to their person centre plans and there is an inherent tension between the informality of the PCP process and the formality of the assessment & care management process. Care managers are unsure about their proper role in PCP, though there is some evidence that they are becoming more engaged with it. The principle barriers to care manager involvement are time, managerial resistance and lack of clarity over role.

Conclusions & Recommendations

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In this section we will summarise the main results of our study and then draw out some implications for policy and practice.

An Overview of the Evaluation Results

There were three components to our evaluation.

- First, we attempted to evaluate the impact that PCP had on the 'quality of life' of 93 people with learning disabilities. For this group of people we collected information on their life experiences every three months over a two year period. During this time PCPs were developed for 65 people.
- Second, We mapped the local support structures for person centred planning and attempted to identify the organisational factors that both help and hinder implementation.
- Finally, we determined the direct and indirect costs of implementing PCP.

The main results of the evaluation are summarised below.

Person Centred Planning Leads to Improved Life Experiences for People with Learning Disabilities

The results of the evaluation clearly indicated that the introduction of PCP had a positive benefit on the life experiences of people with learning disabilities. For, example, the people who had a plan experienced a:

- 52% increase in size of social networks;
- 2.4 times increase in the odds of being in contact with a member of their family;
- 40% increase in level of contact with friends;
- 30% increase in the number of community-based activities undertaken in the previous month;
- 25% increase in the variety of community-based activities undertaken in the previous month;
- 33% increase in hours per week of scheduled day activities;
- 2.8 times increase in the odds of having more choice.

Even when we employed the more conservative 'intent to treat' analyses to evaluate effectiveness (rather than efficacy), PCP was associated with benefits in the areas of:

- community involvement
- contact with friends
- contact with family
- choice.

These positive benefits are consistent with the comments made by the participants themselves, claims made by advocates of PCP[27 28] and the results of the very small number of previous studies that have sought to formally evaluate the impact of PCP.[30-33] They also support the current emphasis within health and social care policy current UK on using PCP to improve the life chances of people with learning disabilities.[1 24 88]

The Benefits of Person Centred Planning Vary Across Areas of Life, People and Contexts

While the results of our evaluation indicated that PCP was both efficacious and effective, they also suggested that the impact of PCP varied markedly across the domains of ‘quality of life’ we investigated, across people and across the contexts in which people were living.

Across Areas of Life

While PCP was associated with benefits in some domains of ‘quality of life’, it had no apparent impact on others (e.g., more inclusive social networks, employment, physical, activity, medication) and there were three areas (risks, physical health, emotional and behavioural needs) where there was evidence of change in a ‘negative’ direction. Specifically,

- *Risks*: Participants were 1.5 times more likely to be perceived to be at risk in or out of the home or from traffic.
- *Physical Health*: There was a 67% increase in the number of health problems reported in the period following the implementation of PCP.
- *Emotional & Behavioural Needs*: There were marked increases in scores on the ‘hyperactivity’ and ‘emotional problems’ subscale of the SDQ, and a marked decrease in scores on the ‘prosocial behaviour’ subscale of the SDQ.

The results pertaining to risk are probably explicable in terms of the participants leading busier and more varied lives following the introduction of PCP. Such changes are likely to have involved an increase in some predictable risks (e.g., from traffic). Risk taking is, of course, part of everyday life and these results cannot be assumed to reflect negatively on the quality of life of participants.

The results relating to physical health were unexpected. It should be kept in mind, however, that the results pertain to health problems reported by a key informant (we did not independently assess peoples’ health status). Given that there is extensive evidence that people with learning disabilities often have extensive unidentified and unmet health needs[89-92], it seems plausible to suggest that these results may reflect the impact of PCP on helping people to get to know the focus person better and understand their health needs (rather than PCP making people unhealthy).

It is difficult, however, to make a similar argument for the reported increase in emotional and behavioural difficulties (and the reduction on positive pro-social behaviour) given that the scale items are simple behavioural descriptions (e.g., ‘easily distracted, concentration wanders’). Perhaps the two most plausible explanations of these results are that the increase in the number and variety of community based and social activities: (1) may serve to highlight the significance of pre-existing behavioural needs; or (2) may constitute sources of stress that lead to an ‘deterioration’ in behaviour.

What is striking is that this pattern of results (benefits in the number and variety of community-based and non-inclusive social activities, but no change in ‘stronger’ markers of social inclusion) mirrors the results of deinstitutionalisation.[93-95] This suggests that, rather than representing a radical departure from previous practices, PCP’s effectiveness builds on the existing capacity of services and supports. In other words, PCP may be best considered an evolutionary step in the long-standing trend towards the increasing individualisation of services.

These results are consistent with the position taken in *Planning with People*,[21] which argued that PCP would be helpful but not enough in itself to promote social inclusion and that additional action to complement improved planning with individuals would be necessary. Such action is likely to include, for example, positive action to remove barriers to employment and mainstream housing options and to encourage specialist services to play a stronger role in enabling more inclusive social networks.

Across People

Our analyses of factors that were associated with the uptake and efficacy of PCP highlighted the importance of a number of characteristics of people with learning disabilities.

- People with mental health or emotional or behavioural problems were less likely to receive a plan and less likely to benefit of they did receive a plan in the areas of size of social networks, contact with friends, contact with family, choice, hours per week of scheduled activity and (depending on the measure used) number of community activities.
- People with autism were less likely to receive a plan.
- Women were more likely to benefit in the areas of number of community activities and choice. Men were more likely to benefit in the areas of number of hours per week of scheduled activity and contact with friends.
- People with more health problems were less likely to receive a plan, but if they did were more likely to benefit in the areas of contact with friends.
- People with restricted mobility were less likely to receive a plan, but if the did were more likely to benefit in the areas of contact with family, hours per week of scheduled activity and number of community activities.

These results, and in particular those relating to mental health and autism, indicate some powerful inequalities in the extent to which people are likely to receive a person centred plan and, if they do, the level of benefits they can expect. Similar inequalities have previously been reported in a wide range of studies on supported accommodation[49 50] and the general life experiences of people with learning disabilities in England.[96]

Across Contexts

Similarly, a range of contextual factors appeared to be associated with whether people were more or less likely to receive a PCP and, if they did, the likelihood that they would benefit in different areas.

- Evidence of the *existence of more person centred ways of working prior to the introduction of PCP* (e.g., having an individual plan and/or keyworker at the start of the project) was associated (perhaps unsurprisingly) with increased chances of getting PCP. It was also associated with *increased* chances of benefiting in the areas of hours per week of scheduled activity and choice, but with *decreased* chances of benefiting in the areas of size of social networks, number of community-based activities and contacts with family. These apparently contradictory results may reflect the success of pre-existing IP systems in addressing the latter three areas, thus leaving less scope for further improvements following the introduction of PCP.
- *Having a care manager* was associated with benefits in the areas of: size of social network; number of community-based activities; choice; and contact with family. It was associated with reduced benefits in the area of contact with friends.
- Similarly, *living nearer to one's family* was associated with increased chances of getting PCP. It was, however, also associated with *decreased* chances of benefiting in the areas of contact with family, contact with friends and hours per week of schedules activity. Again, these results could reflect higher rates of such activities prior to the implementation of PCP, thus leaving less scope for additional improvements.
- *Living in a less affluent area* was associated with benefits in two areas: size of social networks and choice. These results do need to be interpreted with some caution as the more affluent areas in our study were also very rural areas which would be expected to offer fewer opportunities for social activities.

When these analyses were restricted to people in supported accommodation a number of factors appeared to be associated with the chances of getting a plan and the benefits derived for those people who did get plans.

- The probability of getting a plan was associated with possible indicators of leadership (e.g, higher ratios of senior staff), stability of the staff team (e.g., staff turnover) and, as above, evidence of the prior existence of person centred approaches (e.g., better systems for internal planning).
- However, factors associated with the chances of benefiting in particular areas were often indicators of what would be commonly taken to be poorer quality services (e.g., not having a tenancy, poorer internal planning systems, more

institutional practices). As above, it is possible that these are simply indicators of increased capacity to benefit (in that the ‘better’ services have less room for improvement).

The analysis of variability highlighted the potential importance of a number of factors associated with the *process* of PCP.

- Indicators of the *commitment of facilitators* to PCP was the most powerful predictor of whether people would get a plan and was also related to increased chances of benefiting in the areas of: choice; contact with friends; hours per week of scheduled activity; and size of social networks. Indeed, participants were more than twelve times more likely to get a plan if facilitators expressed higher levels of commitment to PCP.
- Indicators of the *personal involvement of the focus person* with learning disabilities (e.g., in directing their own meetings) was associated with increased benefits in the areas of: size of social network; contact with friends; and choice.
- The *identity and role of facilitators* was associated with increased benefits in a number of areas. First, facilitators for whom facilitation was part of their formal job role were more likely to deliver plans and appeared to deliver greater benefits in the areas of size of social networks; hours per week of scheduled activity. Facilitators who were managers within services were associated with greater benefits in the areas of: size of social networks; choice; and community activities. Having a facilitators who was a members of support staff, however, was associated with benefits in one area (size of social networks), but disadvantages in three (community activities, contact with friends, contact with families).

The Introduction of PCP was Not Associated with Any Change in the Costs of Supports to Participants

The direct training and implementation costs per participant were

- £658 if these were calculated across all 93 participants (i.e., including those participants to whom the ‘intervention’ was not delivered) or
- £941 if they were calculated across the 65 participants to whom the ‘intervention’ (delivery of a plan) was delivered.

However, these costs are likely to fall over time as local capacity is built and training is carried out by external trainers but undertaken in house.

For the full sample, the average weekly service package cost per participant before the implementation of PCP was £1,326. By the end of the study this had risen by 2.2% to £1,356. This increase was not statistically significant. For the sub-sample for whom it was possible to develop and sustain a plan, the average weekly service package cost per participant before the implementation of PCP was £1,366. By the end of the study this had risen by 1.6% to £1,388. Again, this increase was not statistically significant. The group for whom a plan was developed and sustained did not differ in their use of services either at the beginning or end of the study from those for whom it was not possible to develop and sustain a plan.

Strengths & Limitations of the Study

As with all research studies, the results need to be considered in the context of the strengths and limitations of the study. We consider the main strengths of the study to be:

- the use of multiple methods (informant completed questionnaires, qualitative interviews with participants, organisational analysis);
- the comprehensive range of outcomes and processes addressed, including costs;
- the relatively large sample size and time-span over which data were collected.

To date, this study represents the largest most comprehensive evaluation of the costs and impact of PCP to be undertaken anywhere in the world.

The study does, of course, also have some limitations. We consider the two most important of these to relate to the time-span of the study and the confidence with which one can generalise the results to other organisations in England who are attempting to implement PCP in the early 21st Century.

While, as noted above, the two-year time-span over which the study was undertaken compares well with previous research, it was only sufficient to evaluate the short and (to an extent) medium-term impact of PCP. This is problematic given the difficulties known to be associated with attaining certain key outcomes (e.g., inclusive social relationships, paid employment) in the short-term.

The confidence with which one can generalise the results to other organisations in England who are attempting to implement PCP in the early 21st Century is dependent on the representativeness of the participants, the organisations and the broader policy context within which the organisations were operating.

- We did not employ any inclusion or exclusion criteria to select the participants. They were the first 25 people per site who were ‘enrolled’ in the local PCP process. As reported in the chapter ‘*The Impact of Person Centred Planning on the Life Experiences of People with Learning Disabilities*’, they were a very diverse group whose abilities and needs covered the full range of those the needs and abilities of people with learning disabilities. We were not aware of any attempt within the four sites to select participants who may have been ‘easier’ to work with or whose situation may have suggested the opportunity for better outcomes. As such we are reasonably confident that the results could be generalised to other potential participants.
- The organisations were, as reported, originally selected on the basis of their apparent commitment to implement PCP in order to enhance the life experiences of people with learning disabilities. That is, we attempted to exclude localities whose primary commitment appeared to be to implement PCP in order to fulfil

organisational obligations and requirements. It is important to note that we did not seek to recruit organisations who evidenced a very strong commitment and capacity to implement PCP. Rather, we sought to exclude organisations whose commitment was based solely on compliance with policy directives. This clearly raises a question regarding the representativeness of the participating organisations. It is not possible to provide a definitive answer to this question. However, we have no reason to believe that the localities selected were untypical of those authorities that are committed to implementing PCP to improve the life chances of people with learning disabilities.

- Finally, it must be kept in mind that the study was undertaken in the early stages of the implementation of PCP in English services. It was in light of this that we undertook development work with the participating organisations. This clearly raises a question regarding the representativeness of the policy and practice context within which the participating organisations were operating. Again, while it is not possible to provide a definitive answer to this question, it is our judgement that the four participating localities operating in policy and practice contexts that are not dissimilar to those faced by similar organisations in England today.

Implications for Policy and Practice

In this section we will draw out some implications for policy and practice that arise from the formal evaluation and from the development work undertaken in the four participating sites.

The results of this project have indicated that PCP, while being cost neutral, is both efficacious and effective in improving the life experiences of people with learning disabilities. It has also indicated that some people are more likely than others to experience the benefits of PCP and that the benefits associated with PCP may not extend into certain areas of peoples' lives without additional action. The results also identified some organisational characteristics that appeared to facilitate or hinder the introduction and efficacy of PCP. The task for the future is twofold.

- First, we need to develop policy and practice to ensure that as many people as possible gain access to the types of benefits that appear to be associated with PCP. This must involve directly addressing the types of inequalities in both access and efficacy that we have described in this project.
- Second, we need to learn more about the conditions under which PCP may have an impact on a broader range of outcomes. This would appear to be particularly important with regard to outcomes central to the social exclusion (e.g., employment, inclusive social networks) and positive health; outcomes that are central to the broader sweep of health and social care policy for adults in England.[26 97]

These twin tasks will require action on a number of fronts. Specifically, they will require that services:

- maintain and enhance investment in PCP as an important component of service improvement
- develop robust procedures for ensuring and monitoring equity of access to and the impact of PCP
- ensure that services have the capacity for delivering person centred results
- continue learning about the conditions under which PCP delivers the maximum benefits for people with learning disabilities

Maintain and Enhance Investment in PCP

The results of the formal evaluation indicated that PCP is both efficacious and effective in improving the life experiences of people with learning disabilities. PCP also reflects the core values of empowerment and personalisation that underlie contemporary approaches to health and social care in England.[1 23 24 26 88] Indeed, there can be little doubt that the continued evolution of procedures to improve the ways in which supports can be tailored to the needs and aspirations of people with learning disabilities will constitute a core task for those commissioning and providing services and supports.[23 26]

In order to help maintain and enhance the current levels of investment in PCP we recommend that the Department of Health develops a clear strategic plan for supporting the development of PCP. This should include plans for financially supporting development activities in the period following any termination of the Learning Disability Development Fund. This will be particularly important to maintain and enhance investment in the development of local training and development capacity including investment in families and people with learning disabilities involvement in their own plans. The strategic plan should be designed to build on and take advantage of the implementation support arrangements developed by the Valuing People Support Team over the past three years.

We also recommend that the Department of Health issue new guidance to Local Authorities and Primary Care Trusts on the implementation of PCP. Much has happened and been learned since *Planning with People* was issued in 2002. We recommend that this guidance should:

- Summarise current knowledge on the organisational context, policies and specific procedures that enhance the impact of PCP and reduce inequalities in access to PCP, with useful examples;
- Stress the importance of viewing PCP as one component in the development of polices and procedures to support person-centred action. As such, the guidance should also summarise current knowledge on effective policies and practices in the use of individualised budgets and service brokerage, providing examples and models;
- Highlight the need to tailor local approaches to local contexts. In order to do this, we suggest that the guidance includes a simple guide that would enable local

  commissioners and providers to develop a strategic approach to developing capacity that is sensitive to local concerns;
- Clarify the role of care management and specialist professionals in respect of person centred planning.

We also recommend that the Department of Health through SHAs seeks to ensure that professional training courses are equipping professional social and health care staff to work in person centred ways and have a familiarity with PCP. Similarly, training courses for first line and middle managers should equip them to use person centred thinking throughout their work, rather than person centred planning as an ‘add on’ to their responsibilities.

Finally, we recommend that learning about person centred planning in adult services is used to strongly inform developments in children’s services as part of the implementation of the children’s National Service Framework.[88]

Develop Systems for Monitoring the Delivery and Impact of PCP

The results of the research clearly indicate that, while effective, the impact of PCP varies considerably across people, contexts and life domains. As a result, it will be important to develop simple robust approaches to monitoring equity of access to PCP and the impact of PCP.

Monitoring equity requires information to be collected on access to PCP in such a way that it can be linked to indicators of potential inequalities associated with geographic locality, social context (e.g., level of neighbourhood deprivation) and the characteristics of consumers (e.g., gender, age, ethnicity, support needs). At present, very few government returns allow for such comparisons to be made.[98] It is recommended that the Council for Social Care Improvement (CSCI) consider the development of a standard approach for recording social context and the characteristics of service users that could be applied at local and national levels.

We also recommend that CSCI consider the development of one simple performance indicator through which access to PCP could be monitored. It is, of course, important that the any such indicator is defined in a manner which encourages the development of effective practice, rather than compliance with procedural requirements which can promote perverse incentives. Linked to this, we recommend that CSCI should develop methods to specify and evidence effective and appropriate use of person centred planning within the provider services they regulate.

More important, however, is the need to develop robust procedures for monitoring the *outcomes* associated with PCP and other social care ‘interventions’.[98] In this context we very much welcome the current commitment of the Department of Health to focus on the development of programme of work to develop measures of the outcome of social care for adults.[26]

Ensure That Services Have the Capacity and Systems for Delivering Person Centred Results

The impact of PCP will always be dependent on the capacity of support services to deliver person centred solutions or action.[99 100] Indeed, the constraints placed on the potential of PCP by local difficulties in developing and sustaining person centred solutions was one of the themes of our development work and organisational analysis.

We believe that the proposals laid out by the Department of Health in *Independence, Well-Being and Choice*[26] (and in particular the proposal to make the use of individualised budgets central to the development of social care for adults in England) will significantly improve the ability of local services to deliver person centred action. For all to benefit, however, we believe that person centred planning and individualised budgets will need to be complemented by the kinds of support brokerage assistance upon which the Green Paper invites consultation. Attention will also need to be paid to developments in commissioning and provider services to ensure that they become increasingly responsive to what person centred planning tells services about people's preferences. We recommend that the new guidance suggested above includes advice on better linkage between person centred planning and service commissioning and delivery systems, both micro and strategic.

To develop local capacity for change, services will need to invest in leadership in person centred planning, build the capacity of first line managers to use person centred thinking and planning, and find effective ways to support facilitators and link learning from planning to organisational change. It would be helpful for new guidance to produce examples and models to support organisations in developing their local capacity.

Continue Learning about the Conditions under Which PCP Delivers the Maximum Benefits for People with Learning Disabilities

The results of our research suggest that that PCP represents a positive step in the direction of delivering individualised support to enhance the quality of life of people with learning disabilities. It is not, however, a panacea.[21] Neither does it appear to represent a radical departure with previous practice. The latter point is important.[99]

If PCP is accepted as making a fundamental departure from previous practice then, by definition, evidence and experience related to previous ways of working (and why they failed) becomes irrelevant. If, however, PCP is considered an evolutionary step then such learning becomes highly relevant. This is not just a matter of semantics. Change within services for people with learning disabilities is often represented in a manner that denies the possibility of historical continuity. New models are often represented as providing 'radical departures' or 'paradigm shifts'. Such an approach serves to discount prior experience and evidence, rather than build upon it. We believe that the evolution of services and supports for people with learning disabilities will be best served by the development of open minded organisations that have a desire to learn from past experience along with a willingness to embrace change and new ideas.

Final Comments

The results of this project have indicated that PCP is both efficacious and effective in improving the life experiences of people with learning disabilities. The benefits identified in the research importantly come without additional service costs. It has also, however, indicated that some people are more likely than others to experience the benefits of PCP and that the benefits associated with PCP do not extend into certain areas of peoples' lives. The research has also identified some organisational factors that need to be attended to, for successful implementation. The task for the future is twofold.

First, we need to develop policy and practice to ensure that as many people as possible gain access to the types of benefits that appear to be associated with PCP. This must involve directly addressing the types of inequalities in both access and efficacy that we have described in this project.

Second, we need to learn more about the conditions under which PCP may have an impact on a broader range of outcomes. This would appear to be particularly important with regard to outcomes central to the social exclusion (e.g., employment, inclusive social networks) and positive health; outcomes that are central to the broader sweep of health and social care policy for adults in England.[26 97]

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Appendix

Significant Differences in Personal Characteristics of Participants across Sites

Table 34: Area in Which Significant Differences Existed in the Personal Characteristics of Participants Across Sites

	Site A	Site B	Site C	Site D	Test Value & sig.
Mean Scores for Ordinal Variables (Kruskal-Wallis)					
Age	45.4	35.7	33.7	44.4	14.52, df 3 p<.01
ABS Self direction	17.3	16.7	11.7	16.5	12.57 df 3 p<.01
ABS Responsibility	8.0	7.5	5.2	6.3	13.86 df 3 p<.01
ABS Socialization	21.5	19.5	16.8	18.1	11.81 df 3 p<.01
Number of health problems	1.4	2.2	2.3	3.0	8.35 df 3 p<.05
SDQ Emotional Problems	0.9	0.6	1.9	2.3	13.79 df 3 p<.01
SDQ Conduct problems	0.9	0.7	2.0	1.5	8.84 df 3 p<.05
SDQ Hyperactivity	1.9	1.4	5.2	3.8	23.80 df 3 p<.001
SDQ Total Score	5.9	5.0	12.1	10.3	20.15 df 3 p<.001
PAS-ADD Total Score	0.2	0.3	3.0	3.5	9.04 df 3 p<.05
LD Casemix Total Score	2.5	3.9	5.1	5.3	7.86 df 3 p<.05
% of participants for dichotomous variables (Chi Square)					
Visual impairment	21%	10%	0%	0%	10.09, df 3, p<.05
Dual sensory impairment	13%	0%	0%	0%	8.79, df 3, p,.05
PAS-ADD Caseness	0%	0%	17%	23%	10.24, df 3, p<.05
Current IPP	75%	41%	46%	13%	19.13 df 3 p<.001
Formal Care Manager	17%	56%	67%	92%	28.74, df 3, p<.001
Lives with informal carer	4%	35%	42%	29%	10.06, df 3, p<.05
Lives in group home	84%	35%	58%	67%	11.72, df 3, p<.01
Lives in independent living	12%	0%	0%	0%	8.43, df 3, p<.05
Lives in LBHU	0%	30%	0%	0%	23.41, df 3, p<.001
Respite	0%	0%	0%	4%	Ns
For Those In Supported Accommodation Only					
Prior home a NHS Hospital	41%	50%	7%	18%	8.36, df3, p<.05
Prior home a residential or village community	0%	0%	21%	0%	11.46, df 3, p<.01
Has lived in NHS Hospital	64%	55%	9%	12%	16.33, df 3, p<.001

Mean or % Values for Variables for Which Significant Change Was Reported in Table 9 for the ‘Efficacious at All’ Comparisons

Table 35: Mean or % Values for Variables for Which Significant Change Was Reported in Table 9 for the ‘Efficacious at All’ Comparisons

Measure	Pre-PCP	Post-PCP
Size of person’s social network	18.6	28.2
Level of contact with family (high score=more active contact)	1.2	1.4
Number of visits to/from/with family	6.4	7.6
Has active contact with family	52%	69%
Active contact with family & family in social network	45%	67%
Level of contact with friends (high score=more active contact)	1.0	1.4
Number of visits to/from/with friends	10.4	13.3
Has active contact with friends	48%	68%
ICI total number of activities	23.4	30.5
ICI number of different activities	6.0	7.5
ICI (extended) number of different activities	29.1	39.2
ICI (extended) number of different activities	7.8	9.7
Hours per week of scheduled day activity	14.3	19.0
Scheduled day activities – recreational activities	33%	47%
Choice improved in preceding 6 months	33%	58%
Seen Occupational Therapist in last 3 months	6%	16%
Seen art/drama/music therapist in last 3 months	5%	9%
Seen advocate in last 3 months	5%	13%
Seen dentist in last 3 months	31%	44%
Seen optician in last 3 months	9%	20%
Seen chiropodist in last 3 months	25%	34%
SDQ Emotional subscale total	1.2	1.8
SDQ Hyperactivity subscale	3.0	4.1
SDQ Prosocial subscale	6.9	5.9
SDQ total difficulties score	7.5	9.9
SDQ total impact score	1.2	1.9
Risk in or out of home or from traffic	7%	10%

Factor Analyses of Facilitator Views

Facilitators were asked to complete a questionnaire containing scales to elicit their views on PCP. The questionnaire sought their views on PCP for a particular focus person and also their views on PCP generally. At the final data collection point, 77 facilitator questionnaires were returned, of which 63 related to a focus person for whom a plan had been developed, and 14 related to a focus person for whom a plan was not developed within the timescale of the project.

Factor analyses were conducted using data from the final data collection round (which represented the largest sample) on four of the scales included in the questionnaire: barriers to PCP for focus person; general views regarding PCP; organisational barriers to PCP; and commitment to PCP. All factor analyses employed principal components analysis with varimax rotation, conducted pairwise (to maximise data for analyses). Items were included in a subscale if the factor loading was above 0.5 (this conservative criterion was used due to the relatively small sample size). Factor analysis results are presented below.

Barriers to PCP

Facilitators were asked to rate the extent to which 23 potential barriers stood in the way of the goals set at planning meetings being met for the focus person from 1 (not at all), through 2 (a little), to 3 (a lot).

Factor analysis produced 4 subscales:

- community and service barriers (6 items: Alpha 0.75, mean I-I correlation 0.33)
- staff barriers (5 items: Alpha 0.81, mean I-I correlation 0.47)
- focus person personal barriers (4 items: Alpha 0.79, mean I-I correlation 0.49)
- focus person physical barriers (3 items: Alpha 0.57, mean I-I correlation 0.32).

General Views on PCP

Facilitators were asked to rate their views on PCP in general without restricting responses to a particular focus person. Sixteen statements regarding PCP were rated on a 5 point scale from 1 (strongly disagree) to 5 (strongly agree).

Factor analysis produced 4 subscales:

- PCP should work for everyone (5 items: Alpha 0.84, mean I-I correlation 0.56)
- commitment to PCP (4 items: Alpha 0.81, mean I-I correlation 0.53)
- right to PCP principles (3 items: Alpha 0.77, mean I-I correlation 0.55)
- importance of PCP principles (3 items: Alpha 0.70, mean I-I correlation 0.48).

Organisational Barriers to Person Centred Planning

Facilitators were asked to rate the extent to which they believed that 10 possible organisational barriers to PCP acted as a barrier to the success of PCP generally within their services (from 1 “not at all”, through 2 “a little”, to 3 “a lot. Factor analysis produced 3 subscales:

- organisational barriers to effective facilitation (5 items: Alpha 0.81, mean I-I correlation 0.46)
- organisational barriers from service providers (3 items: Alpha 0.87, mean I-I correlation 0.69)
- lack of advocacy and funding (2 items: Alpha 0.56, mean I-I correlation 0.39).

Facilitator Commitment to PCP

Facilitators were asked to rate their feelings about implementing person-centred planning (PCP) in the service they worked in, or with. Sixteen statements were rated on a 6 points scale from 1 (strongly disagree) to 6 (strongly agree). Factor analysis produced 3 subscales:

- personal commitment to PCP (5 items: Alpha 0.72, mean I-I correlation 0.33)
- calculative commitment to PCP (5 items: Alpha 0.68, mean I-I correlation 0.31)
- hostility to PCP (3 items: Alpha 0.69, mean I-I correlation 0.43).

Job Descriptions

Post: Commissioning Officer – Person Centred Planning

Responsible to: Strategic Service Manager
Grade: HMG G

Purpose of the Post:
To lead the strategic development of person centred planning in Hampshire in conjunction with the Strategic Team and Partnership Board so that people with a learning disability have the opportunity to have Person Centred Plans and that the 'community' and services are able to respond to their plans.

To work within the values and principles set out in 'Valuing People' and associated guidance documents, on the implementation of person centred planning.

Duties:

To support the Strategic Service Manager to monitor and evaluate the progress of the development of person centred planning through the person centred planning Steering Group.

In conjunction with the Strategic Service Manager, to develop further initiatives to support person centred approaches and individual person centred planning.

To supervise and direct the local person centred planning coordinators and to assist the Local Implementation Groups to;

- Enable people with learning disabilities living in Hampshire to develop person centred plans.
- Develop and support others to arrange and deliver person centred planning and approaches training,
- Develop and support others to arrange and deliver facilitator training for users families and support staff in the area.
- Make available a range of appropriate resources (planning tools) to do this.
- Maintain a register of people who have been trained.
- Support and guide facilitators.
- Ensure that friends and families are fully involved in the planning, if this is what is wanted.
- Ensure that people with learning disabilities have access to advocates where appropriate and have opportunities to facilitate their own planning, if desired.
- Identify and support person centred planning champions in the area.
- Develop and encourage community links, promoting the values underpinning the principles of inclusion, rights, choice and independence in the community.
- Monitor how person centred local services and opportunities are, ensuring that services respond to people's Person Centred Plans where appropriate.
- Develop initiatives to provide facilitation for people's Person Centred Plans.
- Use the information from individuals' Person Centred Plans to influence service and community development locally.

Post: Person Centred Planning Coordinator

Responsible to: Commissioning Officer - Person Centred Planning

Grade: Care Manager Grade

Purpose of the Post:

To assist in the development of person centred planning in conjunction with a range of people and agencies in one of four areas in Hampshire, working within the values and principles set out in 'Valuing People' and associated guidance documents on the implementation of Person Centred Planning.

Duties:

- To assist the person centred planning Commissioning Officer and the Local Implementation Group to enable people with learning disabilities living in South East Hampshire to develop person centred plans.
- To develop and support others to arrange and deliver person centred planning and approaches training,
- To develop and support others to arrange and deliver facilitator training for users families and support staff in the area.
- To make available a range of appropriate resources (planning tools) to do this.
- To maintain a register of people who have been trained.
- To support and guide facilitators.
- To ensure that friends and families are fully involved in the planning, if this is what is wanted.
- To ensure that people with learning disabilities have access to advocates where appropriate and have opportunities to facilitate their own planning, if desired.
- To identify and support person centred planning champions in the area.
- To develop and encourage community links, promoting the values underpinning the principles of inclusion, rights, choice and independence in the community.
- To monitor how person centred local services and opportunities are, ensuring that services respond to people's person centred plans where appropriate.
- To support and assist the Commissioning Officer to develop initiatives, to provide facilitation for people's person centred plans.
- To use the information from individuals' person centred plans to influence service and community development locally.