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The experience of person-centred planning:  
A qualitative study of the experiences of  
people with learning disabilities and their carers

**Final Report – June 2009**

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# Part I - INTRODUCTION

This is the final report concerning the study funded by a local authority of a pilot project that introduced Person-centred planning (PCP) as a means of planning services for people with a learning disability.

The report outlines the background to the study, the study objectives, and its progress, along with process issues and findings in relation to the individual Stages. The main discussion section of the report (Part IV) considers whether the pilot scheme resulted in changes to the expressed hopes and fears of participants in Stage two, the hopes, fears and beliefs of the person-centred planning facilitator and English language literature on person-centred planning published up to and including December 2006.

Recommendations for the development of policy, practice and staff education / training and audit/research are then made.

The study was predominantly qualitative in nature as requested by the funding body. A qualitative study was also appropriate to the questions asked and in relation to the sample sizes (see study objectives, Part I below).

## 1. Background to the Study

Although person-centred working is not a new way of working with men, women and young persons with learning disabilities it is only during the last six years that the widespread implementation of person-centred planning (PCP) throughout the United Kingdom (UK) has been advocated.

The predominant reason for the growing use of person-centred planning within the UK is to be found in the 2001 Department of Health White Paper, '*Valuing People*' (Department of Health, 2001). Whilst in Wales, a strategy document, '*The All Wales Strategy*', was produced in 1983 (Welsh Office, 1983), '*Valuing People*' was the first major strategy document to be produced in England since the 1971 paper, '*Better services for the Mentally Handicapped*' (Department of Health and Social Services and the Welsh Office, 1971).

'*Valuing People*' has four key principles, namely: rights, independence, choice and inclusion. That person-centred planning is regarded as a key means of improving the level of control men and women with learning disabilities have over their lives can be seen from objective three,

*"To enable people with learning disabilities to have as much choice and control as possible over their lives through advocacy and a person-centred approach to planning the services they need"* (Department of Health, 2001).

The government's view of the importance of PCP in England was further demonstrated by the provision of Department of Health Guidance on a person-centred approach to planning services in 2002 (Department of Health, 2002) and by the provision of a Learning Disability Development Fund that has provided some resources to support the development of person-centred planning. Additionally, '*Valuing People*' set targets in England in relation to person-centred planning, for example requiring that local agencies introduce person-centred planning for all people moving from children's to adult's services by 2003 (Department of Health, 2001: p. 43).



In Wales, there is no directly equivalent document to *'Valuing People'*. Although *'Fulfilling the Promises'* was issued in June 2001, it is not a policy document, but is a report that put forward proposals for a framework for services for people with learning disabilities. Despite the Welsh Assembly Government undertaking a consultation exercise with a view to deciding to adopt the proposals contained in the report, little was done at that time to implement any of the proposals. This resulted in there being no clear government mandate that PCP should be introduced on a widespread scale within Wales until August 2004. This said, however, many services sought to provide their services in accordance with the vision of the Learning Disability Advisory Group that were set out in *'Fulfilling the Promises'*. One objective of that vision was that by 2010, services for people with learning disabilities in Wales would be,

*"person-centred (i.e. respond to individual needs, including language, race, gender and religious requirements and circumstances)"* (National Assembly for Wales, 2001: p. 8).

That report further went on to state that,

*"Person-centred planning should be confirmed as the key mechanism to plan people's care and support for their whole lifetime..." and recommended that, "By 2003/2004, all people with a learning disability will have an individual person-centred plan, normally reviewed annually"* (National Assembly for Wales, 2001: p. 10-11).

Further support for the adoption of person-centred approaches, at least by nurses, was also evident in the briefing paper *'Inclusion, partnership and innovation'* (All Wales Senior Nurse Advisory Group (Learning Disability), 2002). Whilst this document does not explicitly refer to person-centred planning, it does state that nurses should be encouraged to,

*"Empower clients to actively participate in developing appropriate packages of care" and "seek the views of the client, their families and the wider community in planning high quality services"* (All Wales Senior Nurse Advisory Group (Learning Disability), 2002: p. 8, 11).

It was not until August 2004 that the Welsh Assembly Government issued its *'Learning Disability Strategy for Adults and Older People with Learning Disabilities'* under section 7 of the Local Authority Social Services Act 1970 (Welsh Assembly Government, 2004). This guidance promotes the use of PCP as a way of managing the care of people with a learning disability.

As a result of such guidance, a number of local authorities decided to implement person-centred planning. One such authority is the one that has funded the present study. Their strategy provided that by the end of the first year of the strategy, up to ten individuals would have started person-centred plans. As part of their strategy, they commissioned the Unit for Development in Intellectual Disabilities, University of Glamorgan to undertake research with the objectives outlined below. **It is important to emphasise at this point that this study was conducted wholly independently of the local authority that has funded the present study and that the views expressed in no way represent the official views of the Council. The exception is the response statement on page 99. The readers' attention is drawn to the aims of the study, which focus on the perspective of people with learning disabilities and their carers.**

## 2. Study Objectives

1. To review existing publications concerning person-centred planning, in order to ascertain: what it is, why it is being implemented, concerns that have been raised about its widespread implementation and data that supports or otherwise its implementation.
2. To identify the hopes and concerns that ten individuals (focus persons) with a learning disability may have about person-centred planning prior to their formulating such a plan.
3. To identify the hopes and concerns that the main carers of the individuals with learning disabilities (in point 2 above) may have about person-centred planning prior to the formulation of their caree's plan.
4. To identify the hopes and concerns that the person-centred planning facilitator may have in relation to the process and outcomes of person-centred planning for the ten focus persons.
5. To explore the lived experience of the process of person-centred planning of the ten focus persons for whom a person-centred plan has been developed.
6. To explore the lived experience of the process of person-centred planning of the main carer for each of the ten focus persons for whom a person-centred plan has been developed.
7. To explore the lived experience of the process of person-centred planning of the facilitator for each of the ten focus persons.
8. To make recommendations for the development of policy, practice and staff education/training.

All the objectives have been addressed by the research team (though with 7 focus persons rather than 10) and are reported upon in the pages that follow.

## 3. Methodology

The research question is qualitative in nature and the predominant method of data collection was qualitative, taking the form of semi-structured interviews. However, it was decided that the research team would also use a modified version of the structured questionnaire developed by Janet Robertson et al. (Robertson, et al., 2005). This was in order to measure such things as the following: satisfaction with current service arrangements; abilities; person-centred planning; choices; and relationships. This was administered after the semi-structured interview had taken place in order that it did not inadvertently shape the direction or content of the semi-structured interviews.

The study was comprised of four stages, and each of these was to inform the subsequent stages. The stages were:

1. A brief review of the literature.
2. Initial interviews with focus persons, carers and the PCP facilitator. These were comprised of a semi-structured interview followed by an adapted version of the structured questionnaire developed by Robertson et al. (2005) (as adapted by the research team).
3. Second interviews with focus persons, carers and the PCP facilitator (as in Stage 2).
4. Dissemination of findings and recommendations.

## 4. Limitations of the Study

The study, being qualitative in nature, was aimed at exploring in-depth the experiences of a smaller number of participants than a wider survey would have. In addition, the qualitative methodology used in the study has not been empirically proven as a valid tool of exploration of the use of PCP for people with learning disabilities and their carers. Another limitation is that the period of time between the interviews was relatively short and it may be that future studies should span a longer period of time. Given the above, the study upon which this report is based should predominantly be viewed as contributing to the wider body of research and literature as well as providing a basis for a future study. Such factors should be borne in mind when reading the report and drawing conclusions.

In addition to the qualitative aspect of the study some quantitative data was collected using the Robertson et al. (2005) interview schedule which was the largest study being undertaken in relation to person-centred planning in the United Kingdom at the time this study was commissioned. We would urge extreme caution in the interpretation of the statistics collected using these tools for a variety of reasons, one of which being the fact that because of the small number of people involved in this study such figures are not generalizable. Additionally, the tools are complex and it was unclear as to the extent that focus persons understood concepts, such the concept of time (see *APPENDIX 3*, which contains the topic guide and interview schedules). They are, however, presented in this report to demonstrate whether changes occurred for the participants during the period of the study. Despite the fact that they can demonstrate whether such changes occurred, they can not be used to demonstrate whether person centred planning is effective in increasing such things as: 'opportunities for community activities', or 'friendship' *per se* as the study was not controlled, that is to say factors other than PCP may have had an influence on any changes which occurred or did not occur.

***NB: Further information on and discussion about the methods chosen and the rationale for such choices was detailed in the study protocol which has previously been provided (should you require another copy of the protocol please e-mail the principal researcher).***

## **Part II – PLANNED AND ACTUAL PROGRESS OF STUDY**

### **1. STAGE 1**

#### **1.1. Brief Literature Review**

This did not commence until 11<sup>th</sup> May 2005 as a result of the time taken to arrange a meeting of the project group. The initial literature review for the study was undertaken by the principle investigator. It was completed by 15<sup>th</sup> June 2005 and was incorporated into the study protocol. This literature review is appended to this report (*APPENDIX 1*) and is used in the discussion (Part IV) of this report along with pertinent English language literature published up to and including December 2006.

#### **1.2. Ethical and Research Governance Approval**

Approval was sought from the Research & Development committees of the local NHS Trust during July. Approval was granted by the Research Scrutiny committee on 3<sup>rd</sup> August 2005 and by the Research Risk Review Committee on 17<sup>th</sup> August 2005. Neither committee suggested any changes to the study protocol.

Approval was also sought from the Central Office for Research Ethics Committees (COREC) during the middle of July. The principal investigator attended the ethics committee hearing in Cardiff on 23<sup>rd</sup> September. Some of the views expressed by some members of the committee in relation to both the project and the study were interesting. For example, some members of the committee did not appear to understand why one would wish to ascertain the views of people with a learning disability. Some lay members felt that person-centred planning was unnecessary due to their belief that special schools provided people with a learning disability with appropriate plans and that there was no need for them to further develop. A large proportion of the committee even questioned whether PCP was ethical in so far as they felt that it would raise service users' expectations and that these expectations would not be met. Finally, despite the fact that service users were involved in the development of such things as the information sheet and consent form, it was argued that the language contained within these forms was too complex. Notification was received from the ethics committee on 23<sup>rd</sup> September that they were willing to give a favourable ethical opinion of the proposed research if the information sheet and consent form were revised after consultation with "an appropriately experienced speech and language therapist". In response to this, the research team sought advice from speech and language therapists working in local learning disability services. Their suggestions were incorporated into the documents and re-submitted the application to the ethics committee. They met again on the 10<sup>th</sup> November 2005 and ethical approval for the study was granted at this meeting. As a result of the above delays, the study was, at this time, behind schedule by some six months.

### **2. STAGE 2**

#### **2.1. Data Collection**

As a result of the delays in attaining ethical approval from COREC, it was not possible for the research team to commence data collection until 13<sup>th</sup> November 2005 when notification of COREC approval was received.

Although the research team had previously been advised that the group of individuals who

were to be offered the opportunity to develop person-centred plans had been identified, their names had not been recorded and neither the team manager nor the PCP facilitator could recall the names of three of these individuals. The research team was informed of that on the 25<sup>th</sup> November that, whilst there had been 7 individuals identified by the multi-disciplinary team (MDT). Following a meeting between members of the research team, the PCP facilitator and his line manager, it was decided that the PCP facilitator would provide the research team with the names of the five individuals he had undertaken some preparatory work with in order that the research team could commence the research in January 2006.

Whilst the first 'information giving' meetings with focus persons and their carers commenced in January 2006, progress with interviews was slow. This was for a variety of reasons which are outlined in the 'process section' (Part III).

Most of the data collection was undertaken by Ms. Iliana Sardi and Dr. Rachel Davies. The principal investigator undertook only two interviews, one of the PCP facilitator and one of FP6, due to FP6's request for a male interviewer.

Due to various difficulties, some of which are outlined in the 'process section' (Part III) the team had only completed the 'Stage two' interview process in relation to two focus persons in April 2006. Other difficulties included: not having been provided with contact details for would-be participants; the fact that the team was unable to undertake the research with one person who had initially been identified as a participant, but who was the subject of an on-going POVA investigation; and, difficulties in relation to family issues with another would-be participant. Given these issues, the team decided to focus on completing data collection in relation to the seven focus persons with whom it had commenced data collection. The team decided that they would, however, continue to seek contact details for a further three potential focus persons. Unfortunately, despite members of the research team leaving numerous messages with the PCP facilitator requesting the necessary contact information, this was not provided. At the next meeting of the research team it was decided that, as contact details for the remaining potential focus persons had still not been provided, the team would complete the transcription process and initial coding of the data that had been obtained and would then meet again to continue the data analysis process. The team met as arranged to undertake further data analysis and it was agreed that they would report the study progress, process and findings in an interim report. The interim report was disseminated by the end of August 2006. The research team commenced the data collection for Stage three of the study in October 2006. This data was then coded as per Stage two of the study prior to it being written up.

## **2.2. Sampling**

The research team had no choice as to the method of sampling used. It was initially envisaged that they were to be provided with the names and contact numbers of persons with whom the person-centred planning facilitator had commenced the person-centred planning process. They were advised that these people had been identified by the community learning disability team responsible for the geographical area as 'persons likely to benefit from PCP'. Although the research team requested information on how these individuals were identified, no such information has, to date, been forthcoming.

As a result of these and other factors outlined in the introduction to this report, the findings of this study cannot be generalised. However, this was never the intention. Rather, the intention was to gain insight into the experience of certain people involved in the pilot PCP project, namely persons at the centre of plans, their main carers and the person-centred

planning facilitator. Service providers' experiences were not sought. Although the sample cannot be said to be representative of all users of learning disability services in the local authority, participants varied in their abilities and many other characteristics. Therefore, whilst generalisation is not possible, the findings are likely to be of relevance to other service users and should be considered when the next phase of PCP is being planned.

Demographic data of the participants is provided in *APPENDIX 2* of this report.

### **2.3. Data Analysis**

Data analysis was conducted using Interpretative Phenomenological Analysis (IPA). The rationale for this choice is outlined in the study protocol (available on request from the principle researcher). As with other aspects of IPA the exact way in which one analyses a number of cases is not specified. Smith and Osborn (Smith & Osborn, 2003) suggest that one can either use themes that emerge from the first transcript in order to analyse further interviews or one can analyse each transcript individually without reference to the themes that emerged from previous transcripts.

Having transcribed and anonymised all the interviews of focus persons and their carers, the research team discussed them in order to decide which of the above two approaches to follow. After discussion, the research team decided to compromise. On the one hand, the research team wanted to give voice to each of the individual participants. On the other, time and other resources were limited. The decision was made to analyse two of the transcripts from scratch, i.e. without reference to themes from other transcripts. The themes from these two interview transcripts were then sought in the remaining interview transcripts. However, we also remained open to the possibility of new themes emerging from the remaining interviews and agreed to include any such themes if they were to emerge. The two transcripts selected were predominantly chosen due to the richness of these interviews. Such a choice is in line with the suggested practice described by Smith and Osborn (Smith & Osborn, 2003) in their chapter on IPA.

Analysis was undertaken in the manner described by Smith and Osborn (Smith & Osborn, 2003). In brief, the transcripts were read a number of times in order for the researchers to become familiar with them. Notes were then made of anything that was interesting or significant. Once this had been done, the researchers returned to the beginning of the transcripts to note emerging theme titles. The researchers then looked for and sought to make sense of the connections between these themes. As the themes emerged and became more abstract, the researchers checked the transcripts in an attempt to ensure that what the person actually said does fit in with the researchers' interpretation of what was said. A table of themes was then produced whereby the themes that had emerged were put in a coherent order and super-ordinate themes were defined. The fifth stage of the process was to construct a final table of super-ordinate themes upon which the researchers focused. At this stage, the researchers returned to earlier transcripts to look for themes that emerged from later transcripts. The final stage of the process of IPA was the writing up stage during which the themes were translated into a narrative, explained and illustrated with verbatim extracts from the transcripts to support the argument being presented. These 'results' are then discussed in relation to the relevant literature.

In practice, the research team sought or looked for what Boyatzis (Boyatzis, 1998) referred to as, 'the codable moment'. That is to say they needed to recognise that 'something' was important. Having seen this, they then sought to consistently and reliably code it as that 'something'. The codes were then developed into themes which were amenable to interpretation. The coding was undertaken on a line by line basis, which, although time

consuming, did force the researchers to think carefully about the material (Charmaz, 1995).

Where interviews were recorded onto mini-disc, data was transcribed by the person conducting the interview using 'Word for windows'. Where the participant had declined to their being recorded on mini-disc, the interviewer typed their notes of the interview into a 'Word for windows' document. Each document was then saved as a rich text file and imported to 'NVivo', a qualitative software programme. The team chose to use NVivo as a tool for coding the transcripts rather than cut and pasting as is recommended by some authors (Plummer, 1995). NVivo allows a researcher to code in a 'top down' manner that is applying codes or themes that have been previously decided upon to the data.

Alternatively a researcher may code in a 'bottom up manner', that is to say by coding 'nvivo' on a line by line basis. Given the exploratory nature of the current study, the latter option was chosen in order to code the first two transcripts. The remaining transcripts were then coded in the former manner with the research team looking for, and applying, the codes present in the first two interviews to the remainder of the transcripts. However, as a result of the research team being concerned that a top down approach to coding may result in missed data, in addition to seeking the codes contained in the first two transcripts, the research team remained alert to the possibility of additional themes emerging in the remaining interviews.

In an attempt to ensure consistency and reliability in coding, although each interviewer coded their own transcripts their coding was then discussed by the remainder of the team. The team gave their views on the attributions that the interviewer had ascribed them (Boyatzis, 1998; Smith, et al., 1999). The research team concurred with the attributions given to the data.

Once all transcripts had been coded, the research team met to seek links between the various themes in an attempt to coherently group the themes into super-ordinate themes.

## **2.4. Findings**

### **The Person-centred planning facilitator**

Data collected via interviews with the Person Centred Planning Facilitator is discussed in Part II; after the findings of both Stages two and three relating to the focus persons and their carers have been reported.

### **Focus persons, main carers and second carers**

A total of forty-one themes were identified in the interviews of the focus persons, main carers and second carers. The research team then sought to place these into a coherent order and to describe super-ordinate themes. Six super-ordinate themes emerged as outlined in *Table 1*, below. These themes will be discussed in turn.

### **Identification of person providing the quotation**

In order to preserve the anonymity of participants, we have used codes rather than names to identify individual participants. Where quotations are provided to substantiate a theme they are preceded by a code, e.g., '2FP' or '2C-2FP2'. This code simply signifies the type of participant making the comment. All codes commencing '2C-' signify that the extract is taken from an interview with the focus person's main carer during Stage two of the study. A person was classed as 'main carer' if they were identified as such by either the focus person or the Multi Disciplinary Team (MDT). All codes commencing '2FP' signify the fact that the extract is from an interview with a focus person during Stage two of the study. Where the research team was unable to communicate sufficiently with a focus person to

obtain their consent to participation in the study the focus person was not interviewed. Rather, a second carer was identified and their views were sought in addition to those of the main carer. Where the quotation is taken from an interview with a second carer during the second Stage of the study it is prefixed by, '2SC-'.

**Table 1 Themes emerging from the interviews with the focus persons, main carers and second carers during Stage 3 of the study**

Super-ordinate Themes	Sub-themes	
1. Current situation	1. Interests and activities 2. Residential provision (+) 3. Day provision (+) 4. Respite 5. Privacy 6. Quiet times 7. Need for structure and routine 8. Limits to independence 9. Life skills 10. Experience of services (+)	Residential provision (-) Day provision (-)        Experiences of services (-)
2. External filters	11. Role of family 12. Carer's initiative 13. Carer letting go 14. Carer's knowledge of focus person 15. Support to enable 16. People who are important 17. Focus person's history	
3. Internal Filters	18. Fears of focus person 19. Expressing preference & autonomy 20. Emotional impact of past experiences	
4. Aspirations	21. Contribution made by focus person 22. Unfulfilled potential 23. Employment possibilities 24. Desire for relationship or family 25. Dreams and goals 26. Fantasy v reality	
5. Emotion	27. Emotional experience 28. Emotional expression	
6. PCP	29. Potential for PCP 30. Knowledge and understanding of PCP	

*In the table, the following abbreviations are used:  
(-) refers to negative experiences or perceptions  
(+) refers to positive experiences or perceptions  
v = versus*

### **2.4.1. Current Situation**

This super-ordinate theme is comprised of ten sub-themes. These are essentially self-explanatory and are concerned with the current situation of the focus person as reported by themselves or a second carer, or by their main carer.

#### **1) Interests and activities**

Weekday activities:



Focus persons undertook a variety of activities. Many of the activities they undertook were arranged through services they attended or resided at and took place in the day time. For the most part, these activities included such things as pottery, painting, rug making, collage, gardening, daily living skills, computer work, animal care, and woodwork. However, one day service also took clients on occasional day trips, an example of one of these being to see a matinee performance at a theatre. Another focus person was taken by his residential service 'white water rafting' for a weekend as a birthday 'treat'.

For two of the focus persons, some of the activities they undertook led towards a qualification. For example, FP7 had completed an NVQ level 1 in animal care and was working towards a GCSE in Art. Likewise, FP3 had undertaken a certificated health and safety in horticulture course.

In addition to activities provided directly by the person's service, two focus persons also had additional 1:1 paid input on a regular basis. The impact of this additional support appeared variable. For FP3 it meant that he had the opportunity to go shopping for two to three hours on a Thursday. For FP2, it had resulted in her, reportedly, having increased opportunities to experience activities that were not generally offered by her day service:

**2C-2FP2, paragraph 550;**

*"... I am not sure whether she would have as much choice if I wasn't there ... FP2 is the only one who has all these extra activities and – I mean – a lot of people have (a) one to one carer but they just go to the centre and use the facilities within the centre."*

These activities included such things as swimming, attendance at a music group and at reflexology. Additionally, she was involved in the carer's family's life. However, it is not clear whether such involvement was designed to maximise the focus person's community inclusion and integration or whether it was simply more convenient for the carer to involve the focus person. For example, the main carer discusses how she has taken the focus person to her son's school, to rugby matches and to a pizza parlour for lunch with her son on his birthday. However, she also discusses how she has included her in other activities that may be more for the carer's benefit than the client's:

**2C-2FP2, paragraph 472;**

*"... she comes to the hospital with, if my sons, I need to go to the hospital, my son injured his leg badly so she comes to a hospital situation ... and dentist – there are situations that – she lives a life through me like anybody else would."*

Most of the focus persons appeared to have limited choice as to the activities they undertook that were organised by their day service or residential placement. This was made particularly clear by FP3's main carer:

**2C-2FP3, paragraph 53;**

*"With the social services you don't really have a choice. That's what's on offer."*

However, despite the fact that they may not have had much choice in the activities they undertook, this does not mean to say that they did not enjoy those activities, as can be seen from the following extract from the interview with 2FP3:

**2FP3, paragraph 65;**

*"It was my social worker who suggested all these places. Now I enjoy coming here because I like the people here."*

Additionally, although the focus person may not have actively chosen the activities they were provided with, those activities may have been selected as a result of staff being aware of the focus person's interests as appears to be the case in relation to 2FP:

**2FP3 paragraph 66;**

*"I do many things here, my cross - , gardening, horticulture with the adult education department. (name of service manager) suggested that I do horticulture because he knows that I like it."*

Other positive and negative views of services are discussed under other headings.

Weekend and evening activities:

Some of the focus persons were involved in a number of activities with other persons during weekday evenings. For example FP6 went out on most evenings of the week. He attended a literacy class, played golf, went to a rugby club and undertook sporting activities. However, all of these activities were organised either through the individual's day service or through a local charitable organisation and were undertaken with other learning-disabled individuals. Likewise FP7 undertook a variety of activities in the evening including, visits to a cinema, going walking or bowling and going to the gym. However, as FP7 stayed at a residential placement during the week it is likely that such activities were organised by his residential service.

Most of the focus persons, however, had far less structure in the evenings and at weekends and were either allowed to occupy themselves or were included in family activities. Self-occupation for the most part involved the focus person listening to CDs or watching television, videotapes or DVDs. Some focus persons also spent time looking at books and playing on 'play stations'.

Family activities included attendance at church, visiting the cinema, visiting the beach, visiting car boot sales, going walking, attending a special interest club with a parent, spending time in the garden and shopping. However, the level of involvement in these activities was at times minimal. For example, FP1 was reported to go shopping on a Saturday morning; however his main carer then describes this:

**2C-2FP1, paragraph 278;**

*"He comes with me to the market to do the Saturday shopping and he usually sits in the van while I'm doing the shopping."*

Likewise, it appears that 'spending time in the garden' for FP2, a wheelchair user, is simply that, and does not involve her participating in activities in the garden:

**2SC-2FP2 paragraph 107;**

*"... you cannot be permanently sort of occupying her, um so really you do have to leave her sitting, you know, just sort of watching what we are doing or - well - I'm trying to keep her with me if I'm, I mean I enjoy gardening so in the summer she spends a lot of time with me when I'm sort of - you know gardening."*

## **2) Residential provision**

Only two of the focus persons participating in the study lived in residential care, one of these lived at boarding school (FP5). The other (FP7) resided in a residential college during the week, returning home at the weekend. Little comment was made relating to current residential provision.

However, FP7's main carer was critical of previous residential services that FP7 had experienced. For example, services were seen as providing inadequate support and being poor at communicating with clients and carers:

**2C-2FP7, paragraph 13;**

*"We felt all along that he didn't get any one-to-one help, or not sufficient one-to-one help. Then there was the incident... Instead of a colleague speaking to FP7 and trying to find out exactly what happened they just suspended him. And it was six weeks before they even asked him about his side of the story."*

When a second incident reportedly occurred, the impression given was that services wish to 'wash their hands' of 'difficult clients':

**2C-FP7, paragraph 15;**

*"I never got down to the nitty gritty of what FP7 actually did or said but somebody put in a formal complaint and we had the same procedure about to start again and his tutor said, 'Look we don't want to put FP7 through this again so can he just leave?' And that was how it was left"*

Additionally, FP7's carer was unable to obtain relevant information about alternative placements for FP7 with the result that he remained at home for a year prior to the carer finding an alternative placement:

**2C-FP7, paragraph 19;**

*"...we felt terribly let down by the system, we should have had this diagnosed earlier (ASD was diagnosed during FP7's 21<sup>st</sup> year) and I felt very cross that we had seen all these different consultants and the GP has known him since he was a baby – for no-one to have picked that up I thought was very bad... Again Social Services didn't seem to have any clue about where FP7 should go. I couldn't find any help from the previous colleges. I arranged an interview and took FP7 but I had to do all this myself, I had no help from outside on any of that at all. You feel you are constantly feeling your way."*

Another thing that emerged in relation to residential care was the extent to which the quality of such provision and the attitudes of staff and other clients could have a major impact on the quality of life of the focus person. For example, FP7's main carer described how one residential placement had affected him:

**2C-2FP7, paragraph 13;**

*"He was so unhappy there, there was bullying and all sorts of other things happening and although he was trying his best he was always the very bottom of the pile and he didn't have the help."*

However, FP7's move to his current residential placement, he has been involved in activities of his choice and has been provided with his own flat. Both of these facts have reportedly resulted in an improved quality of life and his main carer noting that he is much happier.

Of the other focus persons, only one, FP6, made a comment about his place of residence and this was to say that he was happy living at home with his Mum.

### **3) Day service provision**

Four of the focus persons received some form of day provision. For the most part, this was described neutrally as can be seen from the following quotation from the interview with FP6's main carer:

**2C-2FP6, paragraphs 25-31;**

*"Yes he goes to the (name of service) to do all sorts of things for two days a week and to (name of another service) three days where he does gardening mainly."*

**Interviewer**

*"So what does he do at (name of day service)?"*

**2C-2FP6**

*"He does sport and literacy and reading and writing and singing and goes places with a group."*

For some focus persons certain aspects of their day services were commented upon in a positive light. For example FP1's main carer describes how FP1 is accepted by people in his day service despite the fact that some of his behaviours may be seen as disruptive:

**2C-2FP1, paragraph 297;**

*"... he gets on with all the others – you know he gets on quite well, you know he makes jokes with them, he taps them on the head and then runs away and laughs – just to disturb them you know, FP1 just laughs at that, he thinks this is very funny you know, and you know he has this sense of humour, you know he gets on well, nobody takes offence from that, it's just his way of playing around, he gets on well with them..."*

Likewise, FP7's main carer describes how FP7 felt about a previous day placement that he used:

**2C-2FP7, paragraph 15;**

*"Anyway FP7 had this two days a week helping out at this animal sanctuary and he absolutely adored it, it was wonderful for him and he really looked forward to it."*

However, there were also criticisms of day services. For example, FP1's main carer described a service that had been offered to FP1 in the following terms:

**2C-2FP1, paragraph 213;**

*"... there was this man there and there was six or seven disabled people there, and they were with learning disabilities, but they don't, I mean there was nothing... nothing at all."*

He also suggested that limited resources in FP1's day service reduced the opportunities FP1 had to engage in activities:

**2C-2FP1, paragraph 261;**

*"He is obviously missing out on activities... everything is limited because there is not sufficient space on the bus."*

This lack of physical resources was also referred to by one of the focus persons who, having referred to activities that he previously undertook, was asked whether he engaged in these activities now. He replied:

**2FP6, paragraph 177;**

*"No, um. They got no tools in (name of service)"*

In addition to some persons describing a lack of physical resources, one carer suggested that there was a reliance on the good will of certain staff and that services reduced when they moved elsewhere:

**2C-FP6, paragraph 31;**

*"He used to go fishing and really liked that but the man he went with isn't there now so it, like, doesn't happen now."*

In a similar vein, one focus person commented on how staffing levels affected the quality of the services offered:

**2FP3, paragraph 83;**

*"The problem in the (name of service) is that there are too many students and just one lecturer. If there were more lecturers or less students then I could do more, but there is only one lecturer. I don't want to go back to (name of service) next year. I find they are so slow with the courses and the certificates."*

A final criticism of day services was made by FP2's carer, namely that concerns re 'health and safety' and 'manual handling' have reduced clients' opportunities to engage in some activities:

**2C-2FP2, paragraph 568;**

*"...like years ago used to have a physio within the centre um, but through lifting and handling and all different other reasons the people lost out on that physio."*

There were few comments that posited day services in a positive light. However, there were a couple of comments that at least suggested that the focus person enjoyed activities that were either organised by the service or that took place in the service:

**2C-2FP1, paragraph 311;**

*"...he enjoyed it, don't think they went to the seaside last, but the other times were quite OK, he quite enjoyed it, he likes going out."*

Similarly on being asked whether FP2 enjoyed the activities she undertook within the day service the main carer replied:

**2C-2FP2, paragraph 113;**

*"yes, very much. Her would be lost without them or would be less happy without them."*

Likewise, when FP6 was asked whether he was happy with the services he received, he replied in the affirmative. However, because he did not enlarge on this it is not clear whether he understood the question or whether he may have been acquiescing.

#### **4) Respite care**

As with other forms of service provision, the experience of some focus persons was more positive than that of others. For example FP6, considered respite care to be a holiday saying:

**2FP6, paragraph 423;**

*"...it's like a holiday, sometimes some people will stay there and then the end of the week they go home."*

His perception of it as a holiday was also recognised by his main carer:

**2C2FP6, paragraph 79;**

*"FP6 has not wanted to go with us for a while now, he'd rather go to respite at (name of unit). He really likes it there so if we go away he would be happier going there. Sometimes he goes to his sister's but usually he prefers to go to (name of respite unit)."*

However, for FP2, respite care has both positive and negative outcomes. On the positive side, FP2's second carer reported that:

**2SC-2FP2, paragraph 89;**

*"... when she's been to respite I think because it's more busy, she, when she comes back, when she comes back she always seems quite tired and sort of happy (laughs) and sort of relaxed again..."*

This second carer also notes that staff from the respite unit are involved in FP2's care reviews. The main carer, on the other hand discusses another issue which shows the service in a less positive light:

**2C-2FP2, paragraph 193;**

*"... when FP2 goes into respite she may think that things aren't right because she refuses to eat ... but she also doesn't go to the toilet, number twos, em, so whether that is a deliberate action or not we can't tell, but if she goes for a fortnight she doesn't go to the toilet."*

## **5) Privacy**

The opportunity for privacy or the desire of focus persons to keep some aspects of their lives private was only discussed in two interviews. FP6 commented that he had privacy in the form of his own room, whilst his carer stated:

**2C-2FP6, paragraph 115;**

*"He doesn't tell me much anyway."*

## **6) Quiet times**

Quiet times may be related to privacy and were referred to in such a way in two interviews where they were considered as beneficial to the focus person. For example, FP7's main carer stated:

**2C-2FP7, paragraph 115;**

*"Umm, he likes being on his own – he's an only child anyway and likes his quiet times as well, he specifically needs this time"*

Likewise, FP3 discussed how he relaxed:

**2FP3, paragraph 89;**

*"I soak (in) a bath most nights. It just makes me relax."*

However, this is an interesting theme in so far as such periods of time may also be seen to serve other less positive purposes. For some of the focus persons, 'quiet times' were not perceived to be beneficial to the focus person. For example the second carer of FP1 noted that when they had first visited the day service they had seen FP1:

**2SC-2FP1, paragraph 86;**

*"sitting alone in the corner without participating in the group"*

On other occasions, such times may be more for the convenience of the carer than the benefit of the focus person. For example, having described how, at weekends, FP2 was left until she was ready to wake up the second carer then went on to say:

**2SC2-2FP2, paragraph 107;**

*“um, and may be just sort of sitting, I mean if there is, you cannot be permanently sort of occupying her, um so really you do have to leave her sitting you know...”*

**7) Need for structure and routine**

Although this theme was only present in the interviews of two main carers, it is an important issue for those individuals supporting focus persons to make plans to be aware of. Although this is particularly likely to be an issue of concern where individuals are diagnosed as being on the Autistic Spectrum, such as FP7, it may also be of relevance in relation to other focus persons. For example, although FP5 is not diagnosed as being on the Autistic Spectrum, her main carer stated:

**2C-2FP5, paragraph 145;**

*“I don’t know if FP5 would like a change that much. She likes to know what she is doing, she likes to know who she is with...”*

**8) Limits to independence**

A number of persons reported on the presence of factors that currently inhibit the individual’s independence. These are sometimes seen as being a result of the person’s (dis)ability. For example, the need for structure and routine which was related to FP7’s having Asperger’s Syndrome, was seen as limiting his independence. However, it was not only his ‘need’ for routine that made achieving independence difficult, but also his inability to cope with excessive amounts of information being given at one time:

**2C-2FP7 paragraph 252;**

*“Don’t say ‘when you’ve finished that do this and that’ as he can’t take all that in. Say ‘when you’ve finished that come back to me’ and then I will say, ‘can you do that now’. If you overload the system he can’t cope. And I think he was given too many things he should do by too many people and he couldn’t cope.”*

In relation to some focus persons, physical disorders were seen to impede their achieving greater independence. For example, FP2 was considered unable to access some shops as a result of her epilepsy:

**2C-2FP2 paragraphs 483-489;**

*“...FP2 more or less 98% of the time fits when she goes into Morrison’s... she always more or less always has a seizure in Morrison’s and Peacocks... Maybe it’s, maybe it’s the lighting that affects her epilepsy...”*

A further perceived restriction on FP2 achieving greater independence was the fact that she was a wheelchair user:

**2SC-2FP2, paragraph 89;**

*“...when she was younger we did, we did more things, we’d go out in the weekends, you know, as a family and things. As she got older you are sort of less able to sort of go in places with her because of the wheelchair situation.”*

Whether this was because of poor accessibility or the capabilities of the carer is, however, unclear:

**2SC-2FP2, paragraph 113;**

*“I mean that it’s sort of, you know, it’s sort of, more tiring as you get older, to sort of take her out and - you know – in and out of the van and pushing and things, it’s quite hard work.”*

For others the achievement of independence was seen to relate to the individual's lack of skills in particular areas. For example FP6's carer noted that FP6 did not understand the value of money and this was the reason for his not being given more than the, 'odd pound coin'.

Limits to independence were not, however, always seen to be related to the focus person's (dis)ability. Sometimes it was recognised that the individual was limited in developing their independence as a result of the carer's ability. For example FP1's main carer was also the main carer for FP1's mother and was himself somewhat fragile:

**2C-2FP1, paragraph 267;**

*"...so he only goes to the day centre because I can't take him, and you've got to realise that I've had two heart attacks and a stroke. Also I'm over 70, you know what I mean? That limits me. To try to take him and his mother it's impossible 'cause I can't deal with the two of them you see – so he can't, he's got no social life, he can't because I can't do anything with him."*

For some focus persons, achievement of independence was also limited by carers' desire to 'care for' the individual as 2C-2FP6 noted:

**2C-2FP6, paragraph 158;**

*"...I lay his clothes out each night. I probably shouldn't but I always have."*

And,

**2C-2FP6, paragraph 230;**

*"We are probably over-protective I know"*

Concerns about risk on the part of carers, services and insurance companies were also perceived as preventing focus persons experiencing activities that may contribute to their growing independence. For example, FP7 had wanted to go white water rafting but had been unable to do so:

**2C-2FP7, paragraph 67;**

*"...because of these insurance issues that always come up."*

Another perceived current limit to the focus person achieving greater independence is a lack of resources, as was noted above in relation to criticisms of services.

It can be seen, therefore that perceived limits to increased independence were seen to result from both the individual's (dis)ability and from external factors, both of which reduced the focus persons' opportunities for choice, and experiences.

## **9) Life skills**

Related to the focus person's perceived limits to independence are the life skills that they currently possess. However, whilst quotations in this theme recognised this, there was recognition that such skills could be either lost or developed. Such recognition was not apparent in the last theme, 'limits to independence'. For example, one carer was concerned that the focus person for whom she cared might lose life skills that had been acquired if there was a change in the person's service provision:

**2C-2FP5, paragraph 48;**



*“...we don’t want her to live at home with her parents all the time, cause that means there’s a lot that FP5 is gonna loose, her living skills, doing her washing, her drying, and things like that if she lives at home and her mum is doing it for her.”*

There was an awareness, on the part of some carers, that life skills were not solely concerned with activities such as washing and ironing, but also the focus person’s social skills:

**2C-2FP6, paragraph 94;**

*“He’s quite shy... but X at the day centre is doing some work with him to help him make eye contact.”*

Likewise, FP7’s carer recognised that his social skills, or lack of them, were likely to cause him difficulties:

**2C-2FP7, paragraph 174;**

*“For instance on this raft trip Friday night they got up to (name of a predominantly Welsh speaking area) and there was the England and Welsh rugby on the Saturday and they are all ready to go out to this pub in (a predominantly Welsh speaking area) and FP7 puts an English T shirt on. Someone said, ‘you won’t come out alive if you go in like that’, but he hadn’t made the link.”*

And,

*“He’s very health conscious so if he sees someone who is very fat he’ll say so and that can be very awkward. And that is where the sexual comments have got him into trouble because there will be some girl in a skimpy top somewhere and he’ll say, ‘You’ve got nice boobs’ and of course you just don’t say that to a complete stranger in public. I am not quite sure how we handle this, I know at college the psychologist has been doing some work with FP7 about public situations and thinking a bit more.”*

FP7 himself did not discuss such skills, though he expressed a view that he wished to learn other skills,

**2FP7, paragraph 171;**

*“I would like to learn about money ‘cause then I could go out more.”*

## **10) Experience of services**

There were mixed feelings in regards to experiences of services. A carer expressed how she has been let down through the years by different services:

**2C-2FP7, Paragraph 19;**

*Of course this report resulted in it being seen that 2FP(7) had all the classic symptoms of autism and she made the diagnosis and that was when 2FP(7) was 21. So we felt terribly let down by the system, we should have had this diagnosed earlier and I felt very cross that we had seen all these different consultants and the GP has known him since he was a baby for no one to have picked that up I thought was very bad.*

The same carer describes how she felt she lacked support from services on another incident:

**2C-2FP7, Paragraph 19;**

*Again Social Services didn’t seem to have any clue about where 2FP(7) should go. I couldn’t find any help from the previous colleges.....I arranged an interview and I took 2FP(7) but I had to do this all myself, I had no help from outside on any of that at all. You feel you are constantly feeling your way.*

The disappointment of this particular carer derived from different services:

**2C-2FP7, Paragraph 15;**

*2FP(7) went there and he wasn't there more than two weeks when there was another incident where he supposedly fell on top of a girl in the common room. I never got down to the nitty gritty of what 2FP(7) actually did or said but somebody put in a formal complaint and we had the same procedure about to start again and his tutor said "look we don't want to put 2FP(7) through this again and so can he just leave". And that was how it was left. So in the last year he was at home all the time.*

The carer of FP2 suggested that whether or not one has positive experiences from services is fortuitous:

**2C-2FP6, Paragraph 224;**

*We've been very lucky when there have been problems we have had help. There were some problems a while back and social services were very supportive and there were allegations and the ((name of centre)) were backing 2FP(6) up and looking after us as well. We've been really lucky and I know not everyone is.*

The focus person of that particular carer seemed to be oblivious to the range of services that he received, however, commented upon services in a positive light (look also at comments under 'Day service provision' for FP6):

**2FP6, Paragraphs 3-5;**

**Interviewer**

*The things I need to ask you are written down here. As I said I've not got a very good memory. So, can you tell me what sort of services you get at the moment?*

**2FP6**

*Money*

**Paragraphs 88-90;**

**Interviewer**

*So are you happy with the services you get?*

**2FP6**

*Yeah*

## **2.4.2. External filters**

The second super-ordinate theme, 'External Filters' is comprised of seven sub-themes which are discussed below. The commonality between them is the fact that they are concerned with factors that are predominantly external to the focus person, but which may impact either positively or negatively on the ability of the focus person to achieve their aspirations.

### **11) Role of family**

Given that only two of the focus persons live in residential services it should be no surprise that focus persons' families and main carers have a considerable impact on their lives. For most of the focus persons interviewed, their families and main carers provided them with varying levels of support. This included physical support as in the case of FP1:

**2C-2FP1, paragraph 148;**

*"I still have to change him before he goes to bed, because his legs are not ok and he drops... I sleep in the same room as him so I'm careful with that, whether he needs something at night, I help him get out of bed, help him to the toilet, get him back into bed, and - because his hands aren't - he has to lie on the bed and be covered. I have that to do and anything he wants while he's home. If he goes to the toilet I have to wipe him and clean him after he's been to the toilet, that's all part of it..."*

Families and carers also assisted with the inclusion of focus persons in the wider community. For example, FP5's sister was reported to take her out to the cinema and walking.

Another focus person's sister (FP6) accommodated him for periods of time. However, it was not clear why this was the case. It did not appear to be at his instigation and could have been an attempt on the part of his sister to provide his parents with some respite care.

Some family members were also seen as providing emotional support to focus persons. An example of this can be seen in the following extract from the interview with FP7's carer:

**2C-2FP7, paragraph 160;**

*"... he does talk to her on the telephone. He will talk to her at length when he doesn't necessarily with anyone else. He doesn't talk with my other sister."*

As well as providing direct physical and emotional support to the focus person, some families and main carers are perceived, or perceive themselves as influencing the focus person's access to services. An example of this can be seen in the following extract from the interview with FP3:

**2FP3, paragraph 23;**

*"I go to my GP... I've had to go for - because my blood pressure, it has been extremely high and my parents got very worried."*

Some families and carers were less involved in the direct care of the focus person and did not appear to be involved in the planning of the focus person's life. For example the carer of FP5, who was living in a residential school, stated:

**2C-2FP5, paragraph 12;**

*"At the moment FP5 is leaving in July and, and not even her parents know where she is going after here."*

Similarly, when asked whether he had been involved in the care plan put together by the social worker for FP1, his carer stated:

**2C-2FP1, paragraph 154;**

*"No, I don't think I did, but I don't think there is anything I would have objected to."*

Likewise, FP2's second carer appeared to rely upon FP2's main carer to provide FP2 with sufficient activities:

**2SC2FP, paragraph 89;**

*"... to be honest we've got lazy doing things and it sort of tended to, sort of - we felt that she's done quite a lot during the day with (name of main carer) and things, so I don't feel that she sort of needs to do things in the evening."*

## 12) Carer's initiative

In addition to some families and carers providing direct support to the focus person, some suggested that they had had an impact on the level or quality of the services the person they cared for experienced:

### **2C-2FP2, paragraphs 95 – 101;**

*"But it's been, it's been you know, we – we parents and carers have, em, made up what FP2 actually does during ... Well we found a swimming pool for FP2 to go swimming and we found a music group for FP2 to go to and reflexology and ... there are out of day centre things that she has (that) have nothing to do with the day centre."*

Such initiatives appeared to be taken due to the carer feeling that if they failed to do something the focus person's quality of service would reduce:

### **2C-2FP2, paragraph 568;**

*"...FP2 is the only one that still has physio, um, I'm pretty sure that it could have just stopped when the others stopped, but I found a way of being able to make it continue... It's easy just to say 'oh! We can't do it' because you can't find a place or whatever... I've insisted upon these things happening and there's lots of things that FP2 does that other people don't do."*

This was also the case for FP7's mother who had to arrange placements for FP7 after he had been suspended from school following an incident of alleged assault, due to her receiving no assistance from services:

### **2C-2FP7, paragraph 19;**

*"I arranged an interview and I took FP7, I had to do this all myself, I had no help from outside on any of that at all. You feel you are constantly feeling your way."*

It is not clear whether the impact of carer's initiatives was recognised by services, and if so what services' attitudes were to such initiatives. However, the impact of such initiatives was recognised at times by others, for example, FC3's carer recognised the role his father had in improving the services he received:

### **2C-2FP3, paragraph 53;**

*"His dad pushed people to work with FP3 and move him forward."*

## 13) Carer letting go

This sub-theme is concerned with evidence of the focus person's main carers either recognising that they need to 'let go' of their control of the individual or actually consciously permitting them choice.

Some carers recognised that they prevented the person expressing themselves or making choices. For example FP2's carer recognised that they prevented FP2 communicating with other people:

### **2C-2FP2, paragraph 370;**

*"Oh no, 'cause then I suppose I interfere and speak for FP2 then"*

Other carers not only recognised that they were restricting the focus person's choice, but also that this may not be in their best interests. For example, FP6's carer discusses how she undertakes activities on behalf of FP6 un-necessarily:

**2C-2FP5, paragraph 158;**

*“And I lay his clothes out each night. I probably shouldn’t but I always have.”*

One carer, whilst recognising the possibility that by having seizures the focus person was trying to communicate that she did not wish to go into particular shops, had not quite reached the stage where she actually acted on the focus person’s choice:

**2C-2FP2, paragraph 490;**

*“... may be it’s the lighting that that affects her epilepsy. I don’t suppose it’s a - you know whether she prefers to go to Asda or not... I should take that on board because it has happened so many times, em, that – I take, you know I feel that it is 2FP2 saying – you know she obviously doesn’t want to have a seizure – so I think to myself, perhaps I should not go to Morrison’s anymore.”*

Other carers not only recognised that it was appropriate for them to permit the focus person to make decisions but actually facilitated this despite it causing them additional work:

**2C-2FP1, paragraph 255;**

*“He has the choice. I wouldn’t make him go, of course it means doubling my work here because I have to keep an eye on both of them (his wife and son), but I wouldn’t make him go (to the centre).”*

Permitting a focus person to make choices not only may have physical implications for the carer, but it could also affect the carer emotionally. For example, FP7’s main carer appeared to express some sadness that she felt that she was less involved in his life than she had been previously, but recognised that this was appropriate:

**2C-2FP7, paragraph 211;**

*“This is the downfall, if you like, of him being away from home - that people will say they’ve seen him or done something with him and I won’t know about it. Not that I need to as I’ve got to give way at some point but...”*

Fears of carers in relation to focus persons

One reason why carers may have felt reluctant to ‘let go’ was that they had a number of fears for, or relating to the focus person. For example, FP6’s main carer was concerned about what would happen to him once she was gone. This fear was related to a concern with the quality of services:

**2C – FPC6, paragraph 230;**

*“You hear such awful things - you know - on television with these homes and they can be awful. You just want to know that they’re safe and protected and that’s all. I get quite emotional about it.”*

A fear expressed by FP7’s main carer was that he may be accused of offending behaviour:

**2C-2FP7, paragraph 17;**

*“I was concerned that if these incidents had happened at college when he had put his arm around a girl or tried to kiss a girl and she didn’t want him to that this could happen in the street. The next thing could be this was in the hands of the police through no fault of his own really, just a lack of understanding.”*

**14) Carer’s knowledge of the focus person**

One factor that may have considerable impact on the development of a focus person is their carer’s knowledge. If a carer knows a focus person well, it is likely that they will be

able to suggest ways in which the focus person may both wish to develop, and be aware of any skills the person has that may be built upon:

**2SC-2FP1, paragraph 101;**

*Well, basically if you look to plan to the future then you'd have to have people around basically to do the planning with him, people who know him to say, 'well this is going to be best for FP1 or that's going to be best for FP1.'*

Carers generally had sufficient knowledge of the focus person to recognise their likes and dislikes and to be able to communicate with them at some basic level. However, the majority of carers appeared to have limited knowledge about what the focus person did in environments other than those in which they supported them. For example, FP1's father who was his main carer when FP1 was not at the day centre did not know how long FP1 had had a care plan for, nor what it involved. Additionally he was not wholly sure of the activities that FP1 undertook in the day centre:

**2C-2FP1, paragraph 285;**

*"I don't know what else he does there, I mean painting and pottery he does... I mean, what he does in there I don't know."*

Likewise FP2's day-time carer did not know what activities FP2 undertook during evenings and at weekends:

**2C-2FP2, paragraph 127;**

*"You'll have to discuss that with the family"*

Similarly, despite the fact that FP5 was to leave the residential school at which she was placed within a matter of weeks after the interview, her main carer did not know where FP5 was going to move to:

**2C-2FP5, paragraph 42;**

*"I don't know, I haven't got a clue – Social Services are supposed to deal with that, it has nothing to do with me here... no, no, no, I don't know where she'll be."*

Whilst on the one hand the carer is correct in saying that it is Social Services duty to arrange an alternative service, one would have thought that she would have been an appropriate person to support FP5 through the transitional period that she was about to encounter.

## **15) Support to enable**

Participants mentioned a number of factors that they felt would need to be present for focus persons to develop. Some of these factors were relatively inexpensive and would be easy for services to incorporate into the individual's service provision. For example, FP7's mother describes how FP7 could be left unsupervised for periods of time if his activities were pre-planned and communicated to him in an appropriate way:

**2C-2FP7, paragraph 252;**

*"...as I have found with the job cards, you need to give FP7 structure and a timetable so he knows he has got to do these things..."*

However, for many people the factors described as necessary are likely to have a greater demand on services. These included such things as 'one to one' support, the expenditure

of greater time and effort, recognition of the likelihood that a person would need different service provision in the future and better planning.

## **16) People who are important**

Another factor that may have a major influence on the development of focus persons is the extent to which they have a social support network. This theme looks at the types of person who may be part of the focus persons' network.

One group of people who play an important role in the lives of focus persons is 'informal' or 'family' carers. We have already discussed some of the support they provide.

Another group who provide support is formal carers. However, whilst we recognise that they are employed to provide support, many of the focus persons in the study saw them as more than employed carers, particularly when they spend large amounts of time with the focus person. For example, when asked, 'have you got many friends?' FP6 described the staff in the respite care unit as his friends. Whilst this perception on the part of focus persons may be understandable, there are a number of reasons why their perceiving in them such a way may not be beneficial to the focus persons. For example, there is recognition that a failure to maintain professional boundaries may place service users at greater risk of abuse (NMC, 2002).

Some focus persons also saw other people they had regular formal contact with as friends. For example, FP3 considered shop assistants working in a pharmacy and in a supermarket as:

**2FP3, paragraph 101;**  
*"very good friends"*

Yet at the same time as describing them in this way he acknowledged that he did not see them outside of the sales environment which he visited on a weekly basis.

Similarly, FP6 described a person working behind a bar he visits as 'important' and as 'special'.

One focus person described animals, such as his cat, as his friends. However, this appeared to be due to the fact that he hadn't many human friends:

**2FP7, paragraph 171;**  
*"I'd like to have friends, not just animal friends, and holidays with friends."*

Some of the focus persons described other service users as friends, but they did not appear to spend time with them other than when accessing the same services. Even when attending such events, the extent to which focus persons related to other service users they described as friends varied. This may be due to them not knowing how to interact with other people as is suggested by the following extract from the interview with FP6's carer:

**2C-2FP6, paragraph 109;**  
*"It's sad. I mean if we go to a (name of charity) do FP6 will go and sit with a group and not with us – but he is always a bit on the edge and not in the middle with the other lads (pause) I think he wants to be."*

Overall, focus persons appeared to have a paucity of meaningful relationships outside of those involving their family and paid carers.

### **17) Focus person's history**

The final sub-theme we considered to be an external factor that may impact on the development of focus persons was that which we have referred to as 'historical events'. Focus persons had a variety of experiences during their lives which it was felt were likely to impact on their future.

A number of focus persons had experienced rejection by services or had been placed in what may be perceived to be inappropriate services. For example, FP7, having been accused of assault by another service user, had been suspended from his college placement for some considerable time. During this period his mother found him an alternative placement but this failed after a short time as the owner of the placement felt that she was unable to leave him on his own, not because of challenging behaviour, but because:

**2C-2FP7, paragraph 15;**

*"...she would give him a job and then he would either lose interest or lose concentration and would wander off and be boxing with a kangaroo or something."*

Another placement was then found, but his parents were asked to remove him following an incident where he 'fell on top of a girl in the common room'

Such frequent rejection, coupled with the alleged bullying he was reported to have experienced in previous placements is likely to impact on his future behaviour and development.

Although FP1 had not experienced many changes, he was placed in the same day centre for older persons that his mother attended. This was not seen as benefiting him but rather as convenient by his father:

**2C-2FP1, paragraphs 130-136;**

*"He's been in the (name of the day centre) many years now, I think it is – I don't know if he has been there in his own right and how much is under a care plan"*

**Interviewer**

*"So FP1 was going there because his mother was going as well?"*

**2C2FP1**

*"Because his mother was going, because he had no where to go."*

Such a placement is unlikely to be equipped to meet his needs and provide him with appropriate opportunities for developing his skills.

### **2.4.3. Internal filters**

The third super-ordinate theme, 'Internal Filters' is comprised of three sub-themes which are discussed below. The commonality between them is the fact that they are concerned with factors that are predominantly internal to the focus person and may impact either positively or negatively on the ability of the focus person to achieve their aspirations.



## **18) Fears of the focus person**

Whilst family and other carers expressed fears about a number of things as discussed in the last super-ordinate theme, focus persons themselves expressed very few fears.

FP3 expressed concern over two things, firstly; what would happen if family were not around for him and, secondly; that the shunt which had been inserted to alleviate his hydrocephalus might fail.

FP7, who had been physically assaulted by another client, said that he was scared of “coloured people” and didn’t like them.

Although these fears are very different, it is likely that they will have an impact on the willingness of the focus person to experience new phenomena. There was no evidence that any attempt had been made to address these fears.

## **19) Expression of preference and autonomy**

A theme that was quite strong related to the focus person’s opportunities and ability to express preferences and to make choices in their lives. Some focus persons appeared to be given the opportunity to make a number of every-day choices such as what to watch on television, what clothes to wear or, whether to attend their day service. One participant’s choice not to go on family holidays was respected and at these times he went into respite care which he (FP6) regarded as his holiday.

Others were not offered even simple choices, for example they were not offered the opportunity to select the time at which they rose in the morning, the clothes they wore nor the activities they undertook

Most people were, however, regarded as being able to express some preference, particularly in relation to asserting that they didn’t want to do something:

### **2C-2FP3, paragraph 53;**

*“He is fully capable of expressing when he doesn’t want to do something.”*

Even where a focus person had profound and multiple disabilities they were able to express feelings and preferences to some extent, as may be seen from the following extract:

### **2C-2FP2, paragraph 544;**

*“...sometimes she doesn’t smile, so that’s her choice isn’t it? I mean sometimes if I have been away on holiday, I come in and say ‘good morning’ and she actually turns the other way and I go the other side of the wheelchair and she turned her head the other way. This happens at home as well if she doesn’t want something, say, or she doesn’t want to say hello she snaps you with her head.”*

Whether a focus person was given the opportunity to make ‘choices’ did not appear to be dependent upon the extent of their learning disability. It did, however, appear to be partly dependent upon where they were.

For example, FP2 was given no choices about what she ate when she was with her main carer who justified this by stating that she was aware of FP2’s likes and dislikes and that she would not give her food that she disliked. However, when she was in respite care she was able to refuse to eat. Whether this was because she didn’t like the food that was offered or did not like being in respite care was unclear from the comments made by the

main carer. Whatever the reason for her refusing to eat no consideration appeared to be given to health issues that might arise from this refusal, nor was there any acknowledgement that, failing to take any action when FP2 refused to eat, the respite home might be failing to meet its duty of care.

The degree to which some people's important choices and expressed preferences were met was at times limited by services. For example, FP3 wanted a different social worker:

**2FP3, paragraph 17;**

*"I don't particularly want a social worker. I don't really get on well with him. I wanted to change my social worker for months. I cannot open up to my social worker at all - it's impossible. I have asked ages ago to change my social worker, but nothing happened."*

At other times the opportunity to express preferences or make choices was limited by services. For example, FP1 had no choice as to where he holidayed and whether this was with his family or not as Social Services:

**2C-2FP1, paragraph 243;**

*"...sent us on a holiday campus, to a hotel in Blackpool, you know and that kind of thing, but they sent us... he didn't have a choice on where we went."*

Focus persons were also discouraged from making choices or expressing preferences at times. For example, although FP5 was able to choose some activities there were times when her choice was removed for reasons of what might be argued were her 'best interests':

**2C-2FP5, paragraph 78;**

*"...I will say like, 'would you like to do your washing?' and she says 'no' and I say, 'well you will have to do it FP5, you need clothes.'"*

Similarly she was not always given the 'choice' as to what she ate,

**2C-2FP5, paragraph 91;**

*"...if you explain to her why she can't do it – I mean – if you say, 'tonight you can have cucumber instead of crisps' she is quite happy to do it. It's just persuading her ... give her something different."*

These two examples may be regarded as demonstrative of the concern of FP5's carer to balance such concepts as choice for focus persons with the need for carers to fulfil their duty of care to the individual. Alternatively they may be seen as using the service user's vulnerability to the influence of her main carer to get her to do undertake activities and to eat food that she doesn't wish to.

However, it was not only formal carers and services that placed restrictions on the choice of focus persons in such circumstances as can be seen in the following extract from the interview with FP7's mother:

**2C-2FP7, paragraph 186;**

*"At home he decides what he's going to put on but if we're going out for a specific thing and I feel that what he has on is inappropriate or it's dirty, for example, I will tell him he needs to change."*

## **20) Emotional Impact of past experiences**

In some ways, this theme is similar to that of 'Historical Events' discussed earlier. However, the focus of this theme is more concerned with occasions where the emotional impact of such events has affected the behaviour of the focus person. For example, the fact that FP7 had been rejected from three services impacted on his willingness to try a new service,

### **2C-2FP7, paragraph 199;**

*"With (name of college) I had trouble getting him to go to the interview as his experience of colleges was that they were places where they did nasty things to him. So it took a bit of getting him there. When we did get him there for the interview and we said 'would you like to go there?' they were happy to have him there. He said he'd only try it for one day so we to do a bit of playing along and pretend he was going for one day. But I arranged it so he started on the Thursday, so he went along, had one night and was home on the Friday and that broke him in quite well."*

Another example is that described by FP3 when asked if he got on with his neighbours,

### **2FP3, paragraph 77;**

*"One of my neighbours doesn't. I gave his daughter a hug and he got me against the wall. I just keep my distance. I don't associate with them much. Now when I see them I just say 'hello' and try to keep my distance."*

Such experiences were not limited to negative ones, however. For example FP7's mother reported his having experienced a confidence boost as a result of his going white-water rafting,

### **2C-2FP7, paragraph 67;**

*"He thoroughly enjoyed it and it was good for his confidence. It's important for him to do these things."*

## **2.4.4. Aspirations**

This super-ordinate theme contains six sub-themes, all of which are concerned with the focus person's aspirations and the likelihood to which they may achieve them.

## **21) Contributions made by the focus person**

This theme is present only in relation to one focus person, but it was felt to be important. It is concerned with contributions to the family or wider society that the focus person currently makes or has made in the past. Some of these may be considered quite simple such as FP7's role of making tea and cleaning up at one placement, but nevertheless, such things could be built on in order for focus persons to achieve their aspirations.

FP7 expressed a desire to care for people and demonstrate that people with a learning disability can contribute to society, contrary to the views held by some members of the general population:

### **2FP7, paragraph 171-177;**

#### **FP7**

*"I'd like for other people to see what I can do to help more people to do more things."*

#### **Carer**

*"Do you mean to show that people with disabilities do things..."*

## **FP7**

*"Yes, that we can still do things."*

That FP7 was a 'caring' individual was supported by his mother and is exemplified in the following extract:

### **2C-2FP7, paragraph 180;**

*"...in general older people can quite like him because he can be very helpful, very caring, and that's the same with animals. You know, he wants to be caring – he may have the wrong approach but he wants to be caring."*

## **22) Unfulfilled potential**

This theme is concerned with the views of carers as to whether the focus person has reached their potential. Whilst it was not discussed by all participants, it was discussed in relation to both FP7 who was quite able and to FP1 who had a moderate learning disability and whom we, as researchers, lacked the communication skills to interview him directly.

FP7 had at one point been offered a place at a day centre. However, his carer felt this to be inappropriate:

### **2C-2FP7, paragraph 17;**

*"But of course a day centre was not the be all and end all for a young student who still had an educational potential."*

In fact, she felt that he still had much potential, despite him attending a residential college:

### **2C-2FP7, paragraph 19;**

*"From the education point of view I feel very let down because he's bright is FP7. He has a lot of interests and I feel his potential has not been realised."*

In response to being asked whether FP1 was capable of doing more than he was currently doing, his second carer responded:

### **2SC-2FP1, paragraph 203;**

*"Yeah, I honestly, I honestly think if FP1 – regards to, you know things like painting – you know he's showing an – his painting has become gradually neater all the time – gradually he's getting better all the time. It's the practice makes you better isn't it?"*

## **23) Employment possibilities**

As with the previous sub-theme this was not a common theme amongst participants. It relates only two focus persons, focus persons 3 and 7 both of whom were more able individuals.

FP3 had expressed an interest in horticulture and his main carer recognised this and said that she hoped,

### **2C-2FP3, paragraph 23;**

*"... for FC3 to access a garden project and voluntary surroundings that will support his work."*

FP7 had expressed a desire to work with animals. This was not only recognised by his mother, but she also gave an example of how he could be helped to achieve this,

### **2C-2FP7, paragraph 252;**

*“So yes, as far as I am aware he does want to have a job where animals are involved, the small furry types really. I think he will always need some form of one to one supervision, but with a job, as I have found with the ‘job cards’, you need to give FP7 structure and a timetable so he knows he has got to do these things.”*

## **24) Desire for relationship or family**

A number of the focus persons who participated either expressed the view that they had such desires or were reported as having them. For example, FP3 stated:

### **2FP3, paragraph 47;**

*“All I want is a partner and to live a normal life.”*

He was hoping that PCP would help him achieve this desire:

### **2FP3, paragraph 47;**

*On Valentine’s Day I received a card via (the) internet from this girl (girl’s name) and I think that I had my Valentine’s date. That was enough for me, because that for me is my Valentine, the message was there. I hope (PCP facilitator’s name) will do help me, give me advice (on) things like that.”*

Additionally, focus persons’ carers also noted such desires in the person they cared for. For example, FP6’s main carer noted his desire for a girlfriend:

### **2C-2FP6, paragraph 146;**

*“I think he would like to have a girlfriend what with (his sister) and the baby and seeing that they are married and a family and all that.”*

Likewise, FP7’s main carer noted that he was interested in females, though she had not realised the extent to which he had grown attached to one person in particular:

### **2C-2FP7, paragraph 121;**

*“Oh well, he’s very interested in the opposite sex. To the point that he’s now been buying the ‘Sun’. It’s a difficult area. For all his life he has gone on an Easter holiday with a group of walkers and they were my contemporaries, they all got married and had children and are now producing grandchildren so there are about thirty people who go on this holiday. One of the people there, FP7’s contemporary is a girl called A. I hadn’t been aware that FP7 has a big crush or has feelings for A. He became very upset last year when A became pregnant by her boyfriend, a chap called B. And FP7 became quite aggressive towards B, he was ‘going to kill B’ and, ‘do away with him’ and we couldn’t understand why. But we now know this is because he feels very jealous and hurt that A is with B. He also feels that C, A’s son is his, and of course he isn’t. But FP7 has got this into his head and I don’t know how we get it out of his head.”*

However, whilst FP7’s main carer does not appear to understand why FP7 should feel as he does for A she does recognise that his perception is being maintained by A:

### **2C-2FP7, paragraph 127;**

*“...as far as I know there is nothing from A towards him, although it would help us all if A could kill this one so FP7 can move on. And she has not been exactly very helpful as FP7 has bought her presents and she has taken these presents so FP7 thinks, you know, that she is responding to him.”*

## **25) Other ambitions, dreams and goals**

These predominantly included things that should be relatively easy for the focus person to achieve. Such things included going to the gym, going to museums, going to football

matches, and going to the cinema. Other things, whilst still readily achievable may require a little more forethought on the part of those supporting the individual. Such things included going sailing, abseiling, white water rafting, obtaining a Duke of Edinburgh Award, having friends and caring for animals. Finally, whilst the remaining desires are not unrealistic, they are likely to require greater input from services. Such things include the desire to move out of parental accommodation, and to gain greater independence. Contrary to the expectations of some people, including members of the Ethics Committee that heard the proposal for this study, none of the focus persons perceived PCP as offering them a 'blank cheque' and the opportunity to 'achieve the unachievable'. That is to say that none of them suggested that they had any desires or ambitions that would be considered unachievable by a non-learning disabled person.

## **26) Fantasy vs. reality**

Despite the fact that no focus persons expressed a desire to achieve something that would not be regarded as too ambitious by the majority population, a number of carers felt that the focus persons they supported were at times living in a fantasy world. For example FP3's carer felt that he was unrealistic in his view of shop assistants as friends:

### **2C-2FP3, paragraph 41;**

*"One thing is his friends. Friends are often just shop assistants... If the shop assistant that he likes – if they smile, he will come back again and consider that they are his friend until he's asked to leave."*

However, the carer did recognise that she bore some responsibility for FP3 having such a belief:

### **2C-2FP3, paragraph 41;**

*"In person centred planning we plan to change that and be allowed to tell the truth to FP3, because now we don't do that."*

Likewise FP7's mother also thought he was, at times, living in a fantasy world:

### **2C-2FP7, paragraph 160;**

*"He's actually very interested in astronomy, world events, climate change, and green issues. But a lot of this is surrounded by fantasy as well so he might get very upset and shout from upstairs, 'Oh, Mum you must come and look at this, we've nearly been hit by an asteroid'. It might only have hit us by several million miles but FP7 is quite upset. He did do wood work for a while in (name of place) and for his first thing he did make a bird box which was a very good attempt. But the teacher said 'right what would you like to make now FP7?' and he said he'd like to make an ark because of global warming tides are rising."*

Whilst on first reading this, one can understand his mother's belief that FP7 is living in a 'fantasy world', when one takes into account the fact that FP7 has been diagnosed as having Asperger's Syndrome, then neither the concern about the asteroid nor the desire to build an Ark are wholly unsurprising. This is due to the fact that when the asteroid was reported, newscasters did talk in terms of it 'missing the world' and it being 'the closest that an asteroid had come to the earth'. Likewise, there has been considerable media coverage in recent months about rising sea levels as a result of global warming and the fact that many parts of the UK are likely to be submerged under the sea if global warming does not slow down. He may well have been told the Bible story of Noah's Ark. If he has been told Bible stories and that people believe in the Bible, then how unrealistic are his views? This aside, even if his and other clients' views are at times 'fantastical', one must ask the question, 'why should people with learning disabilities be any less entitled to indulge in fantasy than the majority population?'

## **2.4.5. Emotions**

The fifth theme that was present in interviews was that of emotion. Emotion was discussed in two different ways. The first was what we have termed 'emotional experience'.

### **27) Emotional experience**

Data was coded as 'Emotional experience' when it provided evidence that a focus person had experienced emotions, whether these were positive or negative. Both focus persons and their carers made references to such emotions. For example, FP2's main carer discussed how FP2 had been 'bored' and 'non-participatory' in one music group. However, she had since changed groups and was reported to 'show pleasure' and to 'really like going'. Similarly FP6's mother reported that he 'really enjoyed' going fishing. FP7's main carer used numerous adjectives to describe the way her son felt about some of his experiences. For example she reports that he 'thoroughly enjoyed' undertaking an animal care programme at college and that he 'absolutely adored' helping out at an animal sanctuary. She further described him as being 'devastated' when he could no longer work there.

One is presented, therefore, with a wide range of emotions being experienced by focus persons in relation to an equally wide range of experiences.

### **28) Emotional expression**

The second way in which emotion was discussed was in relation to its expression. Whilst there is some overlap between the two categories, this second category is more concerned with the way in which focus persons manifested their emotions. One way in which FP2 was thought to express emotions concerned with displeasure or un-happiness about something was by having a seizure. This was seen in the passage (reported earlier) relating to her being taken into various shops such as Morrison's and Peacock's. Although the carer did think it may have something to do with the physical environment, namely the lighting, she also recognised that FP2 having a seizure may have been her way of saying that she didn't wish to go in those shops. Another way in which she was seen to communicate emotion has also been referred to previously, namely her turning her head away from people when she doesn't wish to engage with them, such as on the return of her main carer from holiday. However, she also communicated emotion through laughing and smiling and this was perceived by her main carer as being a sign of her developing a relationship with others:

#### **2C-2FP2, paragraph 592;**

*"She hasn't built up a relationship with that woman, but that is starting because it's-the last time she had it FP2 was smiling and laughing and - so it is in the early stage, 'cause FP2 takes a long time to build up any relationship."*

FP1 was also unable to express his emotions through conversation. However, his father reported that he expressed happiness through 'laughter'.

FP3 who was able to communicate verbally was said to be intolerant of other clients, particularly if they were noisy. This was intolerance was manifested by his aggression;

#### **2C-2FP3**

*"He expresses himself with physical expression. His is not really physically aggressive, but he has an aggressive tone. He often tells people to shut up. If a person is autistic and makes loud noises and uses Makaton FP3 would kick him from the back and shout at him to shut up."*

FP3 was able to express some emotions verbally to the interviewer, as demonstrated in the excerpt below, which may partially explain his 'intolerance' of other learning-disabled individuals,

**FP3, paragraph 71;**

*"(name of clinical psychologist) made an assessment and he found that I scored better than people thought and that my intelligence is much higher than people thought. I am not as daft as other people worked me out to be. Some of them can't help the way they are. And so, I feel much better since then, and I don't feel that I have learning disabilities, I feel very normal."*

FP7, although reportedly verbally aggressive to A's boyfriend, as previously discussed, was not reported to be physically aggressive. He was reported as expressing his emotions in a number of ways as reported by his mother in the excerpts below:

**2C-2FP7, paragraph 160;**

*"It depends what mood FP7 is in. Sometimes you can't shut him up and he gets sort of over-excitable, other times he just goes along and he's in the background and doesn't say anything."*

And,

**2C-2FP7, paragraph 246;**

*"Now interestingly the humming means he's happy and concentrating. If he's humming you know he is happy and he's doing something. If he stops you know he's up to something, he's doing something he shouldn't be usually."*

## **2.4.6. Person-centred planning**

The final super-ordinate theme of the Stage two findings relates to individuals' knowledge and understanding of the person-centred-planning process and to their beliefs as to its potential to assist change in the lives of focus persons.

### **29) Knowledge and understanding of PCP**

Despite the fact that the research team did not meet with focus persons, their second carers or their main carers until after the PCP facilitator had met with them to explain PCP and to ascertain whether they wished to be involved in both the process of PCP and this study, a number of people appeared to be unsure as to what PCP was. In the case of one main carer, this was possibly the result of his poor health and poor memory:

**2C-2FP1, paragraph 192-6;**

**Interviewer**

*"Did you discuss person centred planning with (name of PCP facilitator)?"*

**2C-"FP1**

*"I don't think we did, and to be honest I don't remember. I mean – we had a day at (name of a college) that involved us and he came here. He was there, he came and talked to us there, but that's the only time that I saw (name of the PCP facilitator)."*

Likewise, FP5's main carer appeared to have little understanding or awareness of PCP, in that her response to the question, 'What is your knowledge of it (PCP)?' was

**2C-2FP5, paragraph 24;**

*"Of this? It's like – a bit confusing."*



When the interviewer stated that she was aware that the PCP facilitator had commenced the Person-Centred-Planning process the carer responded,

**2C-2FP5, paragraph 60;**

*"I haven't seen it yet"*

**Interviewer**

*"You haven't seen anything yet? There is nothing at the moment?"*

**2C-2FP5**

*"Nothing there, and last time I spoke to her (FP5's) mum there is nothing there. So whether she is gonna move to a flat by herself – she needs care, she needs somebody there with her, you can't just leave her."*

Not only was the understanding of some carers limited, but the understanding of focus persons was also limited. For example FP2's carer was asked what she thought FP2's level of understanding was in relation to PCP. She replied,

**2C-2FP2, paragraph 142-9;**

*"Very, very limited!"*

**Interviewer**

*"Very limited?"*

**2C-2FP2**

*"If at all"*

Likewise, FP1's second carer was of the view that he didn't think that FP1 understood what person-centred-planning was about.

On the other hand, FP7's main carer felt that FP7 probably had received information, but was unsure of this and of his understanding if any,

**2C-2FP7 paragraph 217;**

*"He (FP7) hasn't talked to me. And I think he forgets. If there was something, if the person-centred-planning was a piece of paper he could put on his wall then he would know about it, but if it's verbal..."*

Only FP3 was able to express a clear view as to what his understanding of PCP was,

**2FP3, paragraph 35;**

*"That it will help me with my future and guide me in the right direction, make sure I do the right thing in my life, help me when I get stuck."*

Although FP3 clearly recognises that PCP is related to his future, the use of the phrases, 'right direction' and 'right thing' suggests more that he believes it is to be imposed upon him than it is a process by which he is able to take greater control of his life.

### **30) Potential for PCP**

This, the final sub theme is concerned with references to how PCP might facilitate change in the lives of focus persons. As with 'knowledge and understanding', the beliefs expressed by both carers and focus persons as to the likely efficacy of PCP as an agent for change varied.

For example, the main carer of FP1 was somewhat negative as can be seen from the following extracts:

**2C-2FP1, paragraph 190;**

*“Well to be honest it didn’t seem practical down to anything. It is working from a theory and I don’t think there is much practice in it.”*

He later gives the interviewer an insight into his perception of why PCP may not act as an agent of change:

**2C-2FP1, paragraph 213;**

*“...since FP1 has done nothing in his life other than being here with us then how can he know what it is to have a choice, so how can he choose when he knows nothing about choices, you know if you talk to him from that point of view he’s got no experience from anything else, so how can you make him choose anything is it? This is what people don’t seem to think about.”*

He also appeared to think that focus persons would choose unrealistic aims:

**2C-2FP1, paragraph 225;**

*“I think you’ve got to be a lot more – because if you asked these people, there are three or four people there, I don’t want to be negative – one would be an entertainer or what she’d done down in (name of town) with animals... they didn’t know what they wanted to do... and there is too much time wasted on this.”*

FP1’s second carer however did feel that PCP might benefit FP1, saying:

**2SC-FP1, paragraph 65;**

*“Well basically, if anything, it will his life style isn’t it? Anything to improve his life style, anything to improve his quality of life and most important thing of all in FP1’s case is that his parents are elderly and in a not so distant future his parents won’t be around and he will need tremendous support. It is gonna be like getting off a wall isn’t it, so I think should be done now ... start building up for what’s to happen in the future so creating more independence.”*

FP1’s second carer also thought that if the plan were documented, the very fact of its existence could actually help facilitate change:

**2SC-2FP1, paragraph 125;**

*“Yeah, I think it could happen, I think basically if you have a proper centred plan in front of us now, I’m sure experts or professionals would look at that...”*

FP2’s main carer also saw some benefit in PCP in so far that she felt that if there was a plan in existence it would mean that the activities that FP2 enjoyed would continue, even if she (2C-2FP2) was no longer the main carer. This view was shared by FP2’s second carer who stated:

**2SC-FP2, paragraph 59;**

*“Um, what to say? I just think it’s nice to have it, everything sort of pooled together from what you know about FP2 so you’ve got it like a sort of central information um, and hopefully, you know for all the people that come into contact with FP2 that will, that will be a benefit to her and you know, hopefully, you know, people will see through that what FP2*

*enjoys doing – they will continue you know – into the future really, I don't know, can't be more specific than that really."*

Additionally, FP2's main carer, although she wasn't clear how PCP might otherwise benefit FP2, did appear to be in favour of the process:

**2C-2FP2, paragraph 634;**

*"Well, just about discussing things it might come out, I don't know but it might come out that, 'Oh yes! FP2 would benefit from that.' You can only give us a trial, as I say it's only over the years that she's had had all that fun-fair experience or simple things like being out in the rain, or the cold, or the heat, getting sun-burned, you know they are all things that happen you know, ... you know, they are all experiences that everybody does you know – can't tell until it happens can you?"*

PCP was seen in a more positive light by FP3's carer who was 'shocked' that it hadn't been done before. She appeared to recognise the value of formal and informal carers working together and felt that PCP was likely to benefit her son:

**2C-2FP3, paragraph 29;**

*"For me, for this to work, it is important the family and carers have meetings to work. I think in FP3's case he has issues with fears and he does have valid aims for the future, but they can be unrealistic. When people try to help FP3 – I think that when males try something he's got really angry, like with his case manager, and then he says he doesn't want to deal with FP3. The team and family need to go on and his family needs help to go on. So person-centred-planning could help deal with some harsh realities, when you are realistic with people. The support you get with this will help FP3 be independent..."*

FP3's carer also thought it may be beneficial in so far as it might help him with distinguishing between 'friends' and people providing services, such as shop assistants and that it would help him gain more independence by enabling him to move out of his parents' house.

FP5's main carer hoped that PCP would enable FP5 to:

**2C-2FP5, paragraph 36;**

*"...sort of speak up for herself hopefully and not for us to tell her what she has to do (because)...FP5 likes to sort of, she wants to be told ..."*

Likewise, FP7's carer stated that she hoped:

**2C-2FP7, paragraph 43;**

*"...that this PCP will help push things along a bit in relation to FP7's progress".*

FP3, although initially stating:

**2FP3, paragraph 47;**

*"I don't think that person-centred planning could help me."*

Then went on to express the view that he hoped that the PCP facilitator would be able to provide him with advice about personal and intimate relationships.

FP6 thought it would make changes to his day time activities so that he could undertake work with animals, pottery, woodwork and painting.

FP7, who had previously stated his desire to undertake numerous activities, did not refer to those activities when asked what he would like PCP to do for him. Instead, he replied:

**2FP7, paragraph 171;**

*“I’d like a family and to get a job and to live in a mansion. I would like to learn about money, ‘cause then I could go out more. I’d like to have friends, not just animal friends. I’d like for other people to see what I can do to help more people to do more things.”*

He did not, however, express a view as to the likelihood of such things occurring, or the extent to which they may be facilitated by PCP.

## **2.5. Summary of Findings**

Overall, despite the study only being concerned with six focus persons, it demonstrates that they experience a variety of services of varying quality in the eyes of the focus person and / or their carers. An overview of such provision has been provided in the outline of the first super-ordinate theme. This theme also provides us an overview of some of the factors that are perceived as being likely to limit the development of independence in the focus person.

In the penultimate theme, ‘aspirations’, we outline some of the aspirations that the focus person, or their main carer, expressed in relation to their future. In the ultimate theme, people discussed their understanding of the person-centred-planning process and whether or not they felt that PCP was likely to help people achieve those aspirations. Although most people saw PCP as being likely to help people become more independent or achieve aspirations, very few people gave any view as to how they thought PCP might actually help a focus person achieve their aims.

The remaining super-ordinate themes, ‘external filters’, ‘internal filters’ and ‘emotions’ raise issues that interact with the focus persons’ current situation and may either help or hinder in the process of focus persons moving on from their current point in life towards their aspirations. We would suggest that each of these issues needs to be addressed within the person centred planning process in order that focus persons progress towards their aspirations.

Stage 2 of the study has presented snapshots of the, then current, situations of several individuals prior to their embarking on PCP. Some of the factors that may help or hinder their self-actualisation have also been identified. Stage 3 of the study, discussed below in Part II of this report, focuses on the lived experiences of these focus persons, their carers and the PCP facilitator in order to present a fuller picture of the PCP process “in action”.

### 3. Stage 3

Stage three of the project was comprised of second interviews with the focus persons and carers who participated in Stage two of the project. Once these interviews had been undertaken, transcribed and analysed, a second interview was undertaken with the PCP facilitator. Below follow the method of data collection and analysis used in this Stage of the study and reports the findings of Stage 3 of the research project.

#### 3.1. Data Collection

The collection of data for Stage 3 of the study was predominantly undertaken by Ms. Iliana Sardi and Dr. Rachel Davies. Mr Robert Jenkins undertook one interview, that of FP6, due to FP6 requesting a male interviewer.

##### Proposed timescale for the completion of Stage three of the study:

October – Nov 2006	Undertake follow up interviews (IS; RD)
Dec 06 – Jan 07	Transcription and data analysis (IS; RD; PNW)
Feb 2007	Update literature review (PNW)
Feb – March 2006	Produce final report. (IS; RD; PNW)
April – 2007	Submit final report to funding body (PNW)
April – July 2007	Disseminate findings to wider audience through journal articles, conference presentations, etc (IS; RD; PNW)

Although the follow-up interviews were collected and analysed as per the proposed timescale, the production of the final report was delayed due the principle researcher experiencing long-term sickness. This has resulted in a three month delay.

Data was collected in the same manner as in Stage 2, namely each participant was interviewed using a semi-structured interview which was tape recorded with the individual's consent. Additionally, a structured questionnaire, adapted from those used by Robertson et al. (2005) was administered to each participant. The data obtained from the structured questionnaires are provided in tabular / graphic format in *APPENDIX 2*.

#### 3.2. Data Analysis

As with Stage 2, the data collected during the semi-structured interview process of Stage 3 was analysed using Interpretative Phenomenological Analysis (IPA). Analysis was essentially undertaken as described in Stage two. The only difference to that process was that in Stage 3, the research team sought both the themes that had been present in the Stage 2 interviews; and new emergent themes. However, as can be seen by the presented findings, none of the themes that were present in Stage two emerged in Stage three.

Data collected from the structured questionnaire was entered into SPSS and is presented in *APPENDIX 2*.

#### 3.3. Findings

##### The person-centred planning facilitator

Data collected via interviews with the Person Centred Planning Facilitator are discussed in section 4 of Part II, after the findings relating to the focus persons and their carers.

##### Focus persons, main carers and second carers

A total of eighteen new themes were identified in Stage 3. Some of these were sufficiently similar to be merged into other themes which resulted in eight sub-themes. The research team then sought to place these into a coherent order and to describe super-ordinate

themes. Four super-ordinate themes emerged as outlined in *Table 2*, below. These themes are discussed below.

### **Identification of person providing the quotation**

As in Stage two of the study we have used codes rather than names to identify individual participants in order to preserve the anonymity of participants. Where quotations are provided to substantiate a theme they are preceded by a code, e.g., '3FP' or '3C-3FP2'. This code simply signifies the type of participant making the comment. All codes commencing '3C-' signify that the extract is taken from an interview with the focus person's main carer during Stage three of the study. A person was classed as 'main carer' if they were identified as such by either the focus person or the MDT. All codes commencing '3FP' signify the fact that the extract is from an interview with a focus person during Stage three of the study. Where the research team was unable to communicate sufficiently with a focus person to obtain their consent to participation in the study the focus person was not interviewed. Rather, a second carer was identified and their views were sought in addition to those of the main carer. Where the quotation is taken from an interview with a second carer during the third Stage of the study it is prefixed by, '3SC-'.

**Table 2 New themes emerging from the interviews with the focus persons, main carers and second carers during Stage 3 of the study**

<b>Super-ordinate Themes</b>	<b>Sub-themes</b>
1. Implementation of PCP	<ul style="list-style-type: none"> <li>. How PCP had progressed to the date of interview</li> <li>. Frequency of meetings</li> <li>. The person's view of planning meetings</li> <li>. Level of involvement in PCP</li> <li>. Suggested changes to the meetings</li> <li>. Overall view of the process</li> </ul>
2. Challenges to overcome	<ul style="list-style-type: none"> <li>. Barriers to implementing PCP (including anything mentioned by the carer that has negative impact on the focus person or the efficacy of PCP)</li> </ul>
3. Experience of focus persons	<ul style="list-style-type: none"> <li>. Any changes in the focus person's life resulting from PCP and the main benefits of PCP for the focus person</li> </ul>
4. Suggestions for improved efficacy	<ul style="list-style-type: none"> <li>. Suggestions for improved efficacy</li> </ul>

### **3.3.1. Implementation of PCP**

This super-ordinate theme relates to such things as the level of progress that participants felt had been made with PCP at the time of the second interview, what participants felt about the PCP meetings and participants' views on the overall process. The findings of each sub-theme will be outlined and direct quotes used to support the asserted findings.

#### **1) How PCP had progressed to the date of interview**

Given the period of time that had passed between the initial interviews (Stage 2) and the second interviews (Stage 3), the research team thought that participants would report progress. However, not all participants did. Additionally, the interviews demonstrated that some people were more aware of the progress of PCP than others. This is demonstrated in the extracts below.

One main carer (3C-3FP1) appeared confused as to when PCP had commenced and what progress, if any had been made:

**3C-3FP1, paragraph 45;**

*“Well I don’t know, I think there’s a woman gone down there that is trying to teach him this computer thing, but he (FP1) never mentions it now, so I don’t know how much is going on.”*

Such confusion in this particular case was possibly due to 3C-3FP1 having known the PCP facilitator in his other role, that of an advocate, prior to the PCP process commencing. It may also be due to the individual’s age and health.

The remaining participants who discussed this subject said that some PCP meetings had taken place. In some cases they also told us what the meetings had been concerned with:

**3C-3FP2, paragraph 36;**

*“...collating all the different information about 3FP2, from the parents and where 3FP2 lives and all the information has been collated and has been sent back to (PCP facilitator) and we are now waiting for a final outcome.”*

Another individual, (3FP9) stated that she had attended three ‘circle of friends’ meetings. However, she was unable to outline the subject of those meetings and, whether in fact, they attended as a result of the PCP process.

Other participants, although they stated that they had attended PCP meetings, also stated that little progress had been made. Moreover, they suggested that they had had little contact with the PCP facilitator:

**3C-3FP2, paragraph 20;**

*“And then, we haven’t had any contact for 7 months. Em, and 3FP2 is having a plan set up... but nothing has happened yet.”*

**3C-3FP7, paragraph 63;**

*“... there was just complete silence. I could not even get in touch with him (the PCP facilitator) as I had lost his mobile number and the only e-mail address was not getting through. In the end I sent an e-mail to (name of social worker) to say, ‘Look do you know where (PCP facilitator) is because I need this information’...”*

3C-3FP7 had wanted to contact the facilitator because he was under the impression that the facilitator had seen FP7 elsewhere and given him a plan:

**3C-3FP7, paragraph 69;**

*“...now it transpires that he (PCP facilitator) may have gone to see FP7 at (name of place) and given him this plan which I don’t know anything about.”*

## **2) Frequency of meetings**

A number of participants discussed this sub-theme. In particular, the carers of a number of focus persons commented on the frequency of meetings. As can be seen from the extracts below, the frequency of PCP meetings was quite variable:

The person who reported the most meetings was FP9. FP9 had attended three meetings and an additional review meeting was planned for December 2006.

However, other persons commenting on the frequency of meetings had experienced fewer than FP9. For example, 3C-3FP6 stated that although FP6 had had his first meeting in

May 2006, there had not been a second meeting at the time of the 2<sup>nd</sup> interview in October, some five months after the initial meeting:

**3C-3FP6, paragraph 61;**

*"But we didn't have the second meeting. We were supposed to meet in August but (name of person who works with FP6) couldn't make it so it didn't happen and (name of PCP facilitator) was supposed to get in touch to re-arrange it but we haven't heard anything yet (Mid October 2006)."*

3C-3FP2 suggested that FP2's meetings had occurred at six monthly intervals:

**3C-3FP", paragraph 30;**

*"We've had two meetings in a year."*

3C-3FP1 suggested that 8 months had passed since the last meeting:

**3C-3FP1, paragraph 41;**

*"From the last time we met, it was quite a few months ago. I think it was February more or less, when we first met, since that time, till now, (Mid-October 2006) has (name of PCP facilitator) seen 3FP1?"*

FP3 appeared to have experienced the least number of meetings of all the focus persons participating in the study. At the time of the second interview in October 2006 he had not experienced an official PCP meeting for 10 months. Rather, he had engaged in a number of 'unofficial' meetings with the PCP facilitator at the day centre he attended. These occurred as a result of the PCP facilitator attending the day centre to see other clients on a monthly basis. If the facilitator had time left at the end of his visit he met with FP3 as well.

### **3) The person's view of planning meetings**

As with other aspects of the PCP process, participants' views of PCP meetings varied considerably. Two people (3C-3FP2 & 3C-3FP6) said that overall the meetings were 'good', but did not expand on this. 3C-3FP3, however, gave reasons why she felt the meetings were 'very good':

**3C-3FP2, paragraph 17;**

*"I think that PCP meetings are very good because they are the only thing that there is in place at the moment. It brings people from different backgrounds together on the same table and gives 3FP2 the opportunity to speak to them all at the same time. Some times it is difficult to organise a bunch of people from different specialities and PCP has given the opportunity to do that and for 3FP2 to raise his voice knowing that people are listening to him, to what he wants. Also it gave the opportunity to 3FP3 to sum up nicely all his hopes and fears and see what is realistic and not."*

**And at paragraph 61;**

*"They are very good, they are helping improve the participant's life."*

In addition to some participants saying that the meetings were good, a number of participants (3C-FP7 & 3FP9) commented positively on the fact that the focus person had had the opportunity to choose who they wished to attend the meeting and that the PCP facilitator had tried to involve these people.

However, not everyone was wholly positive about the meetings. Some participants had mixed views on the meetings, however, they did not enlarge on the reason they held such views:



**3SC-3FP2, paragraph 5;**

*“Neutral, a mix of good and bad, no opinion either way.”*

Others with mixed views gave reasons why they held such views. For example, 3FP6 when asked if he felt in charge of the meeting answered in the affirmative. However, he went on to say that;

**3FP6, paragraph 527;**

*“the meeting was too long.”*

Similarly, although 3C-FP7 commented positively about FP7 choosing who was to be invited to the meetings, she also commented that the meeting had focused on leisure to the exclusion of other issues that were perceived to be more ‘significant’ in 3FP7’s life. This resulted in 3C-FP7 concluding that the planning meetings were:

**3C-FP7, paragraph 428;**

*“Bad, they have a limited impact on the participant’s life.”*

Some participants were not willing to say anything positive about the meetings:

**3C-3FP1, paragraph 208;**

*“Very bad- they are not having any impact.”*

#### **4) Level of involvement in PCP**

Few people discussed this sub-theme directly, however, as has been discussed under the sub-theme ‘*Participants’ Views of meetings*’, some people (3C-FP7 & 3FP9) commented positively on the fact that the focus person had had the opportunity to choose who they wished to attend the meeting and that the PCP facilitator had tried to involve these people. Similarly, 3C-3FP2 was appreciative of the fact that PCP had given FP2 the opportunity to be listened to in the knowledge that people were listening to her, and to what she desired.

FP6’s carer stated that FP6 had some involvement in the meetings. On being asked, ‘who decided who came’, they replied:

**3C-3FP6, paragraph 19;**

*“Oh, FP6 did. He said who he wanted to come and I think that was right.”*

However, whilst this may have been the case, it is not clear as to the level of involvement FP6 had, as when asked, “did you feel in charge of the meeting?” answered, “yeah” yet later when asked, “Was it the PCP facilitator that was in charge of the meeting, was it you or the PCP facilitator?” FP6 then replied,

**3FP6, paragraph 110;**

*“Em, PCP facilitator”*

However, although some focus persons were involved to some extent in the PCP meetings, 3C-3FP2 also suggested that activities that had been suggested at PCP meetings were not necessarily those of the focus person, but those of the facilitator and a service provider:

**Interviewer**

*“And who made these suggestions?”*

**3C-3FP2, Paragraph 150;**

*"I think it was (name of PCP facilitator) and (name of social worker) and (another name)...saying, 'oh yes PCP says FP2 should join this activity,' but it's no good, if there's no money then you should say there's no money in the first place..."*

Whilst focus persons or their carers who expressed a view felt that the focus persons had been involved it was felt by some carers that other people had been excluded from PCP.

For example, FP1's second carer neither knew what person centred planning involved for FP1 nor had he been involved in the process:

**3SC-FP1, paragraph 88;**

*"I mentioned it, I mentioned it to my line manager the last time you (the interviewer) came about this chap calling and all that, right, but I haven't heard anything at all since."*

A further example is provided by FP6's carer who suggested that the time of the meeting (day time) precluded the attendance of FP6's siblings, with whom FP6 had a strong relationship:

**3C-3FP6, paragraph 85;**

*"I don't think so and they live away. It would be different if the meetings were in the evening, but not in the day."*

Additionally 3C-3FP7 felt she was not involved in things:

**3C-3FP7, paragraphs 85-93;**

*"Yes but I am being kept at such a distance from it."*

**Interviewer**

*"Because you are not being kept informed about what is happening?"*

**3C-3FP7**

*"Yes that's it and it's partly political correctness for treating adults like adults, but of course with people like FP7 you don't really get the feedback from them about what is happening."*

Even FP9 and her carer who had been positive about FP9's involvement commented negatively about not always knowing what was happening:

**3C-3FP9 / 3FP9, paragraphs 579-591;**

**3C-3FP9**

*"And if you miss a meeting you don't always know what's going on, who is taking responsibility for things, no you don't."*

**3FP9**

*"My Dad went and he didn't really know what was going on as it was his first meeting"*

**Interviewer**

*"He didn't get to see what was going on from the previous meeting?"*

**3C-3FP9**

*"There was nothing written down."*

## **5) Suggested changes to the meetings**

As might be expected, given the various views participants held on the planning meetings, whilst some people said there was no need for any changes others felt a number of

changes would be beneficial. In addition to saying that nothing needed changing in relation to the meetings 3C-3FP3 was positive about the facilitator:

**3C-3FP3, paragraph 23;**

*“(Name of the PCP facilitator) is a very good facilitator. There is nothing that I’d like changed. (Name of PCP facilitator) has done a lot of running around. There is no administrative support and that really helped a lot.”*

Similarly 3C-3FP7 felt nothing needed to be changed in relation to the meetings. This did not, however mean she was satisfied overall:

**3C-3FP7, paragraph 435;**

*“The problem is not with the meetings, but with implementation.”*

Changes that were suggested in relation to the meetings included the following:

**3C-3FP1, paragraph 215;**

*“More common sense in assessing people’s abilities and ambitions.”*

**3C-3FP2, paragraph 86;**

*“Well, I hope that there will be regular meetings, that the plan will be updated, perhaps on an annual basis, ‘cause things come to light.”*

And,

**3C-3FP2, paragraph 189;**

*“Not to be so far apart.” and, “To set more realistic goals.”*

**3C-3FP6, paragraph 211;**

*“meetings available locally”*

**3FP6, paragraph 565;**

*“less meetings”*

However, the view of FP6 was the opposite of another participant who suggested that a beneficial change would be:

**3SC-3FP2, paragraph 201;**

*“To have more meetings – frequency is the problem” and to know “who is responsible for changes?”*

## **6) Overall view of the process**

This sub- theme is concerned with comments about the overall process that are not outlined elsewhere in the findings, for example in ‘frequency of meetings’ or ‘views of the planning meetings’.

Some individuals felt the process as they had experienced it was at least to some extent positive as can be seen from the following extracts:

**3C-3FP3, paragraph 35;**

*“I think the main benefit is an arena that brings together everybody.”*

FP7 stated that PCP was a ‘good thing’ when asked by the interviewer whether or not he felt PCP was a good thing.

FP7's carer also felt that there had been some positive aspects of the process for FP7, stating:

**3C-3FP7, paragraph 81;**

*"I think the way he (PCP facilitator) came and spent the day with us was a good idea, in spite of transport difficulties. I mean FP7's social worker really hasn't got a clue how FP7 ticks. She doesn't really understand how FP7 ticks, how FP7 thinks and what FP7's background is and so (name of PCP Facilitator) I think has got a much better understanding now cos he has spent the time, that's always the problem, time."*

However, FP7's carer also felt that the planning process had some negative aspects, such as the fact that it was seen to unreasonably raise the focus person's expectations:

**3C-3FP7, paragraph 45;**

*"And then if it can't be fulfilled he feels let down... People with learning difficulties often believe everything you say and then when it doesn't happen it causes families lots of problems because they are constantly nagging, 'I was told I could have this, when is this going to happen, when am I going to get...' And then you find that the person you know has instigated all this has moved on, Social Services don't have any money to do it – I think it's wishful thinking."*

In addition to perceiving PCP as unreasonably raising focus persons' expectations, 3C-3FP7 suggested that PCP was little more than a paper exercise:

**3C-3FP7, paragraph 142;**

*"I was left thinking that this (the pilot PCP project) was something of a shop window exercise – that's what I think."*

And,

**3C-3FP7, paragraph 174;**

*"Here is this feeling that it's all about chasing pieces of paper and adapting to legal requirements and not the social aspects."*

These issues resulted in 3C-3FP7 expressing the overall view that:

**3C-3FP7, paragraph 413;**

*"All I can see is that this is another project that is going to waste everyone's time and then not achieve anything."*

Most participants had mixed, though predominantly negative attitudes towards the process as they had experienced it. This can be seen from the following extracts.

3C-3FP2 explains how their initial view towards the PCP process had changed, albeit to one that is not wholly positive:

**3C-3FP2, paragraph 79;**

*"Well, I expected it to be done. I was very sceptical to start with. I thought it will be a lot of hog wash to start with and I said, 'Oh God, it's just giving somebody a job', but the more I thought about it I realised that FP2 does actually need to have something written down. I would have thought it would have been up and running by now but then I'm...you know, em, yeah, I did think we would have heard from him by now."*

3C-3FP2 also expresses the view that the process does not take account of practical issues such as finances:

**3C-3FP2, paragraph 130;**

*"...I think they came up with these suggestions at one of the meetings, like saying, 'oh, 3FP2 likes music perhaps she would go to an operatic meeting', or you know join some group like that, but it's not practical, there is no money. 3FP2 struggles with money, so although they made these suggestions, it's not practical..."*

Despite 3C-3FP2's view that PCP is not always practical, she did feel that as a process it had something to offer, namely a method of ensuring consistency:

**3C-3FP2, paragraph 168;**

*"I think it's an inside knowledge into FP2's life, to see inside FP2's head, through me, because FP2 has no, I mean, while I'm here it's not a problem, I'm going to speak on behalf of FP2, but I mean I'm not here all the time and at any point FP2 could be left without me, and so, therefore, if I can put down on paper as much as I possibly can it must help FP2 if I wasn't here."*

3C-3FP2 also described a way in which the plan had it been completed might have had practical value for FP2:

**3C-3FP2, paragraph 73;**

*"...recently FP2 was at hospital and would have been really nice if she could have had it (her plan) then, because it's things like, FP2 doesn't like being comforted, and she had an operation and of course the nurses were doing their best but they were comforting her, but the more they were comforting her the more she was crying... you know if they'd had the folder and they read it they would have realised that if she is upset she is best left to be alone, so it would have helped you know, it would have been nice to have it like that."*

Some what forthrightly, 3C-3FP1 expressed the view that PCP is of no value:

**3C-3FP1, paragraph 68;**

*"...(laughs) alright I'm gonna say it, because that's my honest opinion. They waste so much time, doing things that are unnecessary and of no use at all."*

3C-3FP1 later gives some reasons for his somewhat less than positive view of the PCP process:

**3C-3FP1, paragraph 83;**

*"...everything seems to take so long...as far as I know we have achieved NOTHING with person centred planning for FP1, or if we have, I am not aware of it. I am aware he was gonna be, he was going to use the computer, but by now there should be some results or it should be recognised it is not practical and STOP IT YOU KNOW. IF HE CAN'T DO IT WHY WASTE MONEY, TIME AND TRAINING TO GET HIM TO DO IT (use a computer)..."*

Another view expressed by the same carer was that such interventions had come too late in some service users' lives and that more should have been done previously:

**3C-3FP1, paragraph, 169;**

*"Well, I don't know you see, the thing is, I think, basically, it's been left too late... You know, they don't have to be dull, they don't have to be anything, if they are not taught, they never learn, and the same applies to FP1, that was because (name of service) did such a bloody mess of everything in those days."*

However, despite such strong negative feelings towards PCP, he felt it had to continue as:

**3C-3FP1, paragraph 134;**

*"...because there's got to be someone there...who eventually has to pick up and take over when I am no longer able to do it."*

And,

**Paragraph 144;**

*"Well, it's the only thing that can offer as far as I can see, because what else have you got which can cover it (planning of care), you know, what is in the system? If it's not you or person centred planning, eh, if that isn't there doing it what is doing it? Or who is doing it?"*

### **3.3.2. Challenges to overcome**

#### **7) Barriers to implementing PCP**

This super-ordinate theme outlines participants' (carers or focus persons) views of barriers to implementing person centred planning or the efficacy of PCP.

One view was that too much was expected of the PCP facilitator and that politicians were not necessarily committed to the process:

**3C-3FP1, paragraph 144;**

*"...(name of the PCP facilitator) takes only a couple of days a week, in any case and when you consider it, if he sort of covered the whole of local authority, you know the, what they expect is just unbelievable, what they expect of these people, well I don't know if they expect it or if it is just some politician is putting something in, and just in case to cover his own back, to say, "well, we're doing something about it, you know we've got so many schemes done by him."*

The same carer also felt that people working in services lacked practical experience in implementing services:

**3C-3FP1, paragraph 186;**

*"You know, and this is the thing, because I don't care who it is, they can be as clever and as bright as they like on theory, but if they got no practical experience they fall down...and this is what we find with the tremendous amount of social service people, they got all the theory in the world, they got no practical experience and very few practical suggestions..."*

For 3C-3FP2, there were three major obstacles to achieving change via PCP. The first obstacle was the PCP facilitator. When asked, 'what do you think the main problems have been in trying to implement PCP for this participant so far?' 3C-3FP2 replied:

**3C-3FP2, paragraph 201;**

*"Lack of communication with the PCP facilitator."*

The second obstacle was a perceived lack of direction:

**3C-3FP2, paragraph 214:**

*"There was no direction, no goal!"*

The third thing considered by 3C-3FP2 to be an obstacle was finance:

**3C-3FP2, paragraph 130;**

*"...but it's not practical, there is no money, FP2 struggles with money, so, although they made these suggestions, it's not practical."*

Although FP3's main carer had been positive about the PCP meetings and the PCP facilitator (as noted above), they felt there were a number of barriers to FP3's expressed goals being met, namely; limited employment opportunities, limited choice in accommodation and that the goals which were set were 'mainly unrealistic'. However, when asked the question 'what do you think the main problems have been in trying to implement PCP for this participant so far?' 3C-3FP3 replied:

**3C-3FP3, paragraph 84;**

*"The waiting time for FP3's plan, that many specialities were involved with busy lives and absence of advocacy."*

Another barrier to FP3's goals being met was felt to be his fear of dying as it was felt that this prevented him leaving home. He has a medical condition and is fearful that if he leaves home and there is a problem there will be no-one to help him.

FP6's main carer suggested that one of the main barriers to achieving change for FP6 through PCP was that FP6 does not like to consider the future and unwillingness on FP6's part to discuss certain issues:

**3C-3FP6, paragraph 37;**

*"If he doesn't like something he will just stop saying anything. Like when he had come back from (name of place) and I had to tell him a friend of ours had died and he just said, 'so we won't talk about that then.' That was that really. He lets you know when he doesn't want to talk."*

Additionally, 3C-3FP6 when asked, 'what do you think the main problems have been in trying to implement PCP for this participant so far?' stated:

**3C-3FP6, paragraph 224;**

*"FP6 tends to go along with things and does not make any suggestions of his own."*

Another issue mentioned by 3C-3FP6 is a lack of resources and the fact that when staff change others do not necessarily carry out activities that had previously been undertaken:

**3C-3FP6, paragraph 55;**

*"He'd like to do more fishing...The person who used to take them at (name of place) had left and they don't go any more and he used to really enjoy that so we spoke about that (at the PCP meeting). But nothing has happened with that yet as I don't think they've got the staff."*

**And at paragraph 193;**

*"One thing that FP6 used to really enjoy that again stopped happening because the member of staff who organised it left the service was going to football. He would go with four or five others to see Cardiff City and he really enjoyed it but when the organiser left the (name of the day service) it stopped happening."*

Lack of resources, both in relation to finance and persons able to support focus persons was also perceived to be a 'stumbling block' for FP7:

**3C-3FP7, paragraph 31;**

*"It's the implementation of these things that never seems to happen. You know is there funding to do this, is there someone to give one help? Because so far all we have received is a series of telephone numbers to contact people like (name of an organisation that runs activities for people with intellectual disabilities). So, in effect we've still got to do it for him and I think that lack of practical help is the stumbling block.*

Additionally, although 3C-3FP7 had commented positively on the fact that the PCP co-ordinator had spent time getting to know FP7, she suggested that the PCP facilitator had not actually facilitated change:

**3C-3FP7, paragraph 31;**

*"If I had put in the hours that (PCP facilitator) had put in on the internet, doing this for FP7, I could have done it in half the time and still come up with the answers."*

3C-3FP7 also raised concerns about an apparent lack of communication between the PCP facilitator and Social Services:

**3C-3FP7, paragraph 117;**

*"I think, and it is only an intuitive thing – I have no evidence to say this it is just an intuitive thing – Social Services want to keep apart from PCP. And by doing so it means the two are not communicating..."*

This fact concerned 3C-3FP7 as s/he believed that Social Services should play an important role in PCP:

**3C-3FP7, paragraph 129;**

*"The success or failure of PCP depends on their (Social Services) will"*

Another factor that 3C-3FP7 felt was a barrier to achieving change through PCP was her belief that service providers did not actually know their clients well enough to provide appropriate services

**3C-3FP7, paragraph 174;**

*"You know they are called a 'Social service' but they are not spending enough time getting to know the characters they are dealing with. If they spent a bit of time, a day out or even a half day they would get to know the people involved and would get a far better feeling of what was needed for them."*

A further perceived barrier to 3FP7 achieving change through PCP was the fact that they lived on the border between England and Wales:

**3C-3FP7, paragraph 96;**

*"...being near a border you do get penalised as you get details of things that are a long way away in Wales but nothing for something that happens to be in England but is only two minutes down the road."*

A final barrier referred to by 3C-3FP7 related to the facilitator. When asked what were felt to be the main problems in implementing PCP for FP7, in addition to referring to the raising of expectations and the lack of a plan 3C-3FP7 stated:

**3C-3FP7 paragraph 450;**

*"The facilitator does not have transport which limits rural visits."*



3C-3FP9 felt that bureaucracy or inefficiency amongst Social Services was one of the things that prevented change. This was experienced in the form of various meetings that sought information already provided:

**3C-3FP9, paragraph 34;**

*"When I had social workers here for the meetings the questions had been answered. Instead of going through it once they went through all the questions again and again driving me mad. They keep going over and over again."*

Bureaucracy and the need to rely on services was also an issue in obtaining direct payments:

**3C-3FP9, paragraph 60;**

*"...we've still got some things to sort out with direct payments. We've got to set up insurance and a contract now but it's been delayed with people's holidays and illness so there has been some delay in getting it sorted."*

3FP9 herself felt that social workers could be an obstacle to her achieving change through PCP as they were not interested in PCP nor did they always make plans accessible to service users, unlike other services which the focus person used:

**3FP9, paragraphs 620-630;**

**Interviewer**

*"I remember last time you said about trouble with social workers. Do you think they are interested in PCP?"*

**3FP9**

*"No they're not. (Name of PCP facilitator) has invited (name of social worker) on the 7th December. And I'm not looking forward to him/her coming because of what will be discussed because s/he won't listen to what's going on...The care plan for instance the bits about independent living, instead of putting it all on one piece of paper they put it on seven pieces of paper...Not worded at (people with a learning) disability reading skills. All of these here in the folder for (people with a learning) disability from work have got bigger writing and they're all done for the Disability writing Act (Disability Discrimination Act, 1995 as amended). And at leisure activities people have problems with writing there so they do things bigger there."*

### **3.3.3. Experience of Focus Person**

#### **8) Any changes in the Focus Person's life**

This super-ordinate theme is concerned with any changes in the focus person's life resulting from PCP and reports the main benefits of PCP for the focus person.

A number of persons reported some positive changes having occurred during the period of the trial, though the extent of such changes varied. Additionally, even where some positive change had been experienced this did not preclude focus persons or their carers from being disappointed at not having experienced more change.

For FP3, one direct benefit of his meeting with the PCP facilitator was having asked the PCP facilitator to arrange a meeting between FP3 and a clinical psychologist the PCP facilitator arranged this. Although FP3 wanted the content of the meetings he has with the psychologist to remain confidential he did say that they were of benefit and had:

**3FP3, paragraph 61;**

*"helped me move on with my life. It also made me a little bit more confident."*

He also mentioned the fact that as a result of the PCP meeting his father had taken him to be assessed as to whether he would be able to obtain a driving licence. He was told that he was not capable of driving but although disappointed at this outcome FP3 was glad to have had the opportunity to be assessed. However, some things that were discussed at the PCP meeting had not improved for FP3 as can be seen from the following extracts:

**3FP3 paragraph 48;**

*"Yes, we discussed about my education, but unfortunately as I said earlier the college will not give me extra courses due to limited resources."*

Additionally,

**3FP3, paragraph 75;**

*"...I still have fears about leaving home. This is an aspect that it hasn't helped with as much. And then that I don't have an advocate anymore."*

And,

**3FP3, paragraph 55;**

*"And I have asked for extra hours to my job."*

FP3's carer also felt that the process had been of benefit, though such benefits were not necessarily concrete, but possibly necessary precursors to such change:

**3C-3FP3, paragraphs 88-94;**

*"FP3's understanding that an independent lifestyle is necessary for him and his parents; he has been able to talk over his fears. A bit like cognitive therapy; FP3 can choose to really voice his feelings. To ask freely with professionals to help him about how he can maintain relationships and to understand that his own home could be good for him."*

FP6's carer felt that FP6 had benefited during the PCP process to a small extent. However, the benefit had been arranged by someone already working with FP6 and it is not clear whether the benefit would have been obtained in the absence of the PCP process:

**3C-3FP6, paragraph 49;**

*"And then there was this thing about (name of celebrity). FP6 really loves him, always has, and he said about this and it was decided that FP6 would write to him and that (name of support worker) would help him do this; they would write and ask for a photo... So (name of support worker) sorted this out and FP6 got a really nice letter back from (name of celebrity) saying that he was sorry not to have replied sooner and that he was really busy and putting a photo in and wishing FP6 a happy birthday."*

FP6's carers were also going to set up a bank account for FP6 as a result of a conversation with the PCP facilitator:

**3C-3FP6, paragraph 165;**

*"We give him money all the time right through the week and that's how it's been. But (name of PCP facilitator) said it would be good for FP6 to learn that if there was nothing there (in his bank account) that he couldn't do something. He'd learn to realise about money, so yes, we're going to get that set up so he has his own bank account."*

This does, at first sight, appear to be an attempt to address one of the limitations to FP6's increased independence that was identified in Stage 2 of the study. However, opening a bank account will not, of itself, address a 'lack of understanding of money' and it is not clear whether any teaching was to be undertaken in relation to enhancing FP6's knowledge and understanding of money.

When interviewed FP6 appeared happy with the plan stating that things had got better. However, when asked how things had got better, all FP6 mentioned was that:

**3FP6, paragraph 120;**  
*"I'm talking to people."*

It is not clear from this however, whether FP6 has increased his circle of friends, has overcome his shyness, or is simply talking to more people as a result of the PCP process and the research project. Given the overall perception of his main carer, 3C-3FP6, that little change had been achieved in relation to services, activities, or meeting new people it is likely that FP6's comment that he is 'talking to people' simply relates to the PCP process and research project. When asked, 'Do you think that the PCP process has made a difference to FP6's life?' 3C-3FP6 stated:

**3C-3FP6, paragraph 73;**  
*"Well not really. I don't think it has much to be honest."*

FP9's carer felt that FP9 was in the process of benefiting from PCP at the time of the interview in so far as that during the planning meeting one of FP9's friends said that they knew of someone who might be willing to support FP9 to undertake activities (FP9 has direct payments). Prior to the meeting FP9's carer had advertised for someone to support FP9 but there had been no response:

**3C-3FP9, paragraph 178;**  
*"...if we hadn't had the person centred plan and FP9 hadn't been able to invite who she wanted to the meeting we wouldn't be in this position today, I don't think."*

Whilst the focus persons considered above had experienced some positive change during the trial period, some focus persons were not perceived to have experienced any change:

FP1's main carer felt that there had been no changes in FP1's life as a result of PCP:

**3C-3FP1, paragraph 181;**  
*"...I haven't seen no change. We, we're going on the same every, virtually the same thing every day. No, I haven't seen no change, nothing that has improved it or made it better."*

Similarly, FP2's main carer felt that PCP had not benefited FP2:

**Interviewer**  
*"What do you think the main benefits of PCP have been for this individual?"*

**3C-3FP2, paragraph 195;**  
*"No benefits!"*

FP2's second carer was also of this opinion, and when asked, 'What do you think the main benefits of PCP have been for this individual?' replied:

**3SC-3FP2, paragraph 208;**  
*"There have been no changes."*

FP7's carer also felt there had been no benefits to FP7:

**Interviewer**  
*"What do you think the main benefits of PCP have been for this individual?"*

**3C-3FP7, paragraph 441;**  
*"Nothing at all"*

3C-3FP7 in fact felt that due to PCP raising the expectations of FP7 it had actually had a negative benefit as described under the sub-theme 'Overall View of the person-centred planning process'.

However, 3C-3FP7 did mention the possibility of something beneficial coming out of the PCP meetings:

**3C-3FP7, paragraph 379;**  
*"But I had an e-mail from (name of PCP facilitator) last night and he said they were upgrading computers at his offices so he may be able to get a second hand one for 3FP7."*

FP7 also had an advocate who was present at the interviews. Although not one of the participants in the study, the advocate did voice his/her opinion as to whether or not there had been any change:

**3C-3FP7, paragraph 324;**  
*"What we've been waiting for really is some evidence of some benefit for FP7. As far as I'm aware there just hasn't been none, none whatsoever."*

### **3.3.4. Suggestions for improved efficacy**

#### **9) Suggestions for improved efficacy**

Clearly, in order to improve the efficacy of PCP in relation to it facilitating life change for focus persons one should seek to address the issues perceived to be barriers to implementing person centred planning that were outlined in section 3.3.2. Rather than reiterating the perceived barriers and describing ways in which they may be addressed, something which will be done in the recommendations for future practice, this super-ordinate theme outlines additional suggestions participants made for improving the efficacy of PCP.

One suggestion provided by 3C-3FP1 was that PCP should start early as he felt that the transition from school to adulthood was poor.

**3C-3FP1, paragraph 138;**  
*"What I find continuously is that all these schemes fall down because, you get children in the school, or maybe children at the school age – they seem to be catered for, but 15-16 when they leave there's nothing for him, from then up till 21 and they become adults on their own – And there's just a gap, and there's nothing there really covering for all that. And I'm not the only one, there's a lot of learning disability people find the same thing and have done for years, but no-one has as far as I know, up till now bridged that gap of that, how you call it? Teenagers sort of thing, neither a school child nor an adult, and there's that gap and those people are not really catered for."*

A suggestion for making it work better, given by 3C-3FP2, was the provision of increased finances:

**3C-3FP2, paragraph 174;**

*"I think there are a lot of activities that FP2 could perhaps do if there was more money... you'd have to have, if say she went to, say, a drama group or what ever, you'd have to have a carer to take her, you'd have to pay to go there, you'd have to pay for fuel to get there..."*

For FP7's carer, for PCP to work it needed to be 'followed through':

**3C-3FP7, paragraph 39;**

*"I think it needs follow through. I think promises are good and ideas are good but if there's no follow through then it's setting up for disappointment again. And that's where it fails."*

3C-3FP7 also felt that PCP would work more effectively if notes were actually taken at the meetings:

**3C-3FP7, paragraph 404;**

*"It seems to me that with a lot of social services and with (name of PCP facilitator) is, well, is the lack of business sense. You or I, if you're doing something you want to progress forward, not minutes in the formal sense, but notes of a meeting. What I do after is follow up social services and say, 'today we discussed your doing so and so and I'm doing this' not that they take a blind bit of notice. But at least it's something written down on what has been said, and who is supposed to be doing what."*

This issue was also raised by 3C-3FP9:

**3C-3FP9, paragraphs 567-580;**

*"I don't know about with the person centred planning meetings whether anything should be documented or something. Umm, what shall I say, because we have had these 2 or 3 meetings and it's all had to come verbally from the memory."*

**Interviewer**

*"No minutes are taken?"*

**3C-3FP9**

*"No, and whether that should be so and there is no feedback on who is responsible for doing this or that."*

A focus person, 3FP7 raised a related issue, namely that there should be more information on PCP for participants themselves:

**3FP7, paragraph 592;**

*"Well it would improve it if there was a lot more information."*

In addition to suggesting that PCP would be improved if responsibility for things was clearly assigned, a further suggestion made by FP9's carer was that the changes introduced by PCP should be gradual:

**3C-3FP9, paragraph 513;**

*"I think that should always revolve around the person that the plan is for and to take account of their commitments and their capabilities really, of their lifestyle really, and probably gradual change, perhaps simple change."*

A further suggestion for improving the efficacy of PCP came from FP7 and his carer, namely improved clarity in communication. 3C-3FP7 noted that they had not seen a copy of any plan, but felt that it might be useful if they were to see it. On being asked whether she felt that his mother should see the plan, FP7 replied:

**3FP7, paragraphs 685-688;**

*"Well as it was private I didn't know whether I was supposed to show it to people. I didn't know if it was just for me. I thought it might be confidential."*

**Interviewer**

*"So if (name of PCP facilitator) had said it's ok to show it to your family and talk about it you would?"*

**3FP7**

*"Yeah I would have shown her"*

**3C-3FP7**

*"It's a communication problem I think."*

## **4. The experience and beliefs of the Person Centred Planning Facilitator**

### ***4.1. The style of data collection.***

As with the interviews of focus persons and carers, these interviews were undertaken using a semi-structured format. Unlike other participants, however, it was decided not to use the Robertson et al. scales (2005) as at the time of the interview in Stage 2 of the study the Facilitator had not met all of the potential participants. To have asked him such questions as were contained in the scales would have resulted in little data being forthcoming. Nor were the scales used when the facilitator was interviewed in Stage 3 as it was felt unreasonable to expect him to remember the relevant information on all participants.

### ***4.2. The rationale for interviewing the facilitator***

The facilitator was interviewed at Stages 2 and 3 of the study in accordance with objectives 4 and 7 of the study. The rationale underlying these objectives was that the facilitator interviews would supplement the main study interviews, potentially 'filling some of the gaps' in the researchers' knowledge of what had occurred during each focus persons' PCP process and to explore similarities and differences in perception. The coding for the facilitator interviews differs from coding for the focus persons and carers. This is due to variations between what the facilitator had to say about PCP compared with what focus persons and carers said. The starkest difference is the degree of positivity with which the facilitator discusses almost every aspect of PCP when compared to the interviews with FP and carers (the views of focus persons and their carers are reported in the previous sections and are predominantly neutral or negative). However these differences are not merely differences in perception, but include numerous contradictions which occur even when discussing relatively objective matters. For example, whether plans were actually in place, paperwork completed or if meetings had taken place or were forthcoming.

The decision was taken to undertake an unstructured interview with interviewer prompts kept to a minimum. The exception to this was that in the Stage three interview the interviewer guided the facilitator to discuss each focus person's experience of the PCP process in turn. The researcher was careful not to challenge the facilitator where inconsistencies were present between the focus person's or carer's and the facilitator's account. There were three reasons why this was considered important. Firstly, that to introduce material from the focus person's or carer's interviews would have breached confidentiality. Secondly, doing so could have resulted in the facilitator adopting a defensive stance. However, while the researchers did their utmost to maintain a non-challenging position, the facilitator was clearly aware of some of the criticisms that could be levelled at the facilitator role or the process in general. This resulted in a degree of defensive positioning from the facilitator both in terms of the facilitator's role and person-centred planning processes in general. An underlying motivation for this appeared to be a desire for the research team to "know the truth" and that the record should be "set straight" about the reality of the PCP processes. Of course one of the philosophies that underpinned this study is that truth is a subjective concept and that multiple stakeholders will have multiple perceptions of PCP. Finally, given that the facilitator is considered key to the success or otherwise of PCP (Robertson, et al., 2007) it is important to obtain his or her in depth view of the process. Challenging the facilitator with the views expressed by focus persons and carers may have resulted in the facilitator omitting to inform the

researchers of information that may have been important in considering future implementation of PCP.

It is important to emphasise here that the facilitator’s views were his own and in no way represent the views of the local authority.

### **4.3. The facilitator’s perspective and experience of the implementation of the pilot PCP project.**

The views of the facilitator will be explored here by elaborating on emerging codes and using quotes from the two interviews.

**Table 3 Coding structure for Facilitator Data**

<b>Superordinate Theme</b>	<b>Sub-themes</b>
PCP Facilitator’s Perspective	<ol style="list-style-type: none"> <li>1. Life context</li> <li>2. Role of services</li> <li>3. Types of PCP</li> <li>4. Role of facilitator</li> <li>5. Raising expectations</li> <li>6. Potential of PCP</li> <li>7. Communication</li> <li>8. Role of carers</li> <li>9. Challenges / barriers to PCP</li> <li>10. Conflict of opinion/interest</li> </ol>

#### **1) Life Context**

In the Stage 3 interview the facilitator was asked to discuss the PCP process as applied to each focus person. This meant that much of the background context on the focus person was described and some parts of this had particular relevance to how the PCP process proceeded:

*“I spent time with FP9 talking about her circle and finding out who are the people who she connects with the most and she has got a lot of friends, a diverse group of friends. She’s got someone who works with her in the local supermarket in X (name of town) and she is close to him and he is lovely he’s a really good support to FP9.”* (PCP facilitator, Stage 3)

*few “I’m not sure about the worthiness of that college placement either as I visited FP quite a times and the only thing that I could gather that he was doing that was practical was an art CSE or GCSE and that didn’t seem to be very much for a college placement does it. But there you go.”* (PCP facilitator, Stage 3)

It can be seen that the facilitator makes judgments about the suitability of the life context of the FP prior to PCP and that this inevitably influences the subsequent PCP process. An assessment of whether these judgments are accurate or indeed helpful is beyond the scope of this study. What can be said is that there are often marked contrasts between the perceptions FP and carers have about the life context and the judgment of the PCP facilitator. Additionally, some of the comments made by focus persons or carers lend support to the possibility that the facilitator influenced the PCP process. For example one person reported that ideas had come, not from the focus person or their carer, but from the PCP facilitator, whilst another individual stated that the PCP facilitator was ‘in charge’ of their meeting.



## 2) Role of services

Aligned with describing the life context of individual focus persons, the facilitator had much to say about the local service structure and its impact on both the lives of the focus persons and the PCP process:

*“I think in terms of how it might also work with services, there might also be a recognition that there needs to be more flexibility with finances, for example, so I’m thinking more of things like direct payments and the fact that there’s a very, very low uptake of direct payments. I know in (name of area) particularly, it’s very, very low for people with a learning disability and yet with people with physical disabilities it’s quite high and I think that may-be it could empower people to support and recognise that they don’t have to rely solely on, kind of, traditional kind of restrictive kind of services.”* (PCP facilitator, Stage 2)

*“It was obvious to me that at the day centre she does very little at all even though she has one to one (as X is paid just to work with FP2) but there is very little done with her.”* (PCP facilitator, Stage 3)

These quotations suggest that the facilitator perceives PCP as being a way of filling the gaps left by service shortfalls. However it is not clear whether in reality PCP will have such a benefit given that situations are often more complex than they appear at first sight. For example, the rigidity of service structures may impede the full potential of PCP from being realised. Services can therefore sometimes be the problem and an impediment to a solution.

Additionally, his belief that little was done with FP2, despite her having a 1:1 carer is contradictory of the comments made by FP2’s main carer in the Stage two interview which is reported in section 2.4.2 (Part II) under the subheading, ‘Carer’s Initiative.

## 3) Types of PCP

Not surprisingly more detail on the nature of the PCP process was given by the facilitator than by other participants. In particular the facilitator elaborated on the specific tools and techniques used within PCP such as Path, Map, Essential Lifestyle Planning and why some of these were more suitable than others:

*“The Map process is really good because it’s clear its focussed, it’s simple”* (PCP facilitator, Stage 3)

The facilitator suggested that the different methods of using PCP were explored with the focus people and carers:

*“What ever words you want to use you can talk about Essential Lifestyle Planning , Personal Futures Planning, PATH, MAP, whatever and you can explain how they work, you can explain the principles and philosophies”* (PCP facilitator, Stage3)

If the facilitator had been using alternative styles of PCP this would have been appropriate given that each style was developed for a different purpose or client group. In fact, Black (2000), and Sanderson (2000) both recommend that the choice of style of person-centred planning should be based on how appropriate that plan is for the individual who is to be at the focus of the plan. This was not, however, evident in their interviews. In fact, not only were people unaware of the type of plan that was being developed, but a number of persons remained unclear what PCP was at the time of the second interview.

#### **4) Role of facilitator**

The PCP facilitator spoke at length about the role of the facilitator in the process. In the initial interview this was in general terms regarding the possible function of the facilitator. In the second interview the PCP facilitator expanded on the specific role with individual clients, showing the varied nature of the facilitator role. For example, modelling, educating or enabling:

*“I think there was about 15 or 16 people in her lounge when I first met her and none of them were talking to her so one of the first things I did was a bit of modelling and I went over and knelt down and introduced myself and talked to her and I said to Mum that was how I worked that its about acknowledging that the person is there and part of it and I think that got through to Mum”. (PCP facilitator, Stage 3)*

In some cases the role is less tangible but no less important as it is something about building a good valuing relationship:

*“I think in itself is one of the main benefits. I find that if you visit with people and you don’t go in with a brief case or a big diary and wedge of papers – you know you’re not saying can you come and see me in my office at ten on Tuesday – after about five or ten minutes they usually start to open up to you quite quickly, you tend to kind of, develop a rapport which I find really meaningful and quite powerful and I think that, I can only talk about my own feelings in relation to it, but I do sense in people that they really like that – they feel really valued, maybe for the first time.” (PCP facilitator, Stage 2)*

The view of facilitator that people like to be talked to and that it is important to develop a rapport with them was supported by carers and focus persons, one of whom was very positive about the way in which the facilitator spent time getting to know her son, FP7. However, it appears to contradict the facilitator’s reported approach to FP3, namely that he was seen in the day service by the facilitator if the facilitator had time left after meeting other clients.

The facilitator acknowledged that the actual role of the facilitator may, in some cases, be at variance with what focus persons or carers may perceive that role to be and that this needs to be addressed:

*“PCP for FP3 was quite complicated because initially he seemed more interested in having a relationship, a friendly relationship, with me to start with. So I had to do a lot of work with him about the process and to educate him that I wasn’t there to be a long term friend but this was to help him to get more of what he wanted out of life”. (PCP facilitator, Stage 3)*

#### **6) Raising expectations**

The facilitator was aware of the expectations raised by the introduction of PCP at an individual level. The problem of delivering on expectations at an individual level has been reported in Part II of this report and is considered in further detail in the discussion (Part IV). The facilitator was also aware of service expectations of the PCP process and that as the ‘public face’ of PCP, expectations would inevitably be placed on him.

In relation to individuals, these expectations were often linked to situations where people had previously felt let down by services and hoped that PCP would deliver where other services had failed:

*“She (focus person) had got it totally and said ‘so if I want to go to the gym more than I am and they don’t let me because the money isn’t there that you’ll help me?’ And I said ‘yeah I’ll help you put that together in a plan’ “ (PCP facilitator, Stage 3)*

If the facilitator did use the words reported in the above quotation, they may have been interpreted by the focus person as meaning that the facilitator was going to help her access more money, rather than the reality that this was going to be a goal within the plan. Other participants felt that the PCP process had raised the expectations of focus persons as is described in Part II. Although only one participant directly stated that they felt this to be a problem, others raised the issue by referring to the process as not being realistic, predominantly due to a lack of resources. If expectations are not to be unreasonably raised, there would appear to be a need for clearer communication between the facilitator and focus persons and their carers, an issue discussed in greater detail in the discussion section of this report (Part IV).

## **7) Potential of PCP**

Many of the comments of the PCP facilitator were coded as 'potential of PCP'. This coding first covered references to explicit and implicit outcomes that PCP can produce for the Focus Person:

*"I think that one important aspect of PCP for me is around supporting people to access support through advocacy, um, quite often, I think, because you can't always rely on next of kin or relatives or professionals to provide you with the information that you need." (PCP facilitator, Stage 2)*

*"That's the fascinating thing about person centred planning, you'll find that in essence what I think people with learning disabilities get from it is the interaction, it's shown me how lonely people are and how much they crave interaction, and, um, supp... no, not support, just interaction in general. They want you to talk to them. In every day centre I've visited I've ended up surrounded by about five, six people saying, 'what's your name' and, 'where do you come from?' 'What are you doing with X?' I'll say, well I'm here to talk about this and then they'll say, 'Oh what is that, can I have one?' (PCP facilitator, Stage 2)*

The suggestion, in the second of these quotations, that focus persons are lonely and desire interaction was supported by the findings of Stage two, in so far as few focus persons appeared to have friends who they would meet outside of their day service / placement. Additionally, those persons they described as 'friends' were often paid carers or people who most people would not describe as friends such as shop assistants.

Second, this coding covered areas where progress was seen during the duration of the PCP study. However these improvements are still coded under 'potential of PCP' as we have no way at the moment of assessing their sustainability. In this sense benefits that appeared at Stage 2 are still works in progress:

*"So a lot of what we have done with FP9 is confidence building really, it's a re-affirming process saying "look you have come so far, you have your own flat, so what next, what are you really scared of, what are your hopes and dreams?" (PCP facilitator, Stage 3)*

*"When I was actually doing the first planning session with everyone I said "Let's talk about FP9 all the good things about her and how we see her". And people said they found her to be funny, articulate, loyal, brave, caring, empathic because of all this stuff she does for charity the running and the difference in her was incredible. Such a simple thing that people take for granted and yet the difference in someone like FP9 and she is on cloud nine. You know she straightened up in her chair, she was walking all around the place". (PCP facilitator, Stage 3)*

## 8) Communication

The facilitator appeared to recognise the importance of communication in enabling focus persons to make greater choices:

*“And yet its frustrating because its clear that if he was supported to communicate better and supported to experience new things he would make more choices.”* (PCP facilitator, 2)

However, the way in which the facilitator phrases this, suggests that whilst recognising the importance of communication he does not appear to acknowledge that communication is a two way process. Rather, the ‘failure to communicate’ appears to be laid at the feet of the focus person.

One of the proposed strengths of PCP is that it can help to empower people with learning disabilities including those with high support needs (Ritchie, et al., 2003). It is therefore ironic that communication problems between the facilitator and focus persons appeared in some cases to be a barrier to the PCP process:

*“You can see it in him and he has a great sense of humour and he can be quite cheeky sometimes, he acknowledges this, in a nice way. But I wouldn’t feel comfortable developing a plan because I don’t think it would reflect what he wants as I don’t know what he wants.”* (PCP facilitator, 2)

Communication has already emerged as a major factor in both the process of undertaking PCP and as a determiner of its success or failure as can be seen in the findings of Stage three. This subject is discussed in greater detail in the discussion section of this report (Part IV).

## 9) Role of carers

Inevitably the PCP facilitator interacted with the carers and family members of the focus people and had views on the contributions these people made to the lives of the focus persons:

*“He’s lived with his Mum and Dad all his life and they’re very controlling over him but he loves them to bits. They are very close and its my personal opinion and that of others that their relationship is quite damaging because his care is provided by the local old persons nursing home which is next door to where he lives, in the morning and the evenings which is quite rare”.* (PCP facilitator, Stage 3)

Such views may not, however, be agreed with by the carers. In relation to the focus person discussed above, FP1, his main carer appears to contradict this in some of the things he discusses such as the fact that his son can make progress and that his son is going to have to ‘move on’ as he (the father) is not going to be able to care for him. However, as has previously been noted, people often perceive things in different ways, depending on their positioning. For example, the facilitator may have been brought up in a liberal environment which results in him viewing the manner in which FP1’s father treats him as controlling. On the other hand, FP1’s father may have been brought up in a very strict environment and feel that he is liberal in the way he treats his son in comparison with his own parents.

The facilitator gives another example of the perceived influence of parents and carers on focus persons:

*“But I think because she is such a strong personality he is led by her quite a lot. If you spend any time with him you notice that he mirrors her quite a lot, what she says and he even sounds like her sometimes. It’s a lot like talking to the same person. So he can be quite heavily influenced by her.”* (PCP facilitator, Stage 3)

Family members and carers involvement in the PCP process is considered important, so much so, that Routledge et al. state that the second of the five key features of person-centred planning is that, “Family members and friends are full partners” (Routledge, et al., 2002).

In general the facilitator supports them being educated about PCP in order that they can be active participators in the process, if this is the wish of the focus person. However, their involvement was perceived to cause problems when their expectations as carers differ from those of the facilitator:

*“So what I did for them is using elements of path and map I gave them an outline version of Ls plan which said who was involved, where the session was, what she liked and disliked her hopes and dreams and that kind of thing but that was quite difficult because it didn’t tally with what Mum and Dad wanted unfortunately.”* (PCP facilitator, Stage 3)

In addition tensions arise where there is a lack of clarity on the distinction between the carer role and the facilitator role. This is considered in the discussion section of this report (Part IV).

## **10) Challenges / barriers to PCP**

The PCP facilitator was specifically asked about the barriers to successfully implementing PCP. Despite his mainly positive account of the PCP work in the local authority he had plenty to say about what the problems were and what needed to change in order for both the PCP process in general and the lives of focus persons in particular to reach full potential:

*“I find that the, kind of, accessible information is something that collectively people haven’t really got a grip on and in my experience what you produce is never going to be accessible to everyone, at the very least, and nine times out of ten it’s not that accessible even to those people that people may assume that it is”* (PCP Facilitator, Stage 2)

The issue of communication, which, as can be seen from the quotation above, the facilitator considers to be a barrier to the successful implementation of PCP is something that was raised on numerous occasions by participants. It is considered in the discussion section of this report (Part IV).

*“So, I think it’s about that, it’s awareness raising, it’s education, it’s kind of support and it’s acknowledging that even something like person centred planning can be threatening to people, it can, I think most things can be if they’re different or they’re perceived as being different.”* (PCP Facilitator, Stage 2)

In the above quotation, the facilitator appears to be suggesting that there is a lack of awareness concerning PCP throughout the local authority. However, the facilitator also suggests that PCP is perceived to be threatening. There is some data from the interviews with carers and focus persons to support this view, for example: references are made to focus person’s social workers not attending meetings; that the process cannot work without Social Services involvement, and; that there needs to be better communication between the PCP facilitator and Social Services. If the perceptions of the PCP facilitator and the participants are valid, this may explain, to some extent, why so few focus persons

had experienced positive outcomes, in so far as the PCP facilitator did not have generally have direct control over whether peoples hopes and aspirations were achieved. Rather, the achievement of such aspirations was often reliant on the input of others.

Many of the other themes discussed in this section of the report, such as: 'communication', 'expectations' and 'conflict' were also perceived to contribute to creating barriers to PCP being successfully implemented.

### **11) Conflict of opinion**

A specific barrier to successful implementation of PCP appears to be conflicts of opinion regarding what is in the best interest of the FP. Sometimes the conflicts occur within services:

*"The nurse queried it (FP's continence) in the past but if he is not incontinent at home it can't be that but it must be something more behavioural. The guy in the art department says that there isn't a problem he just needs changing and it's to down to the attitude of the staff. So he's caught up in this really unhealthy atmosphere and environment." (PCP facilitator, Stage 3)*

Conflict also occurred between the facilitator and services:

*"I think a lot of what I have discovered or seen would be helped by people being more creative but when I have said something at a support meeting, well I haven't had one for several months but people have got very aggressive with me and very defensive and have said "we have got really creative um Case Managers" as if I am blaming the Case Managers. I am not blaming Case Managers per se I am jus saying the system is wrong." (PCP facilitator, Stage 3)*

And sometimes between the facilitator and family carers:

*"I spoke to FP and he said "well I've got an advocate" and I spoke to Mum and she said "don't be silly he's got an advocate, I've already told you." So we couldn't do anything about it. FP is convinced that X (family friend and advocate) has his best interest at heart, but if I'm honest I think X has got Mum's best interests at heart." (PCP facilitator, Stage 3)*

## Part III – PROCESS ISSUES IN THE UNDERTAKING OF THIS STUDY

The objectives of this study were essentially concerned with the findings in relation to the experiences of persons with learning disabilities, their carers and the PCP facilitator. However, it is common with qualitative research that the process of data collection is in itself a rich source of information to the researcher on the phenomena of interest (Cassell & Symon, 1994). Certainly the process of conducting interviews as part of the project can be channelled via the researchers' reflexivity into 'process data' that can either stand-alone or support the 'content data' that emerges from the project. In order to fully document process issues and to provide context for their emergence they are presented under the following broad categories: 'Stage 2 specific issues'; 'generic issues', and; 'Stage 3 specific issues'. *Table 4* illustrates the process issues that fit within each category.

**Table 4 Process issues arising during the study**

<b>Stage 2 Specific Issues</b>	<b>Stage 3 Specific Issues</b>	<b>Generic Issues</b>
The impact of the ground-work prior to interviews	Function of the follow-up interview	Diversity in expectation of interview process
The researcher with a 'blank slate'	Perspective of the PCP facilitator	Use of quantitative measures
Use of information sheets	The researcher with 'baggage'	Comparison between focus person and carer interviews
		The impact of the environment

### 1. Stage 2 Specific Issues

#### 1.1. *The impact of the ground-work prior to interviews*

The study used a multiple-case pilot design for achieving a deep level of understanding (Bryman, 2004) on the process of implementing person-centred planning. It was intended that the initial ground-work in exploring the idea of PCP and the willingness of focus persons to contribute to both the pilot PCP scheme and the research study would be undertaken by the PCP facilitator. This meant that the researchers were not intended to make contact with participants until they had expressed interest in the PCP research study. Lack of contact details and insufficient information for the participants constituted the first difficulties in Stage 2.

The researchers were dependent on the PCP facilitator to provide them with this information; thus, sometimes they had to find other means of acquiring information needed to proceed with the project. That had two effects. First, this was a time-consuming procedure and second it raised some health and safety issues. For example, the researchers were not aware that some of the focus persons displayed behaviour that might have had an adverse effect on the researchers while conducting the interviews. However, the ground-work had rarely proceeded to the stage where focus persons had discussed participation in the study with the PCP facilitator. This had a knock-on effect on

the role of the researcher who was then required to adopt the role of marketing the PCP research study and, in some cases, the pilot PCP scheme. To some extent this was inevitable due to some people with learning disabilities requiring information to be repeated on several occasions.

In situations where the PCP facilitator had visited and explained both PCP and the PCP research study this was not, in itself, always sufficient to eliminate the need for the researcher to replicate this information on first meeting. However, this had been anticipated and was reflected by the research team having planned to undertake informal first meetings with potential participants prior to returning to undertake the interview. However, in some cases ground-work by the PCP facilitator was particularly scant and even some carers were unable to articulate what PCP was or the nature of the PCP research study.

A particular problem occurred where consent to partake in the process of PCP became merged, in the minds of potential participants, with consent to participate in the PCP research study. Researchers were always mindful that these consent processes were different and separate and did their utmost to communicate this to participants. However, this difference had not always been clearly explained at the ground-work stage and this resulted in confusion. It was an ethical principle upon which the study was based that interest in engaging in the PCP process did not oblige any individual to take part in the PCP research study. Similarly, consenting to take part in the study was separate from a participant's decision to have a person centred plan. Although clearly they would not participate in the study if they did not want a person centred plan.

The researchers felt that the PCP pilot scheme and the PCP research study were closely aligned in the minds of participants and this may have led to confusion regarding consent. Evidence for this included participants assuming the researchers would attend meetings about their plan, or had come to talk to them about getting a plan, or telling the facilitator what they said in the research interview in order that their plan could be developed. Thus, the present project raised concerns for the participant expectancies as a methodological phenomenon.

This misinformation is of particular concern given the need for the person with learning disabilities to have ownership of the planning process. Ownership cannot realistically be achieved when there is a lack of clarity in the PCP process. It is noteworthy that this misinformation on PCP only came to light almost by default as a result of the researchers' striving to provide clarity for participants on the nature of the PCP research study. Having to distinguish PCP from the PCP research project infiltrated the project's aims. This, in combination with the lack of access to contact details not only delayed the interviews and minimized the number of interviews conducted, but also undermined the credibility of both the study and the PCP process in the eyes of the participants. However, the informal first meetings, prior to the first interview, alleviated this matter to a certain extent. The informal meetings afforded the researchers a chance to become acquainted with the participants and to some degree develop rapport with them. Meeting with the participants unofficially provided the researchers with the opportunity to familiarise themselves with each individual and also to assess their competence in communicating with the focus person.

### ***1.2. The researcher with a 'blank slate'***

There is no such thing as a true blank slate in qualitative research. Researchers inevitably enter data collection with ideas and attitudes about the subject under investigation. Unless the project is following a grounded theory methodology, it is likely, as in this case, that a



researcher will have read around the subject and be aware of some of the main issues . However they begin collecting data as a blank slate in terms of the knowledge and attitudes towards their as yet unmet participants and specific experiences of their participants. One of the strengths of our study was that through the process of working collaboratively as a research team we each brought our different selves to the process. Although all experienced health and social care researchers our diverse professional and personal experiences bring an added dimension to the reflexive process especially when reflexivity is used as a tool in research team meetings (Barry, et al., 1999).

Once contact has been made with participants, even over the telephone, then assumptions start to be made and these need to be bracketed to minimise their impact on the research process. Alternatively they should be 'declared' so that the researcher's reflexive process can be recorded separately from the participants' accounts. One of the reasons for choosing to use IPA as the method of data analysis is that although it seeks to get close to the participant's personal world or obtain the perspective of 'an insider', it recognises that one can not fully achieve such an aim (Smith & Osborn, 2003). This is due to the fact that the researcher's own conceptions and experiences are used to make sense of the participant's world. It is precisely this acknowledgement that results in IPA being compatible with a social constructionist approach to the study. Our main method of addressing our assertions and conceptions was through the keeping of field notes and collating our thoughts in order to produce this process section as a distinct part of the overall report.

### ***1.3. Use of information sheets***

Before going to the ethics committee the teams' main ethical concerns had been in relation to ensuring:

- informed consent of the participants with the learning disability, and
- that potential participants understood that neither a decision to take part in the study nor a refusal would affect their access to the PCP process in any way.

According to guidelines, received from two different speech and language therapists, the initial documents were amended in the following way:

- by adding alternative communication styles as pictures and diagrams,
- by minimizing the amount of written language, and
- by simplifying the language.

Thus, the information sheets and the consent forms were produced in such a format as to be accessible to people with learning disabilities.

Even though every possible measure was taken to ensure the appropriateness of the documents provided to the participants, there was still the case of a prospective participant who reportedly became extremely distressed when he was presented with the information sheets. As a result, the care manager of that person contacted the PCP facilitator to advise that the focus person did not wish to be contacted anymore either by the PCP facilitator or the PCP project's team, due to the fact the he had become psychologically distressed. The exact reason for the distress caused to that person is unknown. What the PCP facilitator speculated was that because people with learning disabilities have difficulties in comprehending complex information, the information given to that particular FP might have been perceived as a challenging activity. This may have led to overloading that caused personal distress. After this event, and following discussion, the project team

had to decide if and how to administer the written information. It was felt that the team had to use the information in the written format as this had been required by the ethics committee. However, they sought to avoid overloading potential participants by augmenting the information sheets using simplified verbal language, non-verbal communication, and other augmentative communication styles. They also allowed additional time before the interview in an attempt to get to know the participant's individual style of communication. This was in accordance with the University's introductory guide on the 'Ethical Issues in Teaching and Research': "Since ethical guidelines express general principles and concerns, individuals have to judge how to apply them to their own practice" (University of Glamorgan, 2001).

The initial intention had been to provide all participants (carers, focus persons and the facilitator) with an information sheet that was accessible to people with a learning disability. However, the ethics committee argued that this was inappropriate and that non-learning disabled participants would be insulted by receiving such information. We therefore had to provide more complex information sheets for those who were not learning-disabled, thereby highlighting to those participants with learning disabilities that they were 'different' to the other participants. Whilst we acknowledge, and accept the principle of fairness that involves: "treating alike people who are alike in relevant aspects; treating differently people who are different in relevant aspects" (University of Glamorgan, 2001), we felt that had we presented everyone with an accessible information sheet, this would have met the needs of both participants with a learning disability and those without.

In addition to the format of the information sheets, another issue relating to them that was of concern was their physical accessibility. Even though both the PCP facilitator and the researchers had handed the focus person's information sheets to the focus persons themselves or to their carers, few of the focus persons had access to them between the first unofficial meeting, and the first and second interviews. Although during the first unofficial meeting it was made clear that the information sheets were intended for the focus persons, on returning for the first interview the information sheets were either locked away in the focus persons' drawer or in other inaccessible places.

## **2. Stage 3 Specific Issues**

### ***2.1. Function of the follow-up interview***

The Stage 3 interview had the function of enabling the research team to 'see what had happened' during the PCP process. Whilst the Stage 2 interviews uncovered participants' fears, anxieties and hopes in relation to the PCP process, Stage 3 enabled the research team to enquire as to what extent those hopes fears and anxieties were realised or allayed. At one level the function of the interview for focus persons and carers was similar, as it presented an opportunity to share the realities of what happened to someone who knew their perspective. Additionally, however, the interviews also had other functions for many participants. Firstly they had a cathartic effect (e.g. someone to vent their frustration or anger on). Secondly, in some cases, they had a catalytic effect (e.g. the participants believed that the interview marked the start of an increase in PCP related activity).

To some people the researchers were seen as the one transparent and straight forward element of the process; that is they were seen to have honoured their commitment to come return at a specified time and this was honoured. It was relatively easy for us to provide a sense of continuity in this way. This continuity and the fact that the same interviewer visited the same participant (with one exception) meant that a relationship had already been developed prior to the Stage 3 interview. This arguably enhanced the quality

of data collected in Stage 3. The downside of this was that the researchers now cared about the outcomes or lack of outcomes for the participants. By gaining access to the reality of their lives as well as their hopes and disappointments it was harder for the researchers to walk away. This difficulty for the researchers was exacerbated when focus persons and carers were left with questions about PCP or uncertainty about what may happen next and the researcher was now ending their relationship with the participant.

## **2.2. Perspective of the PCP facilitator**

Until Stage 3 of the research project, the PCP facilitator was relatively unknown to the two interviewers (the Stage 2 interview was conducted by the Chief Investigator). However the Stage 3 interview with the facilitator was conducted by one of these interviewers after all other Stage 3 data collection was completed. There was an inevitable sense that this interview would 'fill some of the gaps' in the researchers' knowledge of what had occurred in each Focus Persons' PCP process. There was also an assumption that data collected from focus persons and carers would either be confirmed or contradicted by the data collected in the facilitator interview. What was not expected by the interviewers was the extent to which contradictions occurred, even when discussing relatively objective 'hard data'. Examples of such issues included the questions of; whether plans were in place, paperwork completed or if meetings had taken place or were planned for the near future. Although not expected, other research suggests that facilitators tend to be more positive about the outcomes of PCP than others involved in the care of focus persons (Cook & Abraham, 2004).

The decision was taken to undertake an unstructured interview whereby interviewer prompts were kept to a minimum. The exception to this was that the interviewer guided the facilitator to discuss each focus person's PCP experience in turn. The researcher was careful to not interrupt the facilitator with challenges where inconsistencies between the focus person's/ carer's and facilitator's accounts occurred. There were two reasons why this was important. Firstly, to introduce material from the focus person /carer interviews would have breached confidentiality. Secondly, questioning the facilitator about apparent inconsistencies could have prompted the facilitator to adopt a defensive stance. However, while the researchers did their utmost to maintain a non-challenging position, the facilitator was aware of some of the criticisms that could be levelled at the facilitator role in the PCP process. This resulted in a degree of defensive positioning on the part of the facilitator both in terms of the facilitator's role and the planning processes in general. An underlying motivation for this appeared to be a desire for the research team to 'know the truth' and that the record should be 'set straight' about the reality of PCP processes. Of course one of the philosophies that underpinned this study is that truth is a subjective concept and that multiple stakeholders will have multiple perceptions of PCP (Burr, 2003; Gergen & Gergen, 2003).

## **2.3. The researcher with baggage**

By the time the researchers collect data in Stage 3 they have accumulated the 'baggage' of the analysis of Stage 2. This had both positive and negative results. Potentially this may have influenced the way in which questions were asked and thus the outcome of the interviews. In addition, continued problems with communicating with the facilitator gave rise to concerns (on the part of both the research team and participants) about the extent of activity occurring with the PCP pilot project. Informal discussions amongst the research team therefore had a valuable cathartic function in enabling the researchers to remain as open-minded as possible when returning to conduct Stage 3 interviews.

Some of the experiences in Stage 2 enhanced the quality of the research work conducted in Stage 3. One example being that in the Stage 3 interviews they focused questions on specific issues that had proved to be important to the individual at the time of the Stage 2 interviews. Additionally and most significantly relationships that had been established with the focus persons/carers resulted in increased openness when discussing what were frequently for the participants, difficult feelings. In addition focus persons who appeared prone to acquiescence were identified in Stage 2 and the interviewers were especially mindful of this when conducting Stage 3 interviews.

It has been suggested by some writers (Flick, 2002; Williams, 2003) that in order to ascertain the validity of one's findings one should return to participants to ascertain whether they agree with the researcher's findings. However, this was not recommended by Jonathan Smith (2004) who, in response to a question on this subject in the Yahoo IPA Discussion Forum, argued that the more interpretative one's work is the less appropriate participant validation becomes. This is due to the fact that the researcher's interpretation is not necessarily one which the participant would share or feel able to own. This phenomenon may arise due to the fact that interpretation emerges from the analytic dialogue between researcher and participant and thus exists separately from the two. Rather than use participant validation, Smith, along with others suggests the use of independent audit (Flick, 2002; Smith, 2003a) a process the team sought to follow. We also considered each the attributions we each gave to statements made by participants and reached a consensus whether such attributions were appropriate.

Based on previous research the team was aware that it was probable that the PCP process was likely to touch on issues that carried emotional weight for the participants (for example, participants may have had services reduced, or been denied direct payments). This issue was initially discussed by the team and it was anticipated that such matters might arise during the data collection process. Even though alleviating participants' emotional concern had been of great importance for the researchers, it was not always possible to effectively address these issues due to limited time, absence of demographic data and wrongly disseminated background information.

### **3. Generic Issues**

#### ***3.1. Diversity in expectations of interview process***

Expectations of what would be covered in the interview were clearly influenced by the problems with the initial ground-work discussed above. Inevitably the collecting of interview data mirrors the information gathering process that occurs in many appointments with health or social care staff. Therefore an understandable assumption often occurs that the collector of such information will, in some way, 'act on it' to make something happen. In this case the confusion was often around the data being used directly to create the new plan. While it was explained to participants that a separate process would be undertaken to develop the plan with the PCP facilitator, not the researcher, it was not always clear that this expectation had been diminished. An example of such misinformation was the case of one of the carers, who asked if the focus person that he cared for would get any qualification after the implementation of PCP.

All semi-structured interviews were conducted with the questions in no predefined order in order to enable a natural conversational flow. They included fixed but flexible topics, with no response codes and allowed the interviewer to enable the respondents to raise other relevant issues not covered by the interview schedule. Participants varied widely in the degree to which they took ownership of the interview itself. The semi- structured schedule

allowed participants plenty of opportunity to 'tell their story'. Acquiescence amongst people with learning disabilities had been anticipated and there were certainly some focus people who preferred to give short affirmative answers before politely awaiting the next question. But equally there were some people with learning disabilities who were keen to tell the interviewer things about themselves. It was also anticipated that some of the focus persons may find some of the discussion topics somewhat complex. This was the case with some focus persons and as a result of this researchers were unable to fully explore interesting emergent issues.

Opportunities for carers, especially family carers, to have their say can be very powerful and this was certainly the case for some carers in this study. The interview process for them went beyond the remit of the study and in one case became a verbal narrative of the life of the focus person from the perspective of their main carer. This can be quite a humbling experience for the researcher who has set up this opportunity and needs to 'invite intimacy' as part of qualitative inquiry (Birch & Miller, 2000). This experience reminds us of the power we can hold as researchers and the ethical responsibility we have choosing how to respond to this power. Within this study the researchers managed this by taking care not to make promises on behalf of either the PCP facilitator or the PCP process, neither of which they were in a position to honour. However, cosmotheoretic concerns, and hopes and fears for the future were still raised by all carers eventually placing the researchers in a defensive, and in some cases apologetic position during the 'return' interview at Stage 3.

### **3.2. Use of quantitative measures**

These measures were established tools developed by Robertson et al. (2005). However, the measures were problematic to administer within the context of the semi-structured interview as they inevitably repeated much of what had been covered already. There were also some specific problems with the tools themselves. First, participants were required to assess the frequency with which certain activities occurred. It is generally recognised that many people with learning disabilities find the concept of time difficult (Booth & Booth, 1996) and the focus persons in this study were no exception. Using recency prompts helped to some extent but was not foolproof. For example, establishing that the last time someone went to a café was last week and that they had also gone the week before may indicate that they had been to a café on the previous two weeks but does not account for atypical periods. Second, the measures were only as effective as the accuracy of participants' recall, though this is the case with any participant and there is no evidence to suggest that people with learning disabilities are any less honest than other interviewees (Beail, 2002). Third, it was striking how few activities or services were accessed by people with learning disabilities.

Many of the items in the measure did not feature in the lives of the participants and therefore the questions did not hold their interest in the same way as the open ended interview questions did (for example, "what do you like to do at the weekends?") Finally, some questions were open to differing interpretations that can in turn impact upon comparative analysis. A particular example relates to modes of transport. Whilst a carer may be able to differentiate easily between a public bus and a commissioned bus that takes an individual to a day centre, this distinction may be less apparent to a person with learning disabilities. This lack of distinction and the impact this may have in terms of expectations / potential for PCP is in itself of interest as research data.

During both Stages 2 and 3 many of the items had missing values (which means that no pre-coded answer was given). Reasons for this were that: the participants felt that the

questions were 'not applicable'; they didn't know the answer, or; they knew the answer, but didn't know any details. All Robertson et al's scales (A-H) were constructed for closed answers, which were either dichotomous (an answer of 'yes' or 'no') or categorical (Likert scales: a forced choice method where the middle option is a preference of the type "neither good nor bad"). The use of 'yes/no' questions was somewhat surprising given that there is considerable evidence to suggest that these are more likely to lead to acquiescence on the part of people with learning disabilities than other types of question format (Sigelman, et al., 1981; Heal & Sigelman, 1995; Prosser & Bromley, 1998).

Robertson et al's scales would have provided fruitful data provided that all participants came into the interview with a baggage of answers. Unfortunately, a vast number of answers were of the following three types: 1) Not applicable for the FP; 2) I don't know, or; 3) I know, but I don't know details. This constituted a threat to the *construct validity* of the quantitative component of the research study. Construct validity is a term mainly used in quantitative research. In qualitative research it is used to describe the establishment of correct operational measures for the concepts under review (Yin, 2003). According to Yin (Yin, 2003) there are three tactics to increase construct validity in qualitative research: 1) triangulation of data by using multiple sources of evidence; 2) establishing a chain of evidence during data collection, and; 3) having the interview partners review the draft case study report. The researchers of the PCP study have followed all three tactics recommended by Yin (2003). However, there are some threats in research, which cannot be avoided. An empirically proven threat to construct validity is *evaluation apprehension*, which simply means that the participants might be anxious or even phobic about being evaluated and that such anxiety or apprehension may cause them to perform poorly (Salvatori, et al., 2003). It is not possible to state whether the limited responses to the measures used in this study were the result of evaluation apprehension or were due to real lack of knowledge of the focus persons life on the part of his/her carer.

It has been argued above that Robertson et al's scales repeated a lot of what was discussed during the semi-structured interview. For Stage 3, exactly the same battery was used as in Stage 2 plus two more scales (G and H). This means that by the time the participants were answering the battery for Stage 3, it was the fourth time that they had to discuss the same questions during the course of the project. The majority of the participants argued that the scales had a redundant style. In regard to the focus person this redundancy led to a lengthy interview as by default more time was needed on each single question, in order for the researcher to repeat or rephrase the topic under discussion.

Questionnaires with Likert scales, namely C, E, F and G did not pose any difficulties during data analysis. On the other hand, questionnaires with a dichotomous answer and/or were concerned with the number of times (A, B, D) that a certain activity/service had been undertaken, generated problems during the analysis. As will be discussed below, during the 'comparison between focus person and carer interviews', many methodological issues arose. Some of these methodological issues had a direct impact on the analysis of the quantitative data. For example, the vast amount of missing values: (1) not applicable; 2) I don't know, and; 3) I know but I don't know details presented considerable problems. Missing data can be problematic, because it does not allow those people with missing data to be included in the analysis, thereby reducing the overall numbers included in the analysis. The seriousness of missing data depends on the pattern of missing data, how much is missing and why it is missing. The pattern of missing data in this sample was systematic, and happened only in relation to participants who had limited knowledge of the

focus persons, or in relation to focus persons who were asked about activities and services not applicable in their lives.

There are no firm guidelines for how much missing data is allowed, but in social sciences it is generally accepted that more than 5% would pose a threat to the patterns and tendencies of the results. Both of the second carers included in the study could not be included in the analysis for this reason. As for the third question regarding the seriousness of missing data, it was agreed by the researchers that the data was missing because the second carers had limited knowledge of important issues in the focus persons' lives and because of their limited involvement in PCP. A final point in regard to the 'A' and 'D' scales was that it was not possible to establish the number of times each activity/service was used. For the focus persons this was not possible due to the confusion that the concept of time is causing to people with learning disabilities; a problem further discussed in another paragraph of this report. As for the carers, what was said was accepted as true, however, the "subjective truth" was taken into account by the researchers when analysing the data.

### ***3.3. Comparisons between focus person and carer interviews***

One of the strengths of the study design was that wherever possible the same researcher interviewed and subsequently analysed data from both the focus person and the carer. This highlighted both factual and perceptual differences between the focus person and their carers. There are many possible reasons for these ranging from basic misunderstandings that arise from differing interpretations of questions, to reasons with a more psychological basis. While the reasons can only be hypothesised they demonstrate the importance of researchers using reflexive process as a sense-making tool.

One possible reason for differences is that the focus person and /or the carer may be motivated to portray a reality that is either overly positive or overly negative. For example a carer may give a positive account of the life experienced by the focus person in order to protect themselves from any perceived risk of criticism of the care they provide. Meanwhile the person they care for may be portraying their experiences in a negative light in order to maximise any perceived potential for improvements as a result of the interview. However, these motivations are confounded by the perceptions that the interviewer is more powerful than they actually are, with the power to chastise or to award.

It should be added at this point that these are not necessarily conscious motivations but can be operating at the unconscious level. Therefore in the vast majority of cases there is no intention to manipulate the data, researcher or to give an account of the facts that is anything other than truthful. A constructionist interpretation is that there are multiple 'truths'. These arise due to our experiences being processed via our personal internal filters (such as our upbringing or past experiences) in order to make sense of that experience and so construct our truth (Burr, 2003). This approach explains why an apparently simple recounting of an experience such as a trip to the cinema by both the focus person and their carer may be experienced, and therefore reported on, very differently depending upon whose perspective is heard.

A second hypothesis about the differences between focus person and carer accounts is that lower expectations of life experiences may characterise the accounts of people with learning disabilities. A lack of awareness of life's infinite possibilities can result from a lack of access to these possibilities and leads to a self-fulfilling prophecy. This then contrasts with the carers' expectations that are invariably influenced by their life perspective as a non-disabled person and what society perceives 'normal' life aspirations to be. Examples include: desire for an intimate relationship emotionally fulfilling and financially rewarding

work; social relationships, and; holidays. These differences are brought into sharp focus by simple questions such as ‘are you happy?’ Most people recognise that this question can be answered at multiple levels and that our answer may vary depending on who is asking us and the context surrounding our being asked. Awareness of this multiplicity is unlikely to be present for many of the focus people interviewed and it is possible that affirmative answers refer to immediate environmental factors rather than more self-actualising possibilities.

Paradoxically, focus persons sometimes have hopes and dreams that are viewed as unrealistic by carers who through past experiences are all too aware of the possible obstacles to achieving such dreams. This raises the interesting question about whether hopes and dreams are (or even should be) realistic or whether, by definition, they are hard to reach and aspirational in quality. Is it acceptable to modify the hopes and dreams of people with learning disabilities due to real world constraints? Does the psychological benefit of having aspirations outweigh any potential psychological damage of unfulfilled dreams? These questions are not easily answered but are worth posing when considering both the potential of PCP and the influence of the ‘circle of support’ that will have their own perspective on the potential of the person with learning disabilities.

Even though the researchers had the opportunity to have an informal first meeting before the actual interview, it was felt that this was not enough to assess and enhance their competence in communicating with some of the focus persons. Two focus persons did not communicate using speech and so data was collected from a second carer. One of the priorities of the PCP study had been to accurately assess and identify the focus persons’ preferences. Had the study received ongoing support from a speech and language therapist who may have assisted the researchers in communicating with those focus persons, then those focus persons preferences may have been identified and assessed to a greater extent.

Another hypothesis arises from the different roles the ‘carer’ and ‘second carer’ had within the structure of the research study. When the second carers consented to participate in the study, they agreed to do so as “the voice” of the focus person. Despite agreeing to do so, they argued that PCP leaves much to be desired since they (carers) can not know what the needs and wants of the focus person that they care for are. Both of the second carers that participated in the study repeatedly said that they could not entirely know what the focus person needed. Consequently concerns were expressed in the project team for the construct validity of the data collected from the second carers. Unreliability is a reason for invalidity and this was raised by the second carers themselves. Another reason for invalidity is *cultural bias*, which arises as a result of the interview questions having different meanings and relevance between one culture and another, and are also interpreted differently between one person and another, thus the questions have different face validity depending on the interviewee (e.g., political polls - a politician's current popularity is not necessarily a valid indicator of who is going to win an election) (Bryman, 2004). Although this was a drawback in the data collection, it was a phenomenon anticipated by the researchers and not possible to overcome under the particular circumstances.

*Evaluation apprehension* might constitute a threat to the construct validity of the study, not only when analysing carers’ data, but also when analysing the focus persons’ data. Most people with learning disabilities grow up being tested in different settings and for different purposes. As a result they develop test behaviour whenever they participate in research or are assessed in an attempt to: “look smart”; “look good”, or to ‘please’ the assessor/researcher. This tendency in behaviour might have been another source of



discrepancies between FPs' and carers' interviews. At the other extreme, given the increased vulnerability of some people with learning disabilities to be influenced by others, particularly those perceived as more senior in hierarchy to themselves, it is possible that some of the focus persons might have been coached prior to the interviews. Coaching calls into question the credibility of the interview data to an even greater degree when accompanied by the problem of acquiescence, which was the case of some of the focus persons speaking in the presence of other people. Coaching is not, however, limited to persons with learning disabilities, and was discussed as a possible explanation of one of the second carers giving contradictory opinions between the first unofficial meeting and the first and second interviews.

### **3.4. *The impact of the environment***

Initial meetings and interviews took place in a variety of settings including focus persons' homes, carers' homes, day centres and residential colleges. Sometimes the interviewee was alone and sometimes other people were present. The degree of privacy and quiet varied between locations. Given the personal nature of some of the things discussed the impact of the environment on the experience of data collection cannot be ruled out. However, it is sometimes hard to quantify the exact nature and extent of this impact. Once again the reflections of the researcher are valuable in making sense of the experience as they were themselves part of the data collection experience.

Often the presence of other peoples such as 'translators' had both positive and negative aspects. In a positive manner, people who know the person with learning disabilities well can provide access to their 'private language' (Grant, et al., 1998) that was unknown to the researcher. This occurred at an interview with a focus person held in his mother's home. Present at the interview was the focus person, his mother, an independent advocate and the researcher. While the mother took a more formal 'translator' role in helping her son to understand the questions or to remind him of things, the advocate provided an equally valid, though more implicit, 'translator' role. This was of the focus person's private Language of the. The exchanges between the advocate and the focus person had little meaning to anyone else (and were not always verbal) but led to both a more relaxed atmosphere and increased enthusiasm from the focus person towards the interview experience.

Sometimes researchers were negotiating to conduct interviews in environments that were less than ideal. To some extent this is an inevitable compromise intrinsic to social Research. However, given the focus of this project, the emphasis had to be on securing an environment that was preferred by the focus person even if this was not the first choice of the carer. This required sensitivity on the part of the researchers who had to maintain good relationships with carers in order to facilitate their involvement in the project.

## Part IV – DISCUSSION

### 1. Introduction

The main purposes of this study were to explore the hopes and concerns of focus persons and their carers prior to them undertaking the person centred planning process (Stage 2 of the study). Having done this the study was to seek to ascertain their actual experience of the person-centred planning process (Stage 3 of the study). The results of those two Stages are provided above.

Although PCP has been used in the United States of America since 1979 (O'Brien & O'Brien, 2000) use of PCP in the England and Wales has only become common recently, predominantly as a result of government policy (Department of Health, 2001; National Assembly for Wales, 2001) despite the fact that most of the 'evidence' supporting PCP was at the time anecdotal (Iles, 2003). Given its recent 'widespread' introduction in the UK it is not surprising that few efficacy studies of PCP have been carried out in the United Kingdom. Additionally, few tests have been suggested that might be applied to the implementation of PCP to assess success or otherwise. One test that has been suggested by some of the UK's 'leading authorities' on PCP and which has been endorsed by Rob Greig, the National Director of Implementation for Valuing People is contained in the book, 'People, Plans and Practicalities' (Ritchie, et al., 2003). This test outlines four main questions, namely:

- Is person centred planning happening?
- Is person centred planning happening 'right'?
- Is person centred planning changing people's lives? and;
- Is person centred planning changing services?

These questions are then further divided into sub-questions and some examples of good practice are provided. Whilst we acknowledge this test is subjective we believe it provides an index of what the main protagonists of PCP feel equate to success. We will, therefore, use these tests as a benchmark against which this pilot scheme may be compared where this is possible.

In many studies, the interest of the researcher or those commissioning the research either relates predominantly to process or to outcomes. This study sought to consider both. This part of the report discusses the results, making comparisons between the two Stages and between relevant literatures. It is divided into three main sections, 'the PCP process,' 'outcomes' and 'participants' views of challenges to be overcome'.

### 2. The PCP Process

Although PCP is perceived as an ongoing process (Routledge, et al., 2002), this study was time limited and as such the experiences of the process reported upon are restricted to the period of time between the two interviews. This varied for individuals but it was approximately 9 months.

Given that Robertson et al's study was a two year study and only 71% of their 91 participants had a plan at the end of the two years, we did not anticipate that all of the focus persons involved in this study would have a plan in place by the time of the second interview (Robertson, et al., 2005). However, given the small number of focus persons and that only one local authority was involved in the study we did anticipate that most focus persons would be well into the process. The reason for reporting process first is that at the

time of the second interview, many of the focus persons were still undergoing the process and as a result of this, there is more data on participants' experience of 'the process' than on 'outcomes'.

### **2.1. Frequency of meetings**

It was anticipated that the period of time between meetings would be fairly short partly due to the fact that the project had a limited time frame; partly because of the possibility that focus persons might not remember the purpose of the planning process if the time between meetings was long and; partly because focus persons may lose interest or feel negative about the process if no changes occurred within a reasonable period.

However, whilst some people had been offered regular meetings, most had not. Rather, they had to wait between 6 months and ten months between meetings. There may be any number of reasons for the time between the meetings, though only one person commented on this, noting that a meeting that had been proposed did not occur due to someone being unavailable. Whatever the reasons may have been, however, the period of time that had elapsed between meetings for most participants was excessive. This is somewhat worrying given the reasons outlined above as to the importance of regular meetings. Additionally, if one accepts the four tests of success of PCP posited in 'People, Plans and Practicalities' (Ritchie, et al., 2003) the fact that focus persons were having to wait so long for meetings suggests the second test, "Person Centred Planning is happening 'right'" was not wholly being met. This is due to the fact that one aspect of this second test is that, "the person chooses the setting and the timing of the meeting". Whilst the data suggests that some focus persons did choose the setting of the meeting, there is no data suggesting that they chose the timing of the meeting. In fact, the contrary appears to be the case with a number of participants commenting negatively about the length of time between meetings and that the process was taking too long.

### **2.2. Level of involvement of Focus Persons and Carers in the meetings**

The reported level of involvement in the meetings was generally limited. One family carer stated that they were not involved and another felt they were being purposefully distanced from what was happening. Similar issues have been raised in other studies, though of transition planning from school to adult services (Smart, 2004). However, if family carers were purposefully being distanced from the process and this was not at the request of the focus person, it is somewhat worrying given the fact that one of the key features of PCP is that family members and friends should be full partners (Routledge, et al., 2002).

Although some family carers felt that they were not involved in the process, it appeared that most focus persons had the opportunity to choose who they wished to attend the meetings. Additionally some reported choosing where the meeting took place. However, other than the opportunity to say things they wanted, none of the participants described a high level of involvement. This is not to say they were not involved or given the opportunity to be involved, as one participant said that the PCP facilitator had tried to involve those who attended. However, another participant said that the PCP facilitator was 'in charge' of the meeting.

This apparent absence of the focus person from the centre of the process is of considerable concern. However, this may have arisen due to a lack of clarity as to what is meant by, 'at the centre of the plan'. Ritchie et al. give the examples of: the person being consulted throughout the process; choosing who is involved and; choosing the setting and timing of the meetings PCP (Ritchie, et al., 2003: p. 47). However, Cook and Abraham found that what was meant by 'being at the centre' was a cause of debate and that for

some people it was considered that their mere presence, even when they did not understand the proceedings was considered to satisfy the requirement of person centredness (Cook & Abraham, 2004).

Despite this apparently limited involvement of focus persons, few factors were reported as impacting on the level of involvement of either focus persons or their carers.

The factor most commented on was communication. In part, this related to the ability of those involved to communicate with the focus person. The communication methods and ability of the focus persons participating in this project were wide ranging. Some focus persons appeared to have a reasonably large vocabulary and good expressive ability, others appeared to have a poor, almost monosyllabic expressive ability whilst appearing to have a reasonable comprehensive ability and others had virtually no speech and appeared only to have a limited ability to express themselves. Having anticipated this prior to the commencement of the project, the research team had decided that where a person was unable to consent or otherwise to being interviewed that we would interview a second carer instead of the focus person themselves. However, this was not an option for the PCP facilitator, nor for professionals involved such as case managers and social workers. Rather, they had to communicate with focus persons directly. There are at least two reasons for this. Firstly, the very nature of PCP requires facilitators and others involved in the plan to consult with the focus person throughout then process, for example choosing who should be involved in the process and where and when planning meetings are to be held (Ritchie, et al., 2003). Additionally the plan should reflect what is important to the focus person from the focus person's perspective (Ritchie, et al., 2003). Whilst some information about a person's abilities and dislikes may be obtained from proxies such as carers, it is not possible for carers to describe what matters to the focus person from the focus person's perspective. At best, they may provide an educated guess about this. It has long been considered best practice that, wherever possible, one seeks the views of people with an intellectual disability from the individuals themselves (Prosser & Bromley, 1998; Bollard, 2003).

Not only is it considered 'best practice' to communicate with service users directly but, for many people working with them, it is also a legal requirement to communicate with them using accessible information. Since December 2006, public bodies, including Social Services and Health Trusts and their employees have had a duty to, amongst other things, promote equality of opportunity between disabled persons and other persons; to take steps to take account of disabled persons' disabilities, even where that involves treating disabled persons more favourably than other persons and; to promote positive attitudes towards disabled persons. These and other duties are imposed by the **Disability Discrimination Act** (DDA, 2005). One of the requirements under this legislation is that public bodies must make reasonable adjustments to make their services more accessible to people with disabilities. Accessibility is not simply about physical improvements to buildings such as the installation of ramps or guide rails. It includes making information accessible to those people with learning disabilities using the service.

This requirement will be strengthened further once the **Mental Capacity Act** 2005 comes into force fully (in October 2007) as s.4 places a duty on practitioners to take all practical steps to help them make decisions. Examples of such steps outlined in the Code of Practice include: Providing all relevant information in a way the individual can understand; making the person feel at ease and the use of other techniques and support mechanisms such as electronic aids, and the services of relevant professionals such as speech and language therapists and clinical neuro-psychologists.

Communication, or rather a lack of it, was a common complaint of participants in this study. This issue was most frequently raised by carers who had become frustrated by the period of time it took for the PCP facilitator to contact them, or by the fact that they were unable to contact the PCP facilitator. However, some of the complaints related to the way in which information was presented. For example, a number of persons stated that meetings were not documented, with the result that neither focus persons nor their carers were sure what had happened in the meeting. Participants also reported that they were not sure who, if anyone, had responsibility for agreed actions. Moreover, some focus persons highlighted the need for information to be more accessible, both in relation to that appertaining to PCP and to their care plans. The PCP facilitator did refer to himself as being unable to communicate with one individual (section 4.3, under the sub-heading 'communication) but did not suggest this was a problem with other focus persons. Rather, he suggested that other workers lacked the skills to produce accessible information (section 4.3, under the subheading 'challenges'). These issues would again suggest that the implementation of PCP for the participants was not meeting the second test for successful planning as outlined in 'People Plans and Practicalities' (Ritchie, et al., 2003).

Although communication was reported as being problematic in the above ways, the meetings did reportedly allow some focus persons to say what they wished to say about their hopes and fears to a number of relevant persons. However, this did not necessarily mean that what the focus persons considered important was then the main focus of the meeting. For example, one participant reported that the focus of the meeting was on one issue to the exclusion of other issues that were more important in the focus person's life. Similarly another person, who said they had been given an opportunity to be listened to, reported that activities suggested were made by the PCP facilitator and a service provider.

The only other factor commented on as reducing the involvement of people important to focus persons was the time at which the meeting was held. This comment was only made by one participant, but is an important point as it prevented a sibling, with whom the focus person had a close relationship, from attending the meeting. Holding a meeting when a key individual was unable to attend appears to go somewhat against the ethos of PCP which promotes working with family and friends (Routledge, et al., 2002).

### ***2.3. Participants' views of the PCP meetings***

Despite the above criticisms in relation to outstanding meetings and poor communication, two participants felt that overall the meetings were good, though they did not enlarge on this. Another participant said that the meetings were good, noting that they provided an opportunity for a focus person to raise their voice and discuss their hopes and fears. However that participant then placed a qualification on their overall view that the meetings were good by stating that this was, 'because they were the only thing going on.'

Three participants had mixed views about the meetings, for example one felt it had resulted in changes for him but that the meetings were too long. Another noted that it was good that the focus person was able to choose who was invited, but not good that the focus of the meeting was on one issue to the exclusion of others that were more significant in the individual's life.

Two participants felt that the meetings were either bad or very bad as they were had resulted in either limited change or no change.

## **2.4. Participants' suggested changes to PCP meetings**

Few comments were made by participants as to what might be changed for future meetings.

Two participants in the study said that nothing needed changing in relation to the meetings. One of these, however, continued by saying that it was the implementation that was the problem with the pilot scheme rather than the meetings.

Other suggestions reflected participants' comments elsewhere, for example, there were comments relating to the frequency of the meetings and the need for them to be regular and local; there were also comments relating to the need for documentation. However, another comment that was made in relation to how the meetings could be improved related to the need for the application of more 'common sense' in the assessment of abilities and for more realistic goals to be set. Whilst people may dismiss these comments on the grounds that PCP is not an 'assessment', sub sections of the second test outlined in *People, Plans and Practicalities* (Ritchie, et al., 2003) do state that the plan should describe the focus person's capacities and should identify the supports they need. Likewise, Routledge et al. (2002) state that one of the key features of PCP is that the, "planning reflects the person's capacities...". Although we recognise that a person may have long term goals or dreams and that these may not be fulfilled in the short term, it is important that goals are achievable. PCP will not benefit clients if plans are unachievable whether this is due to lack of resources; as a result of attributes of the client that are insurmountable or any other reason. Rather, such plans will unreasonably raise expectations, as was suggested by one carer about this pilot scheme. Causing a person's expectations to be unreasonably raised would be unethical, a concern raised by the ethics committee when this research project was submitted for approval.

## **2.5. Participants' overall view of the PCP process**

Given that few focus persons had completed plans at the time of the second interview, it is perhaps understandable that none of the participants in the study were wholly positive about the PCP process they or the person they cared for had experienced. Despite this, a number felt that they could outline some positive aspects of the process, namely; that PCP creates an arena where all relevant persons are brought together, and; that there is nothing else on offer and planning for the future is necessary. Another positive aspect of the process for one individual was that the PCP facilitator had spent time trying to get to know the focus person they cared for, something that it was felt was lacking on the part of the individual's social worker.

Another individual, whilst unhappy that the process was taking so long did recognise that the process would result in a positive benefit with practical value, namely a plan that would be useful as it would make consistency in care more likely. This, of course, presupposes that the focus person will either have a portable copy of the plan which they can show people or that everyone working with the focus person is provided with a copy of the plan.

However, the majority of the participants in the study found the process to be a negative experience in some way with the result that their overall view of the process was such that they described it as being, 'a paper exercise', 'little more than window dressing', 'impractical', 'a waste of time', 'too long', and 'achieving nothing'.

## **3. Outcomes reported by participants**

As noted earlier, PCP is generally viewed as an on-going or continual process of listening and learning. However, it is more than that, it also requires action that pursues an

individual's aspirations (Routledge, et al., 2002). Secondly, if successful outcomes are not achieved there is the possibility that focus persons satisfaction with life may decrease (Rudkin & Rowe, 1999). Additionally, it is recognised that service providers do not have endless resources and that there is a growing pressure from government to ensure that resources are used to best effect. In view of such factors, it is important that PCP is seen to produce beneficial outcomes for focus persons, preferably at no additional cost to the service provider.

The time frame between the Stage two interviews and the Stage three interviews was relatively short (between 6 and 9 months). This may not have been sufficient time to make major changes requiring the involvement of other agencies, for example; attendance at a college or a move from parental accommodation. In such cases, it was anticipated that some intermediary goals may have been met. For example a person may have visited a number of colleges, chosen a course and steps may have been taken to enrol on that course. In the case of someone wishing to move out of their parental home they may have received information on the alternatives available to them, costs, have viewed different types of accommodation and expressed a preferred option.

Such intermediate goals had been achieved for two persons both of whom desired to live independently. In the case of one of these, the main factor that had prevented this earlier, other than reported bureaucracy associated with the Direct Payments scheme, was that the individual had been unable to find someone to employ as a support worker although she had advertised through 'social care' agencies, and networks. However, this may have been part of the problem as it has been suggested that service users may achieve better support if they advertised in publications aimed at people who like doing the same things as the focus person such as horse riding (Moulster, 2007). Nevertheless, as a result of the PCP meeting, someone who was known to the individual was identified.

In relation to the second individual, one of the factors that prevented a move to a more independent setting was the focus person's fear of dying. Having become aware of this, the PCP facilitator had spoken to a clinical psychologist who was now seeing the focus person on a regular basis. Although the focus person did not think that PCP had helped much with the fear, their main carer felt that the involvement of the clinical psychologist might be a necessary precursor to further achievements. However, other goals of the focus person, such as attendance at college courses had not been achieved, nor was there any apparent progress towards achieving such a goal.

However, whilst progress had been made in relation to the aspirations of the two focus persons discussed above, none was reported in relation to two focus persons who had expressed a wish to be employed, one in gardening and the other with animals.

In addition to some focus persons having expressed a desire to make large changes in their lives, such as: living independently or developing a relationship and having a partner many focus persons expressed desires that should be more readily achieved. Such desires are reported in Part II (2.4.1) of this report, but examples include: visiting the gym, the cinema and football matches, and; going sailing and white water rafting. It was expected that such desires would have been achieved during the period between interviews for most, if not all participants. However, this did not generally seem to be the case.

Only one focus person appeared to have experienced some small changes. He said that he was talking to people, however, it is not clear what he means by this. It could mean that

he has overcome his shy nature and is talking to people generally. However, it could mean that he felt able to talk to people at PCP meetings. He had also received a letter and photograph from a celebrity he liked. However, his main carer said that this had been arranged by someone who was working with the focus person prior to the PCP project commencing. Finally, the focus person's parents had decided, after a conversation with the PCP facilitator, to open a bank account for him. It did not appear that he was doing more of the things that he had previously said he liked such as; craft activities, attending the theatre, cinema or football matches.

For most people, PCP at the time of the second interview had, at best, in the words of participants: 'made no difference', provided 'no benefits' or done 'nothing at all'. Whilst this is of itself of concern, what is even more concern is the fact that it was perceived by some as being, 'unrealistic' and seen to have 'unreasonably raised expectations'.

#### **4. Participants views of challenges that need to be overcome**

In view of the limited number of positive outcomes reported and the difficulties discussed in relation to the process they had experienced, it is understandable that most participants were of the view that there were a number of challenges to overcome. Many of these challenges were felt to arise from various individuals or bodies, they include focus persons themselves, the PCP facilitator and service providers.

##### ***4.1. In relation to focus persons***

A number of challenges were seen to arise from focus persons themselves. These included their general abilities, their communication, their capacity to learn, long standing psychological issues, an unwillingness to consider the future, and acquiescence in relation to what might be suggested to them. That some people are less likely to receive a plan or less likely to benefit from a plan was a finding of the Robertson et al. (2007) research. For example, they found that people with mental health, emotional or behavioural problems; people with Autistic Spectrum Disorder; people with health problems and people with restricted mobility were less likely to receive a plan. Some of the focus persons within this study had such problems, and this may, to some extent, explain the overall findings of this study. However, the Robertson et al. study involved 93 persons over four sites and it may have been the case that facilitators chose to commence working with the focus persons they considered 'easier' (Robertson, et al., 2005).

Whatever the reason for such individuals being less likely to receive plans, it is both unjust and unlawful that they should not benefit from PCP as a result of their additional 'disabilities' (DDA, 1995, as amended). Challenges such as those outlined above in relation to focus persons participating in this project, although arising from the focus person, need to be addressed by service providers. Such an attempt was being made in relation to the individual who had started seeing a psychologist. However, this was not reported to be the case in relation to the other focus persons. Rather, it would appear that such issues were ignored; for example, participants reported that the information was inaccessible, that the PCP facilitator was in charge of the meeting, and that the ideas for activities were those of the PCP facilitator and service provider rather than the focus person and their network of family and friends. This is an issue that was also reported in the Northgate & Prudhoe Trust report. They noted that the main drivers of change appeared to be organisational and financial imperatives rather than the wishes of the focus person (Cook & Abraham, 2004).



## **4.2. In relation to the PCP Facilitator**

There were three main issues felt to arise from the facilitator. None of them are insurmountable, but given the importance of the facilitator in the PCP process (Robertson, et al., 2007) it is likely that they were the predominant cause of a number of the findings. If they, and in particular the first issue, are not addressed it is unlikely that any future implementation of PCP will not succeed in bringing about hoped for changes in focus persons' lives.

One of the main challenges to be addressed in relation to the PCP Facilitator was his perceived lack of communication with focus persons, their family and carers, and with Social Services. Whilst we were aware that there had been some difficulty with his e-mail address early in the project, we are unaware of any other physical or technical cause of his reported lack of communication. The issue of communication is discussed in some detail at section 3 (Part II) under the sub-heading of 'involvement'.

A second perceived challenge relating to the facilitator was his reliance on public transport. Whilst this may not present difficulties in urban areas, this local authority is predominantly rural / semi rural, there being only three large towns in the county. Although some service users live in towns, not all do and it would be of considerable concern if that resident outside of urban areas should receive a poorer service as a result of this.

A third perceived challenge relating to the facilitator was that he reportedly failed to facilitate change. This is not a straightforward matter, however. On the one hand only two focus persons reported having made progress towards major life changes. However, it is not clear whether the expectations the participants had of the facilitator were reasonable or within his job description, if he had one. In the interviews with the PCP facilitator, he did not outline his role in the manner one would expect to find in a job description. Rather, he described his role predominantly through the use of examples of work he had done (see Part IV of this report).

## **4.3. In relation to service provision**

These were quite varied in their nature. The first was a belief that whilst Social Services were able to develop approaches that would, in theory, benefit clients, they were not good at putting such approaches into practice. One possible reason given for this by some participants was that Social Workers did not know their clients sufficiently with the result that they did not understand their clients' needs and were not, therefore, able to provide appropriate services.

Another reason given for this perceived inability to put theory into practice was that there was a reported lack of finances and other resources, such as staff. As a result of this, clients were unable to undertake desired activities. Being unable to undertake desired activities was not always the result of a lack of staff; it sometimes occurred as a result of staff leaving and those replacing them not wishing to support clients in activities that had previously been undertaken.

A further reason given for this perceived inability to put theory into practice was that Social Services staff were too pre-occupied with bureaucracy. This reportedly slowed the implementation of planned changes and resulted in inefficiency. An example of this was that FP9 had not only been waiting over three years for her care package to be put in place, but also ended up in debt as a result of not being able to move into a council tenancy that had been arranged.

Other reasons why it was felt that a person centred approach would not work included a lack of suitable accommodation, and suitable employment for focus persons. The latter issue may not be directly in the control of service providers, but support could be given to clients to find full or supported employment.

Another matter reportedly in need of addressing by Social Services was that too much was expected of the facilitator, and that he didn't have sufficient administrative support. If this was the case, then it may explain, at least to some extent, why the PCP facilitator was reported not to have facilitated change and why people reported that he failed to communicate adequately.

Possibly linked to the facilitator's perceived lack of support were comments about there being a perceived lack of commitment to PCP on the part of Social Services. Although the reasons for this belief were not always clear, one reason was that Social Workers did not always attend focus persons' PCP meetings.

#### **4.4. Other challenges that needed to be overcome**

Participants also referred to other challenges they felt needed to be overcome in order for PCP to have a positive effect. This can not be placed in the categories discussed above. This may be because they refer to other bodies or individuals than those referred to above. For example one thing it was felt was an obstacle to achieving change through PCP was 'a lack of political commitment'. However, it was not clear whether this referred to politicians at local level or in the Assembly. Another such example was the perceived lack of suitable and meaningful employment. This is an issue that needs to be addressed by a number of bodies. For example, people should be provided with appropriate training by Education or the Employment Service to enable them to enter the employment market; the DDA (1995) should be enforced in order that employers employ people with a learning disability, and; adequate support should be provided, where necessary, to enable people to work.

Alternatively, the cause of the perceived problem may be unclear. For example, a number of participants felt that goals that were set were inappropriate to the focus persons' abilities or were otherwise unrealistic. It is not clear why this occurred, as this is not an intention of PCP for although Ritchie et al. state that the plan should reflect what is important to the focus person it should also take account of their capacities and the support they would require to achieve success (Ritchie, et al., 2003). Another example was the perceived need for more advocacy and a belief that there was a lack of advocates. Why this is the case is unclear. It may be an issue local to the individuals, to the local authority, or nationally.

### **5. Further discussion of the findings**

When the pilot scheme and this study were commissioned, few people in Wales had person centred plans. Additionally, although PCP had been mandated in England and was considered good practice in Wales there was little evidence to support its use on a wide-scale basis throughout services. In fact, as outlined in the initial literature review, PCP was not developed for widespread use within formal organisations such as Social Services or NHS Trusts (*APPENDIX 1*). The evidence that was available was predominantly concerned with very small numbers of services users living in the United States of America. Since the commencement of this pilot scheme and study, the findings of a number of studies have been published in relation to the implementation of PCP. For example, in the UK, Northgate & Prudhoe NHS Trust reported their findings on the implementation of PCP for 6 persons then living in hospital (Cook & Abraham, 2004). Outside of the UK a slightly larger study than this one was undertaken in Southern

Australia of the implementation of person centred planning with 25 persons resident across five group homes (Rhodes, 2006). The most important of the studies was reported under the title: '*The Impact of Person Centred Planning*' (Robertson, et al., 2005). The reason for its importance is that it was a large scale study (93n) undertaken across four English counties over a period of two years. They generally reported that PCP was beneficial to clients in a range of areas across their lives at a cost that was not statistically different the cost of previous service plans. This study has been widely reported as providing unqualified support for the implementation of PCP (McIntosh & Sanderson, 2006; Sanderson, et al., 2006). However, Emerson himself was not willing to make such a bold claim when presenting the interim results at a conference in 2005 (Emerson, 2005). Rather, he noted that there were some people in the study that PCP had not helped, that there was a need for realism and that PCP was not a panacea. More recently, Robertson et al. have expanded upon Emerson's comments in an article that considers the factors that are more or less likely to result in successful PCP outcomes for people with learning disabilities (Robertson, et al., 2007).

The findings of this study into the pilot PCP implementation scheme may be considered disappointing in comparison with those of Robertson et al. (2005). However there are a number of possible reasons for this:

Firstly, the organisations selected for participation in the Robertson et al. study were selected on the basis of:

*“their apparent commitment to implement PCP in order to enhance the lives 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 commitments”* (Robertson, et al., 2005: i-ii)

This initially raises a question as to the representativeness of the organisations participating in the Robertson et al. study. Additionally, however, although the local authority may have had such a commitment, it was not clear to the research team whether this commitment was shared by everyone working within the authority. In fact, the reported absence of some key personnel from PCP planning meetings suggests that there was a possible lack of commitment to PCP on the part of some of the persons likely to have considerable influence on the success or other wise of PCP.

Secondly, the Robertson et al. study was undertaken over a period of two years, a considerably longer period than this study (Robertson, et al., 2005). It is possible, though in view of other issues discussed elsewhere in this report, not probable that had the present study been over a similar duration that more focus persons and carers would have reported greater benefits to their lives as a result of the PCP process.

Thirdly, when undertaking their study, Robertson et al. undertook a considerable amount of 'development work' with the organisations participating in their research (Robertson, et al., 2005). Such work was for the duration of two years and involved external consultants who provided materials and training. The purpose of this work was to help the organisations develop policies, procedures and practices for implementing PCP. Facilitators involved in their study each received between 84.5 and 100 hours training, whilst managers each received between 53.5 and 100 hours training (Robertson, et al., 2007). This is a large investment in training and support.

Whilst we were aware that part of the PCP facilitator's role was to provide County Council personnel and family carers with an introduction to PCP, it is our understanding that the

attendance at some of these training sessions was quite low. We are not privy, however, to the types of persons who attended as part of their employment, nor do we know their roles within the organisation. Additionally, we are not clear as to the appropriateness of the PCP facilitator providing such training. When he was interviewed in Stage 1 of the research study, he stated that he was most familiar with, and had been trained in, Essential Lifestyle Planning. He did not claim to have a detailed knowledge of other approaches to PCP such as MAPS, PATHS, Personal Futures Planning or The Personal Planning Book. Given that the emphasis in PCP is on the 'personal', it is important that focus persons should be afforded the type of planning most suitable to their needs. The wide-scale adoption of one or two models of planning by services has given rise to criticisms of services for viewing service users as homogenous (Osgood, 2005).

Also related to training and support, but to the facilitator's rather than other persons, it would appear that the facilitators in the Robertson et al. study had considerable training and support throughout the study. Their training not only included information on PCP directly, but also included other issues of relevance such as; communication styles and communication support for people with non-verbal communication; Health Action Planning as part of person centred working; Autism; Direct Payments; Housing; Risk and Innovation; Community Capacity Building and working with people with complex needs. Whilst we are aware that the PCP facilitator also works as an advocate and may have a good knowledge of some of these issues, it is clear from his comments (section 4, Part II of this report) that he felt that he found difficulties in communicating with some people with complex needs and non-verbal communication. It is not clear whether there were other areas where the PCP facilitator lacked sufficient experience or expertise, nor whether he made his training needs known to his line manager, but the effect of some of these issues may have reduced the likelihood of more positive outcomes for focus persons. Additionally, comments made by focus persons and carers (see: section 2 & 3, Part II of this report) suggest that the PCP facilitator lacked support in a number of areas and that too much was expected of him. Additionally, the PCP facilitator did not, to our knowledge, have the peer support of other facilitators that those involved in the Robertson et al. study had (Robertson, et al., 2005).

One of the findings of the present PCP study, that is supported by the Robertson et al. study (Emerson, 2005), is that the PCP process did not appear to help focus persons in relation to: levels of physical activity; work; inclusive networks or the use of services. For example, no focus persons reported engaging in additional physical activities such as those they had stated that they would like to undertake in Stage two of the research project. Likewise none of the focus persons had gained employment or additional employment. For example although FP3 in his PCP meeting specifically requested that he work more hours he was advised that this was not possible.

The findings of the Robertson et al. study (Emerson, 2005) support the view that the presence of a number of factors made it more likely that focus persons would have successful plans. These were:

- The person having a key-worker at the commencement of the PCP process
- The person already having an Individual Personal Plan / Individual Service Plan
- The person being involved in the study for a longer period
- The person not having Autistic Spectrum Disorder (ASD)
- The person not having mental health problems.

Conversely, the findings of the Robertson et al. study supported the view that people considered to benefit least from PCP were those with: ASD, challenging behaviour, or; profound and multiple disabilities. That is to say, those with the greatest needs appeared to benefit least. Emerson suggested that there were familiarities with their findings and the *Inverse Care Law* first propounded by Tudor-Hart in 1971. Adams et al. (2006) made a related finding in their recent study, namely the fact that having a 'good' quality of life was not related to the quality of an individual's plan, but to their level of ability, that is to say that people with higher abilities tended to have better outcomes.

Whilst the present pilot project and study was considerably smaller in scale than the Robertson et al. (2005) study, it does appear to support the above findings. For example FP7 who has been diagnosed as being on the Autistic Spectrum was reported to have experienced no benefits at all from the PCP process at the time the second interviews were conducted. Similarly, FP1 and FP2, both of whom have profound and multiple disabilities were also said to have experienced no change in their lives as a result of PCP. Conversely, the focus persons reported to have benefited most from the PCP process were FP3 and FP9 both of whom have a mild learning disability and communicate verbally.

Another finding of the Robertson et al. study that may be of relevance to the implementation of the present pilot project and the study findings was that the most important predictor of success and of increasing friendship for focus persons was high personal commitment on the part of the facilitator (Robertson, et al., 2005). Given the difficulties people reported in contacting the pilot scheme PCP facilitator and the reported lack of frequency with which he met with them, one has to question the PCP facilitator's personal commitment to the pilot project.

Robertson et al. also found that in relation to focus persons increasing the size of their social network (as opposed to friendship) the most important predictor was that the focus person directed their own meeting (Robertson, et al., 2007). Although some focus persons in the present study reported choosing who they wished to attend their meeting, it was not at all clear that they directed their own meeting. As has been reported, one focus person felt the facilitator was in charge of the meeting and another felt that the facilitator and a service representative put forward ideas – whilst this may have been helpful, it may have inhibited the focus person from putting forward their own ideas.

In concluding this report we note that the widespread implementation of PCP throughout the local authority would be a considerable undertaking and one that should be carefully considered if it is to be carried out to benefit clients rather simply being a paper exercise for the benefit of services, a concern of a number of commentators (Osgood, 2003; Mansell & Beadle-Brown, 2004a; Mansell & Beadle-Brown, 2005). Additionally, it is an undertaking that should be carried out gradually as there is a need for linked resources and sufficient time for development (Routledge & Gitsham, 2004; McIntosh & Sanderson, 2006) As has been noted by a number of authors, PCP is not a new way of working with people with learning disabilities, nor is it a radical departure from past ways of working. Rather PCP is an evolutionary step from other forms of planning (Felce, 2004; Towell & Sanderson, 2004; Adams, et al., 2006). It is important, therefore, that those seeking to implement PCP learn from difficulties experienced in the implementation of previous forms of planning in addition to considering the findings of this and other studies (Routledge & Gitsham, 2004).

The PCP pilot project and the research study that this document reports on were small-scale. Given this, it is hard to generalise the findings and it is not possible for the research

team to state equivocally whether PCP does or does not result in beneficial changes for people with a learning disability. However, the varied experience of the focus persons and carers who participated in this study does, to some extent, support the findings of the larger English study undertaken by Robertson et al. (2005). However, the experiences of focus persons and their carers also raise a number of issues that require consideration prior to PCP being implemented on a larger scale in the local authority and elsewhere. Such issues form the basis for the recommendations on the following pages.

## Part V – RECOMMENDATIONS

The recommendations below could be categorised as falling under the headings of ‘Policy and Practice’ and ‘Research’. However, there is some cross-over amongst these headings, for example, the monitoring of implementation could be perceived as an audit or as research. In order to avoid repetition of such issues we have only outlined them once. The recommendations are listed, not in an order of importance. Rather, they are loosely grouped with other related recommendations.

### 1. Education – training

#### 1.1. Information and training in key principles of PCP

##### 1.1.1. All personnel working in learning disability services

It is necessary that all personnel are provided with training relating to the nature of PCP. We do not advise that they are trained in a specific format of planning, but on the premise behind PCP and the reasons for person centred working.

##### 1.1.2. Family carers

Given the emphasis on family involvement in PCP it is important that the families of service users are provided with training along similar lines to CC personnel. One of the concerns raised by carers in this study was that PCP was just the ‘latest fad’. They should be aware that PCP is not a ‘fad’ but is a development of previous forms of planning and, that it builds on the principles contained in the *All Wales Strategy* (Welsh Office, 1983) as developed, and upon the statements made in *Fulfilling the Promises* (National Assembly for Wales, 2001).

##### 1.1.3. Service users

PCP should not be compulsorily imposed upon service users (Routledge, et al., 2002). They need to be given accessible information that enables them to make a choice as to whether they want a plan and if so the format of such a plan. That is to say; they, not the service, should have ownership of the plan (Carnaby, 1999).

##### 1.1.4. Facilitators and care managers

Facilitators and Care Managers need to have a good understanding of the various tools currently available (e.g. ELP; MAPS; PATHS; Personal Futures Planning). This is due to each of them having been designed for specific situations (Keyes & Owens-Johnson, 2003; Emerson & Stancliffe, 2004; Mansell & Beadle-Brown, 2004b) and therefore it is more likely that a service user is likely to benefit from one tool in preference to another. Facilitators and other key personnel such as Care Managers need knowledge and understanding of numerous other issues that relate to the implementation of PCP. Such issues include, but are not restricted to:

- *Communication* – e.g. enhanced communication skills, augmentative communication, accessible information and the legal duty to communicate in a manner accessible to clients. Where, having exhausted attempts at communication, it is not possible to communicate with clients, then decisions about service provision should be taken in their ‘best interests’. The concept of ‘best interests’ is currently set out in Common Law, but will shortly have to be decided in compliance with the Mental Capacity Act 2005. Where the focus person’s level of comprehension and expression is in question the

professional services of a Speech and Language therapist should be sought at an early stage in the process (Bradshaw, 2005).

- ***Preference identification*** – One of the issues raised was that some focus persons had not made choices themselves at their meeting. In some, though not all, cases this may have been due to other persons not having the skills to communicate with the focus person. In such cases, others at the meeting may have expressed the view that the focus person likes certain things. Whilst proxy information, such as that gained from parents or carers may be helpful and accurate this is not always the case. In fact a study undertaken by Reid et al. demonstrated that less than half of the items or activities identified as preferences via PCP and included in individuals' plans were in fact enjoyed by the focus persons – in fact, in some cases the focus person actively avoided the 'so-called' preferences (Reid, et al., 1999). Given that determining preferences is the foundation upon which individuals' plans are built, it is clearly an important issue. Fortunately, it is possible to reliably determine a person's preferences even where they lack speech by using techniques that emerged from behaviourist work.

Thus, we suggest that training in techniques such as 'systematic preference assessment' be provided to facilitators and that such assessments are undertaken in relation to things identified at the meeting as the focus person's preference.

#### **1.1.5. Local social services / health trusts/ charitable bodies**

These organisations are large and complex. A Facilitator or Care Manager with little knowledge of one or more of these bodies may find it difficult to negotiate the systems these bodies have in place. The corollary of this being that processes and outcomes sought as part of the planning process may be unnecessarily delayed. They should also be aware of what services are offered by these bodies in order to ensure that the most appropriate body is approached. Although knowledge may be developed by individuals over time it is important that this is shared, perhaps in the form of a directory. This would avoid situations where excessive time is spent seeking information readily available to other people working with service users.

#### **1.1.6. Organisational change**

There was a perception that some personnel were less than positive in their willingness to embrace PCP. Those persons implementing PCP need to acknowledge the hesitation of some personnel to embrace it and be able to bring about organisational change. Simply being charismatic and enthusiastic about PCP will not bring about such change. Rather, the management of change is a complex process which needs to be learned and developed.

#### **1.1.7. Other pertinent Issues**

There were a number of issues that appeared to negatively affect the outcomes of the process for clients. These included the focus person having limited or no verbal communication (see recommendation above); being diagnosed as being on the Autistic Spectrum or having been accused of offending behaviour.

Where focus persons have additional needs, facilitators should be trained as to how best to work with such clients or should be able to draw on resources that will enable them to work more effectively with such individuals.



## **2. Policy – practice issues**

### **2.1. Communication**

The study suggested that communication between service users, the PCP facilitator and service providers such as social workers and care managers was generally poor. Failure to do use appropriate communication techniques in relation to service users amounts to breach of a statutory duty:

- Reliance on verbal and written communication is unacceptable - A wider range of communication methods should be explored including; pictorial communication techniques, signs and symbols, and electronic aids.
- There is a need for clearer and more frequent communication between service users, family and other carers and local authority personnel.

### **2.2. Increased participation by focus persons**

Overall, the focus persons involved in the pilot project were only involved in the planning process in limited ways, for example by saying who they would like to attend the meeting. This was, on one occasion, partly due to the focus person not liking to discuss the future. However, the Robertson et al. study demonstrated that the higher the level of participation of the focus person, the more positive the outcomes (Robertson, et al., 2007). In order to increase focus person participation we would recommend:

- That the Authority determines what is meant by, ‘the person being at the centre’ and making this clear is implementation guidance. For example, it should advise whether it is acceptable for the person to simply be present at meetings or whether they should they be an active part of the process. It should also provide advice on the weight to be given to suggestions made by others, such as parents and carers.
- That focus persons are given better information on PCP and how it may affect their lives; one possible reason for low involvement being that previous experiences have resulted in their having low expectations of services.
- That the most appropriate means of communication is adopted both between focus persons and others and in the way in which meetings are recorded and plans are distributed (There is in any case a legal duty on the NHS and LAs to do this).
- That focus persons are offered the services of independent advocates (IMCAs) when there appears to be conflict between their wishes and those of their carer or the service.
- That focus persons are not simply presented with a set of options that are felt to be achievable by the service, but are encouraged to spend time considering possibilities prior to their planning meeting. This would reduce concerns of acquiescence (Bradshaw, 2005).

### **2.3. Increased participation by parents, other family carers and friends**

One of the ‘key’ aspects of PCP is that family members and friends are full partners (Ritchie, et al., 2003). This was not always the case in this pilot scheme. In fact, some family carers felt purposefully distanced. Whilst it may be the case that individual focus persons do not want their families involved it is important that this is their choice and that they are not discouraged from involving family members and friends. We recommend:

- That a systematic approach be made to contact family carers and friends.
- That a time frame for the meeting is adopted that will allow family carers and friends to attend.

- That meetings are held at a time best suited for the focus person, their family and friends than the facilitator or service provider.
- That meetings are held in the focus person's choice of venue, but that this venue should be accessible.

#### **2.4. Strong management / co-ordination**

Comments made by persons involved in the study suggested that the PCP facilitator was not managed adequately and that focus persons and their carers were unable, at times, to contact him or ascertain the progress of plans. They were also unsure of the facilitator's role and the extent to which he 'should help make the plan happen'.

- There is a need for co-ordination / management of facilitators in order to ensure that progress is made throughout the authority and that those with more complex needs are not neglected.
- PCP facilitators should be provided with a clear job description as people were not clear as to the PCP facilitator's role.
- PCP facilitators should explain their role clearly to focus persons and their carers in order that they know what they can and cannot expect.

Stronger management and co-ordination should not only be concerned with facilitators. Rather, it should be used to demonstrate the organisation's desire to be person centred (McIntosh & Sanderson, 2006). Although training in the principles of person centred methods of working is important, training alone may not result in all personnel engaging with clients in a person centred way (Rhodes, 2006).

#### **2.5. Appointment / Selection of facilitators**

It is unknown to the research team as to how the PCP facilitator was selected. The PCP co-ordinator did have considerable experience of advocacy work. However, there were occasions where the facilitator's commitment to the project was questioned by participants.

- Facilitators should be selected or recruited carefully. This is particularly important given the findings of Robertson et al. that the largest factor in determining the success or failure of PCP implementation is the facilitator (Robertson, et al., 2007).

#### **2.6. Mentoring and support of facilitators**

Comments made by participants suggested that the PCP facilitator in this study received little support from his managers and the Authority.

- Given the nature of the work it is important that facilitators receive mentorship / 'clinical' supervision in order to develop their practice in a non threatening environment and have a facility for off-loading difficult issues (Sanderson, et al., 2006).
- We would also recommend that facilitators be afforded appropriate support to enable them to undertake their role effectively. Examples of such support include administrative assistance or information technology support.

#### **2.7. Policy development**

If the authority is to introduce PCP on a wide-scale basis, it should develop and implement a comprehensive PCP policy. The policy should be in a format that is accessible to all personnel, carers and services users. It should, *inter alia*, explain the rationale for the introduction of person centred ways of working, outline some of the tools that are available and provide sufficient information for service users and persons supporting them to make

reasoned decisions about such things as whether they wish to have a plan, what type of tool they feel would be most helpful and what they might expect in the way of outcomes. The policy should also promote the development of autonomy amongst service users and provide both theoretical and practical guidance on person centred ways of working. Failure to provide a comprehensive and useable policy may result in the 'completion' of a large number of plans without any improvement in the quality of life of service users (Adams, et al., 2006).

### **3. Further research – monitoring of process and outcomes**

#### **3.1. Audit / monitoring**

Both the process and outcomes of the implementation of PCP need to be monitored. Whilst services are understandably most concerned with outcomes, it is evident from this study that the process is of equal importance. Additionally, although measurable outcomes may not always be achieved, for example a person moving into independent living, they may develop skills or overcome issues that are necessary precursors to them achieving more tangible outcomes.

There is a need to focus on both the process, i.e. "Is PCP happening and if so how?" as well as upon outcomes in order to avoid PCP becoming a paper exercise. Whilst there is currently no 'gold standard' concerning the implementation of PCP, there are some 'tests' which have been used including those posited in People, Plans and Practicalities (Ritchie, et al., 2003) and those used in the Robertson et al. study (Robertson, et al., 2005).

#### **3.2. Research**

The study we undertook was limited in a number of ways. If it is to be replicated and/or extended then:

- The sample should comprise participants of different age and level of disability.
- Participants should also be sought from a variety of backgrounds and settings in order to collect richer data.
- The duration of the data collection period should be longer.
- A two-way exchange of information by any means possible should be established prior to the administration of any intervention.

At the end of Stage two of the study we developed a model (*APPENDIX 4*) which showed the way in which PCP could interact with the existing situations in which people were. As a result of most people not having developed plans by the end of the Stage three interview process it was not possible for us to determine whether this model was useful and accurate.

- We would suggest that if PCP is introduced more widely and further research / audit is undertaken that the model be used.

Neither this study nor that undertaken by Robertson et al. (2005) compared the impact of person centred planning on one group of service users with the impact of an alternative form of planning or alternative PCP tool on another group of service users with similar characteristics. Given this, it is not possible to say that any changes that did occur in a focus person's lives were the result of PCP. Such changes may have occurred despite PCP. The Robertson et al. study was, however able to make comparisons between other factors that may influence the outcomes of the planning process. However, in this study

there was only one facilitator so it was not possible for us to consider the effect of different types of facilitation or such questions as whether the background of the facilitator has any bearing on outcomes.

- We would suggest that future research should include a greater comparative element in order to better assess the true impact of PCP and the factors that may facilitate, or otherwise, its effectiveness. This suggestion was, in fact made some years ago (Iles, 2003).

#### **4. Response from service on report**

The Local Authority is keen to promote the development of the principles of person centred planning throughout all services that people with learning disability in the County receive.

It was recognised that to achieve this there would be a need to develop a clear strategic plan for how this would / will occur and invest in training so that service providers and carers would have the necessary value base, skills and knowledge to enable them to support service users in developing plans. To take this forward an independent agency was commissioned and a part time facilitator employed, showing the Local Authority's clear commitment in this area.

During the period commissioned a major focus appeared to be on training and a significant number of people undertook the training offered. The strategy failed to materialise and whilst PCP's were undertaken with a small number of people, it was felt, that the facilitator did not always negotiate with people in the individual's network sufficiently. The facilitator initially employed subsequently left, leaving the tasks initially requested incomplete.

Currently we are continuing to work with the initial agency commissioned and person centred working is seen as an area of significant importance in the Local Authority. We have a new PCP facilitator who has, within the short time that she has been working in the Authority, supported a number of people to explore their aspirations. This has made real difference to these individuals.

The perceived role of the facilitator is as follows.

- To take a lead on the development of a PCP strategy
- To engage with service users to support them in developing PCP's
- To support people who accessed the training in taking person centred planning forward in the county.

There remains a need for a clear strategic plan re the implementation of PCP within the county and this is something that we are actively discussing in line with the implementation of other initiatives such as the development of the personalisation agenda.

Due to the changes of facilitator and specifically the lack of *initial* outcomes we have been delayed in the development of PCP however this is now being addressed.

Whilst both the local authority and the health service staff within the CLDT fully endorse the principles of PCP and aim to work in a person centred manner there are some dilemmas which do need to be considered such as the statutory requirements we have to meet, especially in relation to managing risks and the protection of vulnerable

adults. The research report completed appears to reflect the initial facilitator's view that staff within the community team viewed PCP intervention as negative. We must point out that this was/ is not the case.

It is felt that the research report focussed on a very small number of people that receive services from the team and therefore is not representative of the person centred manner in which the team works. Some views identified in the report are the specific views of the initial facilitator, which were not always clarified or discussed with members of the team to ensure that a balanced viewpoint was reached.

It is felt that it would have been useful, if the views of the team could have been represented within the body of the report, this did not occur and we feel that there was a missed opportunity to clarify the positive impact of person centred working within our county. However, seeking such clarification was outside the remit of the research which was commissioned to focus solely on the views of those receiving PCP and the facilitator and this will be addressed in any further work commissioned.

## PART VI - APPENDICES

### APPENDIX 1 – Literature search and review

#### 1. Literature search

- Searches were undertaken of indices of all electronic journals relevant to Learning Disability available through the Glamorgan 'findit' service for the years 2000 - 2005.
- Manual Searches were undertaken of all issues of Learning Disability Practice and of the last five years of the BILD Current Awareness Service.
- Additionally, some local individuals with knowledge or interest in person centred planning locally were contacted requesting them to provide any appropriate references they were aware of. This resulted in access to two articles in Llais; information on the Emerson Project (yet to be published); access to an Essential Lifestyle Planning Manual and referral to a number of relevant websites.
- Searches of the electronic databases; BNI, Ovid, Psych Info, Web of Knowledge and ASSIA were performed using the following key words, all cross referenced: person-centred planning; person-centred approaches; person-centered planning; person-centered approaches; life planning; lifestyle planning; learning disability(ies); learning difficulty(ies); intellectual disability(ies); intellectual impairment; developmental disability(ies); developmental delay; cognitive disability(ies); cognitive impairment; mental handicap; mental retardation; mental subnormality).

#### 2. Literature review

##### 2.1 Introduction / background

Although person-centred planning (PCP) is not a new way of working with men and women with learning disabilities, as will be discussed below, it is only during the last four years that its widespread implementation throughout the United Kingdom (UK) has been advocated.

The predominant reason for the current interest in the use of person-centred planning within the UK is to be found in the 2001 Department of Health White Paper, '*Valuing People*' (Department of Health, 2001). Whilst in Wales, a strategy document, '*The All Wales Strategy*', was produced in 1983 (Welsh Office, 1983), '*Valuing People*' is the first major strategy document to be produced in England since the 1971 paper, '*Better services for the Mentally Handicapped*' (Department of Health and Social Services and the Welsh Office, 1971).

'*Valuing People*' has four key principles, namely; rights, independence, choice and inclusion. That person-centred planning is regarded as a key means of improving the level of control men and women with learning disabilities have over their lives can be seen from objective three:

*“To enable people with learning disabilities to have as much choice and control as possible over their lives through advocacy and a person-centred approach to planning the services they need” (Department of Health, 2001).*

The government’s view of the importance of PCP in England has further been demonstrated by the provision of Department of Health Guidance on a person-centred approach to planning services in 2002 (Department of Health, 2002) and by the provision of a Learning Disability Development Fund that has provided some resources to support the development of person-centred planning. Additionally, *Valuing People* set targets in relation to person-centred planning, for example requiring that local agencies introduce person-centred planning for all people moving from children’s to adult’s services by 2003 (Department of Health, 2001: p. 43).

In Wales, there is no directly equivalent document to *Valuing People*. Although “*Fulfilling the Promises*” was issued in June 2001, it is not a policy document, but is a report that put forward proposals for a framework for services for people with learning disabilities. Despite the Welsh Assembly Government undertaking a consultation exercise with a view to deciding to adopt the proposals contained in the report, little has been done since that time to implement any of the proposals. Given this, there is no clear government mandate that PCP should be introduced on a widespread scale within Wales. This said, however, many services are seeking to provide their services in accordance with the vision of the Learning Disability Advisory Group that were set out in ‘*Fulfilling the promises*’. One objective of that vision was that by 2010, services for people with learning disabilities in Wales will be:

*“person centred (i.e. respond to individual needs, including language, race, gender and religious requirements and circumstances)” (National Assembly for Wales, 2001: p. 8).*

The report further went on to state that,

*“Person centred planning should be confirmed as the key mechanism to plan people’s care and support for their whole lifetime...” and recommended that, “By 2003/2004, all people with a learning disability will have an individual person centred plan, normally reviewed annually” (National Assembly for Wales 2001: p. 10-11).*

Despite the fact that the recommendations in *Fulfilling the Promises* have not been adopted by the Welsh Assembly Government, further support for the adoption of person-centred approaches, at least by nurses, may be found in the briefing paper ‘*Inclusion, partnership and innovation*’ (All Wales Senior Nurse Advisory Group (Learning Disability), 2002). Whilst this document does not explicitly refer to person-centred planning, it does state that nurses should be encouraged to,

*“Empower clients to actively participate in developing appropriate packages of care” and “seek the views of the client, their families and the wider community in planning high quality services” (All Wales Senior Nurse Advisory Group (Learning Disability) 2002: p. 8, 11).*

As a result of such guidance, a number of local authorities have decided to implement person-centred planning. One such authority is the local authority of the present study. Their strategy provides that by the end of the first year of the strategy, up to ten individuals will start person-centred plans. As part of their strategy, they have commissioned the Unit for Development in Intellectual Disabilities, University of Glamorgan to undertake research.

This literature review is the first step in the research process.

## **2.2. PCP – What is it?**

Although there does not appear to be a universally accepted definition of PCP, in the literature generally or in government policy documents, one definition that appears to have gained acceptance by clinicians is that of Routledge et al. (2002). They were commissioned by the Department of Health (DH) to produce the DH's guidance on person-centred planning. They define person-centred planning as,

*“a process for continual listening and learning, focussing on what is important to someone now and in the future, and acting upon this in conjunction with their family and friends. This listening is used to understand a person's capacity and choices. Person centred planning is the basis for problem solving and negotiation to mobilize the necessary resources to pursue a person's aspirations”* (Routledge, et al., 2002: p. 9).

An alternative, and shorter, definition is provided by Ritchie et al. (2003) who state that it is,

*“...a method for focussing effort and attention around one person's situation so that positive changes can be made”* (Ritchie, et al., 2003: p. 28).

One of the difficulties faced by anyone seeking to define person-centred planning is that it is an approach which does not contain any 'new' interventions. What is seen to be important and is said to distinguish PCP from other forms of person centred approaches is the way that person-centred planning combines particular procedures and principles (Holburn, et al., 2000) and is concerned with power sharing, community inclusion (Sanderson, 2000) and citizenship (Thompson, 2005).

A further complexity in defining person-centred planning is that it is not a single method of working, but is a term used to describe a family of approaches (Mansell & Beadle-Brown, 2004a). There are a number of different styles of person-centred planning used within the United Kingdom including; Essential Lifestyle Planning (Smull & Harrison, 1992), PATH (Pearpoint, O'Brien & Forest, 1993) MAPS and Personal Futures Planning (Mount, 1992). These all have some differences and were devised for specific groups. The main differences are how information about the person is gathered, whether the emphasis is on the individual's current day to day life or upon their dreams for the future, and how prescriptive the styles are in format. (Sanderson, 2000).

Whilst there are a variety of styles available for use Routledge et al. (Routledge, et al., 2002) suggest that there are five key features that should be present in order to refer to a form of planning or assessment as Person Centred Planning. They are:

1. The person is at the centre.
2. Family members and friends are full partners.
3. Planning reflects the person's capacities, what is important to the person now and for the future and specifies the support they require to make a valued contribution to their community.
4. Planning builds a shared commitment to action that will uphold the person's rights.
5. Planning leads to continual listening, learning and action and helps the person to get what they want out of life.

Whilst in bullet format, these key features do appear in the descriptions of Person Centred Planning offered by other authors such as Holburn et al. (2000) and Kilbane & Thompson



(Kilbane & Thompson, 2004). They are also reproduced and expanded upon by Helen Sanderson (Sanderson, 2000), one of the leading advocates of person centred planning.

In selecting a style of PCP for use with an individual, both Black (Black, 2000) and Sanderson (Sanderson, 2000) suggest that the choice of style of person-centred planning should be based on how appropriate it is for the person who will be the focus of the plan. For example, Black suggests that if a person does not wish to talk about their past experiences PATH is more appropriate for them because of its focus on the future.

### **2.3. PCP – A brief history**

Person centred planning was initially developed in the United States of America within what have been termed 'communities of practice', that is groups of people with a shared expertise and passion for a particular venture (O'Brien & O'Brien, 2000)], rather than in formal organisations such as the United Kingdom's Social Services or national Health Service (Osgood, 2003).

O'Brien et al. (O'Brien & O'Brien, 2000) state that the 'community of practice' that shaped the earliest of person-centred approaches functioned in North America between 1973 and 1986 and developed out of the principle of normalisation. However, they then suggest that the formative period of person-centred planning was between 1979 and 1992. This was partly due to its spread to the UK resulting in the 'community of practice' becoming cross-national. During this time, some eleven distinct yet related approaches were developed.

O'Brien et al. state that most person-centred planning formats arose from questions asked in PASS, an instrument developed by Wolfensberger to quantitatively evaluate human services. Initially, people with a learning disability were not asked what they wanted. Instead, staff was encouraged to look at what services were required from the focus person's point of view.

Rudkin & Rowe (Rudkin & Rowe, 1999) whilst not disagreeing with O'Brien et al's view suggest that many of the person-centred approaches to lifestyle planning came about as a reaction to staff or systems-led approaches to personal lifestyle planning such as Individual Programme Planning (IPP) or Shared Action Planning (SAP). This view of person centred planning as having evolved from previous kinds of individualised planning is also supported by Emerson & Stancliffe (2004), Felce (2004), Mansell & Beadle-Brown (2004b) and Towell and Sanderson (2004).

### **2.4. PCP – Concerns**

As noted above, PCP was not developed for widespread use within formal organisations. As a result of this, a number of people have raised concerns about the planned widespread implementation of PCP by organisations such as Social Services and NHS Trusts. The following are some of the most commonly raised concerns.

Routledge et al. (Routledge, et al., 2002) note that during the early stages of their producing guidance on PCP for the DoH a number of persons already involved in person centred planning were of the opinion that guidance on PCP would simply lead to its ownership by services and that this would reduce the power of PCP to help people achieve self determination. This concern has also been expressed as to the widespread uptake of PCP (Carnaby, 1999). Additionally, there is a concern that by requiring that PCP be implemented widely, services may simply adopt the language of PCP but not the

practice (Black, 2000; Our Man in London, 2002). That is to say it may become something else that services do to, rather than with people with learning disabilities. Alternatively, the process may become seen as an end in itself and whilst individuals may have person-centred plans, these plans may result in little change to their quality of lives, a concern that a number of authors raise (Black, 2000; Osgood, 2003).

A further possible concern is that PCP may be undermined as a result of implementation errors. O'Brien et al. (1997) cited in Holburn et al. (Holburn, et al., 2000: p. 405) refer to eight such possible errors, namely:

- (i) a general lack of mindful planning and reflection
- (ii) mandated meeting attendance
- (iii) planning by team members who have little experience with the or knowledge about the person
- (iv) omitting crucial participants such as immediate family members
- (v) proceeding with the process at an unnatural tempo
- (vi) an absence of real problem solving
- (vii) planning in agencies that are not committed to significant change; and
- (viii) focusing on system oriented objectives instead of essential principles to guide the process.

Another concern relating to the wide scale adoption of PCP relates to the need for change in the nature of relationships between service providers, professionals and individuals with a learning disability. Whilst 'person centred approaches' such as Individual Programme Planning (IPP) have been used for some years, professionals have continued to be regarded as powerful experts who are appropriately placed to decide upon what interventions are in the 'best interests' of the individual with a learning disability (Routledge, et al., 2002). Whether or not professionals and organisations will be willing to 'give up' their power and the levels of control they can exert over people with a learning disability is open to question and in some situations would require a major change in attitudes (Emerson & Stancliffe, 2004; Kilbane & Thompson, 2004). Moreover, despite the adoption of 'person centred approaches' the inclusion of men and women with learning disabilities in the planning of their individual programmes has at best been variable, particularly where the individuals have had profound and multiple disabilities or lack speech (Carnaby, 1997a; Carnaby, 1999). For PCP to work individuals with a learning disability (and their circle of support) should be recognised as the experts on their lives. Professionals will, therefore, be required to meet the needs identified by individuals with a learning disability rather than simply fitting the individual into services that are already in existence.

A further concern relates to resources and the organisation of services (Mansell & Beadle-Brown, 2004a). If there is a growth in the uptake of direct payments and/or people with learning disabilities assume greater control of their lives through PCP, this is likely to require considerable organisational change. For example, rather than seeking to fit an individual into a day service that is currently available, the individual may request that they are supported to attend employment or alternative occupational activities. Likewise, if a person who currently lives in a group home wishes to live on their own the implications for resources may be considerable. Other additional resource requirements needed for person-centred planning to become a reality will include the increased availability of Speech and Language services in order to ensure that people lacking speech are able to develop their plans and, Independent Advocacy services in order to ensure that plans are those desired by the individual and not those desired by other interested parties. However,

resources are clearly finite (Felce, 2004) and organisations may find it less inviting to fund a process that has little or no evidence to support its implementation than funding other things which have been proved to result in positive change.

Related to the concern about resources is the concern that services may seek to implement person-centred planning with a view to money saving. The argument posited in support of this concern is that services will emphasise the role of circles of support and thereby move the costs of care from services to individuals, their family and friends (Mansell & Beadle-Brown, 2004b).

## **2.5. PCP – Why do it?**

As Ritchie et al. (2003) state, a simplistic answer would be to say, 'because we have been instructed to do so by government'. However, such an answer fails to demonstrate the rationale for person-centred planning and, in any case, is not truthful in Wales. Moreover, simply implementing an approach because one is told to do so is unlikely to result in people using such approaches in a meaningful way. Additionally, implementing person-centred planning without evidence to support its effectiveness appears to contradict other government policy such as that all 'interventions' in health and social care should be evidence based.

A better answer is that person-centred planning will result in positive changes for people with a learning disability. It is widely recognised that people with learning disabilities may not have had the life experiences and opportunities of the majority of the non-learning disabled population. Similarly people with learning disabilities have often lacked control over their lives (Kilbane & Thompson, 2004). Person-centred planning is seen as tool for addressing these issues and bringing about increased independence, choice and inclusion (O'Brien, 2004). That is to say that it helps one see the deficits in the life of the focus individual and what could be possible given the appropriate support (Towell & Sanderson, 2004). Additionally, it is seen as a rights based approach which recognises that people with a learning disability should be entitled to the same rights as the non learning disabled population.

## **2.6. The need for research into PCP**

As alluded to in the previous section, whilst there is much material available that promotes person-centred planning, there is very little in the way of empirical data to support the widespread take up of such an approach to providing services for people with a learning disability (Rudkin & Rowe, 1999; Holburn, et al., 2000; Felce, 2004) Studies that have been published include those of Carnaby, (Carnaby, 1997; Carnaby 1997a; Carnaby, 1999); Combes et al. (2004), Holburn et al. (2000) and Parley (2001). The results of such studies are, however, variable. For example, a literature review undertaken by Rudkin and Rowe in 1999 concluded not only that there were very few studies on person-centred planning, but that the limited data that did exist did not support its use with people with a learning disability. However a study conducted by Parley (2001), although finding that little progress was made in a number of areas such as power sharing and the involvement of families, also found that PCP resulted in staff being more respectful to service users and in service users having greater opportunities to make 'everyday' choices.

In addition to the lack of data supporting the use of person-centred planning, there is also concern that, even where it is used, people with a learning disability may not be involved in the planning process to the extent that is possible (Carnaby, 1999; Parley, 2001).

Person centred planning is seen by some as a tool for making change happen (Black, 2000; Thompson, 2005). Given this, one issue of concern is the question of whether person-centred plans do in fact work. There are two questions that may be asked relating to this. Firstly does the process work, that is to say are people with learning disabilities being supported to engage in and manage the process with support as necessary? Secondly are the plans being implemented and if so what impact are they having on individuals' quality of life? Carnaby (1999) suggests that most services focus on outcomes rather than the process. Successful outcomes are clearly important and there is a danger that a person's satisfaction with life may decrease if the PCP process simply raises possibilities that are then not realised (Rudkin & Rowe, 1999). However, the planning process is also of importance as it may be empowering for individuals and their families (Black, 2000).

A further question of relevance is that of service practice. A number of writers express the view that a variety of issues may make it difficult for services may find the implementation of person-centred planning difficult. Such issues include fixed investments in staff and buildings, financial inflexibility, and a likely increase in cost and risk (Black, 2000; Osgood, 2003). Given this, it is important to enquire how easy it is for services to adopt such an approach. What changes need to be made in order for services to be able to adopt such an approach? What factors make it more or less likely to be adopted?

A final reason for undertaking evaluative research into person-centred planning is that given that there are only finite resources it is important that we seek to make best use of those. If person-centred planning enables people with a learning disability to get what they need and want and provides a basis for claiming resources for people with an intellectual disability then it is valuable (Mansell & Beadle-Brown, 2004b). However we currently do not have the evidence to support this view.

## ***2.7. A brief review of some methods used to evaluate person centred planning***

Whilst few studies have been published as to whether person centred planning is effective or not, one 'tool' which has been used to evaluate it is O'Brien's five accomplishments (Carnaby, 1999; O'Brien & O'Brien, 2000). For example, the key accomplishments of community presence, community participation, choice, respect and competence were used as the basis for evaluating the outcomes of PCP by Holburn et al. (Holburn, et al., 2000). However, this study did not involve any individuals with a learning disability and thus may be seen to be antithetical to the values upon which person centred planning is based.

A second form of methodology used to evaluate person-centred planning was that described by Parley (2001) as a person centred service review (PCSR). This involved the use of a service reviewer spending time with service users over a period of time in an attempt that they could experience the service as service users did. Such observation was undertaken prior to person-centred planning being implemented and was then repeated after its implementation. The criteria which the reviewer used to review the service were those developed by the National Development Team in 1998, many of which are based upon the five accomplishments. This review was combined with the use of nominal group technique to ascertain the views of the staff involved in the implementation of person-centred planning. This method whilst not directly ascertaining the views of service users does at least make an attempt at gaining an understanding of their experience. However,

how successful an individual can be at reporting someone's experience based on them observing the service they receive is clearly open to question.

Another reported methodology that may be appropriate for evaluating PCP is Q-Methodology, a phenomenological approach that enables a researcher to co-construct the stories of a number of people using text or pictures (Combes, et al., 2004). They found that this method enabled all the people involved in an individual's life (including individuals with moderate learning disabilities and communication difficulties) to evaluate the subjective or phenomenological change that occurred through person centred planning. One of Combes et al's (Combes, et al., 2004) main findings was that both of the individuals with a learning disability involved in their study valued being with their friends and families more than they valued cleaning and everyday activities. Whilst a small study, which is not generalisable to the learning disabled population at large, it does raise questions about the types of activities that are being promoted by services, who find measuring such activities straightforward, and advocates of person centred active support who argue that such activities are meaningful and better than disengagement (Mansell, et al., 2004). This finding also strengthens the argument for individuals to have as wide a circle of support as possible (Combes, et al., 2004).

## **2.8. Concluding remarks**

Whilst there is considerable support for person-centred planning, to date, it does not appear to have reached many individuals within South Wales. This may, in part, be due to the lack of a governmental mandate for widespread implementation of person centred planning in Wales. However, it may also be due to the unwillingness of organisations to implement a process that lacks little in the way of empirical evidence to support it. The findings of the proposed research may, if found to support the use of person centred planning, provide local authorities within South Wales with a evidence based rationale for implementing PCP on a wide scale basis.

## **APPENDIX 2 – Results of the quantitative scales (Stages 2 & 3)**

### **1. Demographic data**

7 Focus Persons (FP) participated in the study<sup>1</sup>. FP5 and the carer of FP5 took part only in Stage 2, as they refused to participate in Stage 3. FP9 and the carer of FP9 participated only in Stage 3 as they agreed to participate in the study only after Stage 2 was completed. As a result, all data from FP5 and FP9 are excluded from any quantitative analysis. Demographic characteristics of the FPs can be found in *Table 1*. Nine carers (including second carers) participated in the study. Their characteristics are shown in *Table 2*.

### **2. Changes between Stages 2 & 3**

Six scales (A, B, C, D, E and F) were administered at Stage 2 and eight scales at Stage 3 (the same as in Stage 2, plus two more scales, G and H, which considered only the implementation of PCP):

---

<sup>1</sup> FP1, FP2, FP3, FP5, FP6, FP7 and FP9

1. Scale A: measured the number of times that the focus person had taken part in activities in the last 4 weeks, from a pre-defined list of activities. Because the number of times that an activity had been undertaken did not have any quantitative value at this level of the research, it was decided instead that the number of activities undertaken would be used in the analysis. Scale A was administered to all participants.
2. Scale B: measured who had been important in FP's life over the past month. The people who had been important were categorized in 7 different social networks, such as 'formal services' and 'family'. For the analysis the number of social networks (from 1 to 7) from which the FP had received support, information, or advice was used. Scale B was administered to all participants.
3. Scale C: measured the satisfaction with current arrangement in the FP's life and was administered only to carers (not second carers).
4. Scale D: measured the use of community-based health and social care services in the last six months. The scale was not administered to FP.
5. Scale E: measured the ways that the FP was cared for and supported in making choices. The scale was not administered to FP.
6. Scale F: measured changes in the FP's abilities in the last 6 months. The scale was not administered to FP.
7. Scale G: measured the impact that possible barriers (from a pre-devised list) might have on the achievement of the goals set at planning meetings. The scale was not administered to FP.
8. Scale H: from this scale only the items 1 (overall rate of the planning meetings) and 5 (changes as a result of involvement in PCP) were used in the quantitative analysis. The scale was not administered to FP.

There have been 3 groups of participants: focus people, carers, and second carers. Not all scales have been administered to all groups. As a result, some scales have not produced enough data for a quantitative analysis to be conducted. The following results are based on comparison amongst the three groups of participants (whenever that has been feasible) and between Stages 2 and 3 of the study.

When reading the following tables it must be taken into account that this study has been a pilot study with 7 participants, and that in the case of two of them data has not been used in the quantitative analysis. Thus, the following tables are only presented for descriptive purposes and should only be used in order to gain an overview of the tendencies in these 5 participants. In addition, many items were answered '*have not been applicable*' to certain participants and/or '*the carer did not have the information/knowledge*' to answer a questions. As a result, there is a large amount of 'missing' data (especially for scales A, D, E, and F). SPSS has three ways of dealing with missing data: list wise deletion, pair wise deletion, and mean substitution. One can also drop selected variables. However, because the data set was small and there was a non-random distribution of missing data the problem was serious and thus the idea of any analysis was abandoned.

### 3. Descriptive results

In Stage 2 participants agreed that the most commonly undertaken activity was shopping. In Stage 3 the most common activities apart from shopping have were going to a cafe and on holiday (*Table 3*). Seven social networks were discussed during the interview along with the possible support the FP receives from these networks. Three of the networks, organizations/clubs, neighbours and other friends increased in number of people that provided support to the FP person, whereas the support from work or day services decreased (*Table 4*). Interestingly the level of involvement in decisions made about the FP was perceived to have decreased between Stage 2 and Stage 3. Most carers thought that the FP they supported felt more negative in Stage 3 regarding their current support from services than they did in Stage 2. However, the carers themselves did not show a significant change between Stage 2 and Stage 3 about the support received from services. Carers reported feeling as informed in Stage 2 as Stage 3. However, their overall satisfaction from one Stage to the next dropped significantly (Pie chart 1).

In Scale G carers discussed the main barriers perceived to stand in the way of the achieving the goals set at planning meetings. There was general agreement that the main barriers include: participant's lack of money; participant's problems with transport; location of participant's home (e.g. rural); not enough staff support for the participant, and a; lack of suitably trained staff to support the participant. Other barriers that were not on the list but were discussed by the participants included: communication; cost of services, and the fact that services were not always geared to the client's needs (*Table 5*).

Participants' views were mixed when it came to their providing an overall rating of the planning meetings (*Table 6*). However, participants' views were more solid when it came to their evaluating changes resulting from the implementation of PCP; 5 out of six carers agreed that there has been no change as a result of their involvement in PCP (*Table 7*).

**Table 1 FPs' demographic data**

Demographic data	Level	N
Age	21-30	4
	31-40	1
	41-50	2
Gender	Male	4
	Female	3
Learning disability **	Mild	3
	Moderate	2
	Severe	1
	Profound	1
Physical disability	None	3
	Mild-moderate	2
	Severe-profound	2
Communication	Verbal	3
	Some verbal	2
	Non-verbal	2
Residence	With parents	3
	Independent	1
	Foster family	1
	College	2*

\* two participants moved from college to their parents' house before Stage 3 took place

\*\* the level of LD does not represent an official diagnosis, but it is estimated by the researchers of this study

**Table 2 Carers' demographic data**

Stage	1 <sup>st</sup> or 2 <sup>nd</sup> carer	Type of carer	N
2	Carer	Mother	3
		Father	1
		Paid carer	1
		Day centre staff	1
		Keyworker	1
	Second carer	Mother	1
	Keyworker	1	
3	Carer	Mother	4
		Father	1
		Paid carer	1
		Day centre staff	1
	Second carer	Mother	1
		Keyworker	1



**Table 3 Scale A**

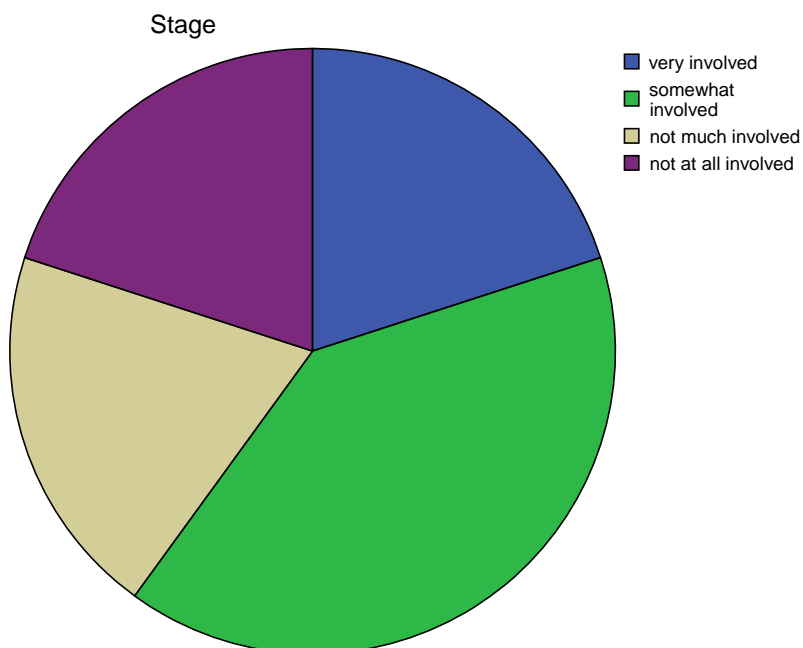
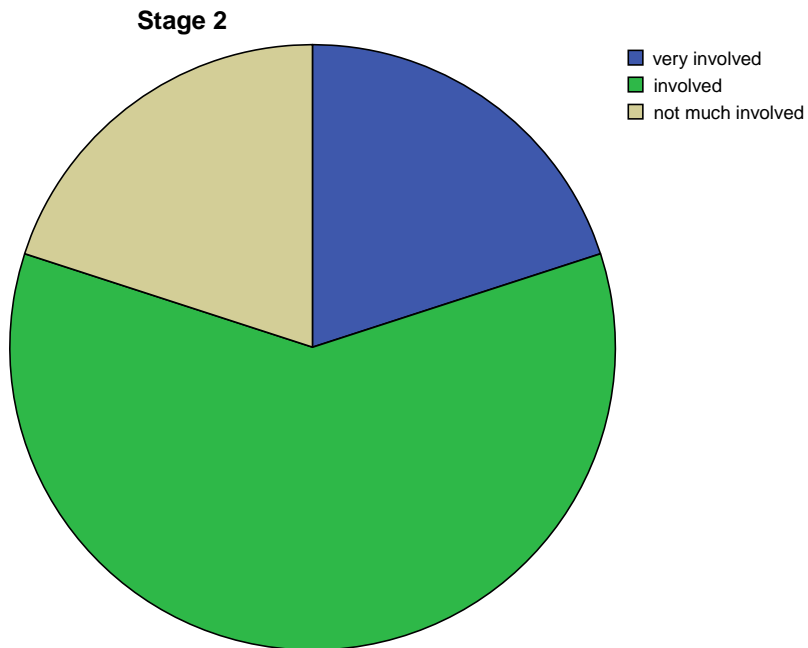
Stage	Scale A: Leisure activities	
	Most common	Least common
2	Shopping	Overnight stay Cafe Hairdresser Sports event Bank/post office Concert/play
3	Cafe Shopping Holiday	Guests Family/friends Overnight stay Social club Hairdresser Concert/play Public bus Bank/post office

**Table 4 Scale B**

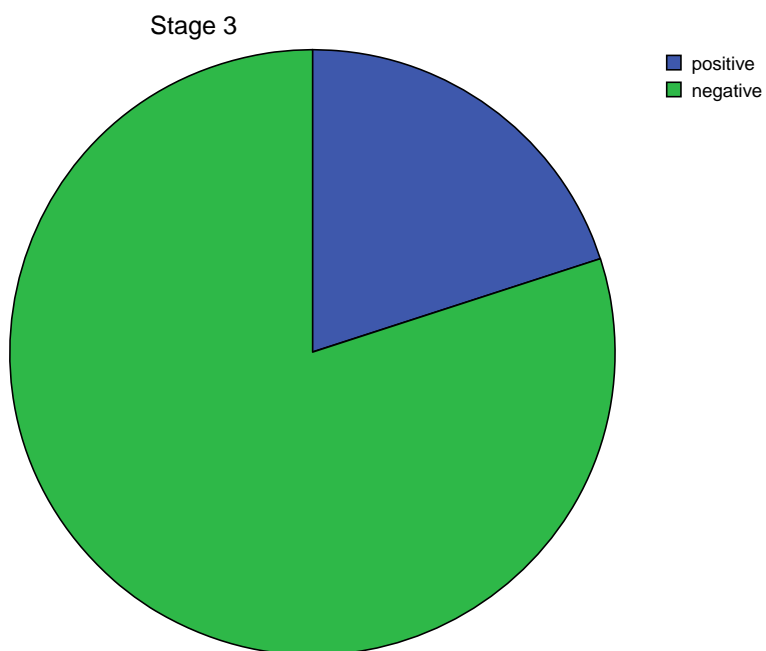
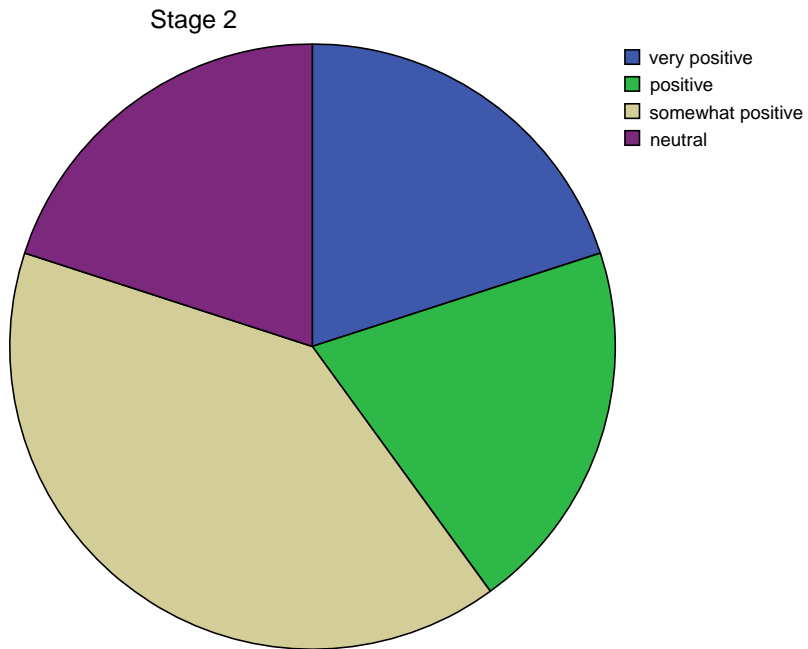
Scale B: Relationships: Social networks	Change in Stage 3
1. Formal services	No change
2. Household	No change
3. Family	No change
4. Work or Day Service	Decreased
5. Organisations or clubs	Increased
6. Neighbours	Increased
7. Other friends	Increased

## Pie chart 1 Scale C

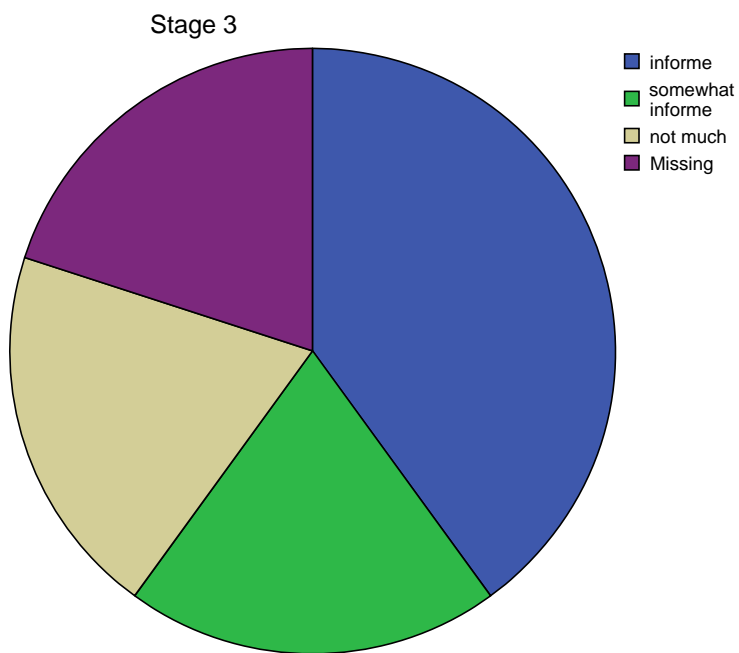
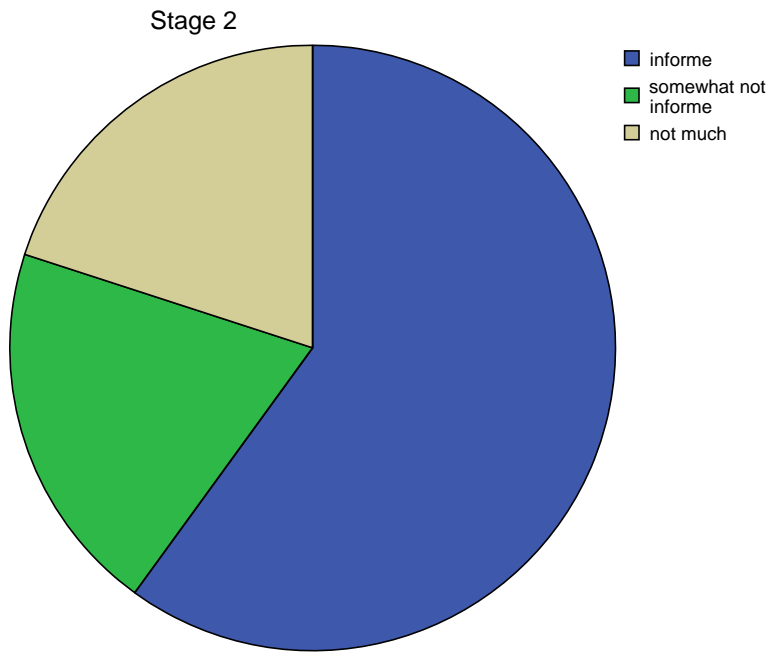
**1. How involved do you feel in decisions made about the person you care for by the services that support them?**



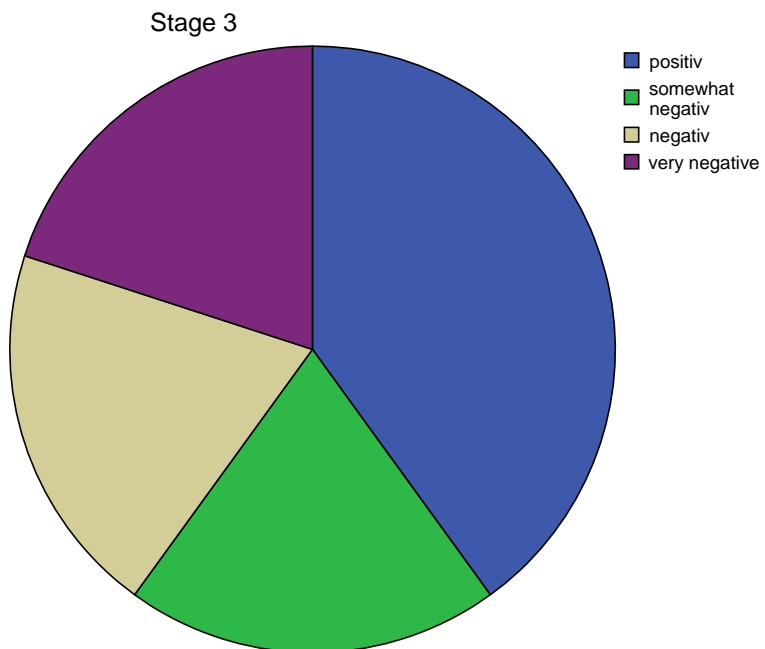
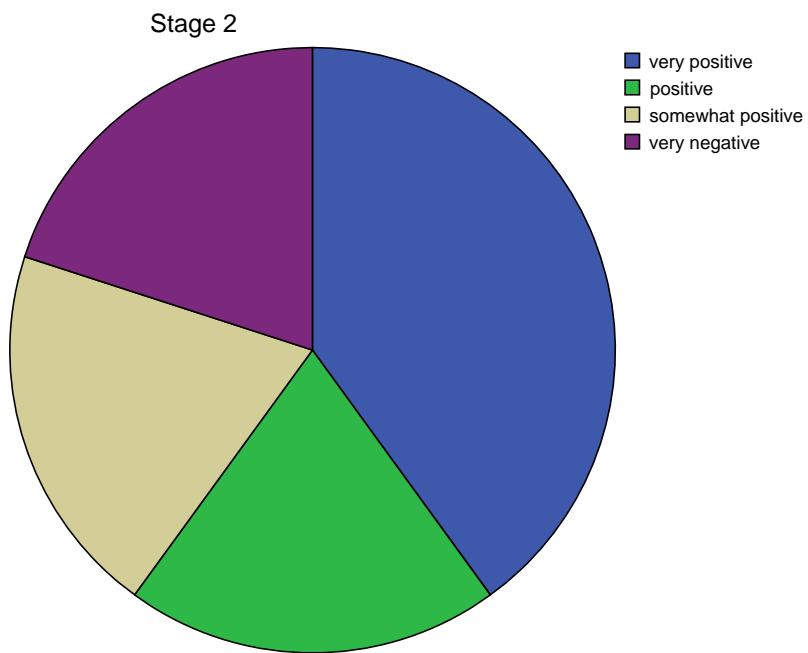
**2. How do you think the participant feels about their current support from services?**



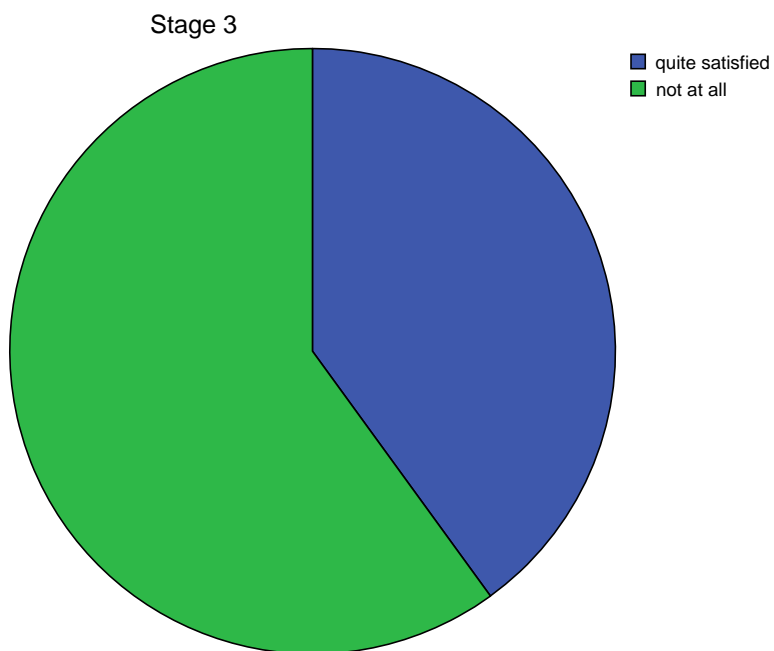
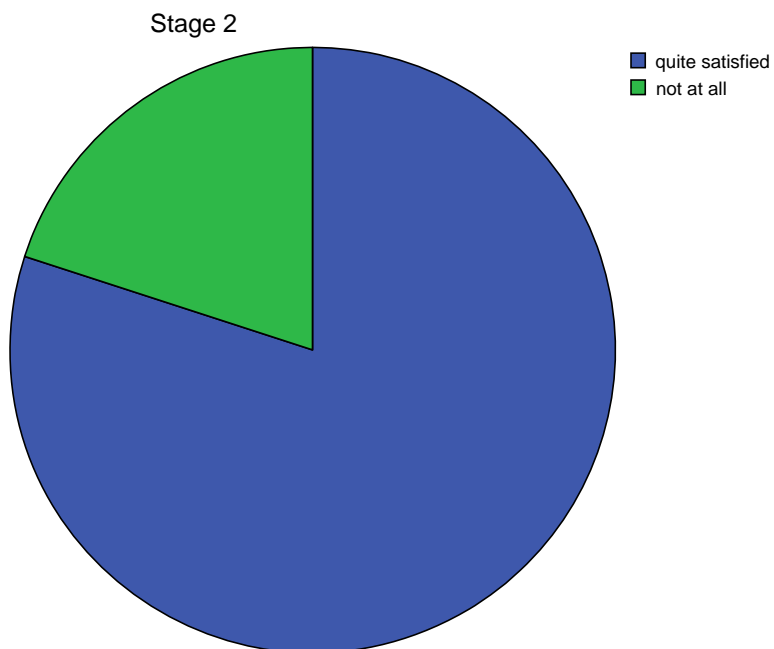
**3. Do you feel you are kept informed of what is going on?**



**4. How do you feel about the participant's current support from services?**



**6. Overall, how satisfied are you with the support you receive from services**



**Table 5 Scale G**

<b>Barrier</b>	
<b>More impact</b>	<b>Less/no impact</b>
Lack of money	<ul style="list-style-type: none"> <li>• FP's reluctance to try new things</li> </ul>
FP's problems with transport	<ul style="list-style-type: none"> <li>• FP's ill health</li> </ul>
Location of FP's home	<ul style="list-style-type: none"> <li>• Support staff not doing what they are supposed to do</li> </ul>
Not enough support staff for FP	<ul style="list-style-type: none"> <li>• Support staff's reluctance to try new things</li> </ul>
Lack of suitably trained staff for FP	<ul style="list-style-type: none"> <li>• Lack of accessible activities in the community</li> </ul>
Other barriers	<ul style="list-style-type: none"> <li>• Limited employment opportunities</li> <li>• Limited choice of housing</li> <li>• Limited choice of day services</li> <li>• Waiting lists for services</li> <li>• Attitude of people in the local community</li> <li>• Unrealistic goals</li> <li>• Goals do not reflect what the FP really wants</li> </ul>

**Table 6 Scale H – Item 1**

	<b>How would you rate the planning meetings overall? (Total N = 6)</b>
Very good	1
Good	2
Neutral	1
Bad	1
Very bad	1

**Table 7 Scale H – Item 5**

	<b>Do you think there have been any changes in the participant's life as a result of their involvement in PCP? (Total N = 6)</b>
Yes	1
No	5

## APPENDIX 3 – Topic guides and interview schedules

### 1. Stage 2 – Topic Guide

NB: Underlined text is the topic of interest. Bulleted texts are possible prompts.

#### 1. Existing Plans:

- What services does the person receive from health and social services?
- Has the person a care plan of any type at the moment?
- Were they involved in developing the care plan?
- What does the current plan include / relate to?
- What is their experience of the plan – is it getting them the support they need, etc?

#### 2. Knowledge, beliefs and expectations of Person-centred planning:

- Has the person been provided with information about person-centred planning?
- What is the person's understanding of person-centred planning?
- Does the person think it will change anything for them / the person they care for? If so, how, what, etc.?
- What three things does the focus person/ the person they care for hope to gain from being involved in person-centred planning?

#### 3. Current levels of Choice:

- Does the person make choices about everyday activities, e.g. time of rising and going to bed, what they eat, what they wear, who they spend time with, etc?
- Does the person make choices about activities that occur less frequently, e.g. where they go on holiday, whether they can change their daytime activities, e.g. from attendance at a day service to attendance at college, did they choose who they lived with and where they lived, did they chose their carer (if employed)?

#### 4. Current levels of respect:

- How is the person treated by other clients (if appropriate)?
- How is the person treated by carers, e.g. privacy, politeness, etc?
- How do other people in the person's local area treat them?
- Do other people listen to, and act upon what the person says to them?

#### 5. Current levels of community participation

- What activities does the person do during weekdays?
- What activities does the person do on weekday evenings?
- What activities does the person do at weekends?
- Who do they do these activities with?
- Where do they do the activities?
- Do they get the opportunity to meet new people?
- Does the person get to try new things / activities?



## 6. Current relationships

- Who are their friends?
- Where did they meet their friends?
- Have they made new friends in the last three months?
- Do they have a girl / boy friend?
- Who are the most important people to them and why?
- How often do they see family members they like?

## 2. Stage 2 – Interview Schedules

## ***2.1. Focus person interview schedule***

### **An Evaluation of the Impact of Person Centred Planning**

#### **Stage 2 – Initial Interviews**

#### **Focus Person Interview Schedule**

**To be administered after the semi-structured interview**

Identification Code: 2FP\_\_\_\_\_

**If you have any questions about the questionnaire please contact:**

**Unit for Development in Intellectual Disability,  
School of Care Sciences,  
University of Glamorgan,  
Pontypridd,  
Rhondda Cynon Taff,  
CF37 1 DL**

The questions I am going to ask are trying to find out about changes that may happen when you have a person centred plan. If you wish to 'pass' on any question that is ok. If you want to stop the interview at any time that is also ok.

If you have any questions about the questionnaire, or the evaluation generally, please feel free to contact Paul Wheeler – his telephone number and address are on the front of this questionnaire.

**Preliminary:**

Identification Code: 2FP.....

Date Interview conducted: .....

Name of Person completing questionnaire: .....

**A: Leisure Activities:** How many times have you taken part in the following activities in the last 4 weeks

**NB: Interviewer – you will need to check the individual’s concept of time, e.g. how do they measure it**

--	--

Activity	No of times in the past 4 weeks
Had guests to stay in your home (no. of nights)	
Had family or friends round for a meal	
Been to a social club (for pwld / for non-learning disabled persons)	
Been on an overnight stay to family or friends (no. of nights)	
Had trips out with family or friends	
Been to a cafe	
Been to a pub	
Been to a hairdresser	
Been shopping	
Been to a place of religious worship	
Been to a sports event (eg watched a football match)	
Been to a cinema	
Been to a concert or play	
Been on a public bus (do not include eg minibus to day centre)	
Been to their bank or post office	
Been on holiday in the last 12 months	
Other (please specify)	

**B: Relationships: Social networks:**

Over the past month, who has been important in your life and who has had regular CONTACT with you. This can include people who have provided you with help with things or have given you information or advice.

In the circle below, I will put the initials for each person you think of in the appropriate space. I do not need to know who the initials stand for.

Formal services: people who come into contact with you as part of their job.

Household: people living with you.

Family: family members who you have contact with.

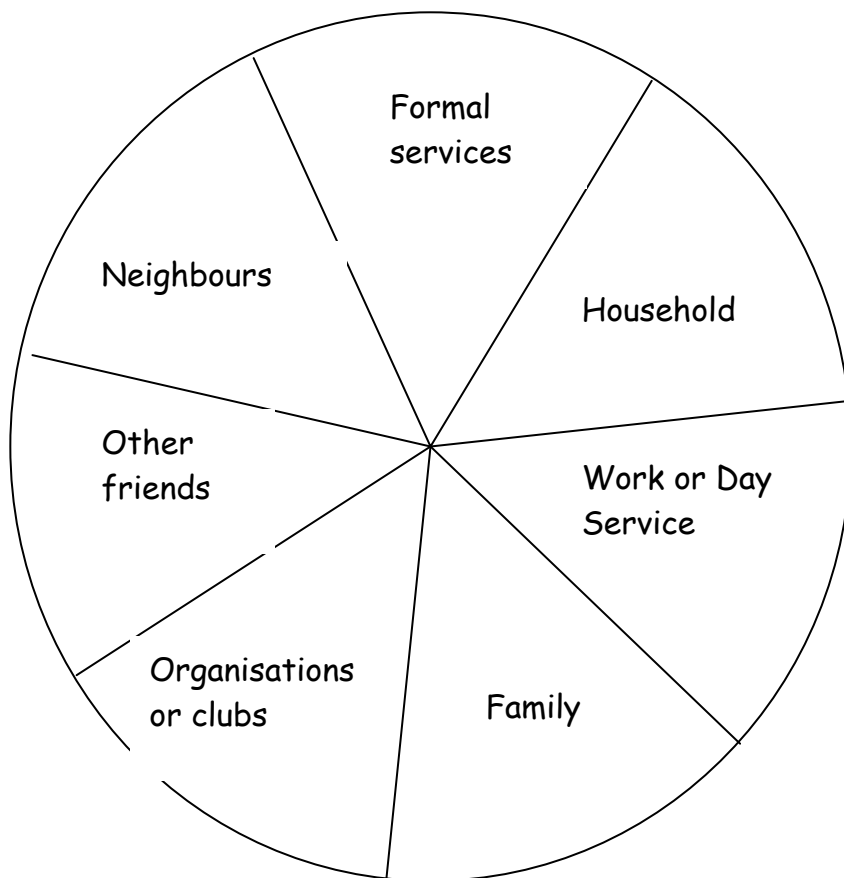
Work/Day Service: people you know from attending work or day service.

Organisations/Clubs: people you know from organisations and clubs or church.

Neighbours: people living close by.

Other friends: any other friends not included in the above.

**If the person identified is a member of staff, or some other person who is paid to work with you, please indicate this by placing a square around their initials. If the person is another person with learning disabilities, please place a circle around their initials.**



## **2.2. Second carer interview schedule**

### **An Evaluation of the Impact of Person Centred Planning**

#### **Stage 2 – Initial Interviews**

**Second Carer Interview Schedule (Only relevant if the focus person lacks the capacity to consent or otherwise or is unable to communicate in a way understood by the interviewer)**

**To be administered to the focus person's 'second' carer after the semi-structured interview**

Identification Code: 2SC\_\_\_\_\_

**If you have any questions about the questionnaire please contact:**

**Unit for Development in Intellectual Disability,  
School of Care Sciences,  
University of Glamorgan,  
Pontypridd,  
Rhondda Cynon Taff,  
CF37 1 DL**

The following questions are to help us find out about any changes in the life of the person who is taking part in person-centred planning pilot project. You are being asked these questions because it is either felt that the focus person is not able to give their consent or because they communicate in a way which the interviewer cannot understand. If you wish to 'pass' on any question that is ok. If you want to stop the interview at any time that is also ok.

If you have any questions about the questionnaire, or the evaluation generally, please feel free to contact Paul Wheeler – his telephone number and address are on the front of this questionnaire.

**Preliminary:**

Identification Code Number: 2SC.....

Focus Person Identification code: 2FP.....

Date Interview undertaken: .....

Name of Interviewer: .....

Relationship of second carer to focus person (e.g. keyworker, parent): .....



**A: Leisure Activities:** Please note the number of times that the focus person (person at the centre of the planning process) has taken part in the following activities in the last 4 weeks. If they have not participated in a particular activity enter 0 in the appropriate column. If the person has taken part in activities not included in the list, for example, any hobbies or other leisure activities, make a note of these by writing them in as “other”.

--	--

Activity	No of times in the past 4 weeks
Had guests to stay (no. of nights)	
Had family or friends round for a meal	
Been to a social club (for pwld / for non-learning disabled persons)	
Been on an overnight stay to family or friends (no. of nights)	
Had trips out with family or friends	
Been to a cafe	
Been to a pub	
Been to a hairdresser	
Been shopping	
Been to a place of religious worship (e.g. church / chapel)	
Been to a sports event (eg watched a football match)	
Been to a cinema	
Been to a concert or play	
Been on a public bus (do not include eg minibus to day centre)	
Been to their bank or post office	
Been on holiday <i>in the last 12 months</i>	
Other (please specify)	

**B: Relationships: Social networks:**

Please tell me the names of people who over the past month, have been important in the focus person's life and have had regular CONTACT with them. This can include people who have provided support or have given them information or advice.

In the circle below, put the initials for each person you think of in the appropriate segment. We do not need to know who the initials stand for.

Formal services: people who come into contact with the focus person as part of their job.

Household: people living with the focus person.

Family: family members with whom the focus person has contact.

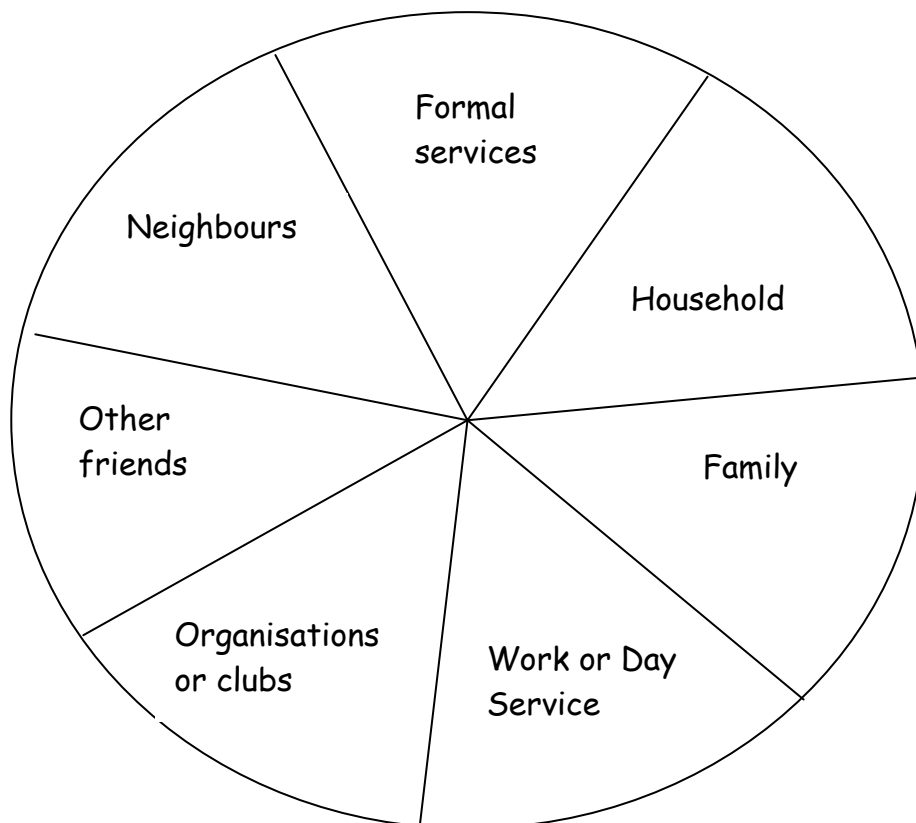
Work/Day Service: people the focus person knows from attending work or day service.

Organisations/Clubs: people the focus person knows from organisations and clubs or church.

Neighbours: people living close by.

Other friends: any other friends not included in the above.

**If the person identified is a member of staff, or some other person who is paid to work with this person, please indicate this by placing a square around their initials. If the person is another person with learning disabilities, please place a circle around their initials.**



**D: Community-Based Service Receipt (There is no item C in this schedule):**

1. In the last 3 months, has the focus person made use of any of the following community-based health and social care services?      Yes 1 No 2

➤ If YES please complete the following table.

<b>Service</b>	<b>Where did the service contact take place?</b> 1 Clinic/surgery 2 Day centre 3 Home 4 Other ( <i>specify</i> )	<b>Total number of contacts (during last 3 months)</b>
Community psychiatrist		
Psychologist		
General practitioner		
Community psychiatric nurse		
Learning disability nurse		
Other community nurse (e.g. district, health visitor)		
Community mental health team member		
Health care assistant		
Speech therapist		
Physiotherapist		
Occupational therapist		
Art/drama/music therapist		
Alternative therapist (e.g. reflexologist)		
Social worker/care manager		
Social work assistant		
Home help/home care worker		
Advocate/counsellor		
Dentist		
Optician		
Audiologist		
Chiropodist		
Employment services/job centre		
Other services used ( <i>please specify</i> )		

## **E: Choices:**

1. In what ways is the focus person supported in making choices about the following areas of their life?

### *Rating Scale:*

- 1 Nothing mentioned
- 2 Some procedure(s) mentioned but unlikely to give person much real choice
- 3 Some procedure(s) mentioned through which person can express preferences but final say does not rest with person
- 4 Procedures in place for person to express preferences and these are the final say unless clearly inappropriate or dangerous.
- 5 The person has the final say.

The content of their meals	1	2	3	4	5
The timing of their meals	1	2	3	4	5
Where they eat their meals	1	2	3	4	5
The leisure activities they take part in indoors e.g. TV, radio	1	2	3	4	5
Going out e.g. pub, cinema	1	2	3	4	5
The time they go to bed in the evening	1	2	3	4	5
The clothes that they purchase	1	2	3	4	5
The clothes they wear each day	1	2	3	4	5
Household routines e.g. shopping for food, housework rotas	1	2	3	4	5
Keeping pets	1	2	3	4	5
Who they live with	1	2	3	4	5
Where they live	1	2	3	4	5
Recruitment of staff	1	2	3	4	5
Staff performance review	1	2	3	4	5
The firing of unsuitable staff	1	2	3	4	5
Involvement with girlfriends or boyfriends	1	2	3	4	5
Their haircut	1	2	3	4	5
Their day time activities	1	2	3	4	5
Holidays: where they go, who they go with and When they go	1	2	3	4	5
The time they spend in the bath or shower	1	2	3	4	5
Their employment	1	2	3	4	5
Access to a private area	1	2	3	4	5
Moving home in the future	1	2	3	4	5
The furnishings in their home	1	2	3	4	5
Personal possessions	1	2	3	4	5

2. Are there any areas where choice is limited for the focus person due to lack of opportunity, for example, difficulty finding suitable employment or day service opportunities, lack of available housing in the area, lack of finance for holidays etc?

Yes 1 No 2

If 'yes', please give details .....

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.....

3. Are there any particular reasons why choice has to be limited for the focus person even if opportunity exists, for example, choices may be inappropriate (e.g. wearing summer clothing to go out in winter), choice has to be constrained due to challenging behaviour, or person has difficulty communicating their preferences?

Yes 1 No 2

If 'yes', please give details .....

..... (29-30)  
..... (31-32)  
..... (33-34)  
.....  
.....  
.....

**F: Changes In Ability in the Last Six Months:**

In the last six months has the focus person shown any changes in the following areas:

	<b>Much worse</b>	<b>Slightly worse</b>	<b>No change</b>	<b>Slightly better</b>	<b>Much better</b>
<b>A: Independent functioning</b> e.g. self-care skills like washing, dressing, eating and toileting, ability in areas such as road crossing, travel on buses, using the telephone, looking after them self.	1	2	3	4	5
<b>B: Physical development</b> e.g. vision, hearing, body balance, walking and running, control of hands or limbs	1	2	3	4	5
<b>C: Economic Activity</b> e.g. using money or banks, shopping, budgeting spending	1	2	3	4	5
<b>D: Language Development</b> e.g. reading & writing, speech or other forms of communication, understanding of communication by others, conversation	1	2	3	4	5
<b>E: Numbers and time</b> e.g. counting, understanding of numbers, telling the time, understanding of days of the week, difference between months/years etc	1	2	3	4	5
<b>F: Prevocational / Vocational Activity</b> e.g. ability to perform jobs or ability in college classes	1	2	3	4	5
<b>G: Self-Direction</b> e.g. using own initiative, ability to pay attention to activities, arranging leisure activities, ability to complete tasks	1	2	3	4	5
<b>H: Responsibility</b> e.g. looking after personal belongings, carrying out assigned tasks, taking responsibilities, self-control	1	2	3	4	5
<b>I: Socialization</b> e.g. cooperation, consideration for others, awareness of and interaction with others, willingness to share or take turns, understanding of social conduct (eg not being too familiar with strangers)	1	2	3	4	5

If any numbers have been circled in SHADED columns (numbers 1, 2, 4 or 5), please give details of the changes that you believe have occurred in the last 6 months under the letter that relates to the appropriate heading:

A:.....

B: .....

C:.....

D:.....

E: .....

F: .....

G:.....

H:.....

I:.....

### **2.3. Carer interview schedule**

## **An Evaluation of the Impact of Person Centred Planning**

### **Stage 2 – Initial Interviews**

#### **Carer Interview Schedule**

**To be administered to the focus person's 'main' carer after the semi-structured interview**

**NB:** If the focus person has capacity and chooses not to consent, then their main carer should not be invited to participate

Identification Code: 2C\_\_\_\_\_

**If you have any questions about the questionnaire please contact:**

**Unit for Development in Intellectual Disability,  
School of Care Sciences,  
University of Glamorgan,  
Pontypridd,  
Rhondda Cynon Taff,  
CF37 1 DL**



As you know, the person you have been identified as main carer for has agreed to take part in a research study looking at the impact of Person-Centred Planning for people with learning disabilities. We want to see if Person-Centred Planning leads to any changes in their life. We also want to see if Person Centred Planning makes any difference to your satisfaction with the services received by the participant. Anything that you tell us will be *confidential* - your name will never be disclosed to services or individuals involved in this person's life.

**Preliminary:**

Identification Code of Person who is the focus of the person centred plan: 2FP.....

Identification Code of family member (or other important person in the participant's life) being interviewed: 2C.....

Contact telephone no if possible:.....

Relationship to participant: .....

Interviewer:.....

Date of interview:.....

**A: Leisure Activities:** Please tell me the number of times that the person you care for has taken part in the following activities in the last 4 weeks.

**Interviewer:** If, for whatever reason, they have not participated in a particular activity enter 0 in the appropriate column. If the person has taken part in activities not included in the list, for example, any hobbies or other leisure activities, make a note of these by writing them in as "other".

--	--

Activity	No of times in the past 4 weeks
Had guests to stay in your home (no. of nights)	
Had family or friends round for a meal	
Been to a social club (for pwld / for non-learning disabled persons)	
Been on an overnight stay to family or friends (no. of nights)	
Had trips out with family or friends	
Been to a cafe	
Been to a pub	
Been to a hairdresser	
Been shopping	
Been to a place of religious worship	
Been to a sports event (eg watched a football match)	
Been to a cinema	
Been to a concert or play	
Been on a public bus (do not include eg minibus to day centre)	
Been to their bank or post office	
Been on holiday in the last 12 months	
Other (please specify)	

**B: Relationships: Social networks:**

Over the past month, please tell me who has been important in the focus person's (the person at the centre of the planning process) life and who has had regular CONTACT with them. This can include people who have provided support or have given them information or advice.

In the circle below, put the initials for each person you think of in the appropriate segment. We do not need to know who the initials stand for.

Formal services: people who come into contact with the focus person as part of their job.

Household: people living with the focus person.

Family: family members with whom the focus person has contact.

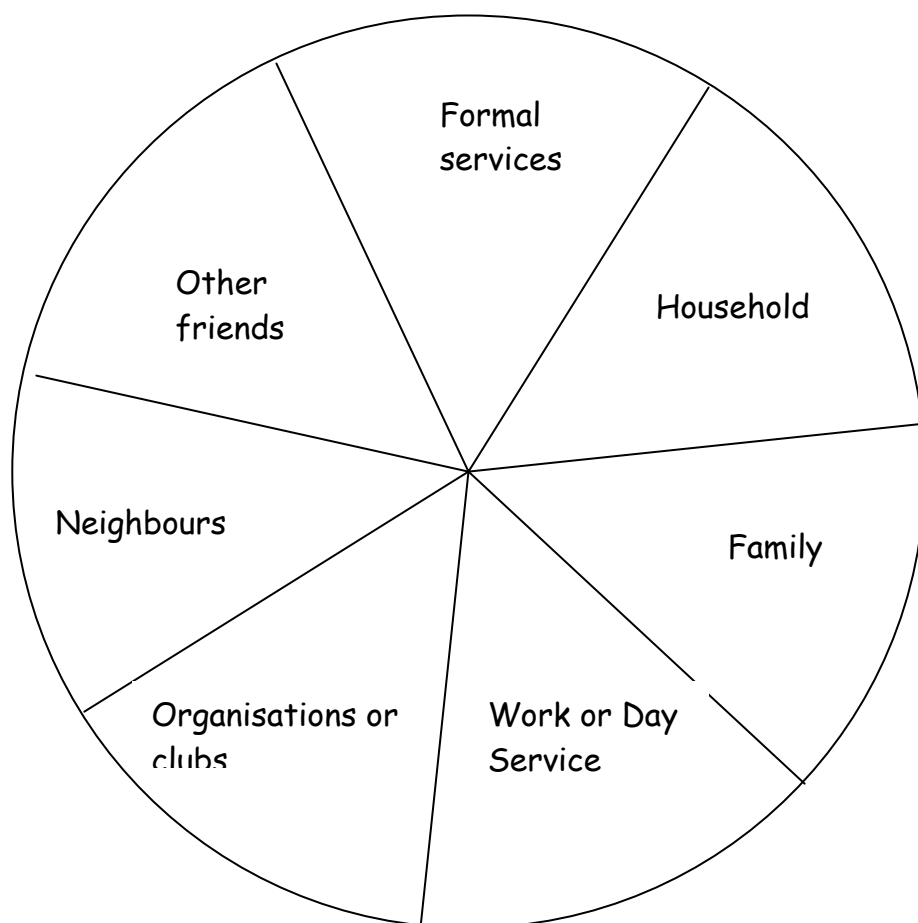
Work/Day Service: people the focus person knows from attending work or day service.

Organisations/Clubs: people the focus person knows from organisations and clubs or church.

Neighbours: people living close by.

Other friends: any other friends not included in the above.

**If the person identified is a member of staff, or some other person who is paid to work with this person, please indicate this by placing a square around their initials. If the person is another person with learning disabilities, please place a circle around their initials.**



**C. Satisfaction with Current Arrangements**

1. How involved do you feel in decisions made about the person you care for by the services that support them?

Very 1	2	3	Neutral 4	5	6	Not at all 7
-----------	---	---	--------------	---	---	-----------------

2. How do you think *the participant* feels about with their current support from services?

Very positive 1	2	3	Neutral 4	5	6	Very negative 7
-----------------------	---	---	--------------	---	---	-----------------------

3. Do you feel you are kept informed of what is going on?

Very informed 1	2	3	Neutral 4	5	6	Not informed 7
-----------------------	---	---	--------------	---	---	----------------------

4. How do *you* feel about the participant's current support from services?

Very positive 1	2	3	Neutral 4	5	6	Very negative 7
-----------------------	---	---	--------------	---	---	-----------------------

5. Overall, how satisfied are you with the support you receive from services?

- Very satisfied ..... 1
- Quite satisfied ..... 2
- Not at all satisfied ..... 3

**D: Community-Based Service Receipt:**

1. In the last 3 months, has the person you care for made use of any of the following community-based health and social care services

➤ If YES please complete the following table.

<b>Service</b>	<b>Where did the service contact take place?</b> 1 Clinic/surgery 2 Day centre 3 Home 4 Other ( <i>specify</i> )	<b>Total number of contacts (during last 3 months)</b>
Community psychiatrist		
Psychologist		
General practitioner		
Community psychiatric nurse		
Learning disability nurse		
Other community nurse (e.g. district, health visitor)		
Community mental health team member		
Health care assistant		
Speech therapist		
Physiotherapist		
Occupational therapist		
Art/drama/music therapist		
Alternative therapist (e.g. reflexologist)		
Social worker/care manager		
Social work assistant		
Home help/home care worker		
Advocate/counsellor		
Dentist		
Optician		
Audiologist		
Chiropodist		
Employment services/job centre		
Other services used ( <i>please specify</i> )		

## **E: Choices:**

1. In what ways is the person you care for supported in making choices with regard to the following areas of their life?

### *Rating Scale:*

1. Nothing mentioned
2. Some procedure(s) mentioned but unlikely to give person much real choice
3. Some procedure(s) mentioned through which person can express preferences but final say does not rest with person
4. Procedures in place for person to express preferences and these are the final say unless clearly inappropriate or dangerous.
5. They always have the final say

The content of their meals	1	2	3	4	5
The timing of their meals	1	2	3	4	5
Where they eat their meals	1	2	3	4	5
The leisure activities they take part in indoors e.g. TV, radio	1	2	3	4	5
Going out e.g. pub, cinema	1	2	3	4	5
The time they go to bed in the evening	1	2	3	4	5
The clothes that they purchase	1	2	3	4	5
The clothes they wear each day	1	2	3	4	5
Household routines e.g. shopping for food, housework rotas	1	2	3	4	5
Keeping pets	1	2	3	4	5
Who they live with	1	2	3	4	5
Where they live	1	2	3	4	5
Recruitment of staff	1	2	3	4	5
Involvement with girlfriends or boyfriends	1	2	3	4	5
Their day time activities	1	2	3	4	5
Holidays: where they go, who they go with and when they go	1	2	3	4	5
Their employment	1	2	3	4	5
Access to a private area	1	2	3	4	5
Moving home in the future	1	2	3	4	5
The furnishings in their home	1	2	3	4	5
Personal possessions	1	2	3	4	5

2. Are there any areas where choice is limited for the person you care for due to lack of opportunity, for example, difficulty finding suitable employment or day service opportunities, lack of available housing in the area, lack finance for holidays etc?

Yes 1 No 2

If 'yes', please explain .....

.....

.....

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.....

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.....

.....

3. Are there any particular reasons why choice has to be limited for the person you care for, even if opportunity exists, for example, choices may be inappropriate (e.g. wearing summer clothing to go out in winter), choice has to be constrained due to challenging behaviour, or person has difficulty communicating their preferences?

Yes 1 No 2

If 'yes', please explain .....

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**F: Changes in Ability in the Last Six Months:**

In the last six months has the focus person shown any changes in the following areas:

	<b>Much worse</b>	<b>Slightly worse</b>	<b>No change</b>	<b>Slightly better</b>	<b>Much better</b>
<b>A: Independent functioning</b> e.g. self-care skills like washing, dressing, eating and toileting, ability in areas such as road crossing, travel on buses, using the telephone, looking after them self.	1	2	3	4	5
<b>B: Physical development</b> e.g. vision, hearing, body balance, walking and running, control of hands or limbs	1	2	3	4	5
<b>C: Economic Activity</b> e.g. using money or banks, shopping, budgeting spending	1	2	3	4	5
<b>D: Language Development</b> e.g. reading & writing, speech or other forms of communication, understanding of communication by others, conversation	1	2	3	4	5
<b>E: Numbers and time</b> e.g. counting, understanding of numbers, telling the time, understanding of days of the week, difference between months/years etc	1	2	3	4	5
<b>F: Prevocational / Vocational Activity</b> e.g. ability to perform jobs or ability in college classes	1	2	3	4	5
<b>G: Self-Direction</b> e.g. using own initiative, ability to pay attention to activities, arranging leisure activities, ability to complete tasks	1	2	3	4	5
<b>H: Responsibility</b> e.g. looking after personal belongings, carrying out assigned tasks, taking responsibilities, self-control	1	2	3	4	5
<b>I: Socialization</b> e.g. cooperation, consideration for others, awareness of and interaction with others, willingness to share or take turns, understanding of social conduct (eg not being too familiar with strangers)	1	2	3	4	5



If any numbers have been circled in SHADED columns (numbers 1, 2, 4 or 5), please give details of the changes that you believe have occurred in the last 6 months under the letter that relates to the appropriate heading:

A:.....

B: .....

C:.....

D:.....

E: .....

F: .....

G:.....

H:.....

I:.....

### 3. Stage 3 – Topic Guide

#### Experience of the person-centred planning process:

- Does the person know the style of plan / can they describe it?
- Does the person know why that style of PCP was chosen?
- Level of participation
- Was the focus person's family / friends involved in the process?
- Number of meetings
- Choices re where and when meetings were held
- Choices about who attended
- How did the facilitator treat the person?
- What things are good / did the person like about person-centred planning?
- Were there any things that were not good / the person didn't like about person-centred planning?
- Did the way things were discussed draw out and build on the positive aspects of the person's culture, ethnicity and background?
- Is the focus person's views regularly considered as they experience new opportunities and demands?
- Frequency with which the focus person's plan been reviewed

#### Outcomes of the person-centred process:

- Does the plan show what is most important for the focus person?
- Does the plan include a clear description of the support the focus person requires?
- Have the things the focus person hoped would gain from person-centred planning come about?
- Is the focus person happier with their life?
- Has everything that was included in the plan happened? If not explore possible reasons for this.
- What services does the person receive from health and social services?
- Has anything changed for the focus person since they started the person-centred planning process? e.g. levels or type of support, etc?
- Is the focus person consistently supported in the way described in their plan?
- Has the person had new opportunities and experiences since the planning process started?

#### Person-centred planning and the future:

- Would you like to carry on being involved with person-centred planning?
- Has a date been set for the plan to be reviewed, if so, when?
- Are there any things you would like to be done differently?

Topics 3-6 from the topic guide for stage 2 will also be discussed.

# 4. Stage 3 – Interview Schedules

#### ***4.1. Focus person interview schedule***

### **An Evaluation of the Impact of Person Centred Planning**

**Stage 3 – Second Interviews to be administered 6-9 months after the  
initial interviews**

#### **Focus Person Interview Schedule**

**To be administered after the semi-structured interview**

Identification Code: 3FP\_\_\_\_\_

**If you have any questions about the questionnaire please contact:**

**Unit for Development in Intellectual Disability,  
School of Care Sciences,  
University of Glamorgan,  
Pontypridd,  
Rhondda Cynon Taff,  
CF37 1 DL**

The questions I will ask are trying to find out about any changes that have happened now you have a person centred plan. If you wish to 'pass' on any question that is ok. If you want to stop the interview at any time that is also ok.

If you have any questions about the questionnaire, or the evaluation generally, please feel free to contact Paul Wheeler – his telephone number and address are on the front of this questionnaire.

**Preliminary:**

Identification Code: 3FP .....

Date Interview conducted: .....

Name of Person completing questionnaire: .....

**A: Leisure Activities:** Since I last met you and asked you some questions about person-centred planning have you...

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Activity	No of times in the past 4 weeks
Had guests to stay in your home (no. of nights)	
Had family or friends round for a meal	
Been to a social club (for pwld / for non-learning disabled persons)	
Been on an overnight stay to family or friends (no. of nights)	
Had trips out with family or friends	
Been to a café	
Been to a pub	
Been to a hairdresser	
Been shopping	
Been to a place of religious worship	
Been to a sports event (eg watched a football match)	
Been to a cinema	
Been to a concert or play	
Been on a public bus (do not include eg minibus to day centre)	
Been to their bank or post office	
Been on holiday in the last 12 months	
Other (please specify)	

**B: Relationships: Social networks:**

**NB: Interviewer – you will need to check the individual’s concept of time, e.g. how do they measure it**

Over the past month, who has been important in your life and who has had regular CONTACT with you. This can include people who have provided you with help with things or have given you information or advice.

In the circle below, I will put the initials for each person you think of in the appropriate space. I do not need to know who the initials stand for.

Formal services: people who come into contact with you as part of their job.

Household: people living with you.

Family: family members who you have contact with.

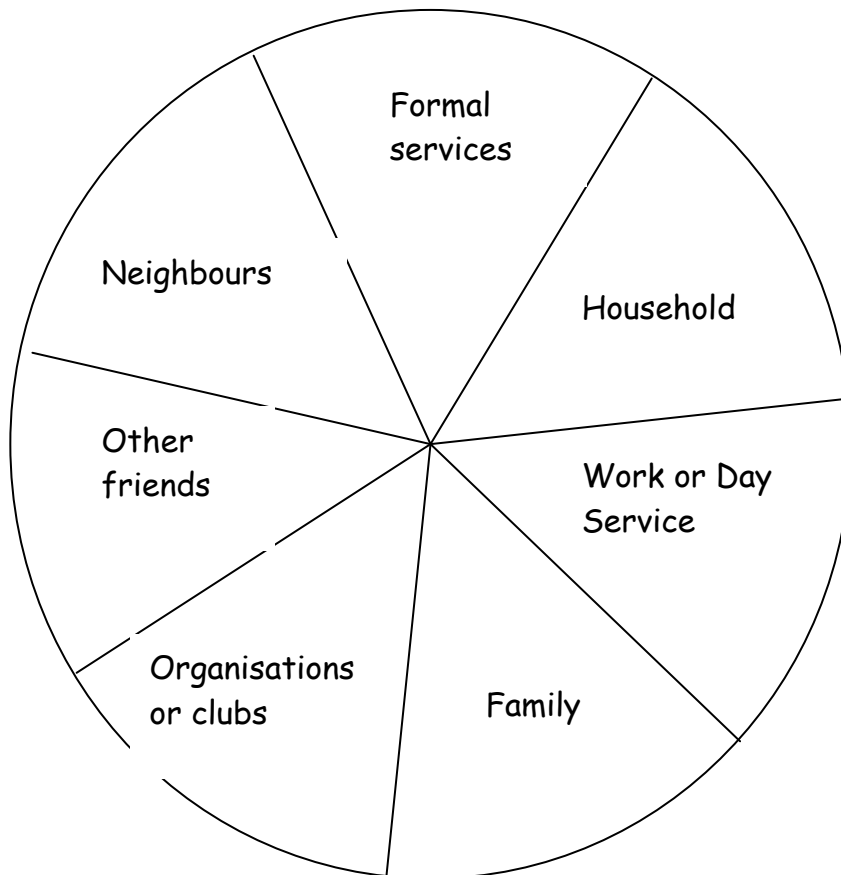
Work/Day Service: people you know from attending work or day service.

Organisations/Clubs: people you know from organisations and clubs or church.

Neighbours: people living close by.

Other friends: any other friends not included in the above.

**If the person identified is a member of staff, or some other person who is paid to work with you, please indicate this by placing a square around their initials. If the person is another person with learning disabilities, please place a circle around their initials.**



## ***4.2. Second carer interview schedule***

### **An Evaluation of the Impact of Person Centred Planning**

**Stage 3 – Second Interviews to be administered 6-9 months after the  
initial interview**

**Second Carer Interview Schedule (Only relevant if the focus person  
lacks the capacity to consent or otherwise or is unable to communicate  
in a way understood by the interviewer)**

**To be administered to the focus person's 'second' carer after the semi-  
structured interview**

Identification Code: 3SC\_\_\_\_\_

**If you have any questions about the questionnaire please contact:**

**Unit for Development in Intellectual Disability,  
School of Care Sciences,  
University of Glamorgan,  
Pontypridd,  
Rhondda Cynon Taff,  
CF37 1 DL**



This questionnaire is to find out about changes in the life of the person who is taking part in person-centred planning pilot project. You are being asked these questions because it is either felt that the focus person is not able to give their consent or because they communicate in a way which the interviewer cannot understand. If you wish to 'pass' on any question that is ok. If you want to stop the interview at any time that is also ok.

If you have any questions about the questionnaire, or the evaluation generally, please feel free to contact Paul Wheeler – his telephone number and address are on the front of this questionnaire.

**Preliminary:**

Identification Code Number: 3SC.....

Focus Person Identification code: 3FP.....

Date Interview undertaken: .....

Name of Interviewer: .....

Relationship of second carer to focus person (e.g. keyworker, parent): .....

**A: Leisure Activities:** Please note the number of times that the focus person has taken part in the following activities in the last **4 weeks**. If, for whatever reason, they have not participated in a particular activity enter 0 in the appropriate column. If the person has taken part in activities not included in the list, for example, any hobbies or other leisure activities, make a note of these by writing them in as “other”.

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Activity	No of times in the past 4 weeks
Had guests to stay (no. of nights)	
Had family or friends round for a meal	
Been to a social club (for pwld / for non-learning disabled persons)	
Been on an overnight stay to family or friends (no. of nights)	
Had trips out with family or friends	
Been to a café	
Been to a pub	
Been to a hairdresser	
Been shopping	
Been to a place of religious worship (e.g. church / chapel)	
Been to a sports event (eg watched a football match)	
Been to a cinema	
Been to a concert or play	
Been on a public bus (do not include eg minibus to day centre)	
Been to their bank or post office	
Been on holiday <i>in the last 12 months</i>	
Other (please specify)	

**B: Relationships: Social networks:**

**Over the past month**, who has been important in the focus person's life (the person who is at the centre of the planning process) and who has had ACTIVE CONTACT with them. This can include people who have provided support or have given them information or advice.

In the circle below, put the initials for each person you think of in the appropriate segment. We do not need to know who the initials stand for.

Formal services: people who come into contact with the focus person as part of their job.

Household: people living with the focus person.

Family: family members with whom the focus person has contact.

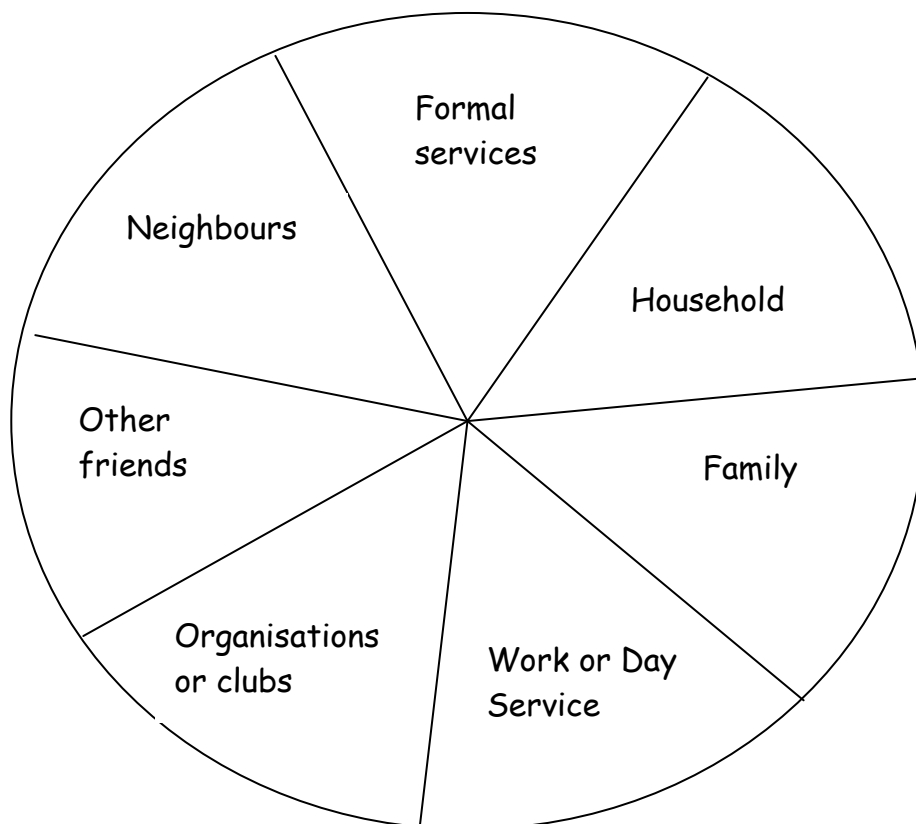
Work/Day Service: people the focus person knows from attending work or day service.

Organisations/Clubs: people the focus person knows from organisations and clubs or church.

Neighbours: people living close by.

Other friends: any other friends not included in the above.

**If the person identified is a member of staff, or some other person who is paid to work with this person, please indicate this by placing a square around their initials. If the person is another person with learning disabilities, please place a circle around their initials.**



**D: Community-Based Service Receipt (There is no item C in this schedule):**

2. In the last 3 months, has the focus person made use of any of the following community-based health and social care services?      Yes 1 No 2

➤ If YES please complete the following table.

<b>Service</b>	<b>Where did the service contact take place?</b> 1 Clinic/surgery 2 Day centre 3 Home 4 Other ( <i>specify</i> )	<b>Total number of contacts (during last 3 months)</b>
Community psychiatrist		
Psychologist		
General practitioner		
Community psychiatric nurse		
Learning disability nurse		
Other community nurse (e.g. district, health visitor)		
Community mental health team member		
Health care assistant		
Speech therapist		
Physiotherapist		
Occupational therapist		
Art/drama/music therapist		
Alternative therapist (e.g. reflexologist)		
Social worker/care manager		
Social work assistant		
Home help/home care worker		
Advocate/counsellor		
Dentist		
Optician		
Audiologist		
Chiropodist		
Employment services/job centre		
Other services used ( <i>please specify</i> )		

## **E: Choices:**

4. In what ways is the focus person supported in making choices about the following areas of their life?

### *Rating Scale:*

- 1 Nothing mentioned
- 2 Some procedure(s) mentioned but unlikely to give person much real choice
- 3 Some procedure(s) mentioned through which person can express preferences but final say does not rest with person
- 4 Procedures in place for person to express preferences and these are the final say unless clearly inappropriate or dangerous.
- 5 The person has the final say.

The content of their meals	1	2	3	4	5
The timing of their meals	1	2	3	4	5
Where they eat their meals	1	2	3	4	5
The leisure activities they take part in indoors e.g. TV, radio	1	2	3	4	5
Going out e.g. pub, cinema	1	2	3	4	5
The time they go to bed in the evening	1	2	3	4	5
The clothes that they purchase	1	2	3	4	5
The clothes they wear each day	1	2	3	4	5
Household routines e.g. shopping for food, housework rotas	1	2	3	4	5
Keeping pets	1	2	3	4	5
Who they live with	1	2	3	4	5
Where they live	1	2	3	4	5
Recruitment of staff	1	2	3	4	5
Staff performance review	1	2	3	4	5
The firing of unsuitable staff	1	2	3	4	5
Involvement with girlfriends or boyfriends	1	2	3	4	5
Their haircut	1	2	3	4	5
Their day time activities	1	2	3	4	5
Holidays: where they go, who they go with and when they go	1	2	3	4	5
The time they spend in the bath or shower	1	2	3	4	5
Their employment	1	2	3	4	5
Access to a private area	1	2	3	4	5
Moving home in the future	1	2	3	4	5
The furnishings in their home	1	2	3	4	5
Personal possessions	1	2	3	4	5

5. Are there any areas where choice is limited for the focus person due to lack of opportunity, for example, difficulty finding suitable employment or day service opportunities, lack of available housing in the area, lack of finance for holidays etc?

Yes 1 No 2

If 'yes', please give details .....

.....

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6. Are there any particular reasons why choice has to be limited for the focus person even if opportunity exists, for example, choices may be inappropriate (e.g. wearing summer clothing to go out in winter), choice has to be constrained due to challenging behaviour, or person has difficulty communicating their preferences?

Yes 1 No 2

If 'yes', please give details .....

..... (29-30)

..... (31-32)

..... (33-34)

.....

.....

.....

**F: Changes In Ability in the Last Six Months:**

In the last six months has the focus person shown any changes in the following areas:

	<b>Much worse</b>	<b>Slightly worse</b>	<b>No change</b>	<b>Slightly better</b>	<b>Much better</b>
<b>A: Independent functioning</b> e.g. self-care skills like washing, dressing, eating and toileting, ability in areas such as road crossing, travel on buses, using the telephone, looking after them self.	1	2	3	4	5
<b>B: Physical development</b> e.g. vision, hearing, body balance, walking and running, control of hands or limbs	1	2	3	4	5
<b>C: Economic Activity</b> e.g. using money or banks, shopping, budgeting spending	1	2	3	4	5
<b>D: Language Development</b> e.g. reading & writing, speech or other forms of communication, understanding of communication by others, conversation	1	2	3	4	5
<b>E: Numbers and time</b> e.g. counting, understanding of numbers, telling the time, understanding of days of the week, difference between months/years etc	1	2	3	4	5
<b>F: Prevocational / Vocational Activity</b> e.g. ability to perform jobs or ability in college classes	1	2	3	4	5
<b>G: Self-Direction</b> e.g. using own initiative, ability to pay attention to activities, arranging leisure activities, ability to complete tasks	1	2	3	4	5
<b>H: Responsibility</b> e.g. looking after personal belongings, carrying out assigned tasks, taking responsibilities, self-control	1	2	3	4	5
<b>I: Socialization</b> e.g. cooperation, consideration for others, awareness of and interaction with others, willingness to share or take turns, understanding of social conduct (eg not being too familiar with strangers)	1	2	3	4	5

If any numbers have been circled in SHADED columns (numbers 1, 2, 4 or 5), please give details of the changes that you believe have occurred in the last 6 months under the letter that relates to the appropriate heading:

A:.....

B: .....

C:.....

D:.....

E: .....

F: .....

G:.....

H:.....

I:.....



**G: Barriers to goals being met:**

How much do you think the following things stand in the way of the goals set at planning meetings being met?

<b>Barrier to goals being met</b>	<b>Not At all</b>	<b>A Little</b>	<b>A Lot</b>
Participant's lack of money	1	2	3
Participant's problems with transport	1	2	3
Participant's reluctance to try new things	1	2	3
Participant's ill-health	1	2	3
Location of participant's home (e.g. rural)	1	2	3
Not enough staff support for the participant	1	2	3
Support staff not doing what they are supposed to do	1	2	3
Support staff reluctance to try new things or ways of supporting the participant	1	2	3
Lack of suitably trained staff to support the participant	1	2	3
Lack of accessible activities in the community	1	2	3
Limited employment opportunities	1	2	3
Limited choice of housing	1	2	3
Limited choice of day services	1	2	3
Waiting lists for services	1	2	3
Attitude of people in the local community	1	2	3
Unrealistic goals set	1	2	3
Goals do not reflect what the participant really wants	1	2	3
Other (please write in)	1	2	3
Other (please write in)	1	2	3
Other (please write in)	1	2	3

**H: Overall view of PCP process:**

1. How would you rate the planning meetings overall?

- Very good, they are helping improve the participant's life.. 1
- Good..... 2
- Neutral, a mix of good and bad, no opinion either way ..... 3
- Bad, they have a limited impact on the participant's life .... 4
- Very bad, they are not having any impact..... 5

2. What three things would you most like to see change about the planning meetings?

- i.....
- .....
- ii.....
- .....
- iii.....
- .....

3. What do you think the main benefits of PCP have been for this person so far?

- .....
- .....
- .....
- .....
- .....

4. What do you think the main problems have been in trying to implement PCP for this participant so far?

- .....
- .....
- .....
- .....
- .....

5. Do you think there have been any changes in the participant's life as a result of their involvement in PCP?..... Yes 1 No 2

If YES please describe the main changes

- .....
- .....
- .....
- .....
- .....
- .....
- .....

**Thanks you!**

### **4.3. Carer interview schedule**

#### **An Evaluation of the Impact of Person Centred Planning**

**Stage 3 – Second Interviews to be administered 6-9 months after the  
initial interview**

#### **Carer Interview Schedule**

**To be administered to the focus person's 'main' carer after the semi-  
structured interview**

**NB:** If the focus person has capacity and chooses not to consent, then their  
main carer should not be invited to participate

Identification Code: 3C\_\_\_\_\_

**If you have any questions about the questionnaire please contact:**

**Unit for Development in Intellectual Disability,  
School of Care Sciences,  
University of Glamorgan,  
Pontypridd,  
Rhondda Cynon Taff,  
CF37 1 DL**

As you know, the person you have been identified as main carer for is taking part in a research study looking at the impact of Person-Centred Planning for people with learning disabilities. We want to see if Person-Centred Planning has led to any changes in their life. We also want to see if Person-Centred Planning has made any difference to your satisfaction with the services received by the participant. Anything that you tell us will be *confidential* - your name will never be disclosed to services or individuals involved in this person's life.

**Preliminary:**

Identification Code of Person who is the focus of the person centred plan: 3FP.....

Identification Code of family member (or other important person in the participant's life) being interviewed: 3C.....

Contact telephone no if possible:.....

Relationship to participant: .....

Interviewer:.....

Date of interview:.....

---

**A: Leisure Activities:**

Please note the number of times that the person you care for has taken part in the following activities in the last **4 weeks**. If, for whatever reason, they have not participated in a particular activity enter 0 in the appropriate column. If the person has taken part in activities not included in the list, for example, any hobbies or other leisure activities, make a note of these by writing them in as "other".

<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------

<b>Activity</b>	<b>No of times in the past 4 weeks</b>
Had guests to stay in your home (no. of nights)	
Had family or friends round for a meal	
Been to a social club (for pwld / for non-learning disabled persons)	
Been on an overnight stay to family or friends (no. of nights)	
Had trips out with family or friends	
Been to a café	
Been to a pub	
Been to a hairdresser	
Been shopping	
Been to a place of religious worship	
Been to a sports event (eg watched a football match)	
Been to a cinema	
Been to a concert or play	
Been on a public bus (do not include eg minibus to day centre)	
Been to their bank or post office	
Been on holiday in the last 12 months	
Other (please specify)	

**B: Relationships: Social networks:**

Over the past month, who has been important in the focus person's life and who has had ACTIVE CONTACT with them? This can include people who have provided support or have given them information or advice.

In the circle below, put the initials for each person you think of in the appropriate segment. We do not need to know who the initials stand for.

Formal services: people who come into contact with the focus person as part of their job.

Household: people living with the focus person.

Family: family members with whom the focus person has contact.

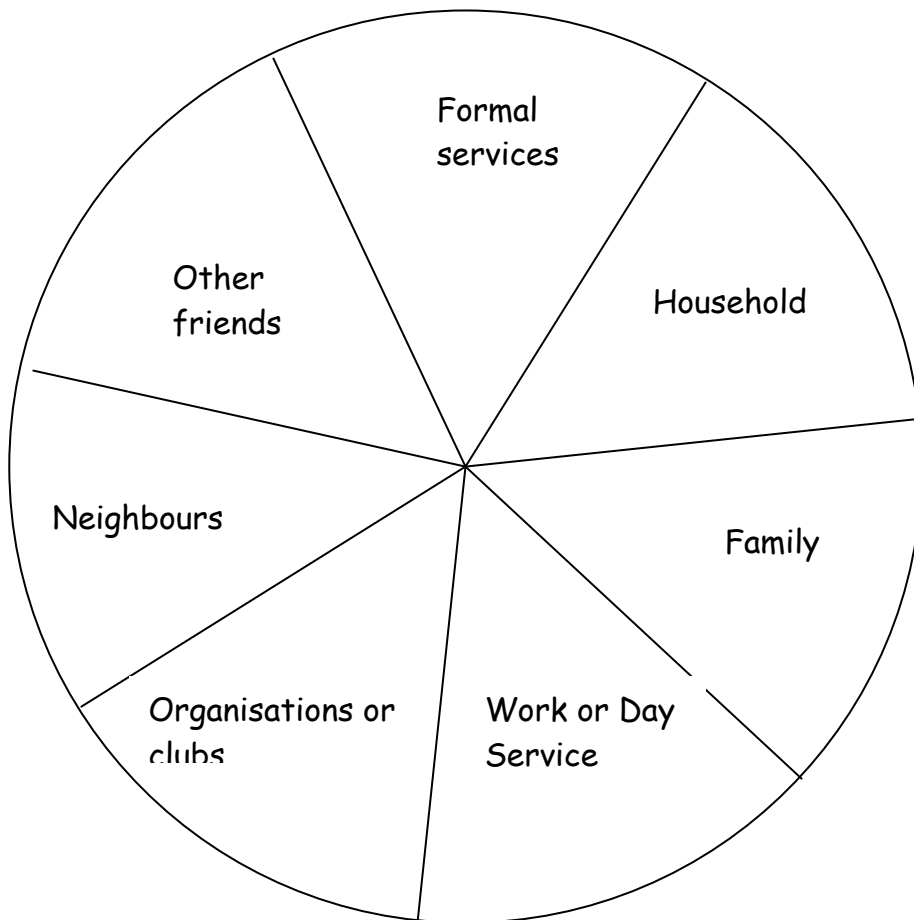
Work/Day Service: people the focus person knows from attending work or day service.

Organisations/Clubs: people the focus person knows from organisations and clubs or church.

Neighbours: people living close by.

Other friends: any other friends not included in the above.

**If the person identified is a member of staff, or some other person who is paid to work with this person, please indicate this by placing a square around their initials. If the person is another person with learning disabilities, please place a circle around their initials.**



**C. Satisfaction with Current Arrangements**

6. How involved do you feel in decisions made about the person you care for by the services that support them?

Very 1	2	3	Neutral 4	5	6	Not at all 7
-----------	---	---	--------------	---	---	-----------------

7. How do you think *the participant* feels about with their current support from services?

Very positive 1	2	3	Neutral 4	5	6	Very negative 7
-----------------------	---	---	--------------	---	---	-----------------------

8. Do you feel you are kept informed of what is going on?

Very informed 1	2	3	Neutral 4	5	6	Not informed 7
-----------------------	---	---	--------------	---	---	----------------------

9. How do *you* feel about the participant's current support from services?

Very positive 1	2	3	Neutral 4	5	6	Very negative 7
-----------------------	---	---	--------------	---	---	-----------------------

10. Overall, how satisfied are you with the support you receive from services?

- Very satisfied ..... 1
- Quite satisfied ..... 2
- Not at all satisfied ..... 3

**D: Community-Based Service Receipt:**

2. In the last 3 months, has the person you care for made use of any of the following community-based health and social care services

➤ If YES please complete the following table.

<b>Service</b>	<b>Where did the service contact take place?</b> 1 Clinic/surgery 2 Day centre 3 Home 4 Other ( <i>specify</i> )	<b>Total number of contacts (during last 3 months)</b>
Community psychiatrist		
Psychologist		
General practitioner		
Community psychiatric nurse		
Learning disability nurse		
Other community nurse (e.g. district, health visitor)		
Community mental health team member		
Health care assistant		
Speech therapist		
Physiotherapist		
Occupational therapist		
Art/drama/music therapist		
Alternative therapist (e.g. reflexologist)		
Social worker/care manager		
Social work assistant		
Home help/home care worker		
Advocate/counsellor		
Dentist		
Optician		
Audiologist		
Chiropodist		
Employment services/job centre		
Other services used ( <i>please specify</i> )		



## **E: Choices:**

4. In what ways is the person you care for supported in making choices with regard to the following areas of their life?

### *Rating Scale:*

1. Nothing mentioned
2. Some procedure(s) mentioned but unlikely to give person much real choice
3. Some procedure(s) mentioned through which person can express preferences but final say does not rest with person
4. Procedures in place for person to express preferences and these are the final say unless clearly inappropriate or dangerous.
5. They always have the final say

The content of their meals	1	2	3	4	5
The timing of their meals	1	2	3	4	5
Where they eat their meals	1	2	3	4	5
The leisure activities they take part in indoors e.g. TV, radio	1	2	3	4	5
Going out e.g. pub, cinema	1	2	3	4	5
The time they go to bed in the evening	1	2	3	4	5
The clothes that they purchase	1	2	3	4	5
The clothes they wear each day	1	2	3	4	5
Household routines e.g. shopping for food, housework rotas	1	2	3	4	5
Keeping pets	1	2	3	4	5
Who they live with	1	2	3	4	5
Where they live	1	2	3	4	5
Recruitment of staff	1	2	3	4	5
Involvement with girlfriends or boyfriends	1	2	3	4	5
Their day time activities	1	2	3	4	5
Holidays: where they go, who they go with and when they go	1	2	3	4	5
Their employment	1	2	3	4	5
Access to a private area	1	2	3	4	5
Moving home in the future	1	2	3	4	5
The furnishings in their home	1	2	3	4	5
Personal possessions	1	2	3	4	5

5. Are there any areas where choice is limited for the person you care for due to lack of opportunity, for example, difficulty finding suitable employment or day service opportunities, lack of available housing in the area, lack finance for holidays etc?

Yes 1 No 2

If 'yes', please explain .....

.....  
.....  
.....  
.....  
.....  
.....  
.....

6. Are there any particular reasons why choice has to be limited for the person you care for, even if opportunity exists, for example, choices may be inappropriate (e.g. wearing summer clothing to go out in winter), choice has to be constrained due to challenging behaviour, or person has difficulty communicating their preferences?

Yes 1 No 2

If 'yes', please explain .....

.....  
.....  
.....  
.....  
.....  
.....  
.....

**F: Changes in Ability in the Last Six Months:**

In the last six months has the focus person shown any changes in the following areas:

	<b>Much worse</b>	<b>Slightly worse</b>	<b>No change</b>	<b>Slightly better</b>	<b>Much better</b>
<b>A: Independent functioning</b> e.g. self-care skills like washing, dressing, eating and toileting, ability in areas such as road crossing, travel on buses, using the telephone, looking after them self.	1	2	3	4	5
<b>B: Physical development</b> e.g. vision, hearing, body balance, walking and running, control of hands or limbs	1	2	3	4	5
<b>C: Economic Activity</b> e.g. using money or banks, shopping, budgeting spending	1	2	3	4	5
<b>D: Language Development</b> e.g. reading & writing, speech or other forms of communication, understanding of communication by others, conversation	1	2	3	4	5
<b>E: Numbers and time</b> e.g. counting, understanding of numbers, telling the time, understanding of days of the week, difference between months/years etc	1	2	3	4	5
<b>F: Prevocational / Vocational Activity</b> e.g. ability to perform jobs or ability in college classes	1	2	3	4	5
<b>G: Self-Direction</b> e.g. using own initiative, ability to pay attention to activities, arranging leisure activities, ability to complete tasks	1	2	3	4	5
<b>H: Responsibility</b> e.g. looking after personal belongings, carrying out assigned tasks, taking responsibilities, self-control	1	2	3	4	5
<b>I: Socialization</b> e.g. cooperation, consideration for others, awareness of and interaction with others, willingness to share or take turns, understanding of social conduct (eg not being too familiar with strangers)	1	2	3	4	5

If any numbers have been circled in SHADED columns (numbers 1, 2, 4 or 5), please give details of the changes that you believe have occurred in the last 6 months under the letter that relates to the appropriate heading:

A:.....

B: .....

C:.....

D:.....

E: .....

F: .....

G:.....

H:.....

I:.....

**G: Barriers to goals being met:**

How much do you think the following things stand in the way of the goals set at planning meetings being met?

<b>Barrier to goals being met</b>	<b>Not At all</b>	<b>A Little</b>	<b>A Lot</b>
Participant's lack of money	1	2	3
Participant's problems with transport	1	2	3
Participant's reluctance to try new things	1	2	3
Participant's ill-health	1	2	3
Location of participant's home (e.g. rural)	1	2	3
Not enough staff support for the participant	1	2	3
Support staff not doing what they are supposed to do	1	2	3
Support staff reluctance to try new things or ways of supporting the participant	1	2	3
Lack of suitably trained staff to support the participant	1	2	3
Lack of accessible activities in the community	1	2	3
Limited employment opportunities	1	2	3
Limited choice of housing	1	2	3
Limited choice of day services	1	2	3
Waiting lists for services	1	2	3
Attitude of people in the local community	1	2	3
Unrealistic goals set	1	2	3
Goals do not reflect what the participant really wants	1	2	3
Other (please write in)	1	2	3
Other (please write in)	1	2	3
Other (please write in)	1	2	3

**H: Overall view of PCP process:**

1. How would you rate the planning meetings overall?

- Very good, they are helping improve the participant's life.. 1
- Good..... 2
- Neutral, a mix of good and bad, no opinion either way ..... 3
- Bad, they have a limited impact on the participant's life .... 4
- Very bad, they are not having any impact..... 5

2. What three things would you most like to see change about the planning meetings?

- i.....
- .....
- ii.....
- .....
- iii.....
- .....

3. What do you think the main benefits of PCP have been for this person so far?

- .....
- .....
- .....
- .....
- .....

4. What do you think the main problems have been in trying to implement PCP for this participant so far?

- .....
- .....
- .....
- .....
- .....

5. Do you think there have been any changes in the participant's life as a result of their involvement in PCP?..... Yes 1 No 2

If YES please describe the main changes

- .....
- .....
- .....
- .....
- .....
- .....

**Thanks you!**

#### **4.4. Facilitator interview schedule**

### **An Evaluation of the Impact of Person Centred Planning**

### **The Views of the Facilitators Nine Months from the commencement of the pilot project**

**Code Number**

**3F** \_\_\_\_\_

**Date**

\_\_\_ / \_\_\_ / \_\_\_

**If you have any questions about the questionnaire please contact:**

**Unit for Development in Intellectual Disability,  
School of Care Sciences,  
University of Glamorgan,  
Pontypridd,  
Rhondda Cynon Taff,  
CF37 1 DL**

This questionnaire is your chance to tell us what you think about Person-centred planning. As you are aware, you are the only facilitator for this pilot project. As a result of this, whilst you will not be named in the report, those persons aware of the project will know the answers given by 'the person-centred facilitator' are your answers. If you wish to 'pass' on any question that is ok. If you want to stop the interview at any time that is also ok.

**A: Introductory:**

1a. What is your relationship to the person (or people) at the centre of PCP?

- Family member..... 1
- Advocate ..... 2
- Support staff            3
- Management staff..... 4
- Care manager ..... 5
- Social worker..... 6
- Other (please write in) ..... 7
- .....
- .....

2. How many people are you PCP facilitator for?.....

3. Is being a facilitator part of your paid employment? Yes 1 No 2

4. Have you attended any PCP training sessions . Yes 1 No 2

If YES, how would you rate the quality of the PCP training sessions that you have attended so far?

- Very good ..... 1
- Good..... 2
- Neutral, mix of good and bad, no opinion either way 3
- Bad..... 4
- Very bad ..... 5

5. What have you found most useful about the training?

.....

.....

.....



(NB: there are no sections B-H within this questionnaire)

**I: Success of PCP for Individual Service Users:**

Please note that this section should be completed for each individual you are the facilitator for.

The following section concerns the success of PCP for Individual 3FC.....

1. Have there been any PCP (Circles of Support) meetings for this participant?  
..... Yes 1 No 2

If YES please carry on to the next section. If you are a facilitator to more than one person, please answer the questions thinking about this participant's PCP meetings.

2. How true are the following statements about the PCP (Circle of Support) meetings for this participant?

<b>Statement</b>	<b>Not True</b>	<b>Quite True</b>	<b>Very True</b>
The planning meetings lead to the participant getting more of what is important to them	1	2	3
The planning meetings lead to the participant getting support in the way that they want it	1	2	3
The planning meetings lead to goals being set that aim to improve the participant's life	1	2	3
The planning meetings look at the things that are important to the participant	1	2	3
If people say they will do something towards meeting a goal, they go away and do it	1	2	3
The planning meetings are leading to a better life for the participant	1	2	3

3. How much do you think the following things stand in the way of goals set at planning meetings being met for this participant?

<b>Barrier to goals being met</b>	<b>Not At all</b>	<b>A Little</b>	<b>A Lot</b>
Participant's lack of money	1	2	3
Participant's problems with transport	1	2	3
Participant's reluctance to try new things	1	2	3
Participant's ill-health	1	2	3
Location of participant's home	1	2	3
Failure of services to give staff time to plan	1	2	3
Lack of staff time to support the participant	1	2	3
Support staff not doing what they are supposed to do	1	2	3
Support staff reluctance to try new things or ways of supporting the participant	1	2	3
Lack of suitably trained staff to support the participant	1	2	3
Lack of accessible activities in the community	1	2	3
Reluctance of people in local community to give their time and support	1	2	3
Limited employment opportunities	1	2	3
Limited choice of housing	1	2	3
Limited choice of day services	1	2	3
Waiting lists for services	1	2	3
Attitude of people in the local community	1	2	3
Unrealistic goals set	1	2	3
Goals do not reflect what the participant really wants	1	2	3
Other (please write in)	1	2	3
Other (please write in)	1	2	3
Other (please write in)	1	2	3

4. How would you rate the PCP meetings for this person overall?

- Very good, they are helping improve the participant's life.. 1
- Good..... 2
- Neutral, a mix of good and bad, no opinion either way ..... 3
- Bad, they have a limited impact on the participant's life .... 4
- Very bad, they are not having any impact..... 5

5. Please use this space for any other comments you would like to make about PCP for this participant.

.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....

**J: Organisational Barriers to Person Centred Planning:**

When completing this section think about the overall PCP pilot project.

1. To what extent do you believe the following are a barrier to the success of PCP generally within this service?

	<b>Not At All</b>	<b>A Little</b>	<b>A Lot</b>
Lack of commitment to PCP by the service	1	2	3
Lack of commitment to PCP from partner services (health, social services, user/carer organisations etc)	1	2	3
Lack of funding for PCP	1	2	3
Lack of training for staff on PCP	1	2	3
Service reluctance to try new ways of working	1	2	3
Lack of trained and committed PCP facilitators	1	2	3
Lack of ongoing support for PCP facilitators eg regular coaching, supervisions	1	2	3
Lack of cooperation between different agencies/services	1	2	3
Other (please write in)	1	2	3
Other (please write in)	1	2	3
Other (please write in)	1	2	3

2. What are the three most serious barriers to adopting PCP within this service?

- i. ....
- ii. ....
- iii. ....

3. What three things about this service give the most support for the development of PCP?

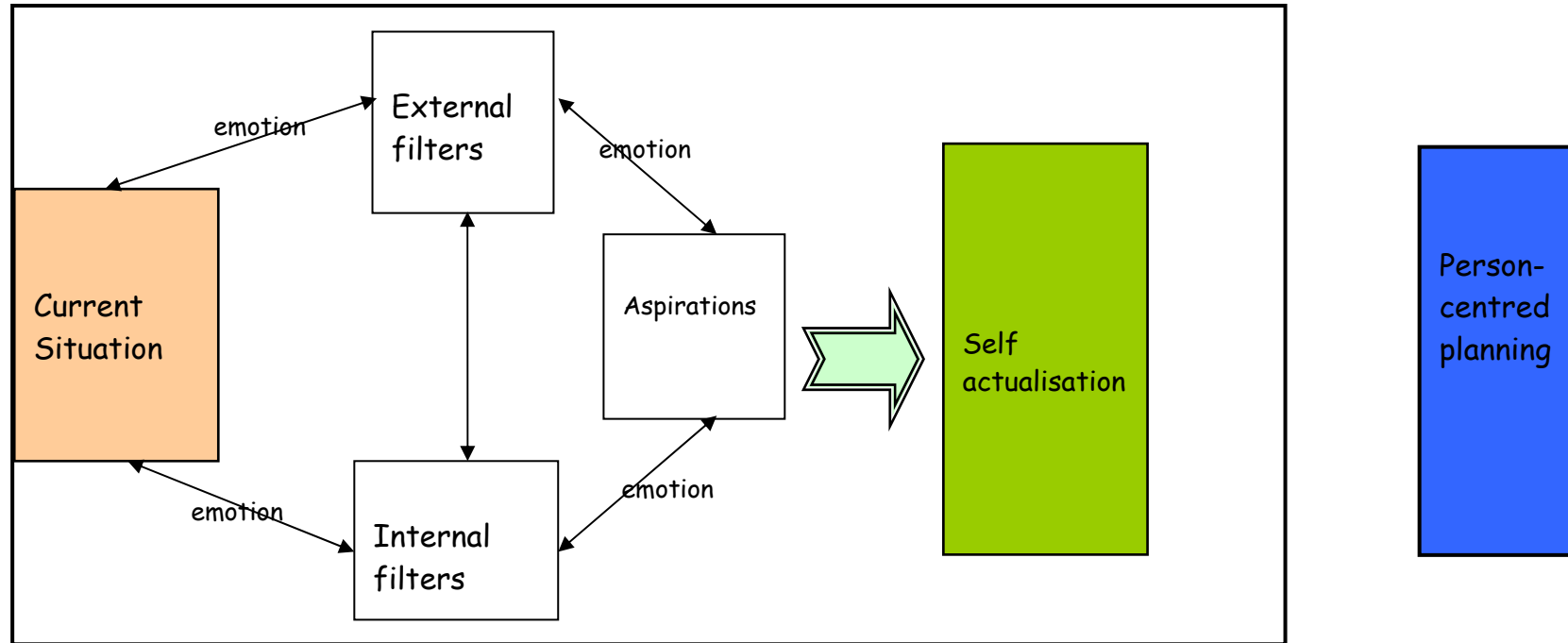
- i. ....
- ii. ....
- iii. ....

4. How would you rate the introduction of PCP in this service overall?

- Very good, it is helping to improve service users' lives..... 1
- Good..... 2
- Neutral, a mix of good and bad, no opinion either way ..... 3
- Bad, it has had a limited impact on service users' lives ..... 4
- Very bad, it is not having any impact ..... 5

**Thank You!**

## APPENDIX 4 – Proposed model of interaction between various super-ordinate themes



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