

Report on the local project

London/Canterbury 2004

Local project (title and city):

The development of person centred planning in services for people with learning disabilities in Kensington and Chelsea.

This project represents a service development and evaluation partnership between the Royal (London) Borough of Kensington and Chelsea Social Services Department (local administration/ municipality), Kensington and Chelsea Primary Care (NHS) Trust and the Tizard Centre, University of Kent at Canterbury (academic partner). This has since developed into a joint learning disability service through a partnership between health (K and C PCT) and social services (RBKC).

Co-ordinator of the local project:

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Background of the local project (problem addressed):

The implementation of person centred planning (PCP) for people with learning disabilities in the local area/ agencies and the evaluation of the process and its effectiveness. This local development initiative is effectively part of the wider national implementation of PCP as part of

the new national Learning Disability Strategy *Valuing People* (Department of Health, 2001).

Objectives of the Project:

The primary objective is to establish effective systems and arrangements for PCP in the local area, which local agencies and professionals are committed to, in which service users play a determining role and in which process and final outcomes are achieved in relation to user participation, self-determination, user satisfaction and quality of life.

Methodology and Strategy:

Mapping and documenting the development and implementation of the PCP process.

Identifying hurdles and opportunities.

Analysing and interpreting problems and potentials and finding solutions.

Defining best practices in PCP. Particularly in relation to:

Comparing local practice and arrangements in PCP with those developing elsewhere.

Comparing local practice to national policy and national learning disability strategy.

During the duration of the project a number of additional research questions have emerged, including:

How service users understand the PCP process and its potential impact on their lives.

How user self-determination and choice can be assessed.

What is the role of the PCP facilitator in relation to accountability to service users and accountability to services.

How culture, ethnicity and spirituality impact upon and affect the PCP process.

The role and influence of family and carers on PCPs and their involvement and interests in the process.

Differences in social networks in learning disability.

The role of advocates and use of advocated as independent PCP facilitators.

Productively linking PCP into service planning and review within the wider care management system and processes operating locally.

How PCP can effectively link into Health Action Planning for individuals.

The aggregation of information generated from PCP for use in strategic commissioning and service planning and development by the partnership board.

Description of the activities of the project:

Developing strategies for planning and consultation.

Working in partnership across health and social care agencies and across commissioning and providing agencies locally.

Developing partnerships with service users and handing power to service users.

Taking advocacy forward for people with learning disabilities.

Reviewing the effectiveness of policies and procedures with relevance to PCP within those organisations commissioning and providing services for people with learning disabilities.

Defining practice, professional and management responsibilities and accountability.

Establishing local contacts and networks.

Disseminating best management and practice through conferences in which users present and are involved.

Developing written materials to help disseminate experience and best practice.

Achievements/Outcomes (Please give specific examples when possible):

Reviewing local macro-organisational systems in relation to PCP (paper)

Reviewing the relationship between PCP and care management and individualisation (paper).

Developing a local comparative framework comprising project profile, organisational and policy context and glossary (papers and various materials).

Reviewing advocacy arrangements locally in relation to theory and practice elsewhere (paper).

Examining race, culture, gender and sexuality (diversity) as it effects access to services and service responses, including PCP (paper and discourse).

Actions through experiences of service users (paper).

Ideas and planning for user conference (various materials)

The successful articulation and dissemination of advocacy and PCP at with users at the May 2004 STEPS conference in London

The development of a book on PCP and care management with a chapter on experience in Kensington and Chelsea.

Information on co-operation between the partners involved and other interest groups:

Establishment of a joint evaluation of PCP with a neighbouring local authority (City of Westminster) conducted by outside researchers from the Institute of Applied Health and Social Policy/ Foundation for People with learning Disabilities.

Developing links and information exchange to the national policy implementation and support teams for 'Valuing People'.

Quality Networks project with service users as inspectors of services in conjunction with project management from the National Development Team.

'It's My Life' group, identifying and examining key themes and issues for people with learning disabilities to help the Partnership Board focus its work and priorities.

Operational connections and links with advocacy and users groups e.g. Equal People.

Work in RBKC to pull together legal issues as they concern people with learning disabilities in the context of disability and disability services more widely.

Involvement of people with learning disabilities:

At all levels and in different ways from the Partnership Board, through advocacy projects to user-inspectors and partnerships in PCP.

Also, see connections reference above and below. Service users were present and presented at the May 2004 London STEPS conference and are central to the PCP project and its aims.

Information on obstacles encountered and how they were resolved:

Challenges included responding appropriately to cultural diversity, linking project work with wider advocacy developments, location PCP in wider macro-organisational and management systems and within local care management arrangements, ensuring user participation is meaningful and productive, facilitating joint working at agency and professional levels, securing outside evaluation and scrutiny, aggregating information from PCP for strategic purchasing and service development.

Products developed and available (minutes, documents, papers ...) – Please send us available products by post.

Papers, reports, official minutes of meetings, pilot projects, reviews, consultation meetings, evaluation records, ongoing discourse etc. – held by project group.

Chapters for a book edited by Paul Cambridge and Steven Carnaby (Jessica Kingsley publishers) on PCP and care management:
Hector Medora and Sue Ledger plus a service user on PCT implementation in K and C.

Paul Swift on implementation and the local evaluation of PCP in K and C and Westminster.

Department of Health funded project on the relationships between Health Action Plans and PCPs in relation to Valuing People, examining 5 PCPs integrated with HAPs.

Project led by Sue Ledger on the histories of people with learning disabilities leaving institutions.

Forthcoming events (What will be the future of your local project?)

The relationships established through the local project will continue in different ways when STEPS finishes later in 2004. However, a second phase of STEPS is currently being planned which might provide an opportunity to continue with collaboration. The local PCP project will continue to be developed and improved in line with local best practice and the involvement of service users at the individual level in their own PCPs and at the general level in self-advocacy and in service processes

and decision-making more widely. PCP had become a central policy objective (of national Government) and all local authorities will be expected to continue the implementation and improvement of PCP processes, with PCP becoming a mainstream policy instrument for helping develop user centred services.

Activities to disseminate the results of the local project:

These include local development work and links with national network, research groups and national and regional policy implementation and support teams, circulation of papers and other publications, dissemination of findings and ideas at meetings and interest groups.

In particular, the experience of PCP within Kensington and Chelsea will be published as a Chapter in an edited volume on PCP and Care management. The authors of the chapter are Hector Medora and Sue Ledger of Kensington and Chelsea Social Services Department and the editors of the book are Paul Cambridge and Steven Carnaby of the Tizard Centre, University of Kent at Canterbury.

Other dissemination will result from the evaluation work currently being carried out by Paul Swift and Barbara McIntosh of the Foundation for People with Learning Disabilities. PCP in Kensington and Chelsea is being compared with that in Westminster and more widely as part of a national evaluation.

Of specific relevance was work undertaken for the London STEPS Conference held May 2004 on the local partnership and its focus on PCP. This included the following inputs:

It's My Life

Presentation by service users (It's My Life self advocacy group) living and working in the Borough. Service Users/Simon Groves.

Developing Person Centred Services

Identifying through two case studies, the ways services can be tailor made for individuals. The session included perspectives on PCP and health action planning, models of advocacy and ensuring services are appropriate to individual needs.

The second part of the session examined the roles and responsibilities of the different stakeholders in the service system, including commissioners, care managers and service providers. (Angela Cole, Paul Rackham, Sue Ledger, Simon Groves, Robert Templeton)

The third part of the session took a national and local comparative perspective on the implementation of PCP within organisations, drawing on research evidence (Barbara McIntosh/Paul Swift).

Recommendations to the project management

See attached documentation and forthcoming comparative evaluation report. It should be noted that this was primarily based on an action research model with ongoing two way development and implementation.

**Hector Medora, Zenobia Nadirshaw and Paul
Cambridge, July 2004.**

Recommendations relating to PCP from the London Conference, May 2004

At the final STEPS conference in London in May 2004 observations on PCP from the London partnership were provided as part of the recommendations to the project.

Work on implementation of PCP in London and elsewhere in the UK has largely been a natural experiment. PCP was introduced by Valuing People, which was itself more of a cultural directive than an evidence based policy initiative. Important values of inclusion underpinned Valuing People and PCP as a policy instrument. The London evaluation for the STEPS project was consequently largely qualitative and interpretative and a mapping of process and approach. The wider evaluation led by Eric Emerson and involving Paul Swift and Barbara McIntosh, which includes PCP in Kensington and Chelsea is well placed to provide a wider comparative frame through a longitudinal research model. This will help place the local findings and recommendations in a wider context.

Two overarching observations can be made regarding the material presented on PCP by the London partnership at the STEPS conference. The first is the importance of value led initiatives. This means that services need to value staff and service users as well as their development work in PCP and that staff value the people they work alongside and support. It was amply evident that such a culture existed in Kensington and Chelsea. The second concerns the location and redistribution of power within social care organisations and considerations of power and powerlessness more widely. To work well PCP requires that power and

authority are devolved not only to practitioners but to service users and in new ways. We identified seven key components to which help to ensure PCP works effectively – each is described by five main characteristics which are discussed below:

1. Person centred organisations

To work most effectively PCP needs to operate in truly person centred organisations. These will value staff and service users, devolve resources and authority to service users and staff and facilitate direct payments. They will also tend towards non-hierarchical structures and have lateral and vertical management systems where managers link into practice by supporting practitioners and having contact with service users.

2. Circles and networks of support

Circles of support and sound wider social networks are required by service users if PCP is to maximise its impact and change people's lives for the better. PCP needs the capacity to access informal resources and opportunities, should advocate for and with the person and link into the community. Those involved in PCP should help lobby for and negotiate change, with the different interests and stakeholders in PCP providing allies for the person and the professionals in their life.

3. Advocacy and empowerment

PCP at its best is a form of self, citizen and professional advocacy, but links with wider advocacy can further empower service users. PCP can be productively linked to and inform wider service commissioning and having users as auditors and inspectors can strengthen knowledge about

services and user choice. PCP can directly help to promote self-advocacy and ground user decision-making. In so doing it plays a part in redistributing power and resources within organisations.

4. Independent location

If PCP is to avoid becoming administratively driven, as has largely been the case with care management, which was also meant to deliver choice and change, then some independence from services is required.

Administrative and management walls between PCP and social services departments are required and PCP should definitely be located outside service providing functions. It should not utilise bureaucratically arrangements and should be organised at arms length from care management and commissioning. It may consequently require ring-fenced or separate funding.

5. Communication and inclusion

PCP is a key instrument for promoting the social inclusion of people with learning disabilities. For such opportunities to be maximised, PCP needs to be inclusive of minority and ethnic groups and interests and be culturally appropriate. Individual and non- traditions forms and communication will be required in order to engage people with complex needs. It should be conducted at the pace of the person and arrangements should be durable and sustainable as well as individual and flexible overall.

6. Links with wider systems

PCP cannot effectively work in isolation of other service systems and processes. Whilst it should not be tied into care management links are required for a constructive dialogue between PCP and care management. There should also be information exchange with individual service reviews and PCP can helpfully inform service audit in addition to aggregate information from PCP helping inform commissioning and guiding strategic service planning and development.

7. Promotes competence

PCP will work best in competent organisations but can also help organisations gain wider competencies. A two way relationship with staff training and development is evident and it can promote user empowerment more widely and competence through positive self-image individually. PCP helps promote flexible and accountable actions and responses. It can be linked to health action plans, helping develop a more holistic approach to intervention and support.

Paul Cambridge, May 2004