Person-centred planning in social care

A scoping review

Sandra Dowling, Jill Manthorpe and Sarah Cowley in association with Sarah King, Vicki Raymond, Wendy Perez and Pauline Weinstein

An exploration of the relevance of person-centred planning in social care.

This report explores why and how person-centred planning has spread from learning disability services to influence the whole of adult social care. The recent emphasis on self-directed support makes this a timely overview of the origins of person-centred planning.

The study describes how person-centred planning began, discusses the existing evidence base and explains why many practitioners find it an effective way to support people with social care needs. The authors take a critical but constructive look at the claims for person-centred planning in the context of current policy and service developments. They explore issues relating to service users, their families, frontline staff and implementation of the approach. The report concludes by identifying barriers to person-centred planning and possible ways to overcome them.

Person-centred planning in social care is relevant to debates about individual budgets, self-directed support and In Control. It will be a resource for policy makers, social care practitioners and students on social work or learning disability nursing programmes who wish to explore new ideas or evaluate contemporary approaches to social care.

JOSEPH ROWNTREE
FOUNDATION

Available in alternative formats

This publication can be provided in alternative formats, such as large print, Braille, audiotape and on disk. Please contact: Communications Department, Joseph Rowntree Foundation, The Homestead, 40 Water End, York YO30 6WP.
Tel: 01904 615905. Email: info@jrf.org.uk

Person-centred planning in social care

A scoping review

Sandra Dowling, Jill Manthorpe and Sarah Cowley in association with Sarah King, Vicki Raymond, Wendy Perez and Pauline Weinstein

JOSEPH ROWNTREE FOUNDATION

The **Joseph Rowntree Foundation** has supported this project as part of its programme of research and innovative development projects, which it hopes will be of value to policy makers, practitioners and service users. The facts presented and views expressed in this report are, however, those of the authors and not necessarily those of the Foundation.

Joseph Rowntree Foundation, The Homestead, 40 Water End, York YO30 6WP
Website: www.jrf.org.uk

KING'S College LONDON

University of London

SOCIAL CARE WORKFORCE RESEARCH UNIT

© King's College London 2006

First published 2006 by the Joseph Rowntree Foundation

All rights reserved. Reproduction of this report by photocopying or electronic means for non-commercial purposes is permitted. Otherwise, no part of this report may be reproduced, adapted, stored in a retrieval system or transmitted by any means, electronic, mechanical, photocopying, or otherwise without the prior written permission of the Joseph Rowntree Foundation.

ISBN-13: 978 1 85935 479 7
ISBN-10: 1 85935 479 3

A pdf version is available from the JRF website (www.jrf.org.uk).

A CIP catalogue record for this report is available from the British Library.

Cover design by Adkins Design

Prepared and printed by:
York Publishing Services Ltd
64 Hallfield Road
Layerthorpe
York YO31 7ZQ
Tel: 01904 430033; Fax: 01904 430868; Website: www.yps-publishing.co.uk

Further copies of this report, or any other JRF publication, can be obtained either from the JRF website (www.jrf.org.uk/bookshop/) or from our distributor, York Publishing Services Ltd, at the above address.

Contents

Summary vii

1 Introduction 1

2 What is person-centred planning? 3
Terminology 3
Philosophy 4
Practice 5
Interpreting the concept 8
Summary 9

3 How services were, how they are now and the contribution of policy in steering service developments 10
How services have been 10
How services are now 11
Policy 12
Background to policy changes 14
Comment on policy 14
Summary 15

4 Organisational structure and working culture 16
Resources 16
Funding 18
Strategic targets 19
Inter/multi-agency working 20
Mainstream and specialist services 20
Service delivery 21
Culture 22
Summary 23

5 Issues relating to service users and their families 25
The scale of the task 25
Focus on ability? 26
Service users 27
Power relations/inclusion 27
Relationship between service users and staff 28
Cultural diversity 29
Families 29
Information for families 30
Relationship between staff and families 30

Issues specific to particular populations 31
Summary 32

6 Obstacles and opportunities from the perspective of frontline staff 34
Staff abilities 34
Training 36
Culture – staff attitudes 37
The role of managers 37
Support for staff 39
Personal dilemmas 39
Summary 40

7 Barriers and bridges to person-centred planning 41
Two new initiatives designed around implementing person-centred planning 44
What works in person-centred planning? 46

8 Concluding remarks and recommendations for future research 48
Recommendations for future research 48

References 50

Appendix: Methods 60

Summary

Person-centred planning is at the heart of much recent policy relating to the provision of social care services. It refers to a family of approaches aimed at enabling people who use services to plan their own futures and to get the services that they need. While the terminology varies between different user groups, the fundamental values of the concept are the same – embracing the principles of independence, choice, inclusion, equality and empowerment as the foundations of service provision. A substantial change is needed in thinking, so that thinking that has long guided approaches to support person-centred planning becomes standard within social care services.

Traditionally, disabled people have been expected to fit into existing services. They have had little input into the design or delivery of the service they receive. There is evidence of a change within services in the direction of person-centred planning; however, this remains partial. While person-centred planning has been widely endorsed, it has not as yet been fully adopted or implemented across social care services. Even though the policy focus is on person-centred planning and it is broadly accepted as the way forward for service provision, it has proved easier to talk about it than to do it.

Current services have inherited resource systems that are based on outdated models of service provision. They were often managed and allocated on a whole-service basis without reference to the individual. Likewise, funding arrangements need to be restructured in order to give individuals more choice and control in designing their own support. An increase in the use of Direct Payments is conducive to increased choice for individuals. Adequate staffing to support work with individuals is needed, together with the allocation of sufficient time for staff to work with service users on devising and delivering person-centred plans. The potential for person-centred planning is improved through the development of strategies to support multi-agency working and through mainstream services being accessible to social care service users. A requirement of these changes is a fundamental change in the culture that permeates services so that the idea of person-centred planning is fully accepted.

Because of the legacy of traditional approaches to service design, service users often feel that they have little impact on the way that services are planned and delivered. However, there are clear calls for more control on the part of service users and their families. The degree of a person's disability, illness or the complexity of their needs should not be regarded as a barrier to person-centred planning, which,

with time and thought, should be available to each person who uses social care services. The inclusion of family members and informal support networks is a key component of person-centred planning. The onus is on services to devise the best way to bring families in and to encourage the growth of informal networks of support. Families and professionals may not always agree about what constitutes the best approach to service delivery, but it is imperative that service providers work to foster good relationships with families. In relation to service users and their families, cultural changes in the form of a realignment of power relations between service users and service providers are needed to facilitate person-centred planning.

Staff are a key resource in the delivery of good-quality social care services. While many skill deficits are identified among frontline staff, there is also an acknowledgment in the literature that the full range of skills that practitioners possess are not always recognised or used. Some staff are described as naturals, in that they instinctively deliver services with a person-centred approach, without having had any training or direction in doing so. Moreover, staff often have gathered skills outside their working environment that could be used within their workplace. While it is important that existing skills are recognised and valued, there remains a need for training for frontline staff and for managers in the delivery of person-centred planning. Training should be designed with the particular needs of support workers in mind and should take a person-centred approach.

Support for staff is crucial. This needs to be in the form of appropriate and person-centred management, and through the development of informal support structures, such as mentoring or the development of support groups made up of members of interagency staff teams. For managerial support to be effective in the implementation of person-centred planning by staff teams, managerial styles need to be person-centred and inclusive. This would develop a whole-service, person-centred culture, increasing the likelihood that it would be a sustainable approach to delivering support.

Several factors need to be in place to make person-centred planning work. These include: adherence to the underlying principles of person-centred planning; sufficient resources and appropriate funding; a trained, confident and well-equipped staff team who are managed in an inclusive and empowering style that institutes clear planning and direction for the future.

Achieving person-centred planning is not a rapid process and it is important that sufficient time is taken for initiatives to be put in place, and for policy makers, practitioners and service users to retain their enthusiasm for establishing this policy, before moving on to the next initiative.

1 Introduction

> Our society is based on the belief that everyone has a contribution to make and has the right to control their own lives. This value drives our society and will also drive the way in which we provide social care. Services should be *person-centred*, seamless and proactive. They should support independence, not dependence and allow everyone to enjoy a good quality of life, including the ability to contribute fully to our communities. They should treat people with respect and dignity and support them in overcoming barriers to inclusion. They should be tailored to the religious, cultural and ethnic needs of individuals. They should focus on positive outcomes and well-being, and work proactively to include the most disadvantaged groups. We want to ensure that everyone, particularly people in the most excluded groups in our society, benefits from improvements in services.
> (Department of Health, 2005, emphasis added)

The promotion of person-centred planning within social care services in the UK is high on the national policy agenda and is regarded as of the essence of high-quality service delivery. Stephen Ladyman, former Parliamentary Under Secretary of State for the Community, described the value of person-centred planning in stating that:

> … by 'person-centred' I mean we have to move away from mass-produced services. Services that too often created a culture of dependency and move towards a future that seeks to develop the potential that is in every single individual.
> (Ladyman, 2004)

While person-centred planning is extensively supported by Government, policy makers, commissioners and practitioners, and not least service users and their families, obstacles to its widespread implementation remain. This scoping review investigates what existing literature identifies as prevailing barriers and bridges to the implementation of person-centred planning in adult social care. It considers a range of literature across the boundaries of adult social care services, and identifies how past service structures affect present provision and where services currently stand in relation to the implementation of person-centred planning. It also examines person-centred planning from the perspectives of service users and their families, and from the perspective of frontline staff.

Chapter 2 explores what is meant by person-centred planning. Chapters 3 and 4 examine person-centred planning from both policy and structural perspectives, as well as focusing on the changes within services in relation to person-centred planning. Chapter 5 considers the issues relating to service users and their families, while Chapter 6 goes on to focus on frontline staff. Chapter 7 reviews the salient barriers and bridges to person-centred planning identified in the literature, and describes two examples of implementation strategies in two different social care settings. In the concluding chapter we set out our recommendations for service development and research.

Taken from: Dowling, S. *et al* (2006) *Person Centred PLanning in Social Care: A Scoping Review*
London: Joseph Rowntree Foundation

2 What is person-centred planning?

> Person-centred planning is based on learning through shared action, about finding creative solutions rather than fitting people into boxes and about problem solving and working together over time to create change in the person's life, in the community and in organisations.
> (Sanderson, 2000)

Person-centred planning is an umbrella term referring to a variety of specific approaches to helping people who use social care services to plan their own futures (Stalker and Campbell, 1998). It is a way in which support for people who use social care services can be organised (Mansell and Beadle-Brown, 2004a) as well as a way of enabling people to take a lead in planning all aspects of how the service they receive are delivered.

Person-centred planning is the result of nearly 30 years' dialogue and investigation. Having been developed in the US and Canada it has grown in importance in the UK. Its origins can be traced to changes that took place in the early 1970s as part of a move to 'normalisation' or ordinary living when long-stay institutions for disabled people began to close down. However, the trend towards a person-centred approach can be found in the work of Carl Rogers (1958) and his approaches to client-centred psychotherapy (Brooker, 2004). Initially developed to support people with learning difficulties, person-centred planning has since influenced work across the range of social care services.

This chapter will review what the literature says about terminology, philosophy and practice in relation to person-centred planning. This will provide a context in which later critical discussion can be located. What follows does not offer comment on opportunities or costs of person-centred planning in services at present. This will be found in later chapters.

Terminology

Several terms are found in the literature (policy, practice and research) that refer to what is described here as person-centred planning. The phrase *person-centred planning* is most commonly found in physical disability and learning difficulty literature, while, in the field of dementia care and services for older people, *person-centred care* is the term that tends to prevail. In the mental health literature the

terminology relies on notions of *empowerment* and *user inclusion*, and tends to emphasise the philosophical foundations of support rather than routes for putting ideas into practice. Literature searches did not reveal papers that focused on homelessness, asylum, addiction services or other types of social care services. Therefore comment cannot be made on the prevailing terminology in these instances.

Discussions of person-centred planning appear in the literature to describe both a philosophical understanding of the concept (Stalker and Campbell, 1998; Parley, 2001; Sanderson, 2003) and a range of practical approaches to offering support (Barker, 2001; Magito-Mclaughlin *et al.*, 2002; Sanderson, 2003; Duffy, 2004). There are several differing approaches to implementing person-centred planning but each shares characteristics that explicitly emphasise the personal empowerment of service users, in which the principal direction for support generates from those for whom planning is being carried out. It encourages the involvement of non-professionals (family and friends) in the planning process. The focus is on the choices, abilities and aspirations of individuals rather than on deficits or needs (Langley, 2001).

> Person-centred planning is grounded in a rights based approach incorporating principles of independence, choice and inclusion.
> (Stalker and Campbell, 1998)

Philosophy

From a philosophical perspective person-centred planning involves a substantial shift in thinking from that which has long governed approaches to care. In the past the needs of disabled people were determined without reference to individuals, the assumption being that the needs of any particular user group were universally rather than individually defined. This mode of thinking meant that organisations took decisions for people about how they should live and the nature of the care they received. This has changed, or is in the process of changing, to an approach where support strategies are negotiated and agreed between service providers and service users.

> Person-centred planning is a strong planning process that puts the person at the centre and deliberately shifts power towards them and can help reclaim some of the freedom which most of us take for granted.
> (Parley, 2001)

This philosophy that underpins practice can be thought of as guiding principles of person-centred planning, and includes increased community access and inclusion, the development of relationships, greater opportunities for choice, the advancement of valued and respected roles, and the development of improved personal skills (Magito-Mclaughlin *et al.*, 2002). Person-centred planning is about equality (Stalker and Campbell, 1998). It challenges the unequal power structures that have long reigned in the relationships between service providers and service users. Sanderson (2003, p. 20) suggests that a change in thinking about power relations is fundamental, where organisations need to operate from a position where they have 'power with' service users rather than 'power over' them.

As a philosophy that espouses notions of choice, independence and inclusion, ideas embedded in the concept of person-centred planning inevitably influence the way that services should be designed. Rather than service users fitting into an existing universal service, a 'one size fits all' design, services should be designed to fit around the needs of individuals. By necessity this implies that services need to be adaptable and able to evolve with the changing and dynamic needs of those who use them. The philosophy is therefore inseparable and continually influential on the practical implementation of person-centred planning. However, while changes in thinking are necessary within services for person-centred planning to become a reality, they are also necessary within wider society so that real progress can be made towards equality and justice for people who use social care services.

Practice

Implementation of person-centred planning relies heavily on a shift in thinking among managers and frontline staff about the way in which support is delivered (Woodrow, 1998; Ericson *et al.*, 2001; Parley, 2001; Sanderson, 2003; Brooker, 2004; Duffy, 2004). This will be discussed in greater detail later in this report. However, once it has been decided to base service provision around a person-centred planning model, questions arise as to how this should be carried out. The idea of including people and asking them what they think or how they would like things to go, although desirable, is not enough. Processes to guide practice are needed and four tools have been developed for the implementation of person-centred planning. These include:

1 the McGill Action Planning System (MAPS)

2 ELP (Essential Lifestyle Planning)

3 Personal Futures Planning

4 PATHS (Planning Alternative Tomorrows and Hope). (See Sanderson *et al.*, 1997.)

> It is not a single technique but a 'family' of approaches that, collectively, seek to give disabled people control over their own lives and ensure that they are respected and valued.
> (Todd, 2002)

Each has a particular approach that is appropriate for different individuals in different situations. Alternatively, a combination of approaches may be used or an individualised method that has drawn inspiration from the methods described briefly below. Stalker and Campbell (1998) provide a good overview of the key characteristics of each type of approach (also see Sanderson, 2000). The McGill Action Planning System (MAPS) brings together a group of people who help to identify the focus on service users' talents and needs, and to negotiate changes to their routines based on their desires and aspirations. This process is useful for gathering information and is often used at an early stage of planning. Essential Lifestyle Planning was developed for those individuals whom Stalker and Campbell (1998) describe as people with 'severe reputations'. It is commonly used to plan for those who are moving out of institutions. Personal Futures Planning focuses less on services and tends towards building relationships with family, friends and the wider community. PATHS can be used in the development of individual action plans.

Attention to the processes needed for the implementation of person-centred planning is important. It should take into account the particular needs of individuals, the aim of the plan, the particular communication style of the service user, others likely to be involved and individual personal preferences.

It should be noted that, although 'planning' features in the terminology, the plan is simply a first step: 'the plan is not the outcome' (Sanderson, 2003). Moreover, the plan itself should not be regarded as fixed and immutable over time, and adhered to in changing situations, but simply a guide in the moment, which needs continual review and updating in respect of the changing needs, decisions and desires of the service user. Mansell and Beadle-Brown (2004a) report some evidence of failures to carry plans forward into action. This constitutes an implementation gap and presents an obstacle to planning and effecting real change in people's lives. It is therefore of considerable importance that planning leads to action in the delivery of a person-centred service.

Although each planning method has different features, common characteristics pertain. They all adopt a perspective that sees the whole person rather than seeing them merely from a medical or clinical point of view. Each strategy is orientated towards the future; it focuses on a person's strengths, investigates their hopes and desires, and advocates creativity in planning and implementation (Stalker and Campbell, 1998). Duffy and Sanderson (2004, p. 15 and 2005, p. 41) identify five 'gears' of care management that can make use of person-centred planning and outline how the planning process 'matures' through:

1 reaching an initial understanding

2 agreeing goals

3 making use of available resources

4 implementing change

5 reviewing, learning and amending.

Another important aspect of person-centred planning is the involvement of non-professionals in the processes of planning and implementation (Stalker and Campbell, 1998; Sanderson, 2000; Ericson *et al.*, 2001; Maudslay, 2002; Kilbane and Thompson, 2004). People who use social care services are often isolated and to some degree excluded from the wider community. Person-centred planning emphasises finding ways to support communities to include everybody. This is reflected in policy, for instance in the Disability Discrimination Act (1995). Part 111, which came into force in October 2004, requires businesses, public buildings and services to adopt an accessible approach to the delivery of their service or in considering the accessibility of a building, website, transport and so on.

Sanderson (2000) considers family and friends to be partners in any planning process; however, she states that this is ultimately the decision of the service user. Circles of support are one way of involving non-professionals in the development and implementation of a person-centred plan. A circle is a group of friends, relatives and other invited people who meet regularly to offer practical and emotional support (Stalker and Campbell, 1998). Sanderson (2000) contends that 'person-centred planning cannot be truly effective without a circle of support'. (For more on Circles of Support the following website is helpful and informative: http://www.circlesnetwork.org.uk/circles_of_support.htm.) Other case study reports of person-centred planning set out less formal arrangements, particularly at the early stages.

> R lived in a residential home with four others and had regular contact with his family. His first PCP *[person-centred planning]* meeting was designed as a type of party. His favourite food and lots of drink were prepared and a room was chosen so he could move around – run, jump, as he wished. His mother was initially asked if she would like to be the facilitator and told that she could be offered support through training if she wished but she felt a bit nervous about the process and the responsibility of this role, and thought it might happen at a later stage. The first meetings were initially facilitated by the care manager and then jointly with the key worker from the home.
> (Mendora and Ledger, 2005, p. 160)

Interpreting the concept

Person-centred planning is central to many current policy initiatives relating to social and health care. This reflects a wider social trend towards a focus on individuality and an emphasis on the importance of promoting independence and autonomy. However, the notion of autonomy, individuality and independence may be at odds with ideas of societal responsibility, interdependence and community values (Nolan, 2001; Nolan *et al.*, 2004). Nolan and his colleagues argue that, for tangible improvements in quality of life to be evident, then values other than independence and autonomy should predominate. Morris (2005) comments that barriers to self-determination lie in threats to life, direct and indirect discrimination, and lack of entitlements to choice and control, including denial of rights to support with communication.

The language of person-centred planning implies that it resides in a ‘community’, which is not always found in the contemporary social environment (Mansell and Beadle-Brown, 2004a). This points to a fundamental inconsistency within the notion of person-centred planning; while independence and autonomy are widely endorsed for users of social care services, for them to be realised there needs to be complementary community action that embraces interdependence and inclusion. Person-centred planning depends on the existence of a kind of community, which in the present social climate is sometimes ideal rather than actual. Therefore, if person-centred planning relies on this imagined community, are we not simply continuing to endorse ‘special needs’ under the guise of ‘ordinary lives’?

Summary

1 Person-centred planning is an umbrella term referring to a variety of specific approaches to helping people who use social care services to plan their own futures (Stalker and Campbell, 1998). It is a way in which support for people who use social care services can be organised (Mansell and Beadle-Brown, 2004a) as well as a way of enabling people to take a lead in planning all aspects of how the service they receive is delivered.

2 There is some variation in the terminology used to describe the concept. The phrase *person-centred planning* is most commonly found in physical disability and learning difficulty literature, while, in the field of dementia care and services for older people, *person-centred care* is more commonly used. In the mental health literature, the terminology relies on notions of *empowerment* and *user inclusion*, emphasising the philosophical foundations of practice.

3 Person-centred planning involves a substantial shift in thinking from that which has long governed approaches to care. It is founded on a rights-based approach, and embraces principles of independence, choice, inclusion and empowerment.

4 Four tools have been designed for the implementation of person-centred planning. Each has a particular approach, which would be useful for different individuals in different situations.

5 There are some contradictions and internal inconsistencies in the notion of person-centred planning, not least that the imagined community in which person-centred planning is supposed to reside is not typical of that which can be found in the contemporary social environment.

3 How services were, how they are now and the contribution of policy in steering service developments

Social care services and support systems exist because of the needs of people who use them. However, the needs of service users have not always been central to the planning of services. Person-centred planning is now at the heart of the Government's strategy for people who use health and social care services (Department of Health, 2005 and 2006). This chapter will consider aspects of past service provision and the legacy this has left within current services. It will discuss policy and the implications of policy edicts in the development and delivery of services. Examples will be given of person-centred strategies that are currently being implemented.

How services have been

Traditionally, planning has sought to fit people into existing services (Sanderson, 2000; Maudslay, 2002). Such services have often taken a philosophical stance that regards service users as passive recipients of care, who do not need to know what lies behind its organisation and do not need to be involved or take an active part in the development of services (Rose, 2003).

Stainton (2002) examines past service provision and reports that there was a focus on inputs or predetermined ends. Attention was on the number of beds, or day centre places, or hours of care and so on, largely irrespective of individual need. Services were interested in quantity, how much or how many, rather than quality from the perspective of service users themselves. Stainton states that the 'needs of the disabled' were determined without reference to the individual, under the assumption that disability-related needs were universal. Service users had little control over who provided the service, or how and when the service was provided. If the service was not appropriate, disabled people could either decide to take their chances elsewhere, or to accept an inappropriate service or no service at all (Stainton, 2002, p. 757).

Changing services requires people to take a close look at all aspects of planning and delivery, and to be willing to alter provision should it be found wanting. As Todd (2002) admits:

> We thought we were putting the individual first, but the more we thought about it the more we realised we weren't. We tended to be paper driven.

Critical review and openness to change are vital as services move towards a new type of provision that places users at the centre in both planning and delivery.

How services are now

Services appear to be in a state of flux. While person-centred planning has become common parlance in services that are concerned with care and support (Jarvis, 2001), it is not the case that it has been fully adopted or implemented across social care provision. Nevertheless changes are reported. Rose (2003) points out that a shifting philosophical position is evident. This is one that draws on the strengths of service users, treats them as responsible adults and is consistent with an ethos where users are partners. Campbell (2001) notes that there has been progress in recent years in relation to user involvement, while Mansell and Beadle-Brown (2004a) report on a greater individualisation of service organisations, which leads to a greater individualisation of practice. Morris (2005) argues that values of self-determination and participation benefit everyone, not just minorities.

It seems possible that, as Nolan (2001) contends, client centredness is likely to become the watchword for the twenty-first century in social care services. But progress in the implementation of person-centred planning in practice is slow. It is hampered by a number of factors (which will be discussed in greater detail in the course of this report), including changes in culture and power relations, funding structures, infrastructure, the adequacy of staffing and staff skill base, as well as approaches to service management and staff supervision.

There is some evidence of good practice within services and improved outcomes among service users following the implementation of person-centred planning. For instance, Parley (2001) reports improvements in the opportunities available for people to make everyday choices, finding that staff were more respectful of service users, following the implementation of person-centred planning within a residential service for people with learning difficulties. However, she also observes that there is little evidence of people becoming more involved in planning their care on a power-sharing basis and that family involvement remains unaffected.

Mansell and Beadle-Brown (2004a), among others (e.g. Towell and Sanderson, 2004), state that systematic evidence is scant, beyond case studies showing improved outcomes following the implementation of person-centred planning.

However, Emerson and Stancliffe (2004) argue that the literature on 'positive behaviour support' (Lucyshyn *et al.*, 2002) and 'active support' (Jones *et al.*, 2001; Felce *et al.*, 2002), as well as on the development of individualised services for people with high support needs (Mansell *et al.*, 2001), provides sufficient evidence to show that individual planning and action result in positive benefits to people with learning difficulties. They believe that this evidence is generalisable to person-centred planning. Robertson *et al.*'s (2005) major study has confirmed this. They write:

> The results of the formal evaluation indicated that PCP is both efficacious and effective in improving the life experiences of people with learning disabilities. PCP also reflects the core values of empowerment and personalisation that underlie contemporary approaches to health and social care in England.
> (Robertson *et al.*, 2005, p. 110)

Policy

Government policy recommends a collaborative and inclusive approach to service delivery within social care. In his speech to the Community Care Live conference (May 2004, quoted in Wistow, 2004), Stephen Ladyman (then Parliamentary Under Secretary of State for Community) announced a new 'vision' for social care, stating that services should be delivered and arranged in ways that are 'person-centred, proactive and seamless'. This vision is taken further in the consultation paper, which states that the vision for adult social care takes as a starting point:

> … the principle that everyone in society has a positive contribution to make to that society and that they should have the right to control their own lives.
> (Department of Health, 2005)

> Person-centred planning has been adopted as a central strand of British public policy for the development of support for people … commensurate with their needs and life or lifestyle ambitions.
> (Felce, 2004)

It is clear that person-centred planning lies at the heart of current thinking relating to the provision of social care services. However, as far back as 1989, principles underlying person-centred planning were present in policy documents. The White

Paper, *Caring People: Community Care in the Next Decade and Beyond* (Department of Health, 1989), states that social and health care services should be designed 'to provide the right amount of care and support to help people to achieve maximum possible independence and … help them achieve their full potential'. A second key concept was to 'give people a greater individual say in how they live their lives and the services they need to help them do so' (Department of Health, 1989, p. 4). An inclination towards inclusion, user involvement and individualised services has been a growing movement and this is clearly reflected in more recent policy (see Cabinet Office Strategy Unit, 2005).

The provision of individualised care is emphasised in most national policy, and for many care settings and in respect of many groups of service users. For example, it is at the forefront of *The National Care Standards* (Scottish Executive, 2001), while person-centred planning is an expected standard within the *National Service Framework for Older People* (Department of Health, 2001a).

The *Essence of Care* document (Department of Health, 2001c) is a patient-centred benchmarking tool for health professionals. However, it does not offer any specific benchmark to evaluate person-centred planning and the tool as a whole does not address the individual's well-being status. Despite the strong emphasis on person-centred care in the *National Service Framework for Older People* (Department of Health, 2001a), the *Essence of Care* document does not explicitly mention person-centred planning in its own right. It focuses on aspects of physical health care such as continence and hygiene. In response, the Alzheimer's Society (2001) offers standards in person-centred care for care homes to supplement the Department of Health's *Essence of Care* document.

The *National Service Framework for Mental Health* (Department of Health, 1999) builds on *The Health of the Nation* key area handbook on mental illness (Department of Health, 1994). Both emphasise the need for NHS commissioners, providers and local authorities to consult with users and carers about community care planning for people with mental health problems.

In the field of learning difficulties, the White Paper *Valuing People: A New Strategy for Learning Disability in the 21st Century* (Department of Health, 2001b) defines a context for person-centred planning that is comprehensive, systematic and challenging to current local and national practices (O'Brien, 2004). This document has been the key to the sustained development of person-centred planning, as the national evaluation demonstrates (Robertson *et al.*, 2005). Lunt and Thompson (1993) state that there is an almost universal declaration of commitment to the ideal of participation, equality and social integration by service providers to people with

intellectual difficulties. These are driven by policy as well as being influential on policy developments in a reciprocal manner, as the development of person-centred planning demonstrates.

These examples, relating to different user groups, illustrate the energetic and consistent focus within public policy towards the provision of services that are person-centred. However, as Nolan cautions:

> … policy often espouses principles which are simple to express but highly complex to translate into practice.
> (Nolan, 2001, p. 450)

Background to policy changes

The implementation of person-centred planning mandates that service providers and practitioners know people as individuals (Williams and Grant, 1998). This is consistent with policy vision across social care services, and evident in, for example, the *National Service Framework for Older People*, which defines care as that which 'respects people as individuals and is organised around their needs' (Department of Health, 2001a). Nolan *et al.* (2004) assert that this focus on the individual reflects wider trends in health and social care services, where the importance of promoting the independence and autonomy of service users is emphasised and that these, as well as notions of user involvement, have become major drivers of policy.

Comment on policy

Nolan *et al.* (2004) state that person-centred planning is an oft-quoted but ill-defined concept, which nevertheless exerts a considerable influence on policy, practice and academic literature. Definitions throughout the literature abound. What does seem wanting is evidence of widespread implementation, which would constitute a move beyond conceptualisation of ideas that remain high on the policy agenda (Rose, 2003). For instance, incorporation of ideas of user involvement and person-centred planning is only recently evident in mainstream services and many regard this as partial (Truman and Raine, 2002).

The scale of the task outlined in policy is very ambitious (Mansell and Beadle-Brown, 2004a). As discussed earlier, the complexity of implementation is not always taken into account in policy documents (Nolan *et al.*, 2004). Contradictions or tensions are

also apparent between policy and practice documents, thus increasing difficulty in implementation. This is exemplified within the field of learning difficulties where Care Standards firmly state that no one can be supervised by someone who is untrained or who has not been checked by the Criminal Records Bureau (Todd, 2002). This may be read as in conflict with the 'informal' supports encouraged within person-centred planning protocols. Alternatively, Cambridge (2005) suggests that, as brokerage services and similar expand, through Direct Payments for example, the system of person-centred planning may be a means to counter the risks of exploitation.

While policy provides direction and vision for the future of social care services, it needs to be followed by widespread changes in practice. For these to take place a revision of the infrastructure and strategic design of services is required, so as to support and facilitate the desired goal of a new style of support for service users. Structural and cultural changes may mean that the vision for the future is less compromised by the legacies of the past.

Summary

1 Traditionally, people have been expected to fit into existing services. Service users had little control over who provided the service, or how and when the service was provided. If the service was not appropriate, users could decide to take their chances elsewhere, or to accept an inappropriate service or none at all.

2 Services appear to be in the midst of changes. While person-centred planning is commonly talked about in relation to services that are concerned with care and support, it has not been fully adopted or implemented across the wider range of social care and public services.

3 Person-centred planning is at the heart of many recent policy initiatives relating to the provision of social care services. Its ethos is consistent across a range of policies directed at particular user groups. It may not be as easy to implement person-centred planning as it is to promote it in policy documents.

4 The focus on the individual in social care policy is reflective of wider trends in health and social care services, where the importance of promoting the independence and autonomy of service users is emphasised.

4 Organisational structure and working culture

Person-centred planning has become the common-sense approach to the development and delivery of social care services in the UK. There seems to be no serious alternative. However, the way that services are organised, the resources available, the funding structures, strategies for multi-agency working and the prevailing culture within services all impact on whether the implementation of person-centred planning can be achieved successfully or not. This chapter is concerned with the way in which facets of organisational structures offer opportunities or present obstacles to the widespread and committed adoption of person-centred planning within social care services. The question of what organisational factors impede or facilitate the introduction and effectiveness of person-centred planning was also one of the key questions asked by the national evaluation of person-centred planning by Robertson *et al.* (2005).

Resources

> For person-centred planning to really help change people's lives it needs to be linked to the way in which resources are allocated and used. (Routledge and Gitsham, 2004)

Contemporary social care services have inherited a resource system based on a now largely discredited mode of service delivery. It is apparent therefore that in order to facilitate a new way of delivering services – that is, through person-centred planning – a change in how resources are managed and allocated is needed (Routledge and Gitsham, 2004). Such a system change is required in relation to authorising, contracting and paying for services (Emerson and Stancliffe, 2004). Mansell and Beadle-Brown (2004a) recommend that greater resources are needed for the provision of smaller-scale community services, wherein person-centred planning finds a clearer path to success. However, while Routledge and Gitsham (2004) point to the need for strategic investment in services, they judge that there is a poor balance between listening to what is important to people and deciding how resources are allocated.

Mansell and Beadle-Brown (2004b) note that resource constraints undermine the ability of service providers to turn person-centred planning into action. For instance, a lack of resources in a particular area may affect the kinds of choices that people make when devising their plans. So, for example, if there is a lack of appropriate

housing, this is likely to limit people's willingness to include hopes for better housing in their vision (Coyle and Moloney, 1999).

People

Staff are a key resource needed for making person-centred planning possible (Sanderson, 2000), both in terms of the adequacy of staffing levels and the skill base of a staff team. Mansell and Beadle-Brown (2004a) warn that skill shortages can impede implementation of plans, while Packer (2000a) points to a strain on resources in terms of lack of staff. Magito-McLaughlin *et al.* (2002) state that staffing levels need to be adequate to meet the needs of one-to-one working that are often required by person-centred planning, as opposed to procedures within traditional services where staff were required to supervise a group of service users.

Crawford (2001) notes that staff shortages can mean standards of care are far from ideal; while Packer (2000b) is concerned that it is service users who bear the brunt of staff shortages, although this is also likely to place increased stress or even despair on staff – another factor liable to impede the implementation of person-centred planning (Packer, 2000d). Staff shortages may also impact on families, who may be relied on for informal support if staffing levels within services are not adequate to meet the demands of person-centred planning (Felce, 2004).

Kydd (2004) states that the solution is not always in the form of increased resources in terms of more staff, but in positive teams who work together to develop appropriate working environments for person-centred planning to be implemented. Likewise, Sanderson (2003) emphasises that teams are a key component of organisational effectiveness in delivering person-centred planning. Magito-McLaughlin *et al.* (2002) raise the important issue of stability within the workforce. They note that direct care staff need to feel that they are effective in their support role, otherwise they are likely to become frustrated and this may result in them moving on and changing jobs. Such instability in the workforce 'can ultimately compromise the successful implementation of even the best person-centred plans' (Magito-McLaughlin *et al.*, p. 130). From the US, Boettcher *et al.*, (2004) suggest staff development programmes for care workers can make a positive difference to practice.

Time

> That it may require time does not appear to be part of its sales pitch.
> (Felce, 2004)

Done well person-centred planning is a time-consuming process (Emerson and Stancliffe, 2004). However, there appears to be no calculation about the resource investment in terms of time that is needed (Felce, 2004). There is likely to be a strain on the system's resources in terms of the time required to create individual action plans for each person who uses the service (Emerson and Stancliffe, 2004). The evaluation by Robertson *et al.* (2005) has shown, nonetheless, that the system need not be any more expensive than those which are not individualised.

Transport

Person-centred planning opens up opportunities that may mean that people require access to public or individualised transport. For example, people may need transport to get to and from paid or voluntary work opportunities, college courses, getting together with friends or family, or recreational and leisure activities. Access to transport should be considered when providing resources for services that take a person-centred approach to the delivery of support. Lack of transport has the potential to compromise the integrity of a person-centred plan (Magito-McLaughlin *et al.*, 2002).

Funding

The implementation of person-centred planning should go hand in hand with restructuring services in terms of required funding arrangements (Felce, 2004), since funding is central to issues of control for consumers (Emerson and Stancliffe, 2004). Changes to funding arrangements need to be in terms of an assessment of funding needs based on an individual's requirements rather than a fixed level based on supposed whole-service requirements (Mansell and Beadle-Brown, 2004a). The piloting of individual budgets was proposed in the Cabinet Office Strategy Unit (2005) report *Improving the Life Chances of Disabled People*. It is restated in the Green Paper on adult social care (Department of Health, 2005) and the *Strategy for an Ageing Population* (HM Government, 2005). From 2006, a series of 13 local authorities embarked on this approach.

> If funding is linked to services rather than individuals, then the choices open to person-centred planning teams are limited to available services from existing disability service providers.
> (Emerson and Stancliffe, 2004)

Direct Payments, where people receive money to buy their own support instead of receiving services, are a relatively recent advance. They enable people to have more choice and control over their lives, and to make decisions about their support in line with the principles of person-centred planning. But most people do not have Direct Payments and Mansell and Beadle-Brown (2004a) recommend that this option be extended to more people in order to facilitate the implementation of person-centred planning – a policy goal more widely espoused (Department of Health, 2005). Commenting on the links between Direct Payments and person-centred planning, Beadle-Brown (2005, p. 176) notes that both face similar barriers in moving from project status to mainstream services, and considers that this lies in their lack of compulsion, guidance and examples, ability to be sufficiently flexible, and understanding of issues of consent and capacity (p. 176).

Cash instead of care systems are not unique to the UK and some make more explicit links to person-centred planning. Fortune *et al.* (2004) describe features of a system for funding in Wyoming, US that supports person-centred planning. This enables people to have an individual portable budget for them to use to purchase services. Another programme, In Control, has been piloted in six local authorities in the UK (Duffy, 2004). This uses a resource allocation system that makes it possible for local authorities to establish how much funding is needed for each individual service user (In Control, 2004). Duffy (2004) states that the benefit of this is that local authorities can plan their own finances more effectively and it encourages greater creativity and community inclusion in the design of services. Further details of In Control are discussed in Chapter 7 of this review.

Strategic targets

Felce (2004) highlights what he regards as a fundamental problem in the development of person-centred services – that is that the Government has abandoned provisional all-service targets in favour of developing services that are person centred. However, he states that 'there is no incompatibility between setting targets for populations as a whole and individual assessment of the precise nature of service input different people require or want' (Felce, 2004, p. 19). As Ray (1999) points out, the notion of standards does not mean taking a standardised approach. Within the principles of person-centred planning it would be an anathema to prescribe what, how much, or how often service users must have something in order to provide quality of care. However, it is possible to develop targets and assess standards without compromising individual planning and service delivery. One target set by *Valuing People* (Department of Heath, 2001b) is for local areas to implement person-centred planning. Recommendations from the evaluation of person-centred

planning (Robertson *et al.*, 2005, p. 110) include requesting that the Department of Health develops a 'clear strategic plan for supporting the development of PCP', including financial support for development activities, guidance for local authorities and the NHS, professional guidance for care managers and specialist staff, and expectations that training equips practitioners to use person-centred planning approaches. Monitoring of access to person-centred planning and its outcomes is also recommended (Robertson *et al.*, p. 111).

Inter/multi-agency working

Interagency or multi-agency collaboration is regarded as conducive to the realisation of person-centred plans (Amado and McBride, 2002). According to Towell and Sanderson (2004), multi-agency engagement needs to be at three levels. First, at a personal level, the focus should be on increasing opportunities available to individuals. Second, at a service level, managers need to increase the capacity of staff to be able to deliver personalised supports. Finally, at a local public services level, the focus should be on developing strategies for community inclusion of service users. Rose (2003) cautions against the assumption that interagency working at a structural/managerial level equals improved outcomes for service users. She states that this is based on the potentially flawed premise that managerial or structural changes will necessarily result in changes for frontline workers or service users. However, multi-agency engagement at all three levels as discussed above may mean that collaboration actually results in positive outcomes within the person-centred paradigm.

Mainstream and specialist services

The literature identifies the benefits of inclusive policies on behalf of mainstream services. This means that people who have traditionally used specialist services gain access to mainstream provision (O'Brien, 2004). Doing this increases the options available to people, thus enabling greater choice and promoting inclusion.

To facilitate this Towell and Sanderson (2004) recommend that specialist services learn how to work with and negotiate access to mainstream services (O'Brien, 2004). Moreover, mainstream services may need to make adaptations so as to be able to accommodate the needs of people who have traditionally engaged only with specialist services. One example of the benefit of inclusive working within mainstream services is found in Dowling *et al.* (2003), where mainstream bereavement services successfully delivered counselling to a group of bereaved people with learning difficulties, with significantly positive outcomes.

Service delivery

As has been discussed, person-centred planning creates opportunities for flexible support. Plans are developed collaboratively with people themselves and with their informal and formal support networks, and typically build on people's strengths, abilities, goals and desires. Principles of choice, empowerment and inclusion are fostered (Sanderson, 2000; Magito-McLaughlin *et al.*, 2002). However, traditional models of service delivery tend to base provision around the perceived needs of many, rather than the agreed needs of individuals. Magito-McLaughlin *et al.* (2002) state that compliance with regulations and the establishment of broad systems that impose rigorous standards of care have taken priority over attainment of individually desired outcomes or inclusion.

Vital to the design of individual support packages is attention to the breadth of each person's background, experience and personal attributes (see box below).

Information necessary to the design of individual support programmes is attention to:

1 history and experiences

2 health and well-being

3 important relationships and social contacts

4 community life

5 preferences

6 rituals and routines

7 communication strategies

8 aspirations and fears

9 reputation

10 level of self-determination (Magito-McLaughlin *et al.*, 2002).

However, traditional models of service delivery tend to serve large numbers of people, and this can be a barrier to planning and delivering individualised support. For instance, overcrowding in living environments, where ten or more people share accommodation, or where people are typically in large groups in day care centres, can result in service users spending time regularly with people they don't get on with or taking part in non-preferred and standardised activities. Moreover, within this format, it is rarely possible for frontline staff to pay attention to people as individuals

(Magito-McLaughlin *et al.*, 2002). 'These factors have the potential to compromise the integrity of the individualised supports' required within the person-centred planning model (Magito-McLaughlin *et al.*, 2002). Thus, person-centred planning is impeded by the traditional model of service delivery, and radical changes are needed so as not to compromise contemporary vision because of the inheritances of the past.

Culture

> If person-centred care is going to work then it is not just about individual change but a whole culture change.
> (Sheard, 2004)

Person-centred planning represents a culture shift for most agencies (Todd, 2002). The importance of recognising the prevailing culture within services as a major factor in underpinning how services are planned and delivered is widely emphasised in the literature (Stalker and Campbell, 1998; Sanderson, 2000, 2003; Ericson *et al.*, 2001; Nolan, 2001; Parley, 2001; Brooker, 2004; Duffy, 2004; Emerson and Stancliffe, 2004; Mansell and Beadle-Brown, 2004a, 2004b; Sheard, 2004; Towell and Sanderson, 2004).

A fundamental change in the culture that governs services is a prerequisite to the successful delivery of person-centred planning. This means a realignment of power relations in the direction of service users (Emerson and Stancliffe, 2004; Towell and Sanderson, 2004). There are a number of strategies that would enable service users to have increased power over the service they receive. For instance, a change in funding arrangements, such as the increased use of Direct Payments, would allow for greater consumer control (Emerson and Stancliffe, 2004). Mansell and Beadle-Brown (2004a) recommend that person-centred planning is given legal weight as it is in some countries, so that service users could challenge the failure of services to deliver the personalised service that is required.

> There is a need to understand person-centred care as a life philosophy – an aspiration about being human, about pursuing the meaning of self, respecting difference, valuing equality, facing the anxieties, threats and guilt in our own lives, emphasising strengths in others and celebrating uniqueness and our own 'personhood'.
> (Sheard, 2004)

Duffy (2004) notes that changes in thinking are evident in practice. This is demonstrated in a report by Todd (2002):

> One agency worked with a client with autism whose life goal was to be an airline pilot. This was unrealistic, but the service wanted to make an appropriate person-centred response. His support worker suggested they go together to Heathrow for an afternoon each week to find out what it was about being a pilot that really interested him – was it flying, the planes, the uniforms or what? After weeks it was clear that he was most fascinated by the baggage carousels and eventually he was supported to get a part-time job as a baggage handler. Service providers can't necessarily make people's ultimate dreams happen (in this case to be a pilot) but person-centred planning enables them to get closer to them. (Todd, 2002)

A service culture that is open to the possibilities of person-centred planning and willing to take risks and think outside of the traditional service model can enable service users to achieve the kinds of successes described above. Embracing ideas of empowerment and inclusion, and believing, as a frontline worker, that there is the possibility of real change and improved outcomes for service users and workers alike will take courage on the part of staff and managers. Cultural changes are whole-service changes, affecting not just the way that services are delivered but also working practice and managerial style (Sanderson, 2003).

One of the greatest barriers to achieving person-centred planning is the lack of belief among frontline workers and service providers that it is a real possibility (Packer, 2000a). It is reported that, while person-centred planning is regarded as visionary, it is also thought to be idealistic and potentially unrealisable (Stalker and Campbell, 1998). A passionate vision, together with a thorough evaluation of belief systems that underpin practice, is needed for person-centred planning to become a reality throughout services (Sheard, 2004). The people who care need a person-centred approach themselves (Packer, 2000c).

Summary

1 Current social care services have inherited a resource system from the traditional model of service provision. In order to facilitate a new way of delivering services – that is, through person-centred planning – a change in how resources are managed and allocated is needed.

2 Staff are a key resource for making person-centred planning possible. Sufficient staff who have received training and appropriate management are needed to support the implementation of person-centred planning.

3 Service providers need to make sure that adequate time is allocated to facilitate person-centred practice.

4 Adequate transport needs to be available to enable service users to make their plans a reality.

5 There needs to be a restructuring of funding arrangements to give more control and choice to the consumer, and facilitate individualised rather than universal services.

6 Strategic targets are required to ensure that services meet high standards in delivery of support. Strategic targets for whole populations do not compromise the development and implementation of individualised plans.

7 Multi-agency working is regarded as conducive to the realisation of person-centred plans; this should be evident at all levels of service and not just at a managerial level.

8 Mainstream services should be encouraged to include social care service users, while links and positive working practices between specialist and mainstream services should be developed.

9 The traditional model of service delivery may impede person-centred planning; therefore radical changes are needed so as not to compromise the vision because of the legacy of past provision.

10 A fundamental change in the culture that governs services is a prerequisite to the possibility that person-centred planning can be successfully delivered.

5 Issues relating to service users and their families

Service users are the reason why public services and support systems exist. People using services aim to live independently in an environment in which they can thrive and live life to the full (Bowling *et al.*, 2002). The main factors that reflect independence from the perspective of people who use services are the ability to make choices and to exercise control over their lives (Boaz *et al.*, 1999; Bignall and Butt, 2000; Bowling *et al.*, 2002). Person-centred planning can help to facilitate these aims.

The expectations of different groups of service users may vary according to their individual needs and circumstances; people's views are not homogeneous and may change over time. This underlines the importance of services that are tailored around the needs of individuals, open to change, sensitive to the changing views of service users and able to adapt accordingly.

This chapter will reflect what the literature identifies as potential barriers or bridges to person-centred planning, with a focus on service users themselves and their families.

The scale of the task

Mansell and Beadle-Brown (2004a, p. 2) state that service-wide implementation of person-centred planning within services for people with learning difficulties is 'an extremely ambitious target for public policy', if only because of the numbers of people involved and the nature of people's difficulties. While they locate their discussion in relation to learning difficulty, the points made are likely to resonate across the range of social care service users. Furthermore, Nolan (2001) discusses the demographic trend towards an increase in the overall population of older people; this is likely to generate increases in demand on services. Again, while Nolan's focus is on a particular population, the point made is relevant to many other groups of service users, where advances in health care have generated an increased life expectancy for people with disabilities, long-term health conditions and learning difficulties.

However, it is recognised that the implementation of person-centred planning will take time (Todd, 2002). Therefore, while the task is considerable and the demands on services are growing, a steady and dedicated approach over a realistic timescale

will enable widespread adoption of person-centred planning within services and for each service user. Towell and Sanderson (2004) challenge concerns about how great the task of implementing person-centred planning is thought to be, by reframing the vision so that quality rather than quantity is emphasised in its delivery. The scale of the undertaking in itself should therefore be thought of as a challenge rather than as a barrier.

Focus on ability?

While the degree of disability, illness or complexity of need should not be considered to be a barrier to achieving a person-centred approach to support for any service user (O'Brien, 2004; Maudslay, 2002), there are more complicated issues associated with more complex needs. For instance, people with a severe disability may have encountered obstacles in the development of sustainable friendships or relationships, which are regarded as central to the facilitation of person-centred planning (Mansell and Beadle-Brown, 2004a). Many people who use residential and day services end up spending their time largely with people who are paid to work with them (Sanderson, 2000). Therefore, the development of a network of informal support or a circle of support may be harder to instigate.

Crawford (2001) recognises the increasing involvement of users of mental health services in shaping developments in mental health practice such as person-centred planning; however, he identifies obstacles that have been encountered in achieving this. He notes that a number of psychiatrists have questioned the ability of people whose insight has been affected by illness to play a role in planning their own care and support.

It may be the case that service users with more complex needs place a greater challenge to service providers in implementing person-centred planning. However, a focus on a person's impairment was a common aspect of former service provision; in contrast:

> … person-centred planning focuses on capacities and capabilities, on what people can do, who they are and what their gifts are.
> (Sanderson, 2000)

Service users

The legacy of services where users were considered to be passive recipients of care and were not asked about what kind of services they needed or would like has led to them often perceiving that they can achieve little in terms of influencing how services are designed or delivered (Truman and Raine, 2002). Crawford (2001) argues that service users are increasingly aware of options and rights as consumers, and Glasby and Littlechild (2002) report clear demands from service users for self-directed support.

Doris Clark and Robert Garland (Clark *et al.*, 2005) report their experiences and argue that circles of support are an integral part of person-centred planning. As they observe, people with learning difficulties are often not short of plans, but these are generally imposed on them. They argue 'the important word is "person centred" not planning' (Clark *et al.*, 2005, p. 69). Being the 'subject' of a person-centred plan is also something that only those concerned can explain, and Robert Garland's personal account suggests that initial feelings of nervousness can be overcome, although some topics may be sensitive.

> Individuals want more control; families want more control; the self-advocacy movement wants people to have more control and central government sees the increasing personalisation of social care as an important goal.
> (Duffy, 2004)

Power relations/inclusion

As shown in Chapter 3, it is widely recognised in the literature that, in order for person-centred planning to be achieved, a change in the culture and thinking within services is needed. Power is an issue because it is not always equally apportioned. This means that some people have more power than others and, traditionally within services, power has resided in the hands of service providers rather than service users. One legacy of this is that service users perceive that their ability to influence services is limited (Truman and Raine, 2002). Sanderson (2000) points out that people who use person-centred planning make a conscious commitment to sharing power.

Stainton (2002, p. 761) reports that social workers seem to generally recognise and accept a change in the nature of their relationships with clients, 'from one characterised more by paternalism and control to one of equality and partnership'.

The increased involvement of service users through, for example, Direct Payments leads to people having increased control over their support. However, Campbell (2001), taking a closer look, questions the reality of growing equality in power relations, where he observes service users are often invited to take part but are never involved in instigating change. A shift in power relations in the direction of enabling service users to have more control is regarded as a prerequisite to person-centred planning and the absence of this is clearly a barrier.

Relationship between service users and staff

The relationship between service users and support staff will necessarily alter with the introduction of person-centred planning. The professional role will no longer involve the collection and storing of information about service users and the authority to make decisions about people's lives. Instead a shared process of decision making with individuals and others who care about them will be enacted. Professionals' relationships with service users should change from them 'being the "experts on the person" to being "experts in the process of problem solving with others"' (Sanderson, 2000).

> Person-centred planning begins when people decide to listen carefully and in ways that can strengthen the voice of people who have been or are at risk of being silenced.
> (O'Brien, quoted in Sanderson 2000)

Positive relationships between service users and staff are needed to make person-centred planning a possibility (Everson and Zhang, 2000). However, Mansell and Beadle-Brown (2004a) point out that 'challenging behaviour' such as aggressive or self-injurious behaviour on the part of individuals may lead to negative emotional consequences for staff. This may make it harder for them to empathise with service users or may discourage them from putting in the effort needed to facilitate person-centred planning. Appropriate supervision and planning of services, perhaps through the mechanism of person-centred teams, could address difficulties such as these, so as to prevent poor relationships between staff and service users becoming a barrier to person-centred planning.

Cultural diversity

It is important that service providers are familiar with cultural practices, religion, religious observance and language of those using their services. However, Iliffe and Manthorpe (2004, p. 283) state that this should not be 'relegated to an ethnic minority agenda', but rather should be applicable to all individuals. The authors are writing about people with dementia; however, the central point resonates for users of all kinds of social care services. They go on to point out that person-centred services, by virtue of the principles that govern the person-centred approach, are likely to take into account the particular needs of individuals (Hasnain *et al.*, 2003), since the service is designed around individual circumstances and need rather than a 'one size fits all' universal service, wherein cultural needs can be inconvenient or overlooked. Khan *et al.* (not dated) report that a person-centred planning approach has been chosen to specifically counter the exclusion of people from South Asian backgrounds from services. The need for such an approach is demonstrated by Hubert's (2004) interviews with 30 families from South Asian backgrounds who felt very unsupported, uncertain of the future and isolated from service and informal networks in the main. Shah (2005) has identified the risks of establishing specialist services to meet cultural needs and to respond to disadvantage and discrimination, and argues that such services may be short-term and hard to sustain. They also do not result in changes to mainstream provision. She warns that it is important to acknowledge that, within person-centred planning, 'the assessment process may itself reinforce cultural and racial stereotyping' (Shah, 2005, p. 144).

Families

The role of families (where they are involved in a person's life) is central to the success of person-centred planning (Ericson *et al.*, 2001). La Fountaine (2004) criticises person-centred planning as too individualistic, failing to see the person within the structure of their family. By contrast, Sanderson (2000) argues that person-centred planning necessarily locates people in the context of their families and the wider community. The role of and the inclusion of non-professionals in the form of family and friends of service users are key components of person-centred planning (Maudslay, 2002). A basic challenge to working in a person-centred way lies in figuring out how best to encourage and include family members, friends and selected others to take part in the process (Sanderson, 2000). However, Felce (2004) cautions that the goodwill of families may wear thin, as informal support networks may mask lack of investment in formal support structures, for instance through families providing informal support where staffing levels are inadequate.

Duffy (2004) notes that some families would like to have more control in the planning and delivery of services. Families of people with dementia commonly prefer that their relative is cared for at home, where 'a little extra something' can be given (Ericson *et al.*, 2001). However, the strain on families can be considerable and it is recognised that they need support too; families have said that they would value confidants to talk to about the problems they face (Ericson *et al.*, 2001). It is important that a balance is found between involving families and ensuring that service users themselves remain at the centre of planning and delivery of their supports.

Brown with Scott (2005) warns that families and other informal networks do not always act in the best interests of disabled people, and they provide a series of examples from practice where the person-centred planning model is 'strained'. In their view, the ethos around person-centred planning has often overlooked risks of exploitation and harm, and its 'acolytes often chafe at the need for safeguards, regulation and screening as if these were superfluous bureaucracy, but in doing so they ignore research studies into abuse of vulnerable adults' (Brown with Scott, 2005, p. 202).

Information for families

Central to helping families to offer informal support within the parameters of a person-centred approach is the provision of information and training for family members (Coyle and Moloney, 1999). Indeed, person-centred planning strategies recommend training for families (and for service users themselves), but Routledge and Gitsham (2004) note that training has been largely focused on staff to the exclusion of families and service users. However, Sanderson (2000) reports that this is changing and that, although many training courses have been held for support staff, there are increasing numbers for families, advocates and self-advocates. The successful inclusion of family members in the implementation of person-centred planning is underpinned by equipping families with information that is relevant, accessible and jargon free, and by providing appropriate training for families.

Relationship between staff and families

Families and professionals may have different ideas about what constitutes best support (Ericson *et al.*, 2001). However, Sanderson (2000) argues that service providers should view families positively. She states that the family understands the person from its own perspective and there is a need for service providers to make a

concerted effort to develop relationships with families. Stereotyping families as either 'over-protective' or 'disinterested' is detrimental to the person-centred planning process.

Issues specific to particular populations

People with learning difficulties

Communication

There is a common over-reliance on verbal communication and staff can often misjudge how much or how little service users understand (Mansell and Beadle-Brown, 2005). Imaginative means of communication can be developed in respect of the needs and abilities of individuals. Dick and Purvis (2005) outline how one county's total communication plan became one of the main footings for the person-centred approaches. They report an example of work with one individual, John, to illustrate ways in which communications can help in the building of a plan, to enable it to be reviewed, to share information and to assess the impact or outcome of a more person-centred approach on his life. In the absence of attention to communication, there is a risk of a lack of understanding between users and service providers – a clear impediment to person-centred planning. In the same volume, Bradshaw (2005) suggests that, where barriers to communication exist for people with complex needs, these can be addressed by multimodal approaches, such as databases of images, individualised communication records and communication profiles.

Expectations

People often have low expectations of what is possible for people with learning difficulties; this can impact on the options that are available (Routledge and Gitsham, 2004).

Choice

For many people with learning difficulties the concept of choice is oblique (Mansell and Beadle-Brown, 2004a). Some may have spent much of their lives in long-stay hospitals, have taken no role in decisions that affect their lives and need a great deal

of support to understand what it means to make a choice. Moreover, the choices that people are likely to consider may be influenced by the limits of their personal experience (Coyle and Moloney, 1999), and these may be shaped by staff who are facilitating the process, resulting in a narrow vision emerging in their plan (Todd, 2002).

People with dementia

Ericson *et al.* (2001) state that it is beneficial for people with dementia to develop relationships with a small number of individuals. They go on to show that care staff can help people with dementia to retain personhood. Assisting people to maintain their individuality in spite of their disability is important in person-centred care. This involves an awareness of the individual's life before dementia, so as to be able to understand the individual in his or her own biographical context (Stokes, 1997). This kind of knowledge is essential to the individualisation of care, and means that there is a greater possibility that activities can be tailored to a person's individual needs and desires. Baker and Edwards (2002) have developed a benchmaking tool for person-centred care in dementia services that puts planning as a central feature.

People with mental health problems

Barriers to inclusion and person-centred planning for people with mental health problems are negative social attitudes towards them (Stainton, 2002). Concerns about public fears of people with mental illness seem to take precedence over their quality of care (Crawford, 2001).

Summary

1 The task of implementing person-centred planning for all service users across services is considerable, but this should not be considered a barrier in itself. By taking time to adopt and deliver person-centred planning and by concentrating on the quality of the work rather than the quantity, the scale of the task appears less onerous.

2 Degree of disability, illness or complexity of need should not be considered as a barrier to person-centred planning. The ethos of person-centred planning states that it is important not to focus on a person's impairment but on what he or she can do and who the person is.

3 Service users may feel that they have little impact on the way that services are designed and delivered, but there is a clear call for more control on the part of service users and for people to direct their own support.

4 A change in the culture of services, which addresses the unequal power relations between service users and service providers, is a prerequisite to the implementation of person-centred planning.

5 Professionals' relationships with service users should change from 'being the "experts on the person" to being "experts in the process of problem solving with others"' (Sanderson, 2000).

6 Person-centred planning locates people in the context of their families and the wider community (Sanderson, 2000). The role of and the inclusion of non-professionals in the form of family and friends of service users are key components of person-centred planning (Maudslay, 2002).

7 A basic challenge to working in a person-centred way is in figuring out how best to encourage and include family members, friends and chosen others to take part in the process (Sanderson, 2000).

8 The successful inclusion of family members in the implementation of person-centred planning is underpinned by providing families with information that is relevant, accessible and jargon free, and by facilitating relevant accessible training for families.

9 Families and professionals may not always agree about what constitutes best support; however, as families are central to the process of person-centred planning, it is imperative that service providers work to develop good relationships with service users' families.

6 Obstacles and opportunities from the perspective of frontline staff

An important goal of most service providers is to enable a good quality of life for service users (Schalock *et al.*, 1989). As discussed in Chapter 2, the range of approaches to implementing person-centred planning aim to guide frontline staff and their managers in doing just that. However, this is not a straightforward process and this chapter will review issues raised in the literature that frustrate or encourage staff to adopt a person-centred approach. This chapter concentrates on issues that affect staff directly; wider structural matters relating to service provision are discussed in Chapter 3.

The role of frontline workers is central to the realisation of services that are based around person-centred planning. The needs and views of frontline workers must be taken into account in order for services to succeed in its implementation.

The way a service is managed directly affects the ability of frontline workers to perform their job well and to promote independent living through person-centred planning. Frontline workers are faced with obstacles that sometimes prevent them from providing what people would prefer (Patmore, 2003). Thus, the capacity of a frontline worker will always be subject to the way the service is managed and to constraints applied, be they through limited resources, lack of training or inflexible approaches to service delivery (Beresford and Croft, 2004).

Staff abilities

Mansell and Beadle-Brown (2004a) identify a skill deficit among many frontline workers, mainly due (discussed below) to limited training for staff. They point to evidence that shows that staff working with people with learning difficulties, particularly those with more complex needs, typically offer little support for people to engage in meaningful activities in their home life or in the wider community (Emerson and Hatton, 1994; Perry and Felce, 2003; Mansell and Beadle-Brown, 2004a). Consequently, people frequently have restricted social networks. This may result in obstacles to further engagement in the community or in the construction of a circle of support to help facilitate person-centred planning (Cambridge *et al.*, 2001; Mansell and Beadle-Brown, 2004a). This is identified as a potential barrier to the implementation of person-centred planning. Limited skills among care staff may

engender further difficulties in implementing person-centred planning. For instance, if personal plans are developed that involve providing expert support for the individual, then staff may be unable to provide sufficiently accomplished assistance, especially for those with more complex needs (Mansell and Beadle-Brown, 2004a).

However, while training staff to acquire the skills to implement new ways of working is central, it is also important that existing skills and abilities are recognised, acknowledged and built on (Todd, 2002; Sanderson, 2003; Kydd, 2004). For instance, Todd (2002) notes that staff who work with people who are deaf and visually impaired often have immense skills in the field of communication. Acknowledging this and recognising it as a key skill in producing plans and actions that are person-centred provides a foundation for staff to develop their practice and is potentially a confidence boost in their ability to acquire other skills needed to implement person-centred planning. Additionally, staff may have interests or skills developed outside their working lives. These may match the expressed interests of service users and therefore it may be possible that skills gathered in other domains can be used to support people using the service (Sanderson, 2003).

Staff often know what they would like to do, but lack the confidence, time or resources to put this into action (Kydd, 2004). From interviews with care staff working in a residential home for people with dementia some staff appear to be what Sheard (2004) terms ‘naturals’, in that they had an instinctive understanding of what it is to adopt a person-centred approach to care. Sheard suggests that skills promotion for this group should be in relation to developing their understanding of theory to back up their practice.

> Staff who are ‘naturals’ are ‘people who instinctively live their lives with the ability to connect to another’s feelings, who use their instincts and gut feelings, who feel person centred care rather than just practise it. They work with their heart rather than their mind’.
> (Sheard, 2004, p. 23)

The contention is that they then stand a better chance of making their points heard and not being overridden by staff who may be more highly qualified, but who may nevertheless be attached to outdated beliefs and modes of practice. This is about valuing good practice where it is found, building staff confidence and challenging the often present over-emphasis on staff hierarchies.

Training

> When we consider all that is involved in giving person-centred care, it is clear that it is unrealistic to expect staff to work in this way if we do not equip them with the necessary skills, facilitate the development of their insight and help them to build on the valuable resources they bring to care-giving.
> (Loveday, 1998, p. 24)

The literature identifies a significant lack of training for frontline staff in working with person-centred planning (Kitwood, 1997; Loveday, 1998; Coyle and Moloney, 1999; Ward, 1999; Packer, 2000c; Mansell and Beadle-Brown, 2004a). Sheard (2004) notes that there is no continuous learning culture within many services, and argues that staff need training that will empower them and encourage them to be proud of their work and to recognise the value of the knowledge they already possess. In this way training will target the lack of confidence apparent among many social care staff (Parley, 2001), particularly in their abilities to take on the challenges inherent in new procedures.

Loveday (1998) states that training should address the 'new culture' and provide time for staff to re-evaluate existing attitudes and practices in line with a person-centred method. This is considered to be an opportunity for staff to reflect on their practice and challenge themselves to consider new approaches. A person-centred approach to training should be taken, as this would enable staff to understand the concept through direct experience. Sheard (2004) goes on to state that, while training is valuable, it is important that new skills are translated into practice. This would seem particularly relevant in relation to attitudinal change, since this provides the foundation for changes in practice.

The training deficit among social care staff has been acknowledged in recent government initiatives, which endorse attempts to increase training opportunities (Department of Health, 2001c, 2002). Ray (1999) makes recommendations regarding the manner in which training is carried out. Drawing on data from a project aiming to develop standards in person-centred planning, she reports on key elements that workers identified should be part of a successful training programme. In their view training should:

- be interesting and informative
- be helpful in unpicking difficult practice issues and concepts in person-centred planning

- take a straightforward, jargon-free approach
- be interactive and flexible in use (Ray, 1999, p. 18).

Likewise, Mansell and Beadle-Brown (2005) argue that training should focus on action and on facilitating change rather than just planning.

Culture – staff attitudes

The need for a culture change within services to facilitate the implementation of person-centred planning is a theme running through much of the literature (Loveday, 1998; Sanderson, 2000, 2003; Ericson *et al.*, 2001; Parley, 2001; Stainton, 2002; Todd, 2002; Brooker, 2004; Duffy, 2004; Kilbane and Thompson, 2004; Routledge and Gitsham, 2004). The culture of a service can be regarded as bringing together the underlying guiding principles that govern the way in which it is run and how support is delivered. It steers the development of relationships between users and providers, and is often evident in the ways in which frontline staff interact with users and deliver the service.

Loveday (1998), discussing services for people with dementia, points out that staff have considerable power and influence over the well-being of service users. She contends that they are often tied to old ways of thinking, but notes that this is not their fault, rather it is a priority of training to challenge the thinking that informs practice. Staff need to be liberated from 'traditional' models of care, and experience a shift in values and attitudes so that person-centred planning can be adopted and effective (Parley, 2001). Changes in thinking require a rethinking of power relations, so that power can be vested in individual service users, thus enabling choice and the potential for inclusion and self-determination (Parley, 2001; Sanderson, 2003).

> Person-centred planning is based on a completely different way of seeing and working with people … which is fundamentally about sharing power and community inclusion.
> (Sanderson, 2000)

The role of managers

Managers have a significant role to play in enabling staff teams to adopt a person-centred approach. Sanderson (2003) advocates that service managers extend the principles of person-centred planning to their staff teams, in order to develop what

she describes as person-centred teams. This would require a change of thinking on the part of managers. The characteristics of person-centred team leaders and person-centred teams are detailed in Table 1.

Table 1 Characteristics of person-centred team leaders and person-centred teams

Characteristics of effective person-centred team leaders	Characteristics of a person-centred team
See themselves as coaches who bring out the best in people.	Sees the team's purpose as supporting people to achieve the lifestyle they want and contributing to their community.
Demonstrate and articulate the values of the organisation.	Highly values personal commitment and relationships with the people it supports.
Look for ways to use staff's interests and strengths in directly supporting people.	Reviews itself, not the people it supports.
Share decision making.	Invests in community connections.
Have a clear vision and direction.	Continually tries new ideas and evaluates whether they improve the support it is providing to achieve the team's purpose.
Encourage personal involvement with the people being supported.	

Source: Sanderson, 2003, p. 20.

Research confirms that frontline workers often lack opportunities for involvement in care planning or other decision-making activities (Kleunen and Wilner, 2000), which may compound their difficulties in providing adequate support to promote independent living. Poor image and low pay also contribute to general feelings of helplessness among frontline workers, and such negative effects are aggravated when workers are not involved in decision-making and planning processes (Eborall, 2003).

Staff state that they are often unsure what managers expect from them and find it difficult to separate person-centred planning from previous planning initiatives (Parley, 2001). Sheard (2004) suggests that there is an overemphasis on hierarchies within staff teams and that taking a position of professional self-distance is encouraged. Sheard goes on to state that managerial styles need to be empathetic in order for frontline staff to adopt person-centred approaches to their work.

Uncertainty, adherence to a chain of command, maintaining a 'professional distance' from service users and a depleted sense of value in the role carried out by frontline workers all stand at odds with the characteristics that Sanderson (2003) describes as essential components of person-centred teams. She suggests that extending the person-centred philosophy throughout an organisation, from working with service users to the management of staff, creates an environment wherein person-centred planning can thrive.

Support for staff

Killick and Allan (2001) emphasise the importance of support for frontline staff in what is often a difficult and demanding role. Descriptions of a number of informal support structures, outside of managerial or agency supervision, are emerging from the literature. Many of them are commended by practitioners themselves as useful support mechanisms. They include the following.

1 Working with other staff teams in a consortium to share problems and discuss solutions; this, it is suggested, will increase confidence and improve practice (Stalker and Campbell, 1998).

2 Staff may experience the work to be emotionally demanding and suggest the development of networks to support them (and families) in their work with people with dementia (Ericson *et al.*, 2001).

3 Staff mentoring – working alongside other staff, who offer guidance and provide a positive role model – may help staff understand different approaches to their work (Loveday, 1998).

Personal dilemmas

Surrendering control over what happens in someone's life is difficult for many professionals when the choices that a person makes are at odds with the choices and expectations of professionals (Kilbane and Thompson, 2004). Choices that people make may conflict with professional training, duties of care, or personal beliefs of staff. Todd (2002) poses the question:

> … what if someone wants to have a sex, drugs and rock n' roll lifestyle, or take up an activity that is dangerous or anti-social? In theory we can agree with any lifestyle choice, but of course we can't allow a lifestyle which conflicts with others' choices or which goes against our 'duty of care'.

However she concludes by saying that experience reveals that most people's free choices are pretty ordinary. Nonetheless, this may raise issues for policy and planning, which are being addressed by the White Paper on adult social care (Department of Health, 2006) and the proposed risk management framework. It is a concern that needs to be addressed to keep staff on board:

> My job was far easier before they brought in all this stuff about choices and speaking up for yourself.
> (Dowling, 2000)

Summary

1 While a skill deficit among frontline staff has been identified, there is a call for the specialist skills that staff possess to be recognised and for their skills gained in arenas other than their working environment to be incorporated into service provision, where appropriate.

2 Training in person-centred planning is needed for frontline staff.

3 Training should be designed with the needs of particular groups of support workers in mind and should take a person-centred approach.

4 The literature identifies a need for a change in the culture of services, so that practice is underpinned by a culture of inclusiveness, equality and self-determination.

5 The actions of managers are key to the advancement of person-centred planning in services. The development of person-centred teams is advocated as a strong foundation for staff to deliver support in a person-centred way.

6 Informal structures for staff, including forming a consortium with other staff teams, the development of support networks to ease the emotional demands of the job and mentoring for staff, are suggestions of potentially beneficial supports for staff in working with person-centred planning.

7 Staff teams should discuss the potential that conflicting ideas about what constitutes an appropriate lifestyle choice for service users may emerge between users and staff. Advance consideration will enable staff to anticipate and cope better. Personal choices made by individuals should not obstruct others' individual choices but they should also not compromise service providers' duty of care.

7 Barriers and bridges to person-centred planning

This chapter aims to address the central question posed by this review – that is, what are the barriers and bridges to person-centred planning in adult social care services? Drawing together the information gathered through review of relevant papers (which are presented in detail earlier in this report), the chapter provides both a summation and targeted response to the research question.

It will set out the barriers and bridges, identified in the literature, to the implementation of person-centred planning in tabular form, for clarity and ease of reference (see Table 2). This will include pointers as to where to locate wider discussion of each point elsewhere in the report. The chapter will conclude with a brief look at two examples of person-centred planning initiatives – one in the field of work with people with learning difficulties and the second within mental health services.

Table 2 summarises the barriers and bridges identified in the literature. They have many similarities to the seven key dimensions identified by Cambridge and Carnaby (2005, p. 227):

- person-centred organisations
- circles and networks of support
- advocacy and empowerment
- independent location
- communication and inclusion
- links with wider systems
- promoting competence.

These prerequisites have all been alluded to in the literature that has been discussed in this review, although there seem to be gaps in the literature in respect of advocacy and, as yet, we have little evidence of the possible independent location of services that are able to be entrusted with sizeable public funds. Issues of governance are not yet discussed in the literature.

Table 2 Barriers and bridges to person-centred planning

	Barriers to person-centred planning	Bridges to person-centred planning
Culture and attitudes (see chapters 2, 4 + 6)	A philosophy embedded in a notion of universal services into which service users are expected to either fit or lose out is outdated and contrary to the principles that support person-centred planning. Thinking underpins action, so outdated attitudes will result in invalid and inappropriate services.	A change in the culture of services, where a person-centred approach informs the development and delivery of service provision – wherein both service users and frontline staff are included and valued – facilitates person-centred planning. This will be enabled by a reconfiguration of power relations and the development of a service culture based on equality, respect, empowerment and inclusion.
Resources (see Chapter 4)	Resource constraints impede the implementation of person-centred planning. Moreover, resources that are bureaucratised and managed at a higher management level, without reference to service users, are also obstructive.	A change in the way that resources are allocated and used is needed. This would entail the control of expenditure by service organisations, thus enabling care managers to design and deliver individually tailored plans.
Funding (see Chapter 4)	Funding that is based on a fixed level of supposed whole-service requirements, without reference to individuals, blocks the delivery of a service that is person-centred.	Funding arrangements that are based on an assessment of individual need and plans facilitate person-centred planning. Direct Payments enable people to have more choice and control, and therefore contribute to the implementation of person-centred planning. Individual budgets may assist further.
Staff skills and training (see Chapter 6)	Skill deficits among frontline workers are likely to impede the implementation of person-centred planning. There is a lack of training for frontline workers in developing their skills to adopt a person-centred approach.	Some staff have a natural ability in delivering a person-centred service. This should be valued and learnt from. Widespread training is needed for frontline staff and managers. This should address practical as well as philosophical aspects of person-centred planning, so as to facilitate its delivery.
Management (see Chapter 6)	Top-down management styles, which fail to include staff in decision making or to involve them in care planning, impede the emergence of person-centred services.	Managers play a key role in enabling staff teams to adopt person-centred planning. By extending the principles of person-centred planning to staff teams, managers can develop an ethos to support practice that is focused on individual needs and desires.

continued

Table 2 Barriers and bridges to person-centred planning – *continued*

	Barriers to person-centred planning	Bridges to person-centred planning
Implementation gap (see Chapter 2)	A failure to carry plans into action means that person-centred planning is incomplete; lack of action therefore impedes actual change through the implementation of person-centred planning.	Planning, using a person-centred approach, is only the first step in the process. Taking action based on plans and continually reviewing individual plans lead to actual rather than partial implementation.
Working with families (see Chapter 5)	It is important not to stretch the goodwill of families by using informal supports to bolster inadequacies in staffing levels within services. Staff should avoid stereotyping families as either overprotective or disinterested.	Inclusion of service users' families is central to the success of person-centred planning. Professionals need to focus attention on developing effective strategies for including families and encouraging them to take a person-centred approach to their involvement. It is important to recognise that families may need support too.
User involvement (see Chapter 5)	Services users often feel ineffective in influencing services – sometimes a legacy of their exclusion from service planning in the past or currently. Race or cultural factors may account for some of this exclusion.	Many service users are more aware of their options and rights, and are increasingly included in the planning of their support. This needs to be continually extended as a bridge to person-centred planning.
Multi-agency working (see Chapter 4)	The failure of agencies to work collaboratively impedes strategies towards person-centred approaches to service delivery.	Strategies to adopt a multi-agency approach to service delivery should be explored. This should aim to increase individuals' opportunities and the capacity of staff to provide individual support, and encourage a community outlook that is inclusive of service users.
Legal weight (see Chapter 4)	There is currently no legal requirement to base services on person-centred planning.	Legal entitlement on the part of service users to 'fair, humane and effective' (Mansell and Beadle-Brown, 2004a) services would mean that service users could challenge the absence of services based on individual need and therefore increase their rights to expect appropriate person-centred services.
Policy and expectations (see Chapter 4)	While person-centred planning is given high priority within policy, there are limited processes through which local authorities can be held to account for failing to deliver person-centred services.	Person-centred planning should be supported in policy by a statement of clear expectations that individualised plans will be achieved and appropriately resourced. This accountability would encourage the more widespread implementation of person-centred planning.

Two new initiatives designed around implementing person-centred planning

In Control

In Control (Duffy, 2004) is a programme that aims to guide local authorities in altering their entire service system towards self-directed support. It is currently being piloted in six local authorities in the UK and is focused primarily on people with learning difficulties. However, it is intended that the model will eventually be extended across the range of social care services.

In Control has developed five ideas that, it is hoped, will facilitate the goal of greater control by service users in the planning of their support. These remain at a piloting stage, so outcomes cannot be reported as yet. Each idea is described below.

1 Fair entitlements: this involves a system whereby resources are allocated in such a way that local authorities are able to assess the amounts needed for each individual service user, thus enabling more effective financial planning and greater potential in the design of individualised services.

2 Supported decisions: people may need help in making decisions. This may be in the form of a proxy. Systems for decision making should be regularly reviewed; the default position should not automatically be that professionals take decisions *for* service users.

3 Assuming capacity: the programme acts on the assumption that people have the capacity to take decisions on how they want to live and to organise the support they need.

4 Support brokerage: people are likely to need help to make plans and implement them. Much of this help can be found outside formal support networks.

5 Contractual freedom: people should have real control in how they use their resources. It is inappropriate for people to be tied into the use of particular services.

In Control is founded on the belief that people with disabilities should not be defined by social care organisations they use or by the parameters of the condition they have, but that they should be seen as a full citizen by right. Duffy (2003) has produced a model of ‘six keys to citizenship’. These include: self-determination,

direction, money, a home, support and community life. Some people will need help to achieve some or all of these aspects of citizenship. However, what is apparent is that positive change is taking place and people are increasingly achieving greater citizenship. The challenge to social care services is to continue to support people in achieving their goals through recognising their citizenship and respecting their individuality. In Control provides a plan for doing this. The outcomes of implementation will inform understanding of the process of successfully implementing person-centred planning.

Support Time and Recovery workers

The Support Time and Recovery (STR) Worker programme is a new public health initiative in the field of mental health (Department of Health, 2003). This national programme was instigated by the Department of Health in November 2003, with the aim of creating 3,000 Support Time and Recovery Workers by 2006. The STR worker is a member of a team that provides mental health services and who focuses directly on the needs of service users. The values that inform the work of STR workers centre on meeting the needs of service users by paying attention to and respecting their wishes to lead as ordinary a life as possible. STR workers help service users to have an ordinary life, facilitating their recovery by assisting with everyday, practical needs in whatever setting they find themselves. They come from different walks of life, with different backgrounds, and include volunteers, and existing and former service users. STR workers are being appointed with a view to the improvement of services for people with mental health problems. Benefits may be to the individual and their carers, but also to the service, in terms of job satisfaction, and recruitment and retention of frontline workers in the mental health teams where STR workers are based.

The role of the STR Worker is outlined in the Department of Health (2003) guidance document. In brief, this includes working to promote independent living, provide companionship, offer practical support, help people to gain access to resources, provide information on health promotion, identify early signs of relapse and support service users to participate in their treatment. STR workers are not involved in clinical decisions, medical treatment or therapeutic counselling. They adopt an inclusive, sensitive, creative and empowering attitude to their role, and work within the bounds of confidentiality and non-discriminatory practice. Each completes the single nationally agreed induction programme and is distinguished from support workers by this, as well as by the singular user focus of their work and by having a specific set of values and skills. STR workers can be found across the range of social care services, as they work across organisations and boundaries of care.

The STR Worker programme is currently being piloted in 19 sites across the country. One of these is East Suffolk Mind, which reports that one role of the Support Time Recovery worker is to promote the idea that people can recover from a mental health problem. Importantly, in relation to person-centred planning, recovery is regarded as a process undertaken by individuals with support from others:

> People will be encouraged to come up with their own definition of recovery and to regain a sense of self, hope, meaning, control, responsibility and enjoyment.
> (www.esmind.org.uk, downloaded 21 February 2005)

This person-centred approach to the support of people with mental health problems is in its early stages, but indications are that service users are greeting it as a welcome addition to mental health services (Huxley *et al.*, 2005). People are saying it is just what they want and need from social care services. Widespread implementation of this strategy may prove if it is providing and resourcing a person-centred service for users of mental health social care services. The evaluation focused on three pilot sites – two in the North of England and one in London – and drew on the views of service users ($n = 16$), as well as staff within the mental health team, including STR workers ($n = 21$ – more than half of those employed at the time), other front-line staff and managers ($n = 24$). The findings showed a very positive response to the STR worker, although some other team members did not understand the role, showing that induction of other team members is important. The involvement of service users in the process of recruitment and so on, and as workers, is a positive feature. The lack of specific funding, the mix of funding for training and the lack of priority given by commissioners may adversely affect the sustainability of the role. Service users appreciate the time spent with them, although some wanted more. The nature of the relationship between the service user and worker was a key to success (and shares many features of the casework relationship), promoting social inclusion and recovery. STR workers had better role clarity than community mental health nurses and social workers (some in the same teams). Working within plans for recovery, this type of work may help translate person-centred planning into action for people with mental health problems who are not so commonly considered in the literature on person-centred planning.

What works in person-centred planning?

The two initiatives described above demonstrate how the principles of person-centred planning can be carried forward into action. A fundamental problem that emerges from the literature is that, while ideas of person-centred planning abound

and the principles are widely applauded and endorsed, there appears to be a hiatus between this and implementation. The national evaluation (Robertson *et al.*, 2005) notes that early enthusiasm seems to be followed by a plateau period of uncertainly, leading to reflection and reassessment. What is encouraging, they observe, is that this generally seems to lead to a renewed but more gradual trajectory of implementation (Robertson *et al.*, p. 101).

It is clear that several factors need to be in place to make person-centred planning work. These include: adherence to the underlying principles of person-centred planning; sufficient resources and appropriate funding; and a trained, confident and well-equipped staff team who are managed in an inclusive and empowering style, which institutes clear planning and direction for the future. Achieving person-centred planning is not a rapid process and it is important that sufficient time is taken for initiatives to be put in place before policy makers, practitioners and users become tired of waiting and new policy initiatives emerge.

Many of the barriers we identify confirm those specified by Kinsella (2000), such as a lack of evidence for person-centred planning, the perceived complexity of the process, the risk of the process becoming tokenistic, the search for the 'best' type of plan, the reliance on the very staff and services to implement a plan that may make them redundant, and a lack of support among some key stakeholders, such as advocacy organisations and some families. However, this overview of the literature does suggest some key developments have take place since the start of the millennium. These include a more robust evidence base (Robertson *et al.*, 2005), more sophisticated understanding of the links between person-centred planning and other elements of social care (Cambridge and Carnaby, 2005), further accounts of practice and examples of service users' experiences (Clark *et al.*, 2005), staff and organisational support for person-centred planning, and strong support from policy (Department of Health, 2001b, 2005) and service development communities. Much has happened in the five years and, as this review has shown, there is now considerable literature that is situated both in the academic and research arenas and in formats that are accessible to service practitioners, and, less commonly, in materials that are written for users and the lay public. This review has charted the early claims to the more recent reflections on practice and evaluations.

8 Concluding remarks and recommendations for future research

This scoping review investigated a range of literature in order to identify the barriers and bridges to the implementation of person-centred planning in adult social care in the UK. The salient points that directly address this question are fully described in Chapter 7. However, two gaps remain: first, what the literature does not say and, second, directions for future research.

It has become clear in the course of this study, through discussions with user consultants and colleagues, that what is not fully represented in the literature is the tide of feeling in support of person-centred planning from the perspective of service users. In the field of learning difficulty, there is a relatively long-established focus on working with self-advocates, and the voice of users has become more audible in recent years. However, even within learning disability, as within other parts of the social care literature, there is a strong bias towards the voices of practitioners and academics. While they are largely in support of person-centred planning, they cannot fully capture the extensive enthusiasm of service users to embrace person-centred planning in their interactions with services. It may be beyond the responsibility of individual service providers to overcome prevailing barriers to person-centred planning and to respond to service users' wishes through recognising their individuality and respecting their needs, and moving this initiative forward. Commissioners and service development organisations, such as the Care Services Improvement Partnership (CSIP), may have important strategic roles as elements of the Green Paper (Department of Health, 2005) move to a legislative footing.

Recommendations for future research

1 In respect of the above, investigating what service users have to say about person-centred planning and any strategies they suggest for its implementation, refinement and development is recommended.

2 Evidence is emerging about the outcomes for service users following implementation of person-centred planning; therefore investigating the effects of person-centred planning across a range of social care and public services would be useful.

3 Person-centred planning takes on different meanings within the lives of different service users; it would be helpful to identify the scope of person-centred planning for different service users and measures to facilitate its successful implementation. Evidence so far is very much confined to people using services for people with learning difficulties.

4 Evaluation of the implementation of person-centred planning needs to consider strategies to cope with difficulties that emerge and to record good practice. The purpose would be to develop practice guidelines, as Robertson *et al.* (2005) also recommend.

5 A longitudinal study with the aim of assessing the outcomes of person-centred planning over time would be highly appropriate to the person-centred planning ethos, which is meant to make a real difference to people's futures as well as their present.

References

Alzheimer's Society (2001) *Quality Dementia Care in Care Homes: Person-centred Standards*. London: Alzheimer's Society

Amado, N.A. and McBride, M.W. (2002) 'Realising individual, organisational and systems change: lessons learned in fifteen years training about person-centred planning and principles', in S. Holborn and P.M. Vietze (eds) *Person-centred planning: Research Practice and Future Directions*. Baltimore, MD: Paul H. Brookes Publishing Co.

Barker, P. (2001) 'The tidal model: the lived experience of person-centred mental health nursing', *Nursing Philosophy*, Vol. 2, pp. 213–23

Baker, C. and Edwards, P. (2002) 'The missing link: benchmarking person-centred care', *Journal of Dementia Care*, November/December, Vol. 10, Issue 6, pp. 22–3

Beadle-Brown, J. (2005) 'Person centred planning and direct payments: opening doors for people with learning disabilities', in P. Cambridge and S. Carnaby (eds) *Person Centred Planning and Care Management with People with Learning Disabilities*. London: Jessica Kingsley

Beresford, P. and Croft, S. (2004) 'Service users and practitioners reunited: the key component for social work reform', *British Journal of Social Work*, Vol. 34, pp. 53–68

Bignall, T. and Butt, J. (2000) *Between Ambition and Achievement: Young Black Disabled People's Views and Experiences of Independence and Independent Living*. York: Policy Press in association with Joseph Rowntree Foundation

Boaz, A., Hayden, C. and Bernard, M. (1999) *Attitudes and Aspirations of Older People: A Review of the Literature*. DSS Research Report 101. London: Department of Social Security

Boettcher, I.F., Kemeny, B., DeShon, R.P. and Stevens, A.B. (2004) 'A system to develop staff behaviors for person-centered care', *Alzheimer's Care Quarterly*, July/September, pp. 188–96

Bowling, A., Gabriel, Z., Banister, D. and Sutton, S. (2002) *Adding Quality to Quantity: Older People's Views on their Quality of Life and its Enhancement*. Research Findings 7. Sheffield: ESRC Growing Older Programme, University of Sheffield

Bradshaw, J. (2005) 'The role of communication in person centred planning', in P. Cambridge and S. Carnaby (eds) *Person Centred Planning and Care Management with People with Learning Disabilities*. London: Jessica Kingsley

Brooker, D. (2004) 'What is person-centred care in dementia?', *Reviews in Clinical Gerontology*, Vol. 13, pp. 215–22

Brown, H. with Scott, K. (2005) 'Person centred planning and the adult protection process', in P. Cambridge and S. Carnaby (eds) *Person Centred Planning and Care Management with People with Learning Disabilities*. London: Jessica Kingsley

Cabinet Office Strategy Unit (2005) *Improving the Life Chances of Disabled People*. London: Cabinet Office Strategy Unit

Cambridge, P. (2005) 'Becoming contractual: the development of contracts and social care markets in England', in K. Johnson and R Traustadottir (eds) *Deinstitutionalization and People with Intellectual Disabilities: In and out of Institutions*. London: Jessica Kingsley

Cambridge, P. and Carnaby, S. (eds) (2005) 'Considerations for making PCP and care management work', in P. Cambridge and S. Carnaby (eds) *Person Centred Planning and Care Management with People with Learning Disabilities*. London: Jessica Kingsley

Cambridge, P., Carpenter, J., Beecham, J., Hallam, A., Knapp, M., Forrester-Jones, R. and Tate, A. (2001) *Twelve Years on: The Outcomes and Costs of Community Care for People with Learning Disabilities and Mental Health Problems*. Canterbury: University of Kent at Canterbury, Tizard Centre

Campbell, P. (2001) 'The role of users of psychiatric services in service development – influence not power', *Psychiatric Bulletin*, Vol. 25, pp. 87–8

Circles Network (2005) *Circles of Support*. http://www.circlesnetwork.org.uk/circles_of_support.htm

Clark, D., Garland, R. and Williams, V. (2005) 'Your life can change if you want it to', in P. Cambridge and S. Carnaby (eds) *Person Centred Planning and Care Management with People with Learning Disabilities*. London: Jessica Kingsley

Coyle, K. and Moloney, K. (1999) 'The introduction of person-centred planning in an Irish agency for people with intellectual disabilities: an introductory study', *Journal of Vocational Rehabilitation*, Vol. 12, pp. 175–80

Crawford, M. (2001) 'Involving users in the development of psychiatric services – no longer an option', *Psychiatric Bulletin*, Vol. 25, pp. 84–6

Department of Health (1989) *Caring People: Community Care in the Next Decade and Beyond*. London: HMSO

Department of Health (1994) *The Health of the Nation, Key Area Handbook, Mental Illness, 2nd edition*. London: HMSO

Department of Health (1999) *National Service Framework for Mental Health*. HSC 1999/223. London: HMSO

Department of Health (2001a) *National Service Framework for Older People*. London HMSO

Department of Health (2001b) *Valuing People: A New Strategy for Learning Disability in the 21st Century*. HSC 2001/016: LAC (2001) 23. London: Department of Health

Department of Health (2001c) *The Essence of Care – Patient Focussed Benchmarking for Health Care Practitioners*. London: HMSO

Department of Health (2002) *Care Homes for Younger Adults and Adult Placement: National Minimum Standards, Guidance for Implementation Groups*. London: The Stationery Office

Department of Health (2003) *Mental Health Policy Implementation Guide, Support Time Recovery Workers*. London: HMSO

Department of Health (2005) *Independence, Well-being and Choice: Our Vision for the Future of Social Care for Adults in England*. London: HMSO

Department of Health (2006) *Our Health, Our Care, Our Say*. London: HMSO

Dick, D. and Purvis, K. (2005) 'Total communication, person centred planning and person-centred care', in P. Cambridge and S. Carnaby (eds) *Person Centred Planning and Care Management with People with Learning Disabilities*. London: Jessica Kingsley

Disability Discrimination Act (1995) www.disability.gov.uk

Dowling, S. (2000) 'Exiled grief: the social context of bereavement in the lives of people with an intellectual disability', *Grief Matters*, Vol 3, No. 4, pp. 32–5

Dowling, S., Hubert, J. and Hollins, S. (2003) 'My mother's name was Marjorie: bereavement in the lives of people with learning disabilities', *Bereavement Care*, Vol. 22, No. 2, pp. 19–21

Duffy, S. (2003) *Keys to Citizenship: A Guide to Getting Good Support Services for People with Learning Difficulties*. Birkenhead: Paradigm

Duffy, S. (2004) 'In Control', *Journal of Integrated Care*, Vol. 12, No. 6, pp. 7–13

Duffy, S. and Sanderson, H. (2004) 'Person-centred planning and care management', *Learning Disability Practice*, Vol. 7, No. 6, pp. 12–16

Duffy, S. and Sanderson, H. (2005) 'Relationship between care management and person centred planning', in P. Cambridge and S. Carnaby (eds) *Person Centred Planning and Care Management with People with Learning Disabilities*. London: Jessica Kingsley

Eborall, C. (2003) *The State of the Social Care Workforce in England*. First annual report of the TOPSS England Workforce Intelligence Unit. www.topssengland.net

Emerson, E. and Hatton, C. (1994) *Moving out: Relocation from Hospital to the Community*. London: HMSO

Emerson, E. and Stancliffe, R.J. (2004) 'Planning and action: comments on Mansell and Beadle-Brown', *Journal of Applied Research in Intellectual Disabilities*, Vol. 17, No. 1, pp. 23–6

Ericson, I., Hellstrom, I., Lundh, U. and Nolan, M. (2001) 'What constitutes good care for people with dementia?', *British Journal of Nursing*, Vol. 10, No. 11, pp. 710–14

Everson, J.M. and Zhang, D. (2000) 'Person-centred planning: characteristics, inhibitors and supports', *Education and Training in Mental Retardation and Developmental Disabilities*, Vol. 35, No. 1, pp. 36–43

Felce, D. (2004) 'Can person-centred planning fulfil a strategic planning role? Comments on Mansell and Beadle-Brown', *Journal of Applied Research in Intellectual Disability*, Vol. 17, No. 1, pp. 27–30

Felce, D., Jones, E. and Lowe, K. (2002) 'Active support: planning daily activities and support for people with mental retardation', in S. Holborn and P.M. Vietze (eds) *Person-centred Planning: Research, Practice and Future Directions*. Baltimore, MD: Paul Brookes Publishing Co.

Fortune, J., Smith, G., Campbell, E.M., Clabby, R.T., Heintein, K.B., Lynch, R.M. and Allen, J. (2004) 'Individual budgets according to individual needs: the Wyoming DOORS system', in R.J. Stancliffe and K.C. Lakin (eds) *Costs and Outcomes: Community Services for People with Intellectual Disabilities*. Baltimore, MD: Paul H. Brookes.

Glasby, J. and Littlechild, R. (2002) *Social Work and Direct Payments*. Bristol: The Policy Press

Hasnain, R., Sotnik, P. and Ghiloni, C. (2003) 'Person-centred planning: a gateway to improving vocational rehabilitation services for culturally diverse individuals with disabilities', *Journal of Rehabilitation*, July – September, Vol. 69, pp. 10–17

HM Government (2005) *A Strategy for an Ageing Population*. London: The Stationery Office

Hubert, J. (2004) *The Accessibility and Appropriateness of Services for People with Learning Disabilities from Black and Minority Groups: A Qualitative Study of 30 Families in the Borough of Merton*. London: St George's Hospital Medical School

Huxley, P., Evans, S., Davidson, B., King, S. and Beresford, P. (2005) *An Evaluation of the Impact of the Introduction of Support, Time and Recovery (STR) Workers to Mental Health Teams*. London: Social Care Workforce Research Unit, King's College London

Iliffe, S. and Manthorpe, J. (2004) 'The debate on ethnicity and dementia: from category fallacy to person-centred care?', *Aging and Mental Health*, Vol. 8, No. 4, pp. 283–92

In Control (2004) *Resource Allocation: Discussion Paper*. www.selfdirectedsupport.org

Jarvis, A. (2001) 'Person-centred planning: a plea for lateral thinking', *Housing, Care and Support*, Vol. 4, No. 3, pp. 26–7

Jones, E., Felce, D., Lowe, K., Bowley, C., Pagler, J., Gallagher, B. and Roper, A. (2001) 'Evaluation of the dissemination of Active Support training in staffed community residences', *American Journal of Mental Retardation*, Vol. 206, pp. 344–58

Khan, N., Rahim, R. and Routledge, M. (not dated) *Person-centred Planning and People from South Asian Communities: Some Experiences from One Locality*. www.valuingpeople.gov.uk

Kilbane, J. and Thompson, J. (2004) 'Never ceasing our exploration: understanding person-centred planning', *Learning Disability Practice*, Vol. 7, No. 3, pp. 28–31

Killick, J. and Allen, K. (2001) *Communication and Care for People with Dementia*. Buckingham: Open University Press

Kinsella, P. (2000) *What are the Barriers in Relation to Person-centred Planning?* www.valuingpeople.gov.uk/documents/PCPJrfpcp.pdf

Kitwood, T. (1997) *Dementia Reconsidered*. Buckingham: Open University Press

Kleunen, A. and Wilner, A. (2000) 'Who will care for mother tomorrow?', *Journal of Aging and Social Policy*, Vol. 11, Nos 2/3, pp. 115–26

Kydd, A. (2004) 'Strategies to personalize care for older people', *Nursing and Residential Care*, Vol. 6, No. 7, pp. 331–33

Ladyman, S. (2004) 'Health and social care advisory service: new directions in Direct Payments for people who use mental health services', speech, Department of Health, London, 18 May

LaFontaine, J. (2004) 'Providing person-centred care for younger people with dementia', *Journal of Dementia Care*, January/February, Vol. 12, Issue 1, pp. 18–20

Langley, J. (2001) 'Developing anti-oppressive empowering social work practice with older lesbian women and gay men', *British Journal of Social Work*, Vol. 31, pp. 917–32

Loveday, B. (1998) 'Training to promote person-centred care', *Journal of Dementia Care*, March/ April, Vol. 6, Issue 2, pp. 22–4

Lucyshyn, J. M., Dunlap, G. and Albin, R.W. (2002) *Families and Positive Behavioural Support*. Baltimore, MD: Paul H. Brookes Publishing Co.

Lunt, N. and Thompson, P. (1993) *Employment Services for Disabled People: A Review of Legislation in Fifteen Countries*. Social Policy Research Unit, Research Series No. 16. York: York University Press

Magito-Mclaughlin, D., Spinosa, T.R. and Marsalis, M.D. (2002) 'Overcoming the barriers: moving towards a service model that is conducive to person-centred planning', in S. Holburn and P.M. Vietze (eds) *Person-centred Planning: Research, Practice and Future Directions*. Baltimore, MD: Paul H. Brookes Publishing Co.

Mansell, J. and Beadle-Brown, J. (2004a) 'Person-centred planning or person-centred action? Policy and practice in intellectual disability services', *Journal of Applied Research in Intellectual Disabilities*, Vol. 17, No. 1, pp. 1–9

Mansell, J. and Beadle-Brown, J. (2004b) 'Person-centred planning or person-centred action? A response to commentaries', *Journal of Applied Research in Intellectual Disabilities*, Vol. 17, No. 1, pp. 31–6

Mansell, J. and Beadle-Brown, J. (2005) 'Person-centred planning and person-centred action', in P. Cambridge and S. Carnaby (eds) *Person Centred Planning and Care Management with People with Learning Disabilities*. London: Jessica Kingsley

Mansell, J., McGill, P. and Emerson, E. (2001) 'Development and evaluation of innovative residential services for people with severe intellectual disabilities and serious challenging behaviour', in L.M Glidden (ed.) *International Review of Research in Mental Retardation*. New York: Academic Press

Maudslay, L. (2002) 'Shifting the focus to the learner's needs', *Adult Learning*, March, pp. 17–18

Mendora, H. and Ledger, S. (2005) 'Implementing and reviewing PCP: links with care management, clinical support and commissioning', in P. Cambridge and S. Carnaby (eds) *Person Centred Planning and Care Management with People with Learning Disabilities*. London: Jessica Kingsley

Morris, J. (2005) *Citizenship and Disabled People*. London: Disability Rights Commission

Nolan, M. (2001) 'Successful ageing: keeping the "person" in person-centred care', *British Journal of Nursing*, Vol. 10, No. 7, pp. 450–4

Nolan, M., Davies, S., Brown, J., Keady, J. and Nolan, J. (2004) 'Beyond "person-centred" care: a new vision for gerontological nursing', *International Journal of Older People Nursing, in association with Journal of Clinical Nursing*, Vol. 13, No. 3a, pp. 45–53

O'Brien, J. (2004) 'If person-centred planning did not exist; Valuing People would require its invention', *Journal of Applied Research in Intellectual Disabilitie*, Vol. 17, No. 1, pp. 11–16

Packer, T. (2000a) 'Facing up to the bills', *Journal of Dementia Care*, July/August, Vol. 8, Issue 4, pp. 30–2

Packer, T. (2000b) 'Pass the hot potato – is this person-centred teamwork?', *Journal of Dementia Care*, September/October, Vol. 8, Issue 5, pp. 17–19

Packer, T. (2000c) 'A person-centred approach to the people who care', *Journal of Dementia Care*, November/December, Vol. 8, Issue 6, pp. 28–30

Packer T. (2000d) 'Does person-centred care exist?' *Journal of Dementia Care*, May/June, Vol. 8, Issue 3, pp. 19–21

Packer, T. (2001) 'From outside looking in: recognising skill in dementia care', *Journal of Dementia Care*, March/April, Vol. 9, Issue 2, pp. 29–32

Parley, F. (2001) 'Person-centred outcomes: are outcomes improved where a person-centred care model is used?', *Journal of Learning Disabilities*, Vol. 5, No. 4, pp. 299–308

Patmore, C. (2003) *Understanding Home Care Providers: Live Issues about Management, Quality and Relationships with Social Services Purchasers*. York: York University, Social Policy Research Unit

Perry, J. and Felce, D. (2003) 'Quality of life outcomes for people with intellectual disabilities living in staffed community housing services: a stratified random sample of statutory, voluntary and private agency provision', *Journal of Applied Research in Intellectual Disabilities*, Vol. 16, No. 1, pp. 11–28

Ray, M. (1999) 'Developing person-centred standards for care homes', *Journal of Dementia Care*, November/December, Vol. 7, Issue 6, pp. 16–18

Raynes, N.V. (1998) 'Involving residents in quality specification', *Ageing and Society*, Vol. 18, pp. 65–78

Robertson, J., Emerson, E., Hatton, C., Elliott, J., McIntosh, B., Swift, P., Krijen-Kemp, E., Towers, C., Romero, R., Knapp, M., Sanderson, H., Routledge, M., Oakes, P. and Joyce, T. (2005) *The Impact of Person Centred Planning*. Lancaster: Institute for Health Research, Lancaster University

Rogers, C.R. (1958) 'The characteristics of a helping relationship', *Personnel and Guidance Journal*, Vol. 37, pp. 6–16

Rose, D. (2003) 'Partnership, co-ordination of care and the place of user involvement', *Journal of Mental Health*, Vol. 12, No. 1, pp. 59–70

Routledge, M. and Gitsham, N. (2004) 'Putting person-centred planning in its proper place?', *Learning Disability Review*, Vol. 9, No. 3, pp. 21–6

Sanderson, H. (2000) *Person-centred Planning: Key Features and Approaches*. York: Joseph Rowntree Foundation.

Sanderson, H. (2003) 'Implementing person-centred planning by developing person-centred teams', *Journal of Integrated Care*, Vol. 11, No. 3, pp. 18–25

Sanderson, H., Jones, E. and Brown, K. (2002) 'Active support and person-centred planning: strange bedfellows or ideal partners?', *Tizard Learning Disability Review*, Vol. 7, No. 1, pp. 31–8

Sanderson, H., Kennedy, J., Ritchie, P. and Goodwin, G. (1997) *People, Plans and Possibilities: Exploring Person-Centred Planning*. Edinburgh: SHS Trust

Schalock, R.L., Keith, K.D., Hoffman, K. and Karan, O.C. (1989) 'Quality of life; its measurement and use', *Mental Retardation*, Vol. 34, pp. 1–12

Scottish Executive (2001) *Draft National Care Standards*. Edinburgh: Scottish Executive

Shah, R. (2005) 'Addressing ethnicity and the multicultural context', in P. Cambridge and S. Carnaby (eds) *Person Centred Planning and Care Management with People with Learning Disabilities*. London: Jessica Kingsley

Sheard, D. (2004) 'Person-centred care: the emperor's new clothes?', *Journal of Dementia Care*, March/April, Vol. 12, Issue 2, pp. 22–4

Stainton, T. (2002) 'Taking rights structurally, disability rights and social worker responses to direct payments', *British Journal of Social Work*, Vol. 32, pp. 751–63

Stalker, K. and Campbell, V. (1998) 'Person-centred planning: an evaluation of a training programme', *Health and Social Care in the Community*, Vol. 6, No. 2, pp. 130–42

Stokes, G. (1997) 'Reacting to a real threat', *Journal of Dementia Care*, January/February, Vol. 5, Issue 1, pp. 14–15

Todd, H. (2002) 'Planning a new future', *Talking Sense*, Autumn/Winter, pp. 20–5

Towell, D. and Sanderson, H. (2004) 'Person-centred planning in its strategic context: reframing the Mansell and Beadle-Brown critique', *Journal of Applied Research in Intellectual Disabilities*, Vol. 17, No. 1, pp. 17–22

Truman, C. and Raine, P. (2002) 'Experience and meaning of user involvement: some explorations from a community mental health project', *Health and Social Care in the Community*, Vol. 10, No. 3, pp. 136–43

Ward, F. (1999) *Modernising the Social Care Workforce – the First National Training Strategy for England. Supplementary Report on Learning Disability*. Leeds: Training Organisation for the Personal Social Services

Williams, B. and Grant, G. (1998) 'Defining "person-centredness": making the implicit explicit', *Health and Social Care in the Community*, Vol. 6, No. 2, pp. 82–94

Wistow, G. (2004) *The New Vision for Adult Social Care: Responses to a Survey Conducted by the Social Care Institute for Excellence, Commissioned by the Department of Health*. London: Department of Health

Woodrow, P. (1998) 'Interventions for confusion and dementia 5: changing cultures', *British Journal of Nursing*, Vol. 7, No. 21, pp. 1329–31

Appendix: Methods

This scoping review was conducted through a review of the literature and by consultation with a team of user consultants. These two methods were integrated and mutually informative, but for ease of description and clarity they will be described separately here.

Literature review

The first task was to gather literature to be reviewed; therefore a search strategy of databases was designed. An outline version of this is detailed in the box below. The search strategy was used to search the following databases: ASSIA, AMED, CINAHL, PSYCHINFO, Age Info and Age Line, Social Science Citation Index, Care Data, Best Practice, King's Fund. In addition, searches were made for materials originating in the voluntary sector, professional and governmental organisations, using the websites of the Modernisation Agency, National Council for Voluntary Organisations and The National Electronic Library for Learning Disability (BILD). Internet searches using 'Google' as a search engine were also made and these identified a plethora of websites concerned with person-centred planning. Finally, journals that produced a significant number of references were hand searched, and reference lists were checked for relevant citations.

Search strategy

1 person centred planning or person centred care or care plan or direct payment or user involvement or personal futures plan or care maps or care paths or circles of support

2 disability or handicap or incapacity or invalid or paralysis

3 1 and 2

4 learning disability or learning difficulty or intellectual disability or mental handicap or mental retardation

5 1 and 4

6 mentally ill or mental health or depression or psychiatric or psychosis

7 1 and 6

8 blind or sightless or vision impaired or visually handicapped

continued

9 1 and 8

10 homeless or destitute or displaced or down and out or rough sleeper

11 1 and 10

12 refugee or asylum seeker or migrant or exile or fugitive

13 1 and 12

14 head injury

15 1 and 14

16 older people or elder or pensioner or senior or older person or aged

17 1 and 16

18 dementia or Alzheimer's

19 1 and 18

20 3 or 5 or 7 or 9 or 11 or 13 or 15 or 17 or 19

All the literature identified in searches was screened for its relevance to the study by reading the abstracts of each paper. If the paper discussed person-centred planning in relation to social care or to a particular service user group, then it was retrieved in full for further assessment of its relevance.

Papers included in the final review were read and data was extracted using a framework method. Eight analytical charts were created, each focusing on a particular theme. These included:

1 general information

2 antecedents

3 context/structure

4 process

5 population

6 outcomes

7 staff

8 evidence.

The theme of each chart was broken down into a number of relevant sub-themes and data from papers was entered into the charts where appropriate. This method enables a clear view of the range of data emergent from the literature and also facilitates comparison between papers. All research tools including the search strategy, inclusion criteria and the analytical framework were developed in conjunction with the team of user consultants, as is described later in this appendix.

Salient and recurrent themes were drawn out of the charts when all data extraction was complete and these were analysed in response to the research questions. It is the result of this analysis that is presented in this research report.

After this project finished (March 2005) two important additions (Cambridge and Carnaby, 2005; Robertson *et al.* 2005) were made to the literature and these have been incorporated into this final report.

Working with user consultants

User consultants were recruited as members of the research team. They are Sarah King from Impact, a mental health user consultancy, Wendy Perez from Paradigm, a learning difficulties user consultancy, Vicki Raymond, an independent consultant on disability, and Pauline Weinstein, from Better Government for Older People. Consultants came to the attention of the research team through contacts with team members and previous experience of working with some of the consultants or their organisations. Each consultant was contacted by telephone or email in the first instance. If they expressed initial interest, a copy of the study's protocol was sent to them, together with an outline of their expected contribution, details of the time they would be expected to spend on the project and the rate of payment that could be offered.

User consultants were regarded as essential to the research process and, as such, took part in three defined and important stages.

The first stage of the consultants' input was in relation to the design of study tools – that is, the search strategy, the inclusion criteria and the analytical framework. Having been sent copies of the initial design, consultants were asked to comment on this and make any suggestions or changes. Suggestions were discussed and in all instances incorporated into the design of research tools.

The second consultancy stage involved consultants being asked to read and analyse three of the retrieved papers and extract data using the analytical framework. The purpose of this was two-fold – it enabled consultants to comment on salient themes emerging from the literature from their perspective and facilitated a checking process, to establish whether the researcher had drawn similar material from the papers as the consultants. Their data extraction was incorporated into the analysis and contributed to the findings of this review.

The final stage of consultancy involved the preparation of the report. Consultants were asked to read and comment on draft chapters, and their comments contributed to and informed the final versions. In addition to this, the consultant from Paradigm worked closely on the production of an accessible summary of the report.

Throughout the consultancy process, the consultants were asked to advise on literature sources they were aware of, in particular those where the voices of disabled people or service users were reported in relation to person-centred planning.

Recommendations for working with user consultants

1 An inclusive approach should be adopted in relation to working with user consultants, who should be regarded as full research team members from the outset.

2 Consultants' contributions should be valued and their contribution designed to make a real impact on the project and to be in no way tokenistic.

3 Requests for action on the part of consultants should be clear and detailed. These should include estimates of how long the work should take to complete and when it is required to be returned to the researcher.

4 Clear information should be given to consultants regarding the amount they will be paid and how they should go about invoicing for payment. The VAT position should be clarified.

5 In costing the project budget, realistic amounts should be included for paying consultants' fees and any travel or other expenses they may incur. This will require some exploration and negotiation when the budget is being designed. Consideration should be given to any extra travel costs needed; for instance, if a consultant uses a wheelchair, then travel costs might be higher than usual.

6 Feedback from consultants should be sought at the end of the project to assess how they viewed their involvement and to seek recommendations on how the joint working process might be improved on for the future.