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Foreword

I am delighted to introduce this important new book on person centred thinking and planning with older people.

Older people say they want real choices and the responsibility to choose the best possible lifestyle for them. CSCI's report *Making Choices, Taking Risks* looked at the experiences of older people and carers who need support to live their daily lives. A key message was the need for help to adjust to the life changes (and societal attitudes) associated with ageing - not just to arrange care services. *Practicalities and Possibilities*, and the development programme that will operate alongside it in 2007-08, offers practical guidance as well as a conceptual framework for enabling this to happen so that real improvements are seen and felt by older people in all aspects of their lives.

Older people tell us: *"You spend your whole life making decisions about things - your work, your relationships, your children - you don't want to suddenly give up that responsibility because you're older."*

Government is committed to developing a health and social care system that is founded on personalisation, choice and control. Person centred thinking and planning is a fundamental stepping stone to achieving this goal - and can be applied within and across all public services to reflect the way that older people want to live their lives. It is essential for the way we all think about and work with older people.

For older people this guide also offers some ideas, including practical tools and ways of working with family, friends and services, to ensure they are in control of the support they receive; and aware of the choices they have about the kinds of support that suit them best.

I hope you can use the powerful stories and examples shared in this book, to influence the way you think and act, whether you are a professional, an older person, family member or policy maker.



Dame Denise Platt
Chair, Commission for Social Care Inspection

Introduction

This book is about using person centred thinking to enable older people to have much greater control and say over what they need and want in order to be full and active citizens wherever they live, whoever they live with, and however they live.

Much work has been done - especially over the last 10 years - about developing person centred approaches in health and social care services in order to deliver better treatment and care for older people. However, very often this means doing things in a more efficient and organised way rather than really doing things differently in ways that make sense for older people. Older people also live their lives outside of health and social care services so we need to develop person centred ways of supporting older people that aren't just about quicker, faster, more efficient services, but are about improving lives and life chances. This means ensuring any kind of support is led, designed and planned by and with older people and their families. We also call this 'self directed support'.

Whilst this automatically means that we're talking about a much broader, and more exciting, range of developments and ways of working, it can also seem daunting for professionals who are involved in providing and commissioning services. That is one of the reasons that we wanted to write this book.

Our work at the Older People's Programme and Helen Sanderson Associates brings us into contact with a diverse range of older people, family and other social networks (neighbours, colleagues, friends, wider communities, volunteers) professionals, services and agencies.

Our decision to develop our ideas and experiences into a practical book was influenced by four issues that arose from, or were associated with our work.

The first issue is a reflection on what happens to people's lives if services come to be the dominant part - whether in terms of where someone lives, the arrangement of their daily lives, or the people with whom they have contact. We often meet older people who are living in two worlds - a 'service world' and 'ordinary life'. Most of their contact is with people who are either paid for providing a particular role or who have a formal volunteering relationship. It is often their 'ordinary life' and their ordinary social networks that shrink - and their 'care life' or 'support life' with its 'formal' network that now dominates. Particular problems can arise for older people and their families when the service world starts to dominate and not support - or allow for - an 'ordinary life' to continue or restart.

This 'shrinking' is most likely to happen when someone's situation suddenly and dramatically changes. It can also happen gradually and almost imperceptibly over time. In older age, the most common

reasons for sudden change like this tend to be; illness, disability, bereavement, divorce, or moving to a new place. But the way people have lived their lives in younger years may also be having an impact now. For example, someone may have lived happily with a very small circle or social network of close friends and relatives, but if some of these have now died or are themselves ill there may be fewer and fewer people to call on or do things with.

We are also often struck by how many older people tell us that they have been told to (for example) "come to day care because I was lonely" - but who, when asked, say they are still lonely even though they now regularly attend a day centre or lunch club. Some services, at least, seem to us to be more about a transaction than about transforming someone's life. In other words, there is greater emphasis on delivering something than on making sure that what is delivered is filling the gap(s) identified by the person.

The third issue was initially drawn from a large-scale residential seminar held by the Older People's Programme in 2002 with Help the Aged and Joseph Rowntree Foundation,

which a large number of older people attended. Those taking part in *Living Well in Later Life* (OPP, 2002) identified seven dimensions to achieving a 'good life' - or what is usually known (in health, housing and social care circles) as 'quality of life' or 'well-being'.

The Seven Dimensions are:

- 1 Being active, staying healthy and contributing.
- 2 Continuing to learn.
- 3 Friends and community - being valued and belonging.
- 4 The importance of family and relationships.
- 5 Valuing diversity.
- 6 Approachable local services.
- 7 Having choices, taking risks.

These are placed in roughly the same order of priority or importance identified by those who participated in the event. Whilst this will clearly differ for everyone - all of us have very different things and ideas about what's important in and for our lives - it is interesting to note that all participants placed services and issues of risk right at the bottom of the list!

Key amongst these seven elements is the importance of relationships and networks. But this isn't just about having a list of people you see or speak with - it is very much about the quality and nature of those relationships and contacts, including how time is spent with those other people.

This issue in particular, has struck us time and again; in other words, the central importance of having people in your life with whom you have good, close relationships and with whom you do certain things that are important to you.

Person centred care has been a particularly key focus of developments in health and social care for older people since the introduction of the Department of Health's National Service Framework for Older People in 2001. Standard Two of the framework is: Person Centred Care. Subsequent publications and national guidance have continued to emphasise the importance of being person centred, and developing person centred services and responses to older people's needs. The most recent of these, *A Recipe for Care - Not A Single Ingredient: a clinical case for change* (DH, 2007) is a report from the National



Director of older people's services which reinforces this message about organising and delivering services based on what is important to older people and their families. Within six key factors for improving the way that services respond to the needs of older people¹, the importance of good partnerships with older people and their families is stressed. Working in person centred ways can help develop a different kind of relationship and trust between services and older people so that these partnerships can flourish.

This brings us onto the fourth key issue, drawn from the reactions that we have heard from many professionals and staff working in different agencies and across the public, private and voluntary sectors, which is that they are 'already doing person centred care'. By this they often seem to mean that they are asking older people what they want, or anticipating what they might want, but often without really involving and engaging them as equal and valued citizens (as opposed to service users). We are therefore not always certain about the quality of these conversations; and particularly about whether professional and older people concerned have developed a

sufficient relationship for this to be achieved; and what they then do (if anything) in response to what is shared.

Why is this important now?

Working with older people in enabling and person centred ways has always been important, but there are particular aspects of the current policy and practice environments which mean that this is a high priority to address, and that more people, agencies and influential bodies are ready to listen and learn than ever before.

One of the main reasons is that older people are the majority group of stakeholders in thinking about designing and developing a health and social care system fit for the future – and especially for developments around self directed support, or what some call 'personalisation'. Recent policy frameworks and White Papers, not least *Opportunity Age*, our national strategy on ageing, illustrate the Government's recognition of the challenges and trends associated with our ageing population, including the 'oldest' older people. However, much of the current debate in this policy agenda is concerned with problems in social

care spending and capacity associated with growing numbers of older people who it is assumed will need support in their later years¹.

It does not reflect the varied characteristics of our ageing population, why and how individuals' age differently especially with respect to their health, wellbeing and disability – and therefore their need for different kinds of support. Nor does it tell us much about older people's aspirations, their rights and demands for equality, choice and greater control regardless of their need for support on a day to day basis. Neither does it say much about older people's contributions or about the dynamic nature of ageing – the changing patterns and trends in terms of housing, family and social networks, employment and other types of economic and social participation. It does not recognise, unlike Thomas Perl from Boston University's New England Centenarian Study that the increasing number of older people living to a very old age (such as those living to be 100 or more years) is not a sign of impending doom, but instead:

"These people disprove the perception that the older you get the

sicker you get. Centenarians teach us that the older you get the healthier you have been."

In all of this it is important to remember what older people want and what they typically experience now if they need support; and especially if they rely on support from services on a daily basis.

What do older people currently experience?

- Fragmented services and support between different agencies, departments, services and teams.
- The health and social care world dominates, and crisis care dominates above all - other parts of your life can often appear to fade away, even though they are central to wellbeing, self esteem and health (e.g. family life and other relationships, being active and contributing, having a role and purpose etc).
- Choice is restricted and support is still largely traditional in nature, especially for older people with high support needs.
- Access to and experience of Direct Payments is increasing, but is still

low overall and in some places is extremely under-developed. Many people are put off at the first hurdle, or leave direct payments if help to unravel or resolve problems is not at hand.

- Whilst it is still early days for authorities and individuals who have an Individual Budget, there are some important early lessons about what helps, what gets in the way, and what matters to older people in taking control of the resources that relate to your support.
- The voices and active engagement of older people are still very quiet, and some older people are very marginalised e.g. older people with mental health difficulties, older people who live in care homes, older people from black and minority ethnic communities.

Person centred thinking and self directed support offer a different approach to thinking not only about services, but also about older people and ageing more widely.

In this book we introduce eight person centred thinking tools, and share older people's stories

and examples of how these tools are used. At the end of each section we suggest where these tools could be used.

We begin this book with a summary of what we are learning about self-directed support and older people, and then introduce each of the person centred thinking tools.

These are:

Appreciations

A key aspect of person centred practice is Appreciation, and having a focus on what we like and admire about people.

Relationships

A relationship map or circle is a good way of identifying and capturing who is important to an older person, to ensure that there is 'at least one person' and to actively seek to widen the connections and relationships that someone has.

What's important to and for people?

The fundamental person centred thinking skill is to be able to separate what is important to someone, from what is important for them.

Important to is about what really matters to the person, from their perspective. Important for is about the help or support that they need to stay healthy, safe and well.

Communication

The communication chart is a powerful and simple way to record how an older person communicates. This is critical if someone doesn't talk, and is also important where people only use a few words, or communicate most powerfully with their behaviours. It can also help if the person has memory or orientation problems, as in the case of people with dementias.

Histories

Older people's histories can easily become lost or be left untold. A conscious effort to listen to and record individual histories can help staff to understand and appreciate people in a different way, and in doing so develop different relationships with them.

Wishing

Older people may be keen to share and explore their own personal goals and dreams - their wishes.

Good days and bad days

One of the ways to discover how best to support someone is to ask about their good days and their bad days.

Working/not working

Simply asking an older person what is working and not working in their life tells us so much. This information may be used to change what can be changed and to help us understand what really matters to people.

We end by exploring how these person centred thinking tools provide the foundation for support planning, and introduce a framework for support planning with older people.

Self directed support and older people

The overarching aims of self directed support are about enabling people who need support to move away from formal mechanisms of delivery where services, agencies and professionals retain control; to a situation where people can live independently and have control over their own lives, and make real choices about the nature and level of support they access from a wide range of networks, options and opportunities.

This chapter summarises some of the early experiences, lessons and observations from the work of in Control members, the individual budget pilot sites, the Circles project working with older people in Oxfordshire and Portsmouth, and person centred planning and support planning with older people in Tameside. It includes information from a background paper prepared for in Control on self directed support and older people and information from an individual budget workshop on support planning.

There is a great willingness to learn more about and apply the practical lessons from developments in self directed support to services and wider systems of support for older people. Some excellent work is taking place in in Control sites and the individual budget pilot sites working with older people to ensure they are taking control over their support needs and the resources to fund them (e.g. with an individual budget or direct payment) so that they can live the lives they want to lead. Whilst there is much to learn from these areas, current progress is limited to relatively small numbers of older people in a few forward thinking authorities and neighbourhoods. There are other innovative projects that are

contributing to our learning, for example the person centred thinking work taking place in Tameside and the Circles Project.

The Circles project run by OPP, worked with over 80 older people and organisations in Oxfordshire and Portsmouth, ran between 2003 and 2005 and explored these issues outside the 'service world' with an emphasis on enhancing quality of life and general wellbeing.

The work was designed to provide practical support, training and advice about establishing and maintaining circles of support for a range of older people, most of whom had support needs of one kind or another. The aim of Circles was to offer a different approach, not only to providing that support (designed and led by the older person) but also to offer the tools and insight into working with older people in a person centred and enabling way, by supporting them to identify and then reach their dreams, hopes and wishes through establishing and/or expanding and strengthening their networks. By working, deliberately, with relatively small numbers of people within these two areas, the Circles project focused in-depth on those individuals' lives and circumstances - both

to better understand what might work and be of value to them personally; and to learn how to adapt 'what works' so that the approach might be shared with larger numbers of older people over time.

By the end of the two year project, this is what older people and others who took part in the work identified as being important in establishing circles of support for them:

- A Circle is the network of people known by an individual older person, however small or large (it may be just one other person), that they identify as being important to them (and to whom they are also important) especially in relation to achieving their personal goals, dreams and ambitions.
- These goals and dreams may be to do with improving health, or recovering from illness or adjusting to a personal loss. But they are also about the fundamental aspects of someone's life that they need some assistance or support to achieve.
- This network or circle includes people with a formal service or support role (paid or volunteer) in the person's life as well as family members,



neighbours and friends. Some people also included their pets as members of their Circle.

- One or more people who the older person knows finding out about his or her wishes, dreams, goals – either by asking directly, or by listening carefully to what is said in general conversation.
- The person(s) who has been told (or has listened) then exploring with the older person whether and how this ‘dream’ or ‘wish’ can be achieved - what would be needed and who might help. This includes exploring the true extent of the older person’s network and supporting them to develop and maintain this network or circle when needed.
- The person(s) providing this support in turn seeking their own support – for example to find out different ideas or contacts that might be useful from within their own networks including colleagues.

Our focus in the stories that are shared from the Circles project in this book, is on extending and strengthening older people’s personal networks, to enable those circles to work together with the older person to achieve their dreams, goals,

hopes and/or aspirations that each has identified would make a difference to their lives and overall well being. These are stories of how people’s lives and/or circumstances changed over a fairly short timeframe (12-18 months in one case, but much less for most other people) through the practice of circles of support and applying the principles of ‘person centred [life] planning’.

At its simplest, Circles was a project about how some older people were asked what they would like to do, have or be – and how they set out to achieve these ‘dreams’ without extra money, specialist staff or new services, or by having every aspect of those dreams ‘done for them’ by someone else.

We believe there are important lessons to learn and use from all these approaches; but there is also a lack of awareness about what is possible and achievable. For example, at present there is far greater understanding about self directed support within those areas that are pilots for testing out and trying new ways of working and developing services (e.g. the Individual Budget pilots, the POPP pilots, Link Age Plus pilots, Innovation Forum pilots and so on).

There is now a need to share, and a desire to learn, these important lessons with authorities that until now have had little input regarding self directed support and person centred thinking with older people. At the same time, we want to make sure that these lessons and approaches are adopted across all public services in relation to older people, rather than being seen as a priority for health and social care alone.

We hope this book contributes to sharing information about how person centred thinking can be used to enable older people to direct their own support.

What have we learnt so far?

A consistent theme across different pieces of work and experiences of using person centred thinking and planning with older people is the importance of starting with, and reinforcing, the fundamental concepts and principles of self directed support and individual budgets. The key points are summarised here.

- Self direction is about choice and control over any assistance and support you need to live your daily life.

- It is about people's lives and improving their quality of life and sense of control - it is not about health and social care or service based solutions, even if for some people these are crucial for day to day survival.
- Introducing the approach, concept and seven step framework of self directed support with personal experiences and lives (i.e. stories) is enormously helpful - for staff as well as for individual older people and their families and friends.
- There is a pattern from working with people with a learning disability which probably means that the person concerned is already known to you, and that everyone involved is familiar with the concept of starting with lives not needs. In addition, person centred thinking and planning with people with a learning disability is often about working with someone who has never been in control before, or had very little control over their lives. With older people the work is often about rebuilding or renewing control for people who have lost control due to ill health, exclusion, discrimination, life events etc. It is important to recognise different starting

points and histories – which will vary from person to person.

- The fact that there are many more older people than there are people with a learning disability - combined with the transient and intermittent nature of many older people's involvement and contact with services - may explain the relative newness of self directed approaches in this field.
- Whatever the reasons (and there are many!) - it's important to start emphasising the potential, the different contexts, the benefits and opportunities for individuals and the system generally - through stories, life histories and biographies of people's lives. Starting with, and reinforcing throughout, the impact on personal experiences and lives will help shift cultural, societal and professional expectations regarding older people (and ageing) away from illness, dependence and frailty towards independence, control, contributions, aspirations and fulfilment.

We have found that the core seven step process for self-directed support developed by

in Control, and person centred planning tools and techniques such as those developed by Helen Sanderson Associates and the Learning Community for Person Centred Practices, seem to work well with and for older people. However, we need to extend this and learn in more detail the specific circumstances where these might need to be adapted. We also need to learn more about the implications both for starting to work in this way with older people, and in ensuring that the ethos and practice of self-directed support continues as, or if, individuals' needs and circumstances change.

An important finding from talking with different places who are exploring these issues is that support planning, a key stage of the seven step process, is a meaningful way for older people to understand self directed support themselves, and for families and staff (and others involved in supporting older people) to begin working in this way. We explore this later, as this builds from the person centred thinking tools that we will begin to introduce in the next chapter.

The following box, Summary of Early Lessons, further highlights these points.

Summary of Early Lessons about Self Directed Support and Older People

The 7-Step (in Control) Framework is a helpful and practical tool that can be used to test “readiness” and review progress as well as a framework for implementing self directed support

Self Directed Support is NOT just about money

- The biggest attraction for older people is increasing control and having a different menu of support.
- Support Planning is therefore crucial.
- Personal stories are really important. We therefore need to get better at using older people’s experiences, knowledge, skills, talents and aspirations.
- This is still a new concept for many people and organisations.
- There is a lot of good practice in dementia care that is not widely shared.

The starting point for older people is usually different from disabled people

- Older people have often experienced ‘cumulative loss’ and lost control (rather than never having had it).
- Funding streams, eligibility criteria and ceilings are different (usually lower).
- The first contact older people have with services, and how their need for support arises affects everything (e.g. in a crisis).

There is an uneasy fit between self directed support and current systems of care

- There is much to do to bring about a closer fit which involves transforming local systems across all public services. It's important to start small and learn about what helps to become person centred at all levels.
- Work on simplifying assessment systems (e.g. through the Single Assessment Process, or the Common Assessment Framework) needs to learn from this fundamentally different approach. Person centred thinking and planning is not a bolt on efficiency saving device. It is a different philosophy and approach which has implications and benefits for how services organise themselves to deliver support differently.
- Both specific and broader 'policy and practice hooks' should be used to influence change at a local level:
 - Opportunity Age - our national strategy on ageing.
 - Sure Start to Later Life - combating social exclusion of older people.
 - The work of older people themselves e.g. through Older People's Advisory Groups, Older People's Forums and Councils (e.g. Brighton and Hove Older People's Council, Newcastle's Elders' Council).
 - Partnerships and Older People Programme (POPP) pilots.
 - Strong and Prosperous Communities, the Local Government White Paper (DCLG, 2006).
 - Forthcoming Housing Strategy for an Ageing Population.
 - Transformational Government for Older People work led by the Cabinet Office and the Pensions Service.