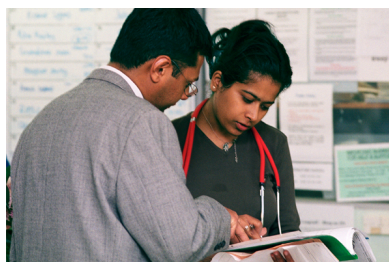




Transforming models of care for people living with dementia

Improving experiences and outcomes for people with dementia and their carers and families



Executive summary

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Introduction

The National Dementia Strategy, *Living Well with Dementia*¹ heralded a set of national policy initiatives focusing on dementia. For the first time, policy makers described outcomes and services that people with dementia and their carers should be able to expect. The Strategy, along with a range of other recent dementia policy initiatives, together highlighted some common areas for improvement, including:

- better access to services
- improving the range of services to include not only health and social care but also other services such as telecare and housing
- dementia services should not be based on age
- service integration
- early diagnosis and treatment
- help and support for carers/families
- supporting independent living, and
- a 'whole systems' or joined up approach to commissioning.

Two years after the publication of the National Dementia Strategy, improvements have indeed been implemented – notably in the provision of early diagnosis and (medical) treatment through the commissioning and development of memory services across the country. However many of the areas marked for improvement – including integrated services, a whole systems approach to commissioning, and support for independent living – have yet to be adequately addressed.

This Executive Summary reports on the key findings and recommendations from the project and is necessarily brief. The full report includes quotes and vignettes from people living with dementia and good practice examples. It also includes an Appendix, suggesting a range of services that could be commissioned in line with the proposed new model of care.

Download the full report at www.dementiapartnerships.org.uk/models-of-care

¹ Department of Health (2009) *Living well with Dementia. A National Dementia Strategy*. London, Department of Health.

Developing a new model

So, despite improvements in recent years, quality and outcomes are still falling behind increasingly high expectations of the public and people living with dementia. Evidence suggests that applying a systematic approach to service models and delivery might contribute to better outcomes.²

In order to ensure any proposed revised model would be grounded in the reality of experiencing dementia, delivering services and commissioning locally, the author used a range of methods over a 6-month period in 2011 in the South West of England. These methods included:

- listening to local people living with dementia
- talking to commissioners, providers, staff and other experts in statutory and non-statutory settings
- visiting local services
- non-participant observation/shadowing practitioners, and
- incorporating evidence of good practice, policy and relevant literature.

A number of themes emerged time and again, leading to a re-think about dementia and the people who live with it. This, in turn, has led to the proposal of a new understanding of the dementia journey and a revised model of care for dementia, aimed at improving experiences and outcomes, and informing service redesign and commissioning.

Note: in this paper, the phrase ‘people living with dementia’ refers to people who have dementia and their carers and families. All names and some details have been changed to protect anonymity.

² Vickrey, B. G. et al (2006) The effect of a disease management intervention on quality and outcomes in dementia care: a randomised controlled trial. *Annals of Internal Medicine*. 145,713-726.

What is meant by a model of care?

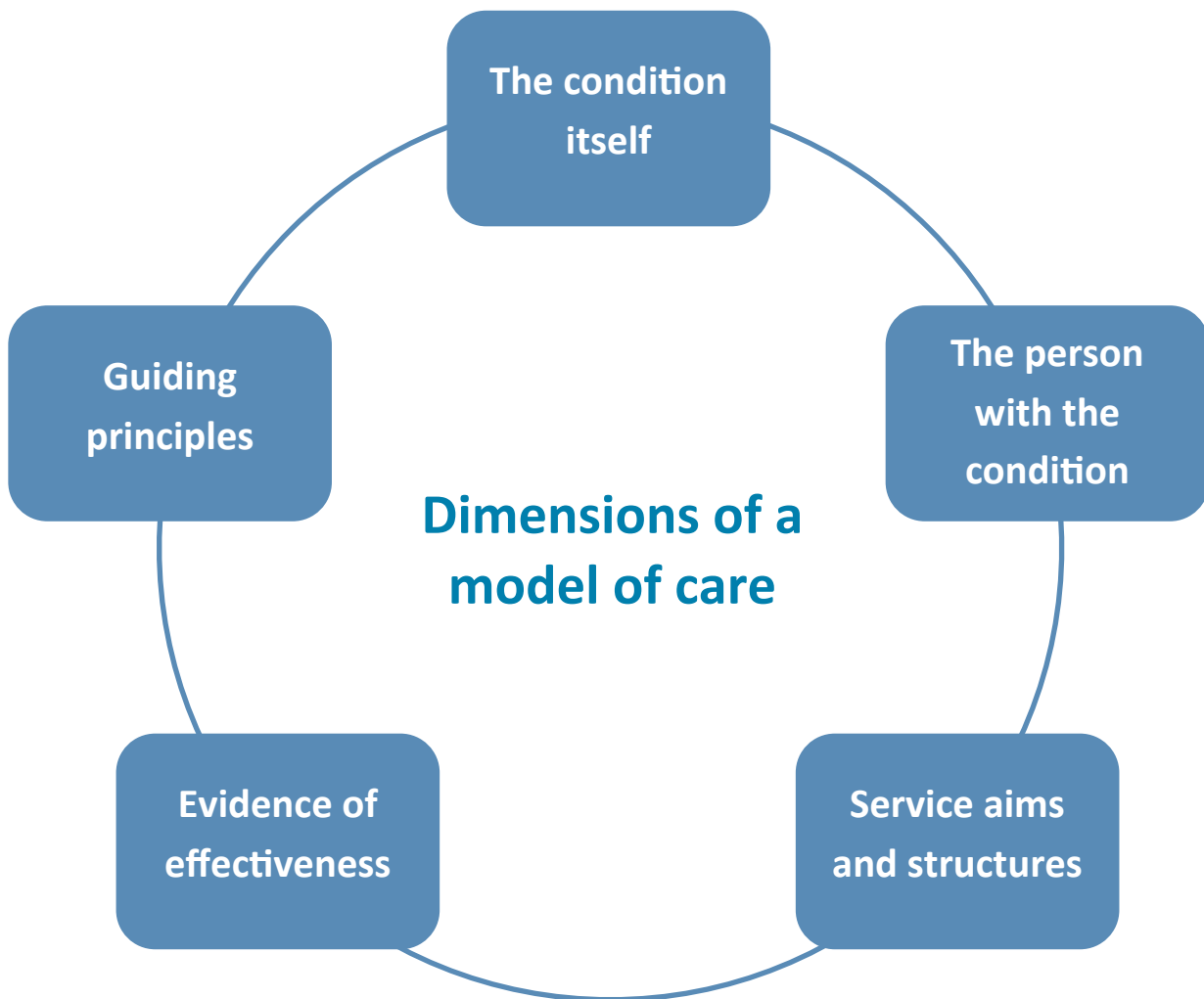
The term 'model of care' is used in a number of ways, often without definition or explanation.

Here the term 'model of care' is being used to describe an overarching design for the provision of a service, based on a number of dimensions as shown in Figure 1:

- theoretical concepts about the condition or disorder and the person living with it
 - a) the nature of a condition or disorder – e.g. what is its course, what effects does it have, is it debilitating, does it affect mind and/or body?
 - b) the person living with that disorder (in this case, dementia) – e.g. are they fundamentally changed by the disorder, do we conceptualise them as individuals or part of a system, do they have capacity to make decisions?
- service aims and type of provision – e.g. should it provide treatment, advice, hospital or home-based care?
- evidence or consensus around the effectiveness of treatment and interventions – e.g. what helps to prevent and manage problematic behaviours?
- guiding principles and ethical considerations that underpin the model



Figure 1: Dimensions of a model of care



A clear model of care can improve clarity of purpose, improve quality and outcomes, and mean better use of resources. Implications for a refreshed model of care for dementia include:

- the whole model needs to be rethought – not just one or two elements
- a range of community- based, mainstream services, that are easily navigable by those who need them, should be the default
- interventions and support need to be early, proactive and effective
- services need to be person-centred
- specialist services, including inpatient care, need to be limited to times of greatest need and have a clear focus and remit, and
- carers are essential partners in delivering services, and need and have a right to support.

Findings

Listening to people living with dementia

People living with dementia were clear about the experiences and outcomes that will improve their quality of life, maintain their lives as part of their communities, and help them plan for their futures.

Their thoughts were used to inform the emerging model of care. These themes can be split into three areas, as shown in Table 1:

- essentials for people with living with dementia
- what services are needed, and
- how services should work.

Table 1: Consistent themes from people living with dementia

Essentials for people living with dementia	Services people say they need	How services should work
<ul style="list-style-type: none"> • Recognition of the person • Inclusion - social, age, minority groups • Managing stigma • Normalising • Family involvement • Early diagnosis with sensitivity • Dignity and respect 	<ul style="list-style-type: none"> • A range of services aimed at keeping people at home • Working with early diagnosis and help early on • Information • Out of hours support • Education and training • Crisis prevention and resolution • Voluntary sector 	<ul style="list-style-type: none"> • Knowledgeable • Proactively anticipating needs and concerns, thinking ahead • Flexibly and informally • Locally • With compassion, humanity and hope • Through building relationships • Valuing contribution of person with dementia and their carers / families

Critical issues that emerged included

- hurdles at the very early stages of dealing with memory problems
- concerns about the process and experience of diagnosis
- the burning need to keep identity, respect, dignity and social involvement for both people with dementia and carers and family
- a gap in follow-on services after early diagnosis
- the need for support to be proactive, timely, practical, and
- the wish to remain at home.

The 'dementia journey' and person-centred outcomes

The work carried out for this project resulted in the elaboration of a dementia journey from the point of view of people living with dementia (Table 2). By understanding the journey, services can be designed around the perspective of those who need them. Other commentators have suggested similar approaches (most notably, the Windows of Opportunity approach)³.

Table 2: The dementia journey

Phase 1	When memory problems have prompted me, and/or my carer/family to seek help.
Phase 2	Learning that the condition is dementia.
Phase 3	Learning more about the disease, how to manage, options for treatment and care, and support for me and my carers/families.
Phase 4	Getting the right help at the right time to live well with dementia, prevent crises, and manage together.
Phase 5	Managing at more difficult times (including if it is not possible to manage at home).
Phase 6	Receiving care, compassion and support at the end of life.

³ Social Care Institute for Excellence (SCIE) (2011) *Windows of Opportunity: prevention and early intervention in dementia*. London, SCIE. <http://www.scie.org.uk/publications/windowsofopportunity/>

The critical premise of a journey – albeit one that can take different turns and is not always linear – is that there are some common predictable elements (or phases), which enables planning and prevention for the people living with dementia and those providing services. There are needs and issues to be addressed at each phase and proactive actions can be identified early on to prevent problems in later phases. Furthermore, outcomes can be identified, linked to each of these phases or more usually that cut across the phases of the journey.

A number of person-centred outcomes can be associated with each phase of the dementia journey. These directly reflect the issues raised by people living with dementia who contributed to this report. They also derive from available literature, linking with the NICE Quality Standards for Dementia ⁴ and the Quality outcomes for people with dementia: building on the work of the National Dementia Strategy ⁵. Table 3 shows some examples from the full report.



⁴ National Institute for Health and Clinical Excellence (2010) *Dementia Quality Standard*. London, NICE. <http://www.nice.org.uk/aboutnice/qualitystandards/dementia/>

⁵ Ibid. 1.

Table 3: Examples of person-centred outcomes for each phase of the dementia journey

<p>Phase 1 Seeking help</p>	<ul style="list-style-type: none"> • I am confident that my primary health care worker/GP has taken my concerns seriously. S/he understands the nature and cause of memory problems, and will refer me quickly for an appropriate assessment if needed.
<p>Phase 2 Learning the condition is dementia</p>	<ul style="list-style-type: none"> • If I am given a diagnosis, it is delivered with sensitivity. • I am able to discuss the condition (and possible diagnosis) with a health professional; my questions and concerns are addressed; and I receive relevant information at the right time for me, and in the right way for me
<p>Phase 3 Learning more and planning for the future</p>	<ul style="list-style-type: none"> • As a carer/family member, my contribution and experience inform the assessment, and next steps. My own information and support needs are considered and addressed • My personal circumstances, and my needs, preferences, strengths and assets are acknowledged and understood.
<p>Phase 4 Living well with dementia</p>	<ul style="list-style-type: none"> • I can access a range of services to enable me to remain at home as long as possible. • As a carer, I can access support, including training, to help cope with the ongoing role of caring for a person with dementia.
<p>Phase 5 Managing at more difficult times</p>	<ul style="list-style-type: none"> • I know that I will be respected as a person, and that I will receive good quality care. • My rights, preferences, interests and culture will be respected. • People supporting me will have the knowledge, skills and attitudes to understand my condition, and care for me with compassion. I feel safe.
<p>Phase 6 At the end of life</p>	<ul style="list-style-type: none"> • I am confident that everything will be done to ensure that I die where I want to, well supported, and that my cultural needs and expectations will be respected.

A refreshed model of care for dementia

Taking into account the findings from this project, a revised model of care for dementia is proposed in Table 4, using the model elements described earlier (guiding principles, the condition itself, the person with the condition, service aims and structures, and effectiveness).

Note that statements about existing approaches are necessarily simplified. Of course, not all services or communities are currently working according to existing approaches or within any one model. Indeed there are many positive practice examples from existing services. The emphasis is on where we can move to, rather than on where we are moving from.



Table 4: Elements of the refreshed model of care: a summary

<p>Principles</p>	<ul style="list-style-type: none"> • From disease centred principles, focussing on managing an individual’s problems, risks and deficits • To person centred principles, focussing on and respecting the unique person and understanding their perspective and that of their carers / families
<p>Dementia</p>	<ul style="list-style-type: none"> • From a debilitating untreatable terminal illness of old age • To a long term condition affecting memory, cognitions, health and behaviour, experienced by a person and their family
<p>Person with dementia</p>	<ul style="list-style-type: none"> • From a frail old person without mental capacity • To a person with a life story, family, community and social network, who will need help and increasing levels of support as the condition progresses
<p>Services</p>	<ul style="list-style-type: none"> • From reactive secondary care services that seek to contain and control risk, with voluntary sector add-ons commissioned and provided separately • To proactive community and primary care services, anticipating and responding to the person’s journey through dementia, commissioned and provided collaboratively
<p>Effectiveness</p>	<ul style="list-style-type: none"> • From a sense hat very little helps, with reliance on medication and institution-based treatment • To a consensus that positive outcomes such as living well with dementia, prevention of crises and a good death can be achieved

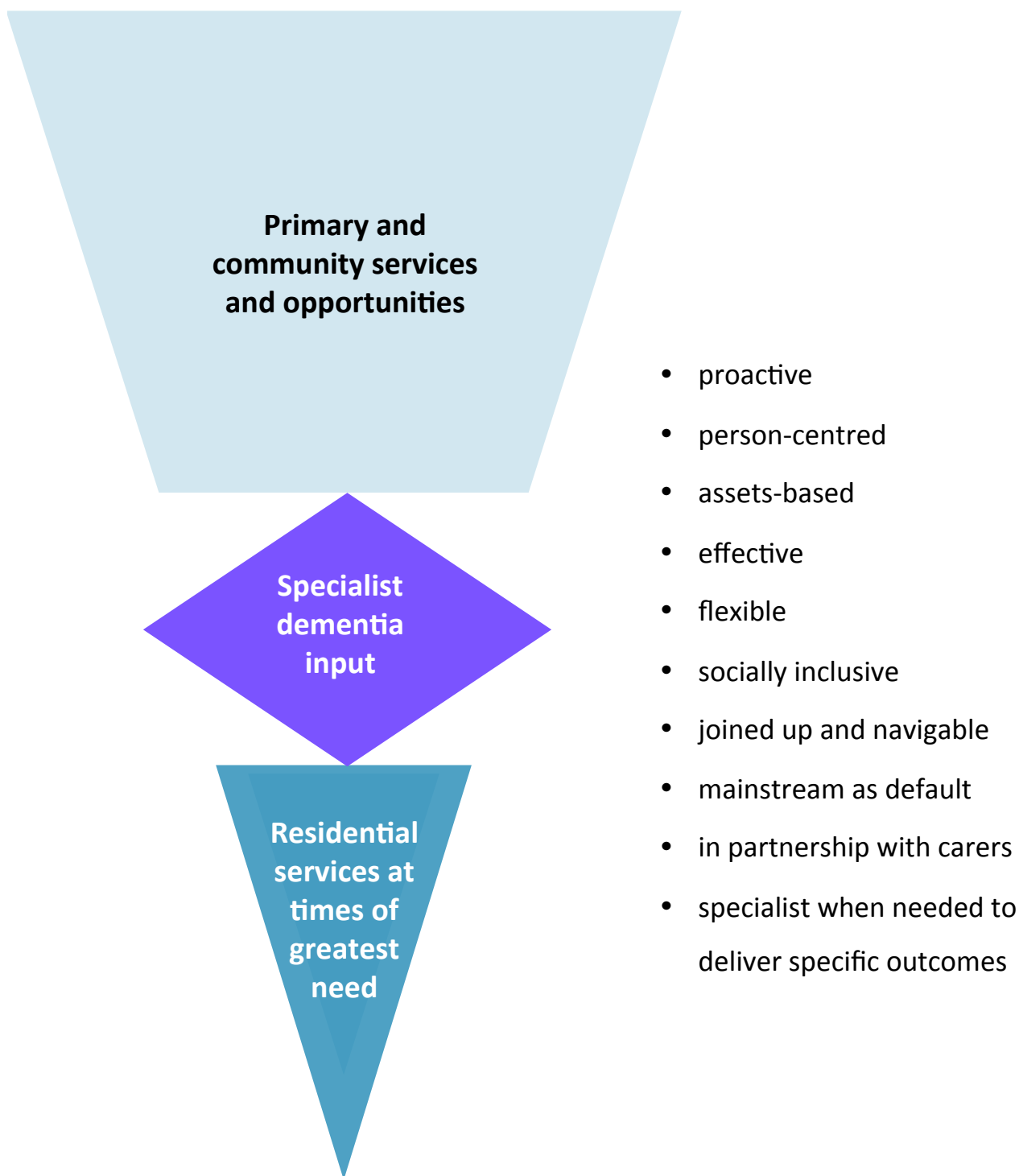
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The model incorporates a revised values base that leads to an understanding of dementia as a long term condition that affects memory, physical & mental health and social experience and behaviour. It is experienced not only by the person with the dementia symptoms but also their family and friends. It can be treated in its early stages and there are a series of relatively predictable needs and phases (a journey) that can be understood, sometimes prevented, planned for and alleviated. The person with dementia needs to be seen, not as a frail old person without mental capacity, but as a person with a personal and social identity. They have a life story, a family, a community and a social network. They can continue to enjoy a good quality of life, make decisions and contribute to society. He or she will need help at times and will certainly need increasing levels of support as the condition progresses.

Critical to the refreshed model is a radically different framework for type, range and placing of services and opportunities. Rather than a traditional approach in which primary care is seen as the initial gateway into specialist mental health services, with some complementary voluntary sector additions, this new model envisages a range of statutory and non-statutory services and opportunities working together and integrated at a commissioning with primary care in the lead, and specialist dementia services at times of specific, defined need (Figure 2).



Figure 2: An initial service framework for a refreshed model of dementia care



Conclusions

From a new model of care to a dementia service for a community

Listening to people living with dementia

People living with dementia are clear about the experiences and outcomes that will improve their quality of life, maintain their lives as part of their communities, and help them plan for their futures.

There are many examples of positive practice where services are achieving better outcomes. The best of these show:

- Collaboration and partnership (for example, between commissioners, health & social care providers and non-statutory sector)
- Practitioners who demonstrate not only knowledge and skills, but also empathy, flexibility and compassion and carry those values into their everyday work
- Clarity of roles
- Involvement of people living with dementia
- Foresight and an emphasis on planning and early intervention in order to manage the person's journey proactively.

However, in many instances people living with dementia find themselves frustrated at the lack of forethought, information, knowledge, skills and person-centred values that they encounter in their local services.

Designing services focused on outcomes

This paper proposes a model that focuses on improving experiences and designing services that aim to achieve person-centred outcomes related to the dementia journey. If commissioners and service developers adopted this model, they could consider a range of services with a clear remit where people living with dementia and practitioners and providers alike know what to expect, what can be achieved and how, and where their relative contributions are valued.

Applying this kind of revised model of care for dementia will differ in each health and social care community. Nevertheless, there are some good indications of which services might be needed to deliver the suggested outcomes.

Facing the challenge of a new model

Establishing a new model of care is likely to be felt as a challenge and requires a cultural and even a language shift. Thinking about people living with dementia as having assets as well as problems, as being able to contribute to services, as needing not so much an increase in services as more access to opportunities, and undergoing a journey that is relatively predictable and can be managed proactively--- all of this constitutes a step-change for the health and social care community. A key concept here is the notion of co-production. Co-production has been defined as a *“potentially transformative way of thinking about power, resources, partnerships, risks and outcomes... The transformative level of co-production requires a relocation of power and control, through the development of new user-led mechanisms of planning, delivery, management and governance”*.⁶ Co-production principles apply not only at the macro-level of service design but also at the micro-level of the relationship between the service user and the practitioner. This means a new way of working for everyone.

Furthermore, there are implications for workforce and resources, potentially requiring:

- new roles
- new skills
- rethinking of resources.

The South West Dementia Partnership has published a series of resources that will help address many of these issues, alongside a leadership programme to support the management of change. It is an ambitious programme, but one that the increasing numbers of people living with dementia need and deserve.

- www.dementiapartnerships.org.uk/workforce-development/
- www.dementiapartnerships.org.uk/leadership-programme/

⁶ Needham, C. and Carr, S. (2009) *SCIE Research briefing 31: Co-production: an emerging evidence base for adult social care transformation*. London, Social Care Institute for Excellence.

Six key messages

The model throws up a number of overlapping issues; however, key messages for future service design and delivery have emerged (Table 5).

Table 5: Six key messages

1	Recognise the dementia journey, and work sensitively, proactively and preventatively to help pre-empt and manage crises.
2	Deliver personalised, co-ordinated care that focuses on the unique person, and design services around person-centred outcomes.
3	Work together with people living with dementia, including carers, recognising their needs and assets.
4	Manage the range of issues associated with dementia – not just ‘mental health’; social engagement is critical. Make sure services and opportunities are joined up.
5	Provide services predominantly in the community, led by primary care.
6	Specify the role of specialist services and treatment, promoting therapies, rethinking the role of inpatient care and reducing reliance on medication.

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