



**DEPARTMENT OF HEALTH CARE AND SUPPORT GREEN PAPER
*SHAPING THE FUTURE OF CARE TOGETHER***

**RESPONSE FROM THE SOCIAL CARE INSTITUTE FOR
EXCELLENCE**

**GREEN PAPER *SHAPING THE FUTURE OF CARE TOGETHER*
SCIE RESPONSE**

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KEY MESSAGES

- 1 – Central government and local authorities should develop cross-departmental strategies for prevention and early intervention. (para 8)**
- 2 – If there is to be a split of national and local responsibilities, defined Resource Allocation System scores and associated funding levels should be allocated centrally; use of funding to get the best personalised match should take place locally. (para 13)**
- 3 – There should be a stronger move away from reliance on segregated provision towards accessing mainstream services and co-production. (paras 16/17)**
- 4 – Government should promote the development of strong local protocols for cross-agency and multi-service responses. (para 19)**
- 5 – Disabled people needing care and support and carrying parental responsibilities need much more joined-up service responses. (para 24)**
- 6 – Local authorities, working with their local partners, should give priority to building and sustaining social capital, recognising carers and volunteers as key contributors. (para 27)**
- 7 – Local authorities should promote and resource peer-provided advocacy and independent brokerage services. (paras 31-32)**
- 8 – Commissioning and decommissioning require substantial development in order to serve personalisation and transformation. (para 39)**
- 9 – The contribution of families to the care of older relatives can be supported and incentivised, but must remain voluntary. (para 44)**
- 10 – SCIE is well-placed to extend its remit to advise on value for money and quality. (para 49)**
- 11 – That extended remit could, in part, draw on work which SCIE has been developing in relation to approaches to economic evaluation suitable for the social care field. (para 54)**
- 12 – The behavioural and other effects of combining an insurance-funded system with assessment-based qualification for care and support need to be further examined. Experience elsewhere suggests there are pros and cons to insurance-based models of care and support. (paras 60-63)**
- 13 – The distinctive circumstances and requirements of disabled working age adults requiring care and support need more detailed consideration. (para 61)**
- 14 – SCIE stands ready to work with the Government and the many other stakeholders in social care to develop the ideas in the Green Paper. (para 66)**

INTRODUCTION: SCIE'S ROLE AND THE WIDER POLICY CONTEXT

1 – The Social Care Institute for Excellence (SCIE) is pleased to be able to offer evidence in response to the Green Paper *Shaping the Future of Care Together*. SCIE's mission is to identify and spread knowledge about good practice to the large and diverse social care workforce, as well as policymakers, educators and the research community, and to support the delivery of transformed, personalised social care services. We use various methods and media to reach and influence practitioners, managers and the sector leadership who have responsibility for service delivery in adults' and children's services. We recognise the central role of people who use services, children, young people, their families and carers, and we aim to ensure their experience and expertise is reflected in all aspects of our work.

2 - SCIE works to:

- capture and co-produce knowledge about good practice. We carry out and commission research and work with other leading organisations to produce information and practical guidance about what works in social care
- communicate knowledge, evidence and innovation. We share our knowledge about what works in partnership with sector partners including improvement agencies, networks of providers, groups of people who use services, including children, young people, their families and carers, regulators and government departments.

Ultimately SCIE aims to be a catalyst for transformation of care services. We believe that the knowledge and guidance we provide will inspire and inform improvement.

Only by understanding what works in practice - and what does not - can services be improved, and the status of the workforce be raised.

3 – SCIE has been actively working with the Department of Health, organisations of service users and carers, and other stakeholders to develop and help implement a number of policies relating to care and support services. These include:

- “*Putting People First*” concordat on personalisation, which SCIE signed
- “*Working to Put People First*” Adult Social Care Workforce Strategy
- Social Work Task Force set up jointly by DH and DCSF
- Dementia Strategy, Carers’ Strategy, Dignity and Respect initiatives, Independent Living Strategy, Valuing People Now, Safeguarding Review
- Implementation of the recent Mental Health and Mental Capacity Acts, and forthcoming Equality legislation outlawing age discrimination.

4 – These policies form the framework for the Green Paper proposals on the reform of care and support services. There are a number of continuities. *Shaping the Future of Care Together* confirms the government’s commitments to personalisation and shaping responses to the individual’s circumstances; to enabling people to exercise choice and maintain control over their own lives; to equality, fairness and social inclusion; to early intervention preventing deterioration and breakdown; to effective multi-agency and inter-professional working; to promoting efficiency and value for money in the use of scarce resources. It also raises important questions about the responsibilities of the state, the individual and the family, and about the roles of central and local government, in the care and support of disabled and older people. As well as submitting this response, SCIE is also a member of the Inter-Agency Group of voluntary and statutory bodies with a keen interest in adult social care and

has endorsed the IAG's response to the Green Paper which has been submitted separately

2 – NATIONAL FRAMEWORK

The Green Paper asked:

“We want to build a National Care Service that is fair, simple and affordable. We think that in this new system there are six things that you should be able to expect:

- prevention services
- national assessment
- a joined-up service
- information and advice
- personalised care and support
- fair funding.

- a) Is there anything missing from this approach?
- b) How should this work?”

5 - SCIE welcomes the proposition in the Green Paper for what is in effect a national contract between the state, and individuals and families, setting out what everyone should be able to expect when they reach the point of needing social care support. As described in the Green Paper, the National Care Service is a framework for achieving greater consistency in assessing needs and allocating resources. The 6-point offer does not have quite the status or substance of the NHS Constitution with its explicit rights, responsibilities and aspirations. Nonetheless it represents a considerable step forward. None of the six elements is new in itself, but presenting the components as a coherent, integrated and universal programme to which people can feel entitled wherever they live is a significant advance. In this section of its response, SCIE considers each element in turn, and comments on how it should work and what might need adding or considering further

Prevention services

6 - SCIE supports the Green Paper's emphasis on free provision of support to enable people to stay well and independent, stop their condition or situation from deteriorating, avoid breakdown, and delay or shorten their need for higher dependency care. We endorse the aim of ensuring those with low or moderate needs receive appropriate support to remain independent, rather than simply being turned away, as they frequently are at present, because they do not meet the criteria for “substantial” or “critical” needs. SCIE would welcome the opportunity of developing and testing new ways to predict and identify those most likely to need higher level care in future, with a view to effectively targeting resources for prevention and early intervention. Diminishing ability in activities of daily living is caused by psychological as well as physical factors, and improving morale can be an important preventative measure. Increased care needs often result from the breakdown in health or death of a caring partner, declining confidence associated with depression or the onset of dementia, or acute episodes such as strokes or falls. These factors would need to be included in work on prediction.

7 - The need for investment in prevention is widely recognised. The fact it is often marginalised in practice is a symptom of the overall shortfall of resources in the system, which the government acknowledges. As an instance, it is not clear how the intention here to “build on the role of disability benefits” in strengthening prevention and early intervention squares with the proposal later in the Green Paper to include “poorly targeted” Attendance Allowance in the pot of funding for high dependency care. Experience indicates higher level, apparently more urgent, needs will always tend to divert resources from prevention and the “little bit of help” which evidence shows makes a big difference to people’s coping ability.

8 - The challenge at national and local level is to develop robust, sustainable, cross-departmental strategies for prevention and early intervention. They must be capable of delivering improved outcomes for people in cost-effective ways, and of capturing funding and contributions in kind from a range of sources and funding streams. Locally, these include wider Council services such as housing and leisure, as well as the work of third sector and community organisations, mainstream businesses and financial services, and universal public services like the NHS, police and benefits. SCIE is keen to work with stakeholder interests on the development and evaluation of such strategies.

National assessment

9 - SCIE agrees with the principle of establishing a consistent and fair assessment framework at national level. It would form part of a strategy to address on-going complaints that people experience markedly different levels and quality of support and care in different local authority areas. The principle is however not straightforward to turn into practice.

10 - The Fair Access to Care Services (FACS) framework was introduced in 2002 to tackle variations between Councils in prioritising and allocating resources. It introduced four nationally-defined levels of need and eligibility for support, but left local authorities to determine and publicise which of those levels they were able or willing to respond to. Under resource pressures, most authorities have gradually withdrawn from meeting the needs of people fitting the criteria of low or moderate need, and concentrated on those at the two highest levels. The national criteria took account of support needed to participate in employment and purposeful activities, but in practice the judgements have been based on levels of risk to life and limb.

11 - Other difficulties emerged from a 2008 review of the working of FACS, carried out by the Commission for Social Care Inspection at the Government’s request. These included:

- a lack of clarity and transparency in practice, particularly related to the; complexity of the framework
- a lack of fairness in the way criteria are applied
- the continuing influence of service-led, rather than needs-led approaches
- limitations of a risk/needs based model that has led to inadequate and

unduly standardised assessments

- insularity and fragmentation, where FACS omits consideration of other important areas such as health, housing and leisure;
- marginalisation of the prevention and inclusion agendas,
- inadequate diversion and signposting and specific problems when people's needs and circumstances are insufficiently explored at their first contact with the council
- the need for FACS to adapt to the changing world of personalisation

12 - The challenge in the future will be to establish a national framework for social care assessment that addresses these concerns. It will be required to support individual decision-making, whether at national or local levels. It will need to be clear whether it is framed around needs, entitlements, or desired outcomes. In the context of personalisation and co-production, it will have to strike the right balance between self-assessment and professional perspectives. It will also be expected to respond to concerns about subjecting people to multiple assessments, and to benefit from the development of the Common Assessment Framework enabling all-in-one consideration of people's needs for comprehensive support from a range of services and agencies.

13 - Simplicity is likely to be the key to consistency. This would suggest that the national element of any assessment process should be limited to applying common Resource Allocation System (RAS) scores to define an individual level of resource entitlement, based on standard assessment and self-assessment criteria, and a percentage level of state contribution reflecting the individual's needs and means. With this level of resource entitlement assured, the person and their relatives would then access local services and networks, their own support systems, and local care and support markets, negotiating for themselves or using care management or brokerage services to arrange the best pattern of support to fit their particular circumstances.

14 - This division of central and local functions is consistent with principles of subsidiarity. It enables the individual, and their advocate and advisors, to know the funds they have available, guaranteed by government, while taking account of local variations in the pattern of inter-agency provision and the availability of statutory, private, third sector and community-based support to devise their own well-tailored personalised solutions. Ensuring the quality, diversity, fitness and responsiveness of provision, both formal and informal, in the local market, leading measures to equip the cross-sector workforce and safeguarding adults at risk, are part of the responsibilities of the Director of Adult Social Services.

A joined-up service

Mainstreaming and co-production

15 - For understandable reasons, the perspectives of local health and social care leaders tend to be service-centred. The focus is on making best use of health and social care resources to meet the needs and aspirations of people entitled to or eligible for care and support. Demand always exceeds supply, and the prospect of

demographic growth coinciding with a tightening outlook for public spending is putting the emphasis on increased efficiency and effectiveness and investing in prevention and diversion. The alternative is the more unpalatable one of even tighter rationing of access to care and support.

16 - A more radical approach might start with the principle of seeking maximum access for people requiring care and support to mainstream public services and the opportunities available to the rest of the population, as of right, in preference to segregated social care provision. This would involve tackling discrimination on grounds of age and disability, supporting people to exercise their rights and responsibilities as citizens, promoting social inclusion and community capacity-building, and enabling people to develop new and flexible forms of natural support. Models are already available in the way people have used their direct payments and individual budgets to establish non-traditional arrangements for their own support and participation. The challenge is to recognise this as the new mainstream, to shift professional mindsets and reskill the workforce to facilitate different ways of working, and to generate a commitment to innovation, evaluation and continuous improvement in a field that is often slow to embrace change.

17 - This development will be assisted by a strong commitment to models of co-production in which people work as equal partners with professionals and service providers. Existing methods of working, including deficit models of demonstrating priority need for support, tend to reinforce a sharp distinction between independence and being fully and permanently dependent on support services. Co-production aims to keep the individual in control of their own life, identifying and enhancing the strengths and resources available in their own networks, and deploying formal resources flexibly to complement their support systems. Evidence from SCIE's work and elsewhere is demonstrating the benefits to the individual and the wider community of these co-production approaches.

People with complex needs

18 - It is generally accepted that people with current or emerging needs for social care are likely also to have needs in other spheres, including acute and longer-term health conditions, housing-related requirements, support with training and employment in the case of working-age adults, and access to various aspects of the benefits system. Government has long exhorted more joined-up working at local level, and people using services, their relatives and advocates regularly quote the difficulties they encounter in seeking to get coordinated cross-agency responses. As the IBSEN study into individual budgets showed, difficulties at local level often reflect problems of policy coordination, compounded by separate funding and accountability streams. Even within a single organisation like the NHS, service structures based on distinct specialism can create problems in obtaining holistic care for those, including the majority of older people, with multiple health conditions and disabilities.

19 - Individuals and families with complex needs would benefit from strong local protocols for cross-agency and multi-service responses. Alongside the extension of personal budgets in social care, personal health budgets, as recommended by Lord Darzi's Next Stage Review, offer scope for more integrated health and social care

support, and more effective partnership working between social care, primary health care and public health. The Ministerial Group on integration of health and social care is considering what are the key obstacles – and possible incentives - to closer joint working.

Disabled parents

20 - Disabled people and those with learning disabilities, mental health difficulties and substance abuse problems needing care and support may also be bringing up children, and need additional support to help them to maintain their parenting responsibilities. The Green Paper acknowledges that: 'People might need care and support to... look after children and fulfil their parenting responsibilities' (p.30). However, there is little further mention of recipients of care and support who have parenting responsibilities in the remainder of the document.

21 - More emphasis should be given to this aspect of support given the proportion of people with care and support needs who also have parenting responsibilities. For example:

- 1.1 million households with dependent children have at least one disabled parent
- A survey of people with learning difficulties in England found that, in a sample of almost 3,000 people, seven per cent had children although this included children who were now adults
- In 2000, 17 per cent of adults with psychotic conditions were in couples with children, and 7 per cent were lone parents .
- There are estimated to be between 200,000 and 300,000 children in England and Wales who have parents who misuse drugs.

22 - It is also important to recognise that large numbers of informal carers are children:

- The Green Paper states that 'Carers who are providing, or who intend to provide, a substantial amount of care on a regular basis will still be entitled to an assessment.' (p. 55). Some of these carers will be children – the 2001 census identified 170,000 'young carers' nationally.
- Young carers should receive the assessment and support that they require. Research reviewed by SCIE suggests that few young carers receive assessments, although numbers are increasing. Our recent research on parental mental health and child welfare also found a lack of understanding of the needs of young carers of adults with mental health problems amongst both adult mental health and children's social care staff. It is therefore probable that adult social care staff also lack expertise in this area.

23 - Adult social care services have an important role in supporting people to discharge their parenting responsibilities, without children having to be categorised as 'in need'. Clearly, adult social care services have a role to play in safeguarding children when they become aware of a child at risk or at harm, as outlined in the 2006 safeguarding guidance *Working Together to Safeguard Children*. However, social care services should also support people to parent to the best of their ability. This forms part of their role in enabling people to fulfil their potential, as outlined in

Putting People First. This includes support during pregnancy and in looking after newborn babies. As has been argued in the case of adults with learning disabilities, adults should be entitled to support with parenting in their own right, without children being identified as 'in need'. Particular consideration should also be given to the needs of parents when determining access to services. SCIE's research on parents with mental health problems found that, despite the interactive and cumulative effect of difficulties within a family, referral and assessment processes for different family members operate 'in parallel'. This may mean that families receive only some of the support they need, or none at all. SCIE's guidance therefore recommends the development of a 'family threshold' for services, to take into account the individual and combined needs of parents, carers and children.

24 - Ensuring services are joined-up is particularly relevant to helping people who need care and support and have parenting responsibilities. SCIE's research regarding disabled parents, and parents with additional needs related to substance abuse or HIV/AIDS suggests that these groups may suffer particularly from a lack of joined up services in terms of:

- Disputes between children's and adults' services about assessment and funding responsibilities.
- Failures of communication and coordination between different services and particular difficulties when a parent falls into more than one service user group, including as a recipient of children's services.
- High eligibility thresholds for both children's and adults' services which mean that support to prevent problems developing cannot be accessed.

Examples of good practice in joined-up working between services, identified in SCIE's knowledge review include:

- Joint working policies and protocols between children's and adult's social care services (Norfolk County Council)
- Development of services specifically for disabled parents/parents with additional needs such as the Community Team for Parents with Learning Disabilities (Stockport Metropolitan Borough Council)
- Multi-disciplinary projects provided by the third sector, such as the CAPE project in Greenwich which works with families in which a parent or carer has mental health problems.
- Research reviewed by SCIE suggests that disabled parents and parents with additional needs value support that is flexible and practical. This may include support that meets the personal assistance needs associated with physical impairment, practical support with getting children to and from school, assistance with getting children into a routine, and so on
- With specific reference to parents with mental health problems, SCIE's research found that services needed to be more flexible in order to meet the needs of individuals and the family as a whole, and to respond to changes in circumstances
- Personalised services, including direct payments have been particularly useful as a way of enabling disabled parents and parents with additional needs to have more choice and control over the way support is provided SCIE's 'Think child, think parent, think family'

guidance also recommends using individual budgets to improve the flexibility of services provided to parents with mental health problems.

Micro-providers and personal assistants (PAs)

25 - Research shows that the market of high-quality, trained and skilled personal assistants is not yet sufficiently developed to offer the type of choice required. Skills for Care England estimated that in the present 'maximising choice' scenario, the number of personal assistants and others involved in self-directed care would need to increase nine-fold by 2025. However, there are some concerns about the wider consequences of expanding numbers and roles of personal assistants. A SCIE review found that these focus on risk, balancing the need to safeguard adults with increasing their choice and control, the emergence of unregulated 'grey' markets, the effects of migrant labour, quality assurance, and employment and training conditions. These concerns need to be discussed with people employing and planning to employ PAs, representatives of PAs who are becoming a significant part of the social care workforce, and the workforce and service regulators who will need to consider new approaches to regulation that fit the new diversified world of personalisation.

Micromarket development

26 – The success of the transformation programme partly depends on the availability of a wider range of services. DH funded a three year NAAPS¹ project to test a business model designed to support and stimulate the development of a range of micro care and support services in order to provide real choice for people. This work has shown problems due to growing regulatory and other barriers and that the number of micro-providers is actually falling. NAAPS recommend a support model that gives current and potential providers the information, advice and help that they need in order to set up a small enterprise or adapt a current service to meet new local requirements (<http://www.naaps.co.uk/en/news>). Identifying and addressing this issue at local level, and facilitating entry of new providers meeting particular needs, should be addressed by Directors of Adult Social Services in their capacity as shapers of local care and support markets.

Building Social Capital

27 - People using services are also themselves major contributors to social capital, and citizenship models of participation in civil society should replace the deficiency and dependency drivers in the current system. Seebom's vision of "the largest possible number of people giving and receiving support" is still relevant. This is reflected in the concept of 'co-production'. This approach emphasises that service users do not just have needs that must be met but have assets such as skills and expertise to contribute to transformation. The Department of Health's review has shown that user led organisations are well placed to articulate those assets and forge dynamic relationships with public services to the benefit of all.

28 - Both the Disability Movement and the broader work of people who use services has been built on the premise that a shared common experience can be utilised to

¹ formerly, the National Association of Adult Placement Schemes, now called "Shared Lives"

support each other and shape the direction of future policy and service developments. Peer support is the bedrock of user organisations. As the Cabinet Office review showed, through training, employment, networking, providing a range of services and promoting civic participation, social capital is built.

Carers and social capital

29 - Planning and policy implementation need to take a comprehensive view of the care economy, not focusing only on council social care resources, but on the inputs from individuals, their family and neighbours, the responsibilities of allied services such as housing, training, employment and the NHS, the value that mainstream businesses and services represent, the extent of mutual inter-generational support, and the contribution of the huge range of voluntary and community networks. The council's roles include supporting, enabling, coordinating and orchestrating this range of inputs. In other words, Joint Strategic Needs Assessments, strategic commissioning plans and brokerage systems need to take account of the full range of community supports available to people, not just care services provided by the state and independent sector.

Information and advice

Advocacy

30 - Until relatively recently there was no legal right to advocacy. The Mental Capacity Act 2005 and Mental Health Act 2007 have introduced for the first time statutory access to advocacy services to protect the rights of those subject to decisions involving loss of liberty and where they lack capacity.

31 - Advocacy services have been shown to work best where service users can access peer support. Research from the UK into the implementation of direct payments found that support services for people using the scheme were essential, with Centres for Independent Living run by and for disabled people at the forefront on this. User-led organisations (ULOs) such as these are able to offer support and models of working that promote choice, control and empowerment based on people having a shared experience of disability and independent living. The Putting People First agenda seeks to increase the number of ULOs across England.

Brokerage

32 - Personalisation is about service users determining their own needs and planning their own support. Many people will find that challenging and will benefit from the support of others who are in a similar situation. Independent support brokerage is an integral part of personal budgets. However, the IBSEN study indicated that its role and definition need to be clarified and understood by people using social care, their carers and social care staff. Brokerage, as defined by In Control, is interpreted to cover advice, and administrative support, if needed, from a range of locally identified organisations (see <http://www.in-control.org.uk>). The values of brokerage are seen as linked – not just to accessing specific services – but to a vision of full citizenship and quality of life to which recipients are entitled.

33 - Research suggests that the support service infrastructure does not have the capacity to deal with the present number of direct payments users, suggesting urgent investment is needed to take account of increasing numbers of personal budget holders. For example, only half of current direct payments users are in touch with support services. Support services staffing levels have been found to be very small, with most organisations employing three people or less and many caseloads were found to be at the high end of the recommended maximum. It is reckoned that caseloads would increase by 60 per cent if all current direct payments users were accessing support schemes. Many local authorities did not tailor support service funding in relation to volume of users.

Personalised care and support

Choice

34 - In social care, service-led approaches can result in people not always receiving the right help at the right time and being unable to shape the kind of support they need. Personalisation is about giving people much more choice and control over their lives in all social care settings and is far wider than simply giving personal budgets to people eligible for council funding.

35 – Indeed, the personalisation agenda goes beyond social care and is linked to the ‘place shaping’ function of local authorities. This means addressing the needs and aspirations of whole communities to ensure everyone has access to the right information, advice and advocacy to make good decisions about the support they need. It means ensuring that people have wider choice in how their needs are met and are able to access universal services such as transport, leisure and education, housing, health and opportunities for meaningful occupation. Policies such as the Independent Living Strategy and the proposed New Horizons mental health policy reinforce this message. The overall aim is to maximise independent living without the need for more formal care services for as long as possible and to ensure that, once care services are required, they are shaped more by recipients than providers. SCIE strongly supports this agenda and produces a range of resources to inform, encourage and support change by managers and staff in councils, providers and elsewhere. These include “Personalisation: a rough guide” setting out the history, context and key messages of this approach and a range of short At A Glance briefings for specific groups, such as home care providers, Personal Assistants and care home providers.

Personal budgets

36 - Support is a crucial aspect of personal budgets. Individual Budgets (IBs) sought to bring together a number of different funding streams and offer a transparent way of allocating resources to individuals. (Many of the lessons of IBs are being utilised in the move to personal budgets – PBs - which are more tightly focussed on social care resources.) Knowing the level of resources at their disposal can help individuals plan and control how their support needs are best met. However, the national evaluation of individual budgets (IBSEN) showed substantial variation in the reactions of users, and specific challenges in integrating health and social care services and in developing staff skills and practice. Older people were more cautious about such budgets, raising questions about the way this service innovation is presented and

negotiated with both the older person and their carer/s, and what supports are required to make personal budgets attractive to this group.

37 - By contrast, people with mental health problems reported a significantly higher quality of life and improved psychological well-being. However, the success of PBs for people with mental health problems needs to be set against certain barriers to take-up and the difficulties in integrating funding streams from health so that support remains unified and effective. Questions about perceived risk and professional decision-making, purchasing non-traditional services and negotiating innovative support choices may also need to be considered for people with mental health problems. SCIE has recently commissioned some work on behalf of DH to enable better understanding of the issues in relation to developing personal budgets for older people and those with mental health problems. This will report in 2010.

38 – Evidence is now emerging from local authorities, as they build this new approach. Current evidence suggests between 6 and 40% of local service users are now using PBs. The average is around 10% and the aim is for at least 30% of eligible service users to have a PB by April 2011, the end of the current reform phase.

Commissioning

39 - In order to stimulate supports in the local community, personalisation will require changes in both commissioning strategies and the range of those from whom councils and individuals (using their own resources, direct payments or personal budgets) commission. Achieving the vision spelled out in *Putting People First* requires a transformation in the commissioning role in terms of the investments (and dis-investments) commissioners make, the markets they work to influence and shape, and the relationships they seek to build.

40 - As councils disaggregate increasing proportions of their investments to individuals to make their own purchasing decisions, commissioners will need to find ways of working in partnership with providers to ensure a good range of choices and the right types of support for personal budget holders and self-funders. Commissioners will also need to make decisions based firmly on national and local evidence and intelligence. This should include knowledge of the local population, equality and diversity issues and what services already exist, particularly in the third sector. This should be set out, with health, in an area's Joint Strategic Needs Assessment. Commissioning strategies should also, importantly, take account of good practice and evidence of what works provided by SCIE, NICE and other sources.

Fair funding.

41 - The Green Paper's definition of "fair funding" is somewhat unclear. It includes the undertaking that "your money will be spent wisely" to fund a care and support system that is "fair and sustainable", and offers better value for money. It also offers the assurance that "everyone who qualifies for care and support from the state" will get some help meeting the costs. The criteria for judging the fairness of the system, and the qualifying criteria for state support, are not spelled out.

42 - Chapter 5 of the Green Paper highlights some of the difficult issues involved in seeking to be fair. Should the system aim to deliver:

- Equity as between people with similar levels of care and support needs (and should the assessment be offset by support offered by families and informal carers, or not)?
- Equity between people with higher and lower levels of need (including adequate investment in prevention)?
- Equity of outcomes, which may require different levels of resource according to the individual's circumstances?
- Equitable treatment of people's income and assets, (and does targeting those with less means penalise savers)?
- Equitable treatment of those in employment and those requiring care and support?

The problem is made more difficult by the marked and growing overall shortfall of resources to meet the care and support needs of disabled adults and older people. Questions of fairness can easily become distorted when the underlying problem is a need for severe rationing. Wanless showed that the care and support system is already underfunded, and CSCI's work demonstrated that people with significant levels of need were failing to meet the eligibility criteria for support.

43 - In places, the Green Paper hints at the idea that families should be expected to contribute to the costs of care for their elderly relatives. Many already contribute substantially by way of help with top-up fees in residential care, assistance with the costs to self-funders, and large volumes of informal care. It is important that these contributions are understood and recognised. In particular, Councils and the NHS need to acknowledge the extent to which family and neighbour care exceeds and underpins statutory provision, and recognise investment in carer support as one of the most effective forms of prevention.

44 - The crucial point however is that this support is voluntary and takes place within the context of family and neighbour relationships. Any move to treat it as an obligation on family members would be counter-productive, and could result in a variety of increased risks. For many reasons, not all relationships between people and their older relatives are positive. It is quite proper for government to create incentives to care, such as extending the carer's allowance to those over retirement age. Even this approach has been shown to carry risks when the financial benefit to the recipient becomes more important than the wellbeing of the person they are supporting. Attempting to create a new obligation to care for older relatives would be a different and riskier proposition.

3 - CHOICE OF FLEXIBLE, HIGH QUALITY, EFFECTIVE AND EFFICIENT SERVICES

The Green Paper asked:

“We think that, in order to make the National Care Service work, we will need services that are joined up, give you choice around what kind of care and support you get, and are high quality.

- a) Do you agree?
- b) What would this look like in practice?
- c) What are the barriers to making this happen?”

Better quality, innovation and value for money

45 – SCIE’s comments on joined-up services and personalised choice are contained in the previous chapter. Here we concentrate on the wider issues of quality and value for money, and the proposal in the Green Paper for an independent body to advise government and the social care sector on these matters.

An Independent Body to advise on effectiveness in Adult Social Care.

46 - SCIE strongly endorses the emphasis on value for money and cost-effectiveness in the Green Paper - whatever the total quantum of resources going into the care and support system now and in the future, it is crucial that such resources are well spent. SCIE welcomes the Green Paper’s proposal for an “independent body to provide advice on what works best in care and support. This will help to make sure that, in future, services are as cost-effective as possible and that they are based on evidence.” It suggests a remit including:

- looking at which interventions work and give best value for resources;
- designing, in conjunction with the Department of Health, a social care evidence and research programme to assess the gaps in the evidence base;
- production of evidence as necessary;
- examining which services or ways of caring could save costs across public services e.g. particular preventative services.

47 - The Green Paper adds that this independent body could be a new organisation or part of an enhanced remit for an existing body such as SCIE. There are clear parallels with the work of both the National Institute for Health and Clinical Excellence and the NHS Institute for Innovation and Improvement. Their roles are similar to those suggested for the new or enhanced adult social care organisation and seem to be a welcome attempt to strengthen the evidence base for care and support as well as taking a broad view of such care and support, encompassing housing and benefits, for example, as well as formal care services.

48 - We believe that enhancing SCIE’s existing remit in the ways proposed in the Green Paper would represent a logical development of the Institute’s existing direction of travel, would enable it to build quickly on its current expertise, reputation and brand and would maximise the value of its existing strong links with a range of relevant stakeholders. This role builds on SCIE’s existing remit as a body charged with obtaining and disseminating evidence of what works in social care. We therefore welcome the opportunity to pursue this issue in more detail with the Department.

Why is SCIE well placed to take on these additional functions?

49 - The Social Care Institute for Excellence is named in the Green Paper as a possible organisation which could take on these functions. Unsurprisingly, we believe – as, we understand, do a number of our key stakeholders – that there are several strong reasons to enhance SCIE’s remit in this way:

- it is an established independent organisation in the care sector with a strong reputation and brand, signifying rigour and relevance;
- it is already responsible for assessing the evidence base in social care and for promoting the dissemination and take-up of good practice. SCIE recently launched a framework for identifying and substantiating good practice with a new emphasis on digital dissemination;
- it uses internationally recognised methods for systematic reviews of the evidence in social care, drawing on a wide range of types of knowledge;
- it would avoid the need, cost and inevitable delay in establishing a new organisation;
- it would maximise the impact of several new dissemination approaches, such as Social Care TV, an electronic dementia “gateway” and resources to enhance the e-enablement of the sector;
- it would build on existing work in this area which SCIE has already undertaken to explore more relevant and reliable methodologies for social care, including their economic dimension.

50 - On this latter point, SCIE has been working with other key organisations, including NICE, the Personal Social Services Research Unit and the Department’s Care Services Efficiency Development Unit to establish a workstream on social care economic evaluation. For instance, we have been developing a statement setting out our approach to economic evaluation in social care, and begun to examine the issues involved in evaluating the costs of care and support provided by family, friends and neighbours. This puts us in a good position to support the Department in establishing what constitutes ‘best value’ because we have already:

- gone a considerable way in forming a clear view about the kinds of economic evaluation which are suitable for social care, a view shared and endorsed by major stakeholders and the academic community; and
- developed an understanding of the methodological challenges associated with this kind of analysis.

51 - Were SCIE to take on the functions outlined in the Green Paper and make recommendations to the sector about what works and at what cost, the Institute would need to demonstrate rigorous and transparent methods to substantiate the recommendations. As already noted, SCIE has established a reputation for reliability and quality with

- well established and respected methods for systematic review in social care,
- a highly regarded project information team (providing literature searches and scopes),

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- a method for conducting practice, surveys/enquiry
- and clear guidelines for the involvement of people who use services in knowledge production.

These are sound building blocks on which to develop the methods and processes to deliver these functions.

What personalisation means for costs

52 - One example of this approach to cost-effectiveness is the assessment of Individual and Personal Budgets. The IBSEN work suggests that individual budgets have 'the potential' to be more cost effective and there is improved satisfaction for some groups of people who use services. Reliable evidence on the long-term social care cost implications is not yet available. This is an area which needs urgent attention to sustain confidence.

53 - Another cost-effectiveness issue emerging from the international research on personal budgets is that social care may be saving the NHS money at its own expense. The Cash and Counselling pilot in the US reduced nursing intervention by about 17% but this was a saving to health and not to social care. Hence the need for some pooled or aligned funds – possibly for mental health, long-term conditions and older people who need both social and health care.

54 - SCIE's economic evaluation work on costing care provided by relatives and friends has shown that the costs of informal care are substantial, particularly in social care. Their consideration can have a major bearing on whether an intervention appears cost effective. Much methodological work has been undertaken to help improve the way in which informal care can be valued. None of these methods is perfect; ideally the opportunity costs of informal care would be best reflected by the values that individuals place on the alternative use of their time, such as wages foregone. Accurately identifying all of these opportunity costs may be challenging. Whatever method of valuation is used however, it is critical that more emphasis is placed on identifying the incremental time spent caring over and above normal household activities, as well as identifying the time inputs of both primary and secondary caregivers.

What might be involved in delivering the new functions?

55 - Improving the evidence base and so driving greater cost-effectiveness in care and support services requires a range of activities at all levels. As a recent Nuffield Trust paper on the NHS points out, 'a comprehensive approach to improving efficiency is needed, encompassing simultaneous actions at the system, organisation, team and practitioner levels'. The paper goes on to say that at the system level, the menu of options includes 'using information to produce cost-effectiveness guidance...to analyse the use of resources on different areas of care ...and to benchmark performance'.

56 - This suggests that a multi-pronged approach to improving cost-effectiveness in care and support would be required. Tools and techniques might include:

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- cost-effectiveness guidance;
- providing accessible information to inform commissioners, including individual consumers' purchasing decisions; and
- benchmarking between different councils or between different services in different geographical locations;

57 - On this latter point, DH recently published a paper on *Use of Resources in Adult Social Care* showing the persistence of substantial variations between different councils in important areas, such as the rate of usage of residential care, many of which variations cannot be explained by need or demographics but tend to reflect historic, non-evidence-based patterns of utilisation, geography (such as retirement areas), etc. This is the type of benchmarking information designed to challenge current practices which a body charged with improving value for money in adult social care could produce in future.

58 - In taking forward this agenda, the body will need to seek appropriately to balance the (sometimes conflicting) factors which deliver value for money. In other words, value for money is high when there is an optimum balance between three factors – relatively low cost, high productivity and successful outcomes. The range and complexity of social care services, and the multiple policy, commissioning and delivery agencies involved – not to mention the growing impact of individual service users and their family carers – suggests that work to enhance the cost-effectiveness of guidance and information in this area needs to be broadly based, with strong stakeholder buy-in. It would make sense therefore for SCIE (or anyone else) to pursue this agenda in close partnership with a range of other players, including relevant regulators, academic units and others.

4 - RESOURCE ISSUES AND CENTRAL/LOCAL ROLES

The Green Paper said:

“The Government is suggesting three ways in which the National Care Service could be funded in the future:

- Partnership – People will be supported by the Government for around a quarter to a third of the cost of their care and support, or more if they have a low income.
- Insurance – As well as providing a quarter to a third of the cost of people's care and support, the Government would also make it easier for people to take out insurance to cover their remaining costs.
- Comprehensive – Everyone gets care free when they need it in return for paying a contribution into a state insurance scheme, if they can afford it, whether or not they need care and support.

a) Which of these options do you prefer, and why?

b) Should local government say how much money people get depending on the situation in their area, or should national government decide?”

Resourcing care and support

59 – There is general agreement, backed up by increasingly robust evidence from regulators and others, that funding for long-term care is inadequate, nor is the present system likely to be sustainable into the future when faced with serious demographic pressures and rising expectations. The funding options in the Green Paper have, as intended, generated substantial comment and debate. Widespread public misunderstanding of, or indifference to, the operation of the current social care system, and its associated charging regimes, has hampered the serious debate which the Green Paper has sought to promote. We therefore welcome the fact that the political profile of these issues is rising, as a critical precondition of progress. In this section we touch on the different implications for older and working age adults.

60 – Older people

- The Green Paper deals in general circumstances, typical likelihoods of needing care and support, and average costs and benefits. This is appropriate for modelling purposes, but options need to be translated into a system that is workable, affordable and feels fair to individuals. In insurance models, generally the smaller the risk pool, the higher the premium. Insuring against a one-in-four or one-in-three chance of needing care and support may balance out in aggregate but is unlikely to find favour with many older people, not least because they have contributed through taxation, national insurance and pension schemes throughout their working lives. This is despite the relative affluence of many, through housing assets particularly, as the Green Paper points out. This suggests that any preferred option will need careful “selling” and may need to be backed by compulsion.
- Combining an insurance principle with assessment-based resource allocation is likely to be controversial. People who thought they were paying for peace of mind at 65, by insuring against lifetime care costs, may still find themselves turned away at 85 or 90 because their need for care and support either does not meet qualifying criteria or, conversely, rises above any set ceiling. In addition, excluding accommodation costs from residential care settings will be hard to explain, though private insurers might respond to that requirement with more affordable products.
- Incentives require further consideration. Would being insured for long-term care costs discourage people from engaging with prevention, self-care and reablement schemes, and lead to earlier admission to residential care or longer-term dependency on higher levels of domiciliary support? Would it act as a disincentive to family carers, whose contribution greatly exceeds in value the scale of public spending on social care? Could there be a provision similar to a “no-claims bonus”, creating incentives for relatives to extend their care and defer the need for individuals to enter the care system? How far would insurance for social care encourage or undermine joint provision with the NHS?
- Relative costs and benefits also need careful examination. Group care in a residential or nursing home may on the face of it look cheaper per head than

maintaining people with similar levels of need in their own homes; but home care solutions offer much more scope for co-production between relatives, neighbours and formal services in the provision of support, and so may be more economical in some cases. Raising eligibility thresholds for people entering group care may reduce numbers, but consequent higher levels of need are likely to increase unit costs. Conversely, a residential care place may tend to be more costly than, say, extra-care housing if available; but it will be significantly less expensive than hospital care, and better value if that is the alternative.

61 - Working –age adults

- In relation to this group, a Green Paper focussing on broad principles and approaches has inevitably raised a significant number of important questions and issues to be resolved. For example, it argues that most eligible disabled people of working age would qualify for free care and support. This is because they tend in the main to live on low incomes or benefits, and to have few or no capital assets. Similarly, older people with few means or assets would receive most of their care free. It is not clear whether disabled people under 65 with higher incomes or housing assets would be eligible or required to participate in some of the funding options, but it is important that the preferred approach does not fall prey to charges of age discrimination.
- In the current system, some disabled people are caught in a bureaucratic trap, requiring high-dependency care, capable of working but unable to move off benefits and into employment because they could not command an income to cover their care costs.
- This difficult area of policy, where care charges, personal income and assets and benefit rules interact in highly complex ways, is prone to perverse incentives. Government policy is to encourage into employment disabled people, those with learning disabilities, and people with severe and enduring mental illness. Many in these groups have unexplored potential and, with appropriate personal support and reasonable adjustments in the workplace, might be able to access reasonable levels of income once the jobs market improves. They may be wary however of thereby crossing the threshold from free care and support to chargeable care services. On the other hand, for some people, provision of free care and support might create disincentives to using preventive and rehabilitative services to achieve more independent living in their own homes.
- The implications of other aspects of the Green Paper funding proposals for working age adults need further consideration. The overarching model, devised primarily with older people in mind, assumes the 6-part universal offer prevents the need for higher level care and support as long as possible, until with rising needs people may eventually cross the threshold to longer-term care. For younger groups, that process will often be reversed. They may have received high levels of support and care in the family home, or residential school or college, and be aiming to graduate from high-level care to more independent settings. Experience indicates that with the right types of support, many will become increasingly capable, skilled, independent and able to manage their own lives and their support arrangements.

- This is particularly true for people with learning disabilities – just 10 per cent of people with learning disabilities receiving adult social care services are employed. The development of a dedicated employment strategy aimed at people with moderate to severe learning disabilities, provides an important opportunity to support adults with learning disabilities into work. Personal budgets can and should be used for this (Department of Health 2009a).

Impact of insurance options on behaviour and incentives

62 - Options 3 and 4 in the Green Paper rely on private or social insurance models. Such models have a number of potential advantages for individuals who might need care and support in future (existing needs/conditions cannot be insured against). These include:

- greater clarity than is offered by the present system as to the circumstances when the insurance will pay out;
- an ability to cap personal care costs; and so
- greater peace of mind if care and support needs arise;
- more affordable insurance products, because the risks are pooled more effectively than with out-of-pocket payments and because, under the Green Paper proposals, the coverage of the insurance may be limited to care costs. In turn this limitation of state schemes could lead to
- more affordable private insurance products for hotel costs.

63 - However, there might also be certain disadvantages – either to individuals or to the system as a whole – which would need to be guarded against. For instance:

- (i) care insurance payments are typically made when the client can no longer perform a number of activities of daily living (ADLs). ADLs cover activities such as washing, cooking, dressing, etc. In the past, long-term insurance policies in England paid claims on the basis that “3 ADLs had been failed or that the policyholder was suffering from cognitive impairment.”² This gives everyone more clarity as to when the insurance will “kick in” and is a fairly objective means of deciding the level of need. It is important to note that ADL failure at the 3 level represents a significant level of disability.

On the other hand, longstanding adult social care policy in England has been to support people to “live independently, stay healthy and recover quickly from illness”.³ Using ADLs as an assessment tool is essentially to rely on a “deficit model” of assessment, ie one which emphasises what people can no longer do for themselves rather than encouraging them to consider what they could still do with appropriate support. It would therefore be important to ensure that the triggers used to pay insurance claims, whether ADLs or some other form of standardised tool, did not inadvertently encourage people to over-emphasise their loss of functional abilities. It is noteworthy in this context that

² Private funding mechanisms for long-term care. Sandy Johnstone. Joseph Rowntree Foundation. 2005

³ Putting People First – a shared vision and commitment to the transformation of Adult Social Care. Multi-agency concordat. December 2007.

the JRF report already cited makes the factual point that: “[Insurance] Benefits were payable for life, *providing the ADLs continued to be failed.*” (SCIE italics)

- (ii) There is an obvious risk with this type of approach that public authorities, especially PCTs and councils, will, if there are not strong countervailing pressures, disinvest from preventative and re-ablement services to reduce costs, relying on insurance to pick up more serious needs, ie a form of cost shunting. This would run counter to current policy of seeking to maximise, and where necessary restore, functional abilities for as long as possible, eg the drive to expand intermediate care services.
- (iii) It will also be important to design the insurance assessment tool in such a way as to take account of the input of informal carers. This crucial role is an important element of current assessments of need but might be minimised in a client-insurer relationship, pushing up the insurance claims and so the costs. Alternatively, excluding informal carers from the determination of insurance-related payments could be significantly beneficial to those carers, though more costly to the insurance provider and so more likely to increase premiums (and costs to the State for those unable to pay themselves). A study in 2000 for the US Department of Health and Human services concluded that, whilst many informal carers had not reduced the amount of care they provided since receipt of insurance benefits by the cared-for person, “an overwhelming majority [of informal carers] said that the presence of insurance-financed formal care had reduced the level of stress associated with caregiving.”⁴

64 - On the other hand, it might be possible to increase the incentives on individuals to stay healthy by offering reductions in premiums or even “no claims bonuses” for those who did not claim for certain periods or until certain age limits, etc. Again, there would be a danger of under-claiming with such a regime and of just “struggling on”, which might build up more severe (and costly) problems later on.

65 - Insurance models have much to commend them (not least in their ability to pool risk) and experience in the US, Germany and elsewhere suggests that people only claim when they need care and support and that they do so in the greater knowledge of what their entitlements are under the insurance scheme. However, balanced against this might be a range of other possible effects, including a focus on Activities of Daily Living failings which runs counter to much current policy, and a lack of attention to family carers and to preventative and re-ablement solutions.

Conclusion

66 - SCIE welcomes the Green Paper as a vitally important contribution to a much-needed debate. Many of the ideas in the paper appear to command widespread

⁴ Informal Caregivers of Disabled Elders with Long-Term Care Insurance. Cohen, Weinrobe and Miller for US Dept of Health and Human Services. January 2000

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support, not least the key elements of the proposed National Care Service. We recognise, however, that the Green Paper was setting out some key issues and principles for the future and was not, nor did it claim to be, able to describe the policy, practice and implementation issues which will need to be tackled in the next phase of reform. We therefore stand ready to support the work of DH and other Departments involved, along with the many other stakeholder groups with a keen interest in adult social care, in taking these ideas forward.

SCIE
November 2009

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