



Self-Directed Support:
A Review of the Barriers
and Facilitators

**SELF-DIRECTED SUPPORT:
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**Jill Manthorpe, Jessica Hindes, Stephen Martineau, Michelle
Cornes, Julie Ridley, Helen Spandler, Ann Rosengard,
Susan Hunter, Simon Little and Bill Gray**

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1 EXECUTIVE SUMMARY

- 1.1 This is a report on the published literature on the barriers and facilitators of self-directed support. It was undertaken to inform a research study funded by the Scottish Government 2009-2011 that is evaluating initiatives in three local authorities. These initiatives aim to improve take up of self-directed support for people eligible for social care and other public funds. The three test site areas are working to reduce bureaucracy; to make the processes easy and 'light touch'; and to provide training and leadership to people working on these developments. Scottish Government has provided extra money to assist these three authorities and to help people in other areas learn from their experiences.
- 1.2 This literature review asked what the barriers are to self-directed support and what helps it work (the facilitators) (how the literature was reviewed is described at the end of this summary). By literature we mean research that has been carried out on self-directed support to find out what works and for whom. Research is not extensive and so we also looked at other documents, such as case studies, descriptions and commentaries.
- 1.3 Our definition of self-directed support was very wide; this is because it means different things to different people. We used it as an umbrella term to describe a system of publicly funded social care and support that may involve other government money. Being publicly funded by local authorities and other parts of government means that people have to be eligible for the funding and that in some instances they have to pay part or all of the cost, if their income and savings are assessed as being enough to make this co-payment. Under the system of self-directed support, people are asked to think about what matters to them. They can choose to spend the sum allocated to them in a way that best meets their needs and is under their control. In many ways it continues a system that promotes choice and control that has been running for many years; Direct Payments. In England the new system is often called Personal Budgets, and sometimes Individual Budgets, but this may apply only to local authority funded social care. In Scotland a range of government funds are involved in this development.
- 1.4 **Overall the literature reveals:**
 - Much agreement about the barriers to the development of self-directed support.; and;
 - Many suggestions and experiences about ways in which self-directed support may be facilitated.
- 1.5 However, much of the research relates to Direct Payments and there is very little evidence about other forms of deployment (the ways in which people can choose to manage their money and the ways in which various funds work together).
- 1.6 Not surprisingly, we found that barriers and facilitators are sometimes linked – for example, lack of **information** is a barrier and good or accessible

information appears to be a facilitator. Similarly, lack of **legal clarity** is a barrier, while clarity appears to assist users, carers and practitioners alike. But other subjects are not so simple. We found that there were few easy conclusions to draw about the **management of risk** and **cost-effectiveness**. There are not simple trade-offs in these areas. Indeed, many studies tell us little about risks and fail to provide details of costs and outcomes or results.

- 1.7 We have very little evidence about the best ways to **monitor** self directed support but there are suggestions that 'light touch' monitoring may open up risks at a number of levels as well as helping to reduce burdens of administration. These are matters for wider public debate in Scotland and beyond, not least when money is tight. One limit of existing research for today's social care is that it took place before the current recession.
- 1.8 There is wide agreement that **reduced bureaucracy and less 'red-tape'** are welcome (unless there are concerns about abuse and exploitation) but how these actually work is only touched upon by a few studies. Many studies and commentaries find it hard to decide what is over- or under-protection and few expand on links with adult safeguarding.
- 1.9 **Leadership** may help with promoting changes in practice and in attitudes to self-directed support (as it does in any change); however, most commentaries and experiences focus on situations where self directed support is an innovation rather than mainstream activity. We do not have much evidence about the ways to sustain changes, but many commentators note the importance of service users and carers supporting each other. **Training** for almost everyone is seen as valuable but there is not too much detail on what skills are needed and how they can be developed; sometimes training may just describe giving information.
- 1.10 Finally, the availability of **transitional funding** (temporary money to help start up a new system while still running the old system) is a helpful spur for innovation but we generally have only the views of those people and organisations that are likely to gain from this. There is little evidence about the long-term effectiveness of self-directed support and its impact on other areas, parts of the system, or other groups of users that might have similarly welcomed any or extra resources. All these comments support the importance of a system wide approach to the rollout of self-directed support and understanding of its implications for Scottish citizens.

Specific Barriers

- 1.11 The research suggests that many of the **barriers** to the take up and use of self-directed support are experienced by service users, carers, practitioners and other stakeholders. There is strong evidence that processes and systems have not kept pace with the values incorporated under the umbrella term of self-directed support. Some of the barriers may be resolved by government guidance which may reduce confusion and uncertainty.

1.12 Within the research the following specific **barriers** were identified:

System wide levels

- *Self-directed support is publicised insufficiently.*
- *If the local third sector is not actively involved then practical and peer support for individuals may be insufficient.*
- *It is not always clear how self-directed support works with other parts of welfare or public services.*
- *It's not easy to decide what are health or social care responsibilities and how self-directed support systems fit with other provision.*
- *Processes and procedures can seem under-developed leading to uncertainty.*

Practice and practitioner levels

- *Staff are concerned about their jobs and roles in the light of self-directed support.*
- *Some fear self-directed support may worsen working conditions for social care staff – especially care workers or families.*
- *They are concerned that self-directed support may be more expensive than block contracts (buying social care in bulk so that unit costs are less).*

Service user and carer levels

- *Some feel the administrative burden of self-directed support is too great.*
- *Users (or carers) do not always want the responsibility of managing their own money/services.*
- *Employment of Personal Assistants (PAs) is not always simple.*
- *Employment of family members may not be easy or best.*
- *Funding allocation systems and the rules on expenditure are not always clear to users and carers*

Legal and procedural frameworks

- *These may not be clear and lead to worries about accountability and blame*
- *Rules vary and change, leading to confusion*

Management and leadership levels

- *These may not be sufficiently expert or experienced; they may have other demands on their time.*
- *What happens in a pilot may not be sustainable.*

What helps Self-Directed Support?

1.13 The following **facilitators** were identified from the research:

System wide levels

- *Agreements over policy help clarify what is permitted and what the changes are intended to bring about.*
- *Realistic action plans help to translate aspirations into working practices.*
- *Clear implementation procedures provide assurances to staff about their employers' aims.*

Practitioner perspectives

- *Training and skills development are needed so that practitioners can be better equipped to work with the new systems and to explain them to others.*
- *Staff too can benefit from sharing experiences, problems solving and information in networks.*

User and carer levels

- *Information on self-directed support needs to be accessible and widely available.*
- *Comprehensive support for users and carers can help when they are thinking about change and what might be needed over time.*
- *Social networks among users can help in sharing ideas and experiences.*
- *Being able to employ family members is welcome by some people.*
- *Brokers and advocates who are independent of the local authority can help with the details and also in challenging the local authority.*
- *Plans to deal with possible emergencies are necessary.*

Management and Leadership

- *Self-directed support champions or other inspiring people can help with start up and with addressing later problems.*
- *A steering group helps spread the load and enables messages about good practice and knowledge to reach everyone necessary.*

How this study was carried out

1.14 This report is based on a systematic search of the research literature examining self-directed support in social care and factors that act as barriers or facilitators to the up-take and development of self-directed support in the United Kingdom (UK). We broadened the scope of this study beyond self-directed support to include research in the area of personalisation (the term often used in England). Several methods helped identify studies and contextual material, including the searching of key bibliographic databases, in August 2009 and updated in August 2010. The search was primarily conducted using online

research databases (Web of Knowledge, PubMed, Social Care Online). Additional searches were also carried out using relevant government (such as the Scottish Government and Department of Health) and third sector websites (such as In Control) for literature that may not be available on research databases.

Next Steps

1.15 The next stage of the research is investigating what is happening in the three local sites in Scotland. This involves collecting data about take-up of self-directed support and other local authority information. We are interviewing people using self-directed support and their carers, and working with managers and frontline staff in the local areas.

2 INTRODUCTION: DEFINING SELF-DIRECTED SUPPORT

- 2.1 This study on the published literature on the barriers and facilitators of self-directed support was undertaken to inform a research study funded by the Scottish Government 2009-2011 that is evaluating initiatives in three local authorities. These initiatives aim to improve take up of self-directed support for people eligible for social care and other public funds. The three test site areas are working to reduce bureaucracy; to make the processes easy and 'light touch'; and to provide training and leadership to people working on these developments. Scottish Government has provided extra money to assist these three authorities and to help people in other areas learn from their experiences.
- 2.2 This chapter examines the use of the term self-directed support. Chapter 3 describes the methodology employed in conducting the review of the published literature. Chapters 4 and 5 report on the barriers and facilitators to SDS respectively. The final chapter, Chapter 6 provides a summary of the findings and reflects on these in relation to future development of SDS in Scotland.

Defining Self-Directed Support

- 2.3 This review uses the term self-directed support (SDS) as an umbrella term. SDS is a subject that encompasses many concepts and practices in social care; sometimes these are used interchangeably; at other times they have different meanings and cultural variations ⁽¹⁾ ⁽²⁾. Many definitions and descriptions of self directed support are unclear and rely on imprecise terms. One of the most common reference points to SDS is the concept of personalisation, which has become widely used in England, but this is likewise a very broad term, generally using terms such as choice and control interchangeably and with little specificity. There are wide advantages to terms that are 'elastic' in that they can be shaped to local circumstances and are adaptable to changing emphases. However, there are also disadvantages, such as imprecision, the risk of confusion, misunderstanding and geographical variations.
- 2.4 The Scottish Executive ⁽³⁾ has been using the following, widely cited, definition of SDS:

Direct payments: 'A term used interchangeably with self directed support and appearing in legislation...The definition is historical and focused on a system of delivery rather than the flexible independence outcomes that individuals can achieve when they choose and control their lives. Self directed support is for people who have been assessed as needing help from health and social care services, and who would like to arrange for their own care and support instead of receiving them directly from the local authority. A person must be able to give their consent to be on self directed support and be able to manage it even if they need help to do this on a day-to-day basis.'

2.5 More recently, the Scottish Government ⁽⁴⁾ has employed this definition in its *National Strategy for SDS*:

- Self-Directed Support (SDS) *is a term that describes the ways in which individuals and families can have **informed choice about the way support is provided** to them. It includes a range of options for exercising those choices. Through a co-production approach to agreeing individual outcomes, options are considered for ways in which available resources can be used so people can have greater levels of control over how their support needs are met, and by whom.* (Emphasis in the original)
- In terms of current take-up, in Scotland 3,678 people received Self-Directed Support (Direct Payments) in the year 2009/10. This was an increase of 661 (22%) from the 2008/09 level.⁽⁵⁾

2.6 It is important to note that the requirement that individuals must demonstrate capacity to consent has been superseded by a change of Regulations in England. In particular, new arrangements for proxy decision-making now enable other people (such as carers) to consent to and manage social care public funding on behalf of users of social care services but the difficulties encountered by carers of people with dementia in Scotland in accessing Direct Payments suggest that there are other barriers to making care more personalised as this report illustrates.⁽⁶⁾ In Scotland this area is partially covered by the Adults with Incapacity (Scotland) Act 2000, Community Care (Direct Payments) (Scotland) Regulations 2003, in relation to parental consent for young disabled people. The Scottish Executive Guidance on SDS ⁽³⁾ also refers to supported decision making, through user controlled trusts, circles of support and advocacy.

2.7 Both within Scotland and beyond, there are attempts to clarify the field.^{(2) (7)} A recent definition from the Scottish group Changing Lives ⁽⁸⁾ defines personalisation very broadly, and does not confine it to social care or to adults; it reads that personalisation:

... enables the individual alone, or in groups, to find the right solutions for them and to participate in the delivery of a service. From being a recipient of services, citizens can become actively involved in selecting and shaping the services they receive. (p1)

2.8 In light of the importance of clarifying terminology, the section below describes the various definitions or meanings ascribed to certain key terms.

Personalisation

2.9 This phrase is often accompanied by the term 'agenda', meaning that it is government policy or an overarching policy theme; for example:

- *The government is working hard on its personalisation agenda, setting an ambition that all service users have control over the support they need.*⁽⁹⁾

2.10 From the viewpoint of a Commission set up by an English local authority to explore what this might mean more precisely, a definition emerged that

a... 'personalised' adult social care system... emphasises the individual's dignity, right to self-determination, choice, control and power over the support services they receive (p7)⁽¹⁰⁾

2.11 There are also attempts to define personalisation by its antithesis or opposite: 'The new model of personalisation is much more than 'direct payments plus'... At the heart of the model are the three concepts of user control, choice of service and flexibility of support' (p9),⁽¹¹⁾ although this is not universally agreed. More often there are broad aspirations for what personalisation should be: a personalised system is one 'which is fair, accessible and responsive to the individual needs of those who use services and their carers' and one where users should be able to live independently, exercise control over their own life and to participate as active and equal citizens in community life (p2).⁽¹²⁾ In such definitions, the aims are instrumental and personalisation is 'a means of offering greater choice, empowerment and freedom' (p19).⁽¹³⁾

2.12 As will be described below, in turning to the specifics, 'personalisation means putting people at the heart of the design and delivery of services, giving them more choice in how they live their lives and better access to services. Developing individual budgets for service users is at the heart of this'.⁽¹⁴⁾ Here we begin to encounter definitions of personalisation that are focused on social care services in the public sector: 'The aim of the personalisation of social care is to ensure that everyone who is eligible for social care support... has more choice and control over what that support is, how that support is delivered and by whom' (p6).⁽¹⁵⁾ In terms of how such messages are being interpreted, there is some evidence that although personalisation is a broad concept, social workers generally interpret it in terms of specific initiatives: direct payments (DPs), individual budgets (IBs), and so on.⁽¹⁶⁾

2.13 It is not surprising therefore that there are now efforts to refine definitions:

- *Personalisation is, quite simply, the design and delivery of public services in accordance with the identified needs and declared requirements of each individual rather than the commissioning of services perceived to meet the assumed needs of members of predetermined groups. (p2)*⁽¹⁷⁾

2.14 This has also revived the political dimension of the definitions:

- *Personalisation is a political term being used to describe the intended transformation of relationships between government, service providers and service users in social care. (p9)*⁽¹⁸⁾

Direct Payments (DPs)

2.15 In essence, these are cash payments provided instead of traditional services⁽¹⁹⁾ and are:

- *a means where disabled people can buy in the help and assistance they need for their everyday needs and support... help disabled people do things for themselves instead of relying on services directly from the Local Authority social services. (p3)⁽²⁰⁾*

2.16 Policy-makers in England outlined the rationale for DPs as being 'to give recipients control over their own life by providing an alternative to social care services provided by a local council' (p3)⁽²¹⁾. This is a similar basis to policy in Scotland. It is important to note that Direct Payments (DPs) are not part of the benefits system but are set within publicly funded social care services; 'the payments that are made to individuals who have been assessed as needing social care services in order that they can make their own arrangements to meet their needs' (p1).⁽²²⁾

2.17 DPs rest on a legislative base: 'The Community Care (Direct Payments) Act 1996, which came into force in April 1997, gave local authorities the power to offer a direct cash payment in lieu of services to adults assessed as needing community care services and new sections 12B and 12C were inserted into the Social Work (Scotland) Act 1968' (p4)⁽²³⁾ and section 13 amended. The option of offering DPs was at first restricted to people aged 18-65 years. However, since July 2000 in Scotland (February 2000 in England) this power was extended to include disabled people aged 65 and over, and expanded in 2001 to include young disabled people between the ages of 16 -18 years. Since June 2003 in Scotland (April 2003 in England), local authorities are obliged to offer DPs to all those eligible. Not surprisingly, research generally uses a shorter definition of DPs as 'user-controlled purchasing of social care' (p97).⁽²⁴⁾

2.18 However, some researchers and activists have emphasised that there is a distinction between a DP and a Third Party scheme.⁽²³⁾ In a third party scheme, payments are not made directly to the disabled person but to an agency or another person. Some researchers only use the term DP in circumstances where, 'the money must be paid by the local authority direct to the disabled person.' (p4). In a few instances, the definition used in a research study notes the potential for cash payments to be made to a third party or 'indirect payments':

- Direct payments is a form of welfare whereby cash payments are made directly to the individual to purchase the services they are assessed as requiring... The term 'direct payments' [in this study] is... being used generically to cover all cash payments made to individuals to purchase services, whether these are made through a third party or not. (pp75-77)⁽²⁵⁾

2.19 The literature reveals many different uses of these terms. For example, as the paragraph above notes, sometimes DPs are described as being predominantly

made directly to the user, generally with a specific service in mind. Other descriptions use terms such as Individual Budgets (IBs) when talking about a transparent allocation of resources (telling people what they are entitled to in terms of the money allocated to them), which may bring together funding from several sources.⁽²⁶⁾ However, some of the definitions offered are not widely shared in the literature and need to be carefully examined. For example, there are reports that some policy makers see DPs as funding from the LA social care budget; self-directed support as funding from multiple streams; and IBs as being like SDS but placed in a single bank account to deliver seamless support.⁽²⁷⁾ There is a great need for care over these complicated definitions.

2.20 Despite this, there is wide agreement that DPs enable service users to purchase their own support^{(28) (29) (30)}, although there are sometimes unspoken assertions that the sums provided under DPs are directly equivalent to the costs of LA funded services. In other words, there is not much discussion of ways in which some DPs may be less than the total sum awarded because various 'on costs' are taken out of them before the money reaches the end user:

- *Direct payments are a means by which people can be given control over the resources that would otherwise have been used to pay for services to be provided to them. (p19)⁽³¹⁾*

2.21 In essence, these definitions suggest that DPs are an alternative funding mechanism, sufficient to meet social care needs:

- *Direct payments are a means by which people who require social care directly receive community care monies so that they can choose and pay for their own support to meet their needs.⁽³²⁾*

2.22 There are further implicit suggestions in other studies that once a person has been provided with a DP then they are not likely to call on other local authority social care services: in these definitions users are described as having 'control over money spent on meeting their community care needs, rather than receiving services arranged for them by the local authority' (p459).⁽³³⁾

2.23 Furthermore, some definitions focus on what can be purchased under the mechanism of DPs; one study noted that the system running described itself as offering cash payments designed to purchase 'personal assistance': 'The payments can be used to pay an agency to provide the support the individual wants, as well as to directly employ personal assistants to enable the person to live the way they want.' (p644).⁽³⁴⁾ Goods and equipment might have been hard to fund under this system but these were seen as completely acceptable in the IB pilots.^{(35) (36)}

2.24 Interestingly, few definitions refer to the potential in England (but not Scotland) for carers to receive DPs. Stuart is one of the few that adds carers to users in his definition of DPs:

- *More people than ever before can now choose to have cash payments to purchase their own personal assistance rather than using services arranged for them by local authorities. This scheme is called 'direct payments'... There are two key components to direct payments. The first is the care manager's assessment of the needs of service users and carers... The second component is the support services that will help users and carers manage their direct payments. (pVIII)⁽³⁷⁾*

2.25 Lastly, there are definitions that focus on matters in common between terms such as DPs and SDS rather than defining difference.⁽³⁸⁾

Cash and Counseling (American spelling)

2.26 Research has generally noted that DPs are found in other developed countries but with different terminology. The United States (US) experience is widely reported (in the US) and the research there has been longitudinal, in-depth and multidimensional. The term used in most US studies is 'Cash and Counseling', which is defined as the provision of:

- *a flexible monthly allowance that consumers can use to hire their choice of workers (including relatives) and purchase other services and goods that meet their personal assistance needs... Cash and Counseling also provides counseling and fiscal assistance to help consumers plan and manage their responsibilities and allows them to designate representatives (such as family members) to make decisions on their behalf. (p2)⁽³⁹⁾*

2.27 The similarities between Cash and Counseling and DPs are considerable as Cash and Counseling is described as 'offering elders and younger persons with disabilities a cash allowance in place of agency-delivered services' (p812),⁽⁴⁰⁾ although the nature of the information services provided differentiate these from UK schemes. 'The Cash and Counseling model offers a cash allowance and information services to clients so they can purchase personal care services, assistive devices, or home modifications that best meet their individual needs.' (p646).^{(41), (42)} In contrast to the UK, there has been early development of 'Cash and Counseling schemes for all age groups... (it) gives frail elders and adults and children with disabilities the option to manage a flexible budget and decide for themselves what mix of goods and services will best meet their personal care needs.' (p1).⁽⁴³⁾

Individual/Personal Budgets

2.28 Turning to the UK, and in particular, England, individual budgets (IBs) emerged early on as a term that virtually summed up the meaning of personalisation in adult social care. Many researchers have relied on the Department of Health's definition or 'product branding' of IBs:

- *[they] bring together various existing funding streams (community care purchasing budgets, community equipment budgets, Supporting People*

funding, Disabled Facilities grants, Independent Living Fund, Access to Work) in order to permit social care users to construct care packages to suit their needs and provide them with the outcomes that they [want]. (p18)⁽⁴⁴⁾

- 2.29 Definitions mention that this blending of funding streams theoretically enables IB 'holders' to fund other forms of support than through employment of support workers: 'IBs are a form of individualised funding (IF). In an IF system, disabled people are given public funds that they can use to buy services or employ support workers'.⁽⁴⁵⁾
- 2.30 Early in their conceptualisation, there were comments that financial allocations were more 'visible': 'an individual budget is essentially about being clear with people from day one how much is available to spend on meeting their needs, and ensuring that the person and those close to them have as much control as they want over how this money is spent on their behalf' (p2).⁽⁴⁶⁾ It is evident from the start what the resource allocation will be; it is 'up-front' (p3).⁽⁴⁷⁾ Indeed, funding broken down to the level of the individual is prominent in most definitions: a personal budget is 'an arrangement which provides disabled and older people who are eligible to council social care with "a clear, upfront allocation of funding to enable them to make informed choices about how best to meet their needs".' (p22).⁽⁴⁸⁾ Nonetheless, other elements are depicted as crucial: 'a number of important principles underpin IBs – self-assessment; self-definition of desirable outcomes, with user choice about how these are achieved; integration of funding streams, with clarity about budgets and service costs; support for users in planning how to use resources (see the influential and detailed evaluation (termed IBSEN) of IBs by Glendinning et al ⁽³⁵⁾).
- 2.31 Turning to attempts to distinguish IBs from DPs, several themes emerge: such as combined funding streams: DPs are predominantly made directly to the user, generally with a specific service in mind. IBs are intended to provide a transparent allocation of resources, bringing together funding from several sources ⁽²⁶⁾, although the IBSEN study found very little blended funding. Many involve social care funding alone or possibly 'combined with Supporting People money for housing related support' ⁽⁴⁹⁾ from the local authority.
- 2.32 Like the definitions of IBs, newly emerging definitions of personal budgets (covering only social care funding) stress the importance of choice and control: if someone knows how much money is available to them, and the outcomes to be achieved; the person or their advocate could exercise control over the money to the extent of spending it when and how seemed right for them.⁽⁵⁰⁾ A personal budget is also a term used in translation when referring to experiences in other parts of Europe: Kremer ⁽⁵¹⁾ describes how, across the continent, 'patients can now opt for cash and spend that money on the direct employment of carers who deliver this care in their own home.' (p385) (note, the Dutch Personal Budget, the focus of Kremer's article, is highly regulated, although it allows for the payment of family carers.) The greater permissiveness of IBs is revealed in early studies of how they are being interpreted; for example, those who use them have greater flexibility about how to spend

money than with DPs.⁽⁵²⁾ This stands in contrast to the barriers to employing close and co-resident relatives under DPs.

- 2.33 Overall, IBs' early definitions theoretically allowed and promoted self-assessment, a monetary budget (not hours per week), allowing direct purchasing of services, incorporating several funding streams, and permitting this to be spent on a variety of support options.⁽⁵³⁾ IBs were to combine different funding streams, align assessments, encourage self-assessment and introduce a transparent Resource Allocation System (RAS) (a system for working out how much money a person is entitled to). They were to focus on outcomes and allow users to choose where to purchase their support.⁽⁵⁴⁾ The IBSEN evaluation found limited experiences of blended funding streams (money from different parts of the welfare system); and 'self-assessment' has been revised as a concept because assessment cannot legally be delegated by English local authorities.⁽⁵⁵⁾ One early aspiration of IBs was also that they might streamline 'assessment across agencies responsible for a number of support funding streams, resulting in the transparent allocation of resources to an individual, in cash or kind, to be spent in ways which suit them' (p3).⁽⁵⁶⁾
- 2.34 What is common and enduring in many definitions is the focus on control about the spending of the allocated resource, even though the term IB is being replaced in most (but not all) parts of England by personal budgets, 'a means of giving people more control over the public resources allocated for social care services' (p2).⁽⁵⁷⁾ Personal budgets may only be related to social care and so the debate around choice centres on this area. It is often observed that there are various ways of doing this, meaning that while DPs are clearly a sub-set or part of personal budgets, there are alternative ways of managing the resource through 'other forms of deployment'.⁽⁵⁸⁾ Little evidence exists on other forms of deployment to date but they can include legal Trusts or Provider Held Accounts.
- 2.35 In terms of the development of these ideas, many commentators allude to the evolution of personal budgets, which built on learning from DP and the In Control (IC) programme. IC's key contribution was to develop and model, with local authority partners, an alternative 'operating system' – self-directed support. 'This aims to shift power to people via major adaptations to the way in which social care resources are allocated, controlled and used' (p16).⁽⁵⁹⁾
- 2.36 Finally, while US literature often refers to Cash and Counselling schemes as noted above, some use the term IBs: 'The "individual budget" model is a service option that offers beneficiaries an individual budget that they manage to obtain services they need, in place of the traditional package of Medicaid supports and agency-provided services' (p1).⁽⁶⁰⁾ It is worth noting that they do not mean the same as UK examples.

Self-directed support (SDS)

- 2.37 Amid the many attempts to locate terms in a history of ideas, are those that cast SDS and other descriptors in the disabled people's movement literature. For example, the Department of Health (DH) describes how 'Self-directed

support emerged as a means of giving control over services and outcomes to individuals, with appropriate support where needed. While self-directed support may be in the form of a direct payment, people may also choose to manage it in a different way' (p16).⁽⁶¹⁾ This evolution can also be depicted as a departure. 'The personalised approach of SDS represents a profound shift in focus: instead of being passive recipients of services, older people become active participants in their care and support' (p1).⁽⁶²⁾ More simply, SDS may be described as 'self-directed support, where people control their own budgets for their own support' (p26)⁽⁶³⁾ or more guardedly, noting that this relates to the art of the possible: 'Self-Directed Support is the name for the whole-system change of the current social care system to a system where people are put in as much control of their own support as possible' (p3).⁽⁶⁴⁾ For some there is an emphasis on minimal assessment but this is not generally observed; SDS 'places control over an individual budget in the hands of the person needing support [or their representative]... This is achieved by allocating resources to people at the start of the support process and following the completion of a simple questionnaire' (p2).⁽⁶⁵⁾

2.38 Thus there is great variety in the definitions of SDS, ranging from that which sees it as synonymous with IBs – e.g. SDS gives people an individual budget, responsibility for which is shared between the service user and the Local Authority. Funds are allocated to this budget through a RAS (resource allocation system) and the budget managed by the individual, their representative, a social care provider or the local authority (p5),⁽⁶⁶⁾ to seeing SDS as qualitatively different: e.g. SDS is a continuum of options from DP through IB to 'Total Transformation'.⁽⁶⁷⁾ At what might be seen as the mid-point of the spectrum of definitions, SDS is described as 'when disabled people are themselves more directly in charge of, and responsible for, the shaping of assistance to meet their needs' (p44).⁽⁶⁸⁾ Even here, at the mid-point, different emphases emerge, such as the extent to which people's choices are supported or controlled by professionals; SDS 'allocate[s] people budgets so they can shape, with the advice of professionals, the support and services they need' (p9).⁽⁶⁹⁾ Similarly, some commentators identify the greater role for family members in SDS than in other systems: SDS means 'people work[ing] with their families to develop individually tailored packages of support' (p4).⁽⁷⁰⁾ SDS 'places control over an individual budget in the hands of the person needing support [or their representative]... This is achieved by bringing the allocation of resources to the front end of the process' (p4).⁽⁷¹⁾

Other terms

2.39 Briefly, the literature reveals use of a number of other terms, mentioned below.

Personal Assistance Services program (US)

2.40 In the United States (US), terms such as 'Personal Assistance Services (PAS) refer to help that people use to assist with functional tasks including activities of daily living (ADLs) such as bathing and eating, and instrumental ADLs (IADLs) such as shopping and preparing meals.' (p28).⁽⁷²⁾ 'Funded under Medicaid... the Personal Assistance Services (PAS) program offers individuals with

significant disabilities the opportunity to hire, train and manage their own personal assistants to provide essential hands-on care and complete household tasks' (p4).⁽⁷³⁾

Individualised funding

2.41 This term has been used by the influential organisation *In Control*, and describes individualised funding - either direct or indirect payments that enable disabled people to manage the funds available for their support.⁽⁷⁴⁾ It is also used in the US: 'individualised funding refers to the allocation of support dollars directly to the person, in contrast to a service agency' (p72).⁽⁷⁵⁾

Cash for care

2.42 In the UK, the term 'cash for care' has been used to describe DPs and, very occasionally, IBs or personal budgets. 'Cash for care schemes are premised on the concept of the care-user receiving cash from the state in order to directly employ their own labour' (p25).⁽⁷⁶⁾ While not generally found in the research literature, partly because the term appears imprecise, the term is commonly used.

Individualized Quality of Life project

2.43 In North America, the Individualized Quality of Life (IQOL) project aimed to provide to individuals with ID (intellectual disability) and their families, person-centred planning, access to individualised funding, support in accessing community supports, and assistance in monitoring and reviewing their individual plans. It also aimed to assist people in developing support networks and making meaningful connections to the community (target groups: children 0-6; young adults; and adults living with their parents).⁽⁷⁷⁾ It is sometimes referred to in the UK literature.

Consumer-directed care

2.44 Lastly, the term consumer-directed care, more commonly found in the US, describes a system that offers services, assistive technologies and other supports over which recipients or their representatives have control. In most areas this is Medicaid funded.⁽⁷⁸⁾ As with the US Cash and Counseling schemes (see above para 1.21), a consumer-directed approach 'support[s] more consumer control and choice within service delivery' (p34).⁽⁷⁹⁾ The US research literature employs both terms; consumer-directed home and community services 'give beneficiaries, rather than agencies, the power to hire, train, supervise, and fire workers' (Executive Summary).⁽⁸⁰⁾

Summary and implications for research

2.45 Any research on self-directed support needs to carefully describe the parameters of this system, with further care to define certain elements of it that are used in different ways. It also needs to establish whether the study is exploring DPs or other forms of arrangement or deployment. Extensions to a scheme should also be noted, for example, the change in DPs that extended

them to older people in 2000. Comparisons with SDS schemes internationally and between Scotland and other parts of the UK need to be mindful of the importance of local contexts e.g. what individuals might have to contribute financially to the budget. Lastly, the definitions reveal differences in whether SDS schemes are able to offer payments or budgets to disabled people's proxies or representatives. This may affect take-up and the nature of disabilities, for example, when a proxy is willing and able to receive a DP then this will likely enlarge the numbers of people with dementia having this form of support.^{(6) (81)}

3 METHODOLOGY

- 3.1 This report is based on a systematic search of the research literature examining self-directed support (SDS) in social care and factors that act as barriers or facilitators to the up-take and development of SDS in the United Kingdom (UK). Based on the above work outlining the range of definitions being employed in this area, we broadened the scope of this study beyond what is self-defined as SDS. We used several methods to identify studies and contextual material. First, a search of key bibliographic databases was undertaken in August 2009 and updated in 2010. The search was primarily conducted using online research databases (Web of Knowledge, PubMed, Social Care Online). Additional searches were also carried out using relevant government (such as the Scottish Government and Department of Health) and third sector websites (such as In Control) for literature that may not be available on research databases. The references were entered into Endnote X1, a bibliographic database.
- 3.2 To supplement this process, references used in the articles identified were also examined to locate any further material. Additionally, the references identified through these search methods were compared with those used in the recent literature review of personalisation for mental health service users, conducted by Val Williams, Pauline Heslop and Helen Spandler for the MIND research project 'Putting Us First' to which we were kindly given early access. We also contacted researchers working in this area to obtain material that is in press. We are grateful to them for their assistance.
- 3.3 Search terms used were (including truncation symbols, exact phrases, and Boolean logic): direct payments; self directed support; individual budgets; personal budgets; cash and counselling; cash and counselling; personalisation; personalization. The searches covered words in the title, abstract or in key words. As chapter 1 outlines, a notable feature of this review is that the area is in flux with a considerable range of terms being used. While we are using the term self-directed support as a general term, for example, many of the articles located did not mention this phrase. Commonly found terms included: direct payments, individual budgets, personal budgets, and consumer directed care. There were also some mentions of person-centred planning/support/care and independent living. Particular attention was paid to mention of bureaucracy and 'red tape', to leadership and to transitional funding in order to relate this review to Scottish Government policy interests and to the wider study of which this review is a part.

Inclusion criteria for search

- 3.4 Publications were included if they covered adult social care, were in the English language and made reference to barriers and facilitators. In light of the recent developments in this area, there was no limit on the date of material accessed.

Exclusion criteria for search

- 3.5 Publications were excluded if:

- They did not contain evidence of barriers or facilitators of SDS
- They were statute or regulations
- They were summaries of reports already cited that did not contain new findings or analysis.

3.6 After the online searches, relevant publications were extracted, and the database contained 161 references.

Screening procedure

3.7 The references found through the literature review were read by the review team, initially by the abstracts, where available, and a subjective judgement about their relevance to the review. If the team agreed that the article or material was relevant, the full item was read. Summary notes were then created for each of the publications, based on a data extraction tool developed by the review team that had been commented on and agreed with the Research Advisory Group

Comments on research quality

3.8 When examining the evidence from across the UK and internationally⁽¹⁶³⁾ the limitations of the research base emerge. First, there is much variation in the scope and focus of evaluation studies or implementation accounts. Some are looking at certain groups or at particular funding approaches. Second, studies are often small-scale and/or characterised by small sample sizes with little long-term follow up. Third, some accounts are commentaries or hypotheses. Furthermore, much of the literature reported the experiences of people who are most likely to be offered, or to take up, SDS schemes and therefore when looking at barriers to take up, for example, this group may not provide the best source of evidence. However, it is important to note the limited evidence base for much social care. Direct Payments are among the most studied areas of social care and the Evaluation of Individual Budgets (IBSEN study) is one of the most detailed and robust studies in social care.

4 BARRIERS

4.1 In this section we outline the main barriers to achieving self-directed support that have been identified in the research and other literature. These barriers have been identified at system wide level; in respect of practitioner experiences and expectations; from the point of view of people using services and carers; in relation to legal and procedural frameworks and lastly those covering management and leadership issues.

System wide

4.2 One of the consistent comments, and from a variety of sources, is that SDS is publicised insufficiently. In this section we outline the various claims made about this theme.

4.3 A number of studies and reports comment that the new ways of organising social care and increasing options are not known or understood by **people using services**. These have been found in studies of users of various 'client groups' ^{(29) (80)} (the latter relating to older service users), ^{(82) (83) (84) (85)} (deaf/blind people) ⁽⁸⁶⁾ (mental health (MH) service users). The authors of such studies generally recommend that general publicity be improved. However, a study in Scotland also observes that many members of the public are unsure about social care provision overall. ⁽⁸⁷⁾

4.4 Similarly and perhaps causally related, SDS is reported to be insufficiently known among **people working in social care services** (both in local authorities and in provider services). Again, this comment is made on the basis of work in various areas of social care, for example, among people working in mental health services. The following studies point to lack of staff familiarity with the term and system of SDS. This applies to studies of DPs, for example, ⁽⁸⁶⁾ and later expansions to SDS ^{(88) (89) (90)}.

4.5 More generally, government studies; ⁽⁹¹⁾ overviews ⁽⁹²⁾ and research ^{(93) (35) (70)} ^{(94) (95) (85)} all point to a lack of information or knowledge. There is little interrogation of where such learning might take place, and it may be a long-standing problem. For example, the regulator of social care in England, the former Commission for Social Care Inspection (CSCI), ⁽⁸⁴⁾ comments that newly qualified social workers were inadequately informed about direct payments (DPs) many years after they were introduced (1996). It raised the possibility that students are not taught about these during qualifying programmes, as had been earlier suggested. ⁽²³⁾

4.6 Within local authorities, specific staff groups not working directly with service users are identified as lacking awareness of DPs. This may account for perceptions that the new system is still too 'bureaucratic' because accountancy processes remain unchanged. For example, one study ⁽⁹⁶⁾ cites **lack of information among finance department staff** as a barrier to the successful implementation of DPs. They conclude that finance and administrative staff need to understand how money tied up in existing services can be transferred

into DPs and to be able to communicate this effectively within the authority (see also.⁽⁹⁷⁾

- 4.7 Overall, there are criticisms that there has long been a **lack of accessible information on SDS**. While this might mean that the information needs to be in plain English and easy to read, some researchers talk about this in relation to specific groups of potential users. For instance, commentary⁽⁹⁸⁾ ⁽³⁷⁾ relates such concerns to Black and Minority Ethnic (BME) users. Others make the point more generally in relation to all service users⁽⁷²⁾ ⁽⁹⁹⁾ ⁽³⁰⁾ ⁽⁷⁰⁾ The point is also made in respect of people with communication needs, for example, about deaf/blind people⁽⁸⁵⁾ who may need particular support and in relation to people with learning disabilities⁽⁹⁷⁾.
- 4.8 Even where people are aware of the principles of SDS there is a view that many are **confused** by the many different terms used in discussing SDS.⁽⁸⁴⁾ The move in England from individual budgets to personal budgets is an example of such confusion for many.⁽⁴⁴⁾ ⁽⁵⁴⁾ ⁽⁸⁹⁾ ⁽¹⁰⁰⁾ ⁽¹⁰¹⁾

SDS cannot be implemented successfully without an active local third sector

- 4.9 This claim is made on the basis that the third sector or voluntary sector may be able to **advocate for the wider implementation** of SDS.⁽⁴⁶⁾ ⁽⁸²⁾ ⁽⁹⁶⁾ ⁽¹⁰²⁾ ⁽¹⁰³⁾ At one level the voluntary sector may be well placed to **advise and support SDS recipients**.⁽³⁵⁾ (for MH users) ⁽³⁷⁾ ⁽⁸⁵⁾ ⁽⁹⁹⁾ ⁽¹⁰⁴⁾ ⁽¹⁰⁵⁾ ⁽¹⁰⁶⁾ ⁽¹⁰⁷⁾ ⁽¹⁰⁸⁾ ⁽¹⁰⁹⁾ This may be because social workers are at risk of becoming overburdened.⁽¹¹⁰⁾ The financing of this activity in the third sector is not reported in terms of costs and outcomes.

Relationships between SDS and other benefits

- 4.10 It is not clear to many users and practitioners how SDS relates to other benefits, such as those that are means tested, eligibility based, and disability related.⁽²⁰⁾ ⁽⁴⁹⁾ ⁽⁸⁴⁾ ⁽¹¹¹⁻¹¹³⁾ ⁽¹¹²⁾ ⁽¹¹³⁾ In particular, the Independent Living Fund arrangements (**ILF**) **cause particular problems**⁽¹¹⁴⁾ for reasons to do with the effects of ILF funds on other benefits and the strict ILF criteria.

SDS interfaces with other parts of the public sector are unclear

- 4.11 There is some evidence that many users do not understand the divide between NHS and local authority services and their remits, and are unsure about what services they can purchase with SDS money.⁽³²⁾ ⁽¹¹⁵⁾ This can lead to interagency competition or tension about which agency funds certain services (particularly for MH service users) if the NHS or local authority tries to transfer or shunt costs onto each other.⁽³¹⁾ ⁽⁸⁸⁾ ⁽⁸⁹⁾ ⁽⁹⁰⁾ ⁽¹¹⁶⁾ It may be that these problems are broader in scope and relate to problems of **interagency working between NHS and local government**.⁽³⁰⁾ ⁽³⁵⁾ (MH users) ⁽⁹²⁾ ⁽¹¹³⁾

Lack of choice

4.12 However, there are also problems in that **users can't make choices** if there are not several services or individuals or products for them to decide between.

These deficiencies may be related to:

- general problems of supply and capacity in social care, the workforce or wider;^{(61) (68) (98) (117)}
- existing services not reflecting users' needs or being inappropriate;^{(35) (51) (62) (118) (119)}
- services closing as block commissioning contracts are withdrawn;^{(33) (57) (59) (69) (102) (120)}
- LAs paying insufficient attention to market development.^{(59) (83) (112) (121)}

4.13 Others comment that introducing SDS is a **slow process**; it takes a time to become mainstream.^{(95) (98) (120) (122)} Such experiences may contribute to a view that the process remains governed by administrative requirements or 'red tape'. For individuals there can be a **long interval** between application, assessment and having the money in their bank accounts.^{(54) (59) (70) (100) (109) (118) (123) (124)}

Practitioner experiences and expectations

4.14 One important barrier is that some staff may think SDS is **not 'appropriate'** for particular groups or individuals. Many studies have found this in relation to different groups:

- People using Learning Disability services;^{(74) (82) (83) (92) (125)}
- People using Mental Health services;^{(17) (34) (82) (83) (86) (88) (90) (92) (109) (116) (125) (126)}
- Older people;^{(40) (62) (67) (80) (110) (127)}
- Among user groups in general^{(16) (21) (78) (94) (95) (113) (121) (128)}

4.15 The underlying reason for this concern appears to be that staff are anxious that SDS has the potential to put **vulnerable clients at risk** generally of abuse, exploitation and general distress, or lack of wellbeing arising from the 'hassle' of managing new consumer relationships.^{(11) (17) (26) (35) (47) (67) (74) (76) (88) (90) (91) (92) (94) (95) (97) (105) (109) (117) (127) (129) (130) (131) (132) (133) (134)} The Evaluation of the Individual Budget Network (IBSEN) report in England observes that adult safeguarding issues had not been initially considered in many pilots and that this was of concern to care managers.⁽¹³³⁾ Prior to the greater emphasis on personal budgets, there were reports that practitioners are concerned about the loss of 'early warning systems' operating in commissioned services that enable them to hear of declining well-being or growing mental distress and so intervene in a timely manner.⁽⁸⁶⁾

Staff are concerned about their jobs and roles in the light of SDS

4.16 The reasons found in published research for this are fivefold:

- Because they think they will lose their jobs if services such as day centres close or if assessment and monitoring become the responsibility of third sector bodies; ^{(23) (56) (59) (83) (88) (102) (110) (122) (127)}
- Because they think they lack the professional skills to work within this framework; ^{(1) (67),(135)} (the latter referring especially Newly Qualified Social Workers);
- Because they don't want to relinquish professional control; ^{(44) (46) (59) (64) (98) (104) (115) (117) (136)}
- Because they are resistant to system change in general; ^{(11) (17) (52) (64) (88)}
- Because of the administrative burden any new system brings; ^{(47) (77) (95) (110) (122) (132)}, particularly the complexity of administrative procedures ⁽⁴²⁾

Staff concerns about equity and risk of abuse

4.17 However, there are also concerns based on political interpretations of the possible effects of SDS. Some staff express fears about the negative effect that SDS will have on **existing services and users**:

- Because they fear it will lead to inequality or 'creeping privatisation'; ^{(86) (102) (107)}
- Because they think that wide uptake of SDS will force some existing services to close; ^{(125) (132)}
- At individual levels, practitioners also voice concerns that users will mispend their money leading to harm or lack of wellbeing. This view relates to a number of risks;
 - Risks expressed in general terms; ^{(20) (46) (89) (106) (129) (137)}
 - Among some there is the view that extending choice may mean that people will spend public money on items or services that could be seen as 'frivolous' (perhaps because non-traditional services may be viewed as non-essential) – this could also be a problem if public opinion does not support such choices; ^{(17) (59) (67) (69) (93) (110) (133)}
 - That there are higher risks of fraud among users; ⁽⁷⁹⁾
 - That service users and carers share this worry about risks of exploitation, and that it might be carried out by other users; ^{(138) (139)}
 - Fear that users' families/carers will be able to commit fraud or abuse users more easily ^{(53) (67)} and that insistence or guidance about checking any criminal record in respect of people directly employed by service users is not enforceable (Disclosure Scotland).⁽³⁾

4.18 Part of this seems to relate to problems with staff being unsure about what SDS monies can **legitimately** be spent on ⁽⁹²⁾ because of lack of local authority or government guidance. In other research, it is pointed out that some of the concerns expressed by staff are because they do not understand that users do not have to *personally* manage their budgets ^{(86) (114) (140)} and that there are multiple forms of deployment or ways of managing personal budgets. Matters such as knowing the extent of duty of care were unclear among practitioners working in the Individual Budget pilots.⁽³⁵⁾ In England, the Association of Directors of Adult Services published a guide to legal matters arising in relation

to personal budgets ⁽⁵⁵⁾ that addresses, although does not minimise, some of these concerns.

SDS may result in poor working conditions for directly employed staff

4.19 The contention that SDS may result in poor or poorer working conditions for people working in social care rests on reports of a **lack of support and/or training** for directly employed care workers and their **possible isolation**.^{(27) (56) (73) (77) (80) (124) (141) (142)}

4.20 **Conditions of employment are at risk:** people working directly for service users may lack employment related benefits; they may be exploited they may lack employment contracts and professional or personal boundaries may become unclear.^{(1) (56) (73) (79) (90) (92) (124) (143)} The risk of 'casualisation' of care staff appears to run counter to efforts to increase care workers' skills.

SDS is a damaging and expensive move from block contracts

4.21 The risks of this are perceived to lie in the effects on current and future social care capacity both privately provided in the market, in the third sector (voluntary sector) and in public services. The following assertions have been suggested:

- SDS may create financial insecurity for service providers;^{(120) (130)}
- Financial uncertainties may result in the closure of some important services;^{(34) (69) (101) (120)} especially in rural areas;⁽⁵⁷⁾
- Local Authorities (LAs) may find it hard to extricate themselves from existing contracts and will perhaps have to bear the expense of transitionally to double fund SDS and services.^{(97) (132) (139) (144)}

4.22 Some of the problems associated with SDS are seen as ones that may be managed by the creation of new job roles, including that of **independent brokers or navigators** (as this review observes later). However, there is evidence that the role of the broker is insufficiently defined and rarely costed.^{(10) (77) (121)} Are brokers acting as agents of the local authority, how are they funded, to whom are they accountable and do they act in a person's best interests? Indeed, are they really necessary?⁽¹⁴⁵⁾ All these questions remain largely unanswered by evidence from research.

4.23 Finally, some earlier research on DPs suggested that staff may view SDS as a **last resort**, for certain complex or cases of concern, not a mainstream alternative.^{(102) (110)}

Service user and carer perspectives

The administrative burden of SDS is too great

4.24 This point is widely reported by studies directly drawing on the views and sometimes the **experiences** of service user and carers.^{(19) (34) (35) (51) (78) (83) (84) (109) (111) (124) (126) (136) (144) (146) (147)} While this may not be a majority experience, these studies cover older people, people with mental health problems and

carers. Concerns about administrative burden are also commonly expressed in commentaries. More specifically:

- Completion of tax forms may be a particular problem.⁽⁹¹⁾
- Some carers spend a long time (typically several hours per week) on administration and feel that they should be compensated for this time.⁽¹¹⁸⁾
- There may be a trade-off between the benefits of DP and the administrative burden they bring; ⁽²⁸⁾ this may be why 'less disabled' people sometimes do not opt for DPs because the associated administration or 'red tape' is not 'worth it' for the size of DP they will receive.
- Administration may be a particular challenge to older service users (whose health status may be poor).^{(57) (148)} Similar points may apply to about mental health service users, ⁽³²⁾ especially if they suffer from fluctuating conditions.⁽⁸⁶⁾ These observations are mainly related to SDS when operating as DPs.
- Some users experience problems opening bank accounts and feel that the system is over-bureaucratic and that there should be a light touch to monitoring.⁽²⁷⁾ Some people are said to be unclear about matters such as whether they are permitted to use contingency funding (material from the Mental Health Foundation 2009 has recently provided guidance to users and the banking industry about some of these challenges).

Users (or carers) may not want the responsibility of managing their own money/services

4.25 This point is widely evidenced, particularly when SDS is proposed or introduced, and the details of this are covered in 4.25. While some of the research identifies this as a particular concern for older people, studies have also investigated the perceptions of carers ^{(11) (54) (62) (older users) (66) (carers) (82) (85) (92) (101) (older users) (105) (107) (108) (112) (139) (149) (150) (151) (carers) (152)}

4.26 Some carers who are also parents may be **over-protective** and reluctant to allow their adult offspring to take control.^{(29) (141)}

A number of studies point to challenges with the employment of Personal Assistants (PAs)

4.27 They are hard to recruit:

- In general there are reported to be difficulties in recruitment. ^{(2) (29) (78) (85) (97) (107) (108) (113) (117) (150) (152) (153)}
- This may be a specific geographical problem, associated, for example, with rural areas. ^{(15) (57) (72) (76) (92) (94) (154)} However, there are reports that it may be easier to recruit in rural or shire counties.⁽¹⁰⁵⁾
- This may be a problem if a service user can offer only a few hours' work. ^{(19) (155)}
- It may also be difficult for those without strong social networks which can be the most effective way of finding someone who will be suitable and available. ^{(43) (123) (156)}

- This may relate to low rates of pay ^{(77) (96) (132)} (note: no studies have taken place exemplifying this in the context of current economic problems and rising unemployment).
 - This may be difficult for Black and Minority Ethnic users ⁽³⁷⁾ (suggested in a commentary).
- 4.28 Users find it difficult to manage the employer/employee relationship: Flynn ⁽¹⁴²⁾ observes that users are often friends with or related to their PAs and so boundaries (between professional and informal relationships) are unclear.
- 4.29 There is often no cover in emergencies. ^{(39) (73) (85) (97) (111)}
- 4.30 There may be problems over insurance cover (users don't tend to have this). ^{(118) (149)}
- 4.31 Possibly related to perceptions of excessive 'red tape', users experience problems opening separate bank accounts for SDS funds. ^{(30) (91) (117) (126) (132)}.

Negative aspects over the employment of family members

- 4.32 In England this has become easier with the development of SDS. Formerly, with DPs, this was often only agreed to by the local authority in exceptional circumstances. Issues arising include:
- The use of family carers to compensate for a lack of services; this can institutionalise a system of low-paid care and make family members dependent on the service user for whom they are caring. ⁽¹¹⁹⁾
 - Family carers may ask for more money than is realistic within the SDS budget ⁽¹⁵¹⁾.
 - Paying family members through SDS might impact on benefits and make the family worse off overall. ⁽¹¹²⁾
 - An emphasis on family recruitment might discriminate against users without strong social networks. ⁽¹⁷⁾
 - Social expectations that family care is a duty can create suspicion or disapproval about paying for this kind of care or treating it as a commodity. Carers may feel that they are being harshly judged for accepting payment. ^{(137) (138)}
 - Users might prefer the authority of an employee/employer relationship rather than the complications of paying family members and transgressing social norms. ⁽¹⁴⁶⁾
- 4.33 Other problems arise from judgments that SDS **payments are too small** to ensure high quality support and to promote real user choice. This problem, or these perceptions, arise:
- In general but also because some people think of SDS as a cost-cutting measure and a way to reduce public expenditure. ^{(19) (68) (93) (118) (126)}
 - In the context of being able to pay PAs a reasonable wage. ^{(30) (56) (72) (83) (96) (111) (118) (132) (149)} This leads to fears that a 'grey' or casual market in care staff can develop (see above).

- Because local authority social care funding is itself insufficient.^{(9) (14) (17) (57) (90) (93) (102) (104) (137)}
- Because NHS monies are not currently included ⁽⁴⁶⁾ thus making the total amount of money available too small to do anything with.
- As a result of users' reports that they sometimes have to 'go without' in order to afford one-off costs or new solutions.⁽¹⁹⁾
- Because the subject is no longer 'glamorous' when it has moved beyond pilot stage when start up monies and resources are no longer available.⁽⁶⁸⁾

Users are unsure of expenditure limits

4.34 As reported above, some practitioners are unsure about the legitimacy of the use of SDS monies. This lack of clarity is also expressed at times by people who have experiences of social care support through SDS:

- Because there is said to be no clear guidance.^{(27) (94)}. This lack of clarity was found by the IBSEN study (some of these significant uncertainties might have arisen in the early days of the pilots).^{(54) (151)}

4.35 One report suggests that users may not understand SDS because they do not understand existing services, in other words they do not really know what SDS is intended to replace.⁽²¹⁾

4.36 Users too have expressed concerns around **training** – its amount and its content:

- Some users are suspicious of brokers/support staff with too much training. They have had bad experiences of social services in the past and view 'professionalization' negatively ⁽⁴⁵⁾ (see also a later discussion paper) ⁽¹⁴⁵⁾
- Some users are wary of traditional training routes and want to have a say in how their PAs are trained if they are to experience choice and control ⁽¹⁴²⁾
- Users may be put off from SDS if they are asked to undergo substantial training on SDS because this gives the impression that managing SDS requires a high level of expertise ⁽⁷⁹⁾

4.37 We lack evidence about the **barriers facing carers**; partly because they are rarely offered SDS in their own right.^{(19) (151)}

4.38 Users consider that **eligibility criteria** for services are set too high and that they will not be entitled to SDS. Alternatively, users with severe needs may be deemed ineligible because they are 'incapable' of managing SDS. Fair Access to Care Services (FACS) criteria setting thresholds for eligibility have been perceived as inconsistent and may not fit well with SDS.^{(17) (20) (MH users) (26) (67) (88) (109) (113) (116) (MH users) (133) (155) (157)}

4.39 Users may find it hard to 'think outside the box' when imagining solutions that could be funded by SDS.^{(68) (98) (LD users) (140) (158)} To address this potential problem there are suggestions that keeping a diary to set out specific needs and wishes could help;⁽⁴⁷⁾ or that providing real life examples may make this seem more authentic.⁽¹⁴⁸⁾

Legal and procedural frameworks

- 4.40 SDS means that users may rely on **new models of support networks**. This concern does not fit with some findings from some research^{(94) (125)} that LAs are choosing to fund their own support services at the cost of existing, user-run disability support networks, the latter consequently losing out on funding. However, there are other reports⁽¹³¹⁾ of at least one LA entering into contracts with two independent support services during a pilot programme: this double provision was judged to be excessive and confusing. Others note **concerns about over reliance on informal support networks**;⁽⁹⁸⁾ and again the **role of the broker is unclear**.⁽⁴⁵⁾ Some point to the potential for **conflict of interest** if a broker is also a service provider⁽⁴⁸⁾ while some say that this can become a contested area.⁽¹⁴⁵⁾
- 4.41 In terms of **risks** to users of services, as mentioned above, there are concerns that there are no enforceable administrative mechanisms for registering or background checking PAs, who could present risks of harm to vulnerable people.^{(26) (49) (79) (94) (110)} The Independent Safeguarding Authority is only becoming operational in England and Wales at the time of writing and is under review (2010). There are uncertainties about who, if anyone, bears responsibility for the risks presented e.g. by unregulated PAs,^{(95) (110) (112) (137)} although guidance has tried to prospectively address these matters.⁽⁵⁵⁾ The Commission on Personalisation in its interim report⁽¹⁵⁹⁾ recommends legislation enshrining a 'right to control', noting that users lack satisfactory means of redress when things go wrong and that a lack of regulation leaves them vulnerable to exploitation. In England, the Law Commission is due to report on adult social care law reform in summer 2011 which may open up debate more widely on the legal framework of SDS.
- 4.42 More practically, there are reports that **payments are often delayed**, causing serious difficulties for service users.^{(21) (30) (111) (136) (153)}
- 4.43 Some councils offer **guidelines** on how DP/IB should be spent, which some users may view as patronising and restrictive, partly because they seem to negate the flexibility that is SDS' main benefit.^{(30) (33) (83) (84) (88) (121) (157) (160)}
- 4.44 **Integrating funding streams** consistently proves difficult,^{(59) (120)} a key finding of the Individual Budget pilot evaluation.⁽³⁵⁾ This may arise because of clashes between guidance governing different funds, how they should be spent and whom they target.^{(26) (35) (67) (especially ILF) (91) (especially ILF) (135)} The reason for this is attributed to a **lack of government guidance and powers** over integration.⁽⁹²⁾
- 4.45 The **resource allocation system** (RAS) (the system for allocating the budget to users on the basis of need or desired outcomes in the context of means testing) can cause problems:
- If there is a major discrepancy between the results of the RAS and the funding that a user is currently receiving;⁽¹²⁰⁾
 - Because the RAS is difficult and complicated to devise;^{(35) (120)}
 - Because existing pricing mechanisms are unclear⁽

- Because it discriminates against those living in the family home with carers;^{(144) (161)}
- Because there has been over-reliance on the RAS developed by in Control, which is designed for learning disabled people;^{(35) (76)}
- Because the transparency of RAS can reveal existing inequalities between different user groups that then have to be addressed;^{(11) (50) (135)}
- Because existing charging policies may be badly worked-out or not well understood.^{(106) (133)}

4.46 Finally, administrative and procedural problems have been reported in the areas around **assessment**:

- By social workers or care managers:
 - Older users are less likely to actively participate in assessment and social workers may collude in this ;⁽¹⁶²⁾
 - Social workers often fill in assessment forms back at the office, suggesting that the forms would perhaps reflect their own priorities rather than those of the service user;⁽¹⁶²⁾
 - Assessments by social care staff typically reflect existing services' organisation and priorities, rather than people's needs.^{(34) (86) (162)}
- People may under or over-estimate their needs in assessment:
 - Users may under- (especially older users) or over-estimate their needs;^{(35) (54) (101)}
 - Carers may be overlooked in self-assessment processes;^{(35) (99)}
 - 'Forms' or formal systems are inherently limited as a means of assessment;^{(26) (54) (120)}
 - It is not clear how self-assessment aligns with LA eligibility criteria for social care services.^{(26) (67)}

Management and leadership factors

4.47 Problems arise around target setting or performance indicators for managers:

- Targets for SDS uptake are not differentiated by user group; underrepresented groups like MH users may get lost amongst positive overall statistics;^{(22) (89)}
- An emphasis on targets (such as percentages of people receiving SDS) can mean social workers may over-emphasise the benefits SDS for users who may not want to take it up;⁽¹¹⁸⁾
- An emphasis on targets can lead to SDS being viewed as an end in itself, rather than a means to a more important end (helping users achieve desired outcomes);^{(59) (67) (69) (104)}
- Scottish local authorities have proven resistant to central government targets, or have not been given targets.^{(94) (107) (125)}

4.48 Some consider that guidance from central government is **vague and unclear**. That which is intended to be flexible, can result in inconsistency. Practitioners who are uncertain of where they stand may shy away from recommending SDS to service users.^{(27) (91) (94) (110) (125) (132)}

Summary

- 4.49 The evidence suggests that many of the barriers to the take up and use of SDS are commonly experienced by service users, practitioners and other stakeholders. There is strong evidence that processes and systems have not kept pace with the values incorporated under the umbrella term of SDS. Some of the barriers may be resolved by government guidance, which may reduce confusion and uncertainty. The balance of risks does not appear to have been informed by evidence from practice. Few studies have considered the costs of the recommendations that they proffer.
- 4.50 The implications for research in this area are that there are many dynamics at play when talking of barriers to SDS. Some barriers identified may apply to social care support generally, while others reflect the start of many innovations, in that there is a lack of clarity initially. The barriers identified here form the basis for exploration of SDS in Scotland, building on the considerable research evidence from experiences with Direct Payments.

5 FACILITATORS

5.1 The research evidence and accounts of practice and personal experiences contain many examples of what are termed facilitators or levers that help develop the positive outcomes of SDS. These relate to clear policy messages and encouragement, to the role of leadership in developing SDS, the reports from end users and from carers of the benefits of SDS, flexible and transparent policies and procedures, and enthusiasm and good experiences among practitioners.

Policy

5.2 Policy and practice guidelines help support the development of SDS. While the role of personal assistants (PAs) (the employment model most often described in research and other accounts) may be individually negotiated, there is some evidence that this relatively new model of social care support is assisted in policy terms by:

- Clear guidelines, outlining the employee's role and what is expected,^{(142) (164)}
- Policy encouragement of the development of networks of support for individual PAs,⁽¹⁴²⁾
- Encouragement for users to minimise risks to themselves by being good employers, for example, encouraging people to check references and possibly if a PA has a criminal record or has been dismissed from work with vulnerable adults.^{(3) (16) (53) (58) (85) (165)}

5.3 Incorporating **NHS funding** into an IB would significantly increase its size and usefulness according to some studies.^{(46) (120) (135)} (In parts of England and Scotland, the NHS is currently experimenting with individual health budgets).

5.4 LAs should be prepared to **monitor** SDS spend and support plans, as well as to review whether SDS is working well for particular users. They are still responsible for individuals receiving SDS.^{(15) (17) (55) (56) (61) (64) (69) (74) (77) (99) (112) (127) (133) (139) (144) (160) (165) (166) (167)} This may be particularly relevant in the case of older users, because their needs are likely to change over time.⁽¹⁰¹⁾ There are suggestions that using **payment cards** may be an easy way of monitoring individual spend.⁽¹⁶⁸⁾ Theoretically, these can be charged up with money so that there is no need for a separate bank account (which may be difficult for users to establish). It is not clear how such ideas about monitoring relate to calls for 'light touch' approaches (as called for by Homer and Gilder)⁽²⁷⁾ and there is no evidence of how they work in practice across the social care system. Monitoring is said to be **particularly important in rural areas** as people in these locations could become isolated.⁽¹⁵⁾ **LAs may need to take some responsibility for emergency planning,**^{(57) (118)} building this capacity into support plans.

5.5 SDS should not be viewed as primarily or even necessarily a cost-saving exercise. It can be **expensive**^{(9) (68) (95) (114)} and while outcomes may be better they may be more costly.^{(35) (36)} Some argue that government at local and national levels must be prepared to provide extra funds during the

implementation process.^{(98) (103) (104) (106)} This may be easier for larger LAs with more sizable budgets because start-up costs may mean that aspects of SDS are more efficient to run on a larger scale.⁽²⁴⁾

5.6 There is a view that LAs should be prepared to spend **more money in rural areas** for the following reasons:

- To cover higher transport costs;^{(15) (92)}
- Because some older people in rural areas may not want to hire care workers from their immediate local area because they may be embarrassed about exposing vulnerabilities within a small community;⁽¹⁵⁾
- To pay for/set up advocacy services where these do not exist;⁽⁸⁴⁾
- To encourage providers to move into these areas.⁽⁵⁷⁾

5.7 SDS policies/individual support plans should be **focused on outcomes**, not on fitting users into existing services. This will encourage flexibility and creativity.^{(17) (21) (64) (67) (75) (90) (116) (140) (144) (160) (162) (168)}

5.8 Service users should be **consulted and involved** in SDS implementation schemes from the outset to ensure it works.^{(10) (17) (19) (21) (56) (61) (75) (95) (96) (99) (106) (123) (128) (131) (132) (165) (169)} So too, should **front-line staff**.^{(12) (35)}

5.9 Evidence from early schemes is that the **time** at which SDS is offered is important. People in crisis (such as when in very poor health) are not in a good position to make long-term choices about their support. Some suggest that the best time for them might be at first review stage.⁽¹²¹⁾ This might be appropriate for older people in particular.^{(35) (49) (62) (117) (148)}

5.10 Nonetheless, others argue that it should be recognised that SDS is a universal system and that IBs or DPs may not be the 'right' option for every service user.^{(64) (90) (128)} However, there is little evidence of the working of different forms of **deployment**. Some users have welcomed the opportunity to 'split' support, managing some money themselves but leaving the LA to provide other services.^{(33) (66) (100)} This option is said in relation to older people in particular, because they may be more wary of managing money; their needs may be fluctuating or they may not wish for the responsibility of employing or choosing staff. Again this is sometimes said in relation to older people.^{(62) (148)}

Leadership

5.11 It is suggested that **SDS champions** should be identified so that they may spread support for the policy.^{(89) (90) (96) (97) (107) (113) (125) (128) (148)} For example, specific or dedicated DP officers or even a team could be established within each LA^{(94) (107) (125) (128) (131) (160)} or for specific service user groups⁽¹¹⁶⁾ such as mental health users. Furthermore, some suggest that a national forum would enable leadership staff to share best practice.⁽¹⁰⁶⁾ For problems that may not be resolvable at local level, or appear to be commonly experienced, a DP hotline may be a way to offer advice to staff uncertain about specifics.^{(91) (97) (131)}

5.12 Overall, it is widely observed that **strong leadership** is a key enabling factor and that the characteristics of this might include:

- Being able to work with and to motivate teams.^{(61) (88) (89) (90) (98) (112) (113) (126) (129)}
- Being able to work in a discrete or innovative team to develop a new system while the current system is still in place.⁽²⁷⁾
- Being able to work within the LA itself with credibility, and having the ability to work with others' priorities and concerns.^{(27) (32) (37) (61) (69) (88) (89) (92) (93) (96) (105) (109) (113) (122) (128) (131) (132) (133) (135) (148) (150) (152)}
- Central government support from named or discrete teams able to manage political interfaces.^{(84) (92) (105) (122) (150)}
 - This is because targets set by central government increase SDS uptake.^{(94) (107) (125)} There has been a suggestion that targets should be set and then publicised in order to be most effective.⁽³⁾ The costs of this are not seen as unduly high.⁽¹⁷⁰⁾
 - One study concludes that a government lead would be helpful generally to change cultures.⁽¹⁰⁷⁾
 - In New Zealand, a report summarising international experience identifies a need for: 'clear policy and political mandate and leadership'⁽¹⁶³⁾ with strong emphasis on coherence or consistency, a commitment to equity, and accessibility.

5.13 Similar to observations that culture is important within localities (and that this may explain variations in SDS take up),⁽¹⁰⁷⁾ some experiences suggest that a **steering group should be established to support leaders**.^{(32) (93) (106). (129)} The latter report recommends that user representation is helpful on such groups and another report suggests that these groups should be multi-agency and multi-disciplinary.⁽¹⁰⁹⁾ More widely, **multi-agency working** is reported to be essential if SDS is to work effectively.^{(10) (12) (32) (75) (90) (97) (98) (103) (109) (113) (128) (164)}

5.14 Whatever form SDS takes at local levels there are calls for SDS implementation or roll out to have a **realistic action plan and clear implementation procedures**,^{(89) (129)} including the provision of publicity materials.⁽¹⁰⁷⁾

5.15 Several studies have suggested that within the wider LA, **commissioning** procedures may need to change in recognition of the different requirements of SDS. It is suggested that these may entail moves:

- Away from large agencies towards smaller, local provider organisations;⁽⁹⁾
- To greater focus on developing a market within which service users can make choices;^{(59) (116)}
- Away from block contracts;^{(18) (50)}
- To ensure that all user groups are adequately (presumably this also means equitably) served, including people with mental health problems.⁽³²⁾

5.16 Others observe that SDS needs to be part of **wholesale system change** within social care.^{(11) (32) (46) (52) (88) (96) (102) (130) (131) (134) (135) (155) (166)}

User and carer interests

5.17 There is much comment on the need for information about SDS and its optimal characteristics. Similar points are made about the quality of information needed for the workforce, service users and carers:

- It should be accessible and intelligible.^{(20) (22) (23) (29) (32) (40) (58) (70) (83) (92) (97) (105) (109) (111) (121) (127) (128) (132) (139) (152)} Clearly, no-one argues that information should be inaccessible and in England and Scotland a wide variety of third sector groups^{(90) (171)} has recently produced publicity and information about SDS. Such work echoes the long-held views that local support organisations facilitate SDS take up and sustainability.⁽²³⁾ Some studies advocate the production of accessible information⁽¹⁷²⁾ and their general suggestions include using a variety of formats (including, for example, video for those unable to read), targeting information at particular groups, signposting information clearly on websites, and assuring users that information is up to date.
- There have been calls for specifically targeted information for Black and Minority Ethnic (BME) communities.^{(32) (90) (109)} There are reports of the success of outreach work targeted at these and other minority groups,^{(125) (128)} although observations are made that many older people from BME communities in Scotland are not generally aware of social care arrangements.⁽⁸⁷⁾
- SDS should be widely publicised⁽³⁴⁾ among staff in the NHS, and amongst General Practitioners (GPs) (often the first port of call for older service users).⁽¹³⁹⁾

5.18 Users should have access to **comprehensive support** throughout the SDS process of assessment and support planning. However, definitions of comprehensive support are various and not costed in most instances (the Individual Budget evaluation (IBSEN) in England is an exception).^{(35) (36)} Elements of comprehensive support include items that are sometimes ill-defined but the main core appears to be:

- Information about fair pricing for services;^{(35) (106)}
- Advice about service quality;^{(19) (73)}
- Information about what services are available (e.g. a register of PAs);^{(15) (29) (43) (44) (70) (72) (73) (123) (156) (173)}
 - One research overview briefly describes how some Swedish users have formed a group which awards 'quality stamps' to PAs.⁽⁵⁶⁾
- Voluntary/user led support services;^{(10) (15) (22) (25) (30) (32) (34) (46) (50) (56) (60) (62) (83) (84) (93) (105) (108) (115) (117) (118) (120) (126) (128) (130) (152) (168)}
- Peer support networks;^{(17) (20) (27) (40) (65) (77) (89) (92) (93) (97) (120) (136) (151) (for carers)}
- Advocacy services, usually part of independent advocacy;^{(21) (29) (32) (44) (109) (128) (141) (174)}
- Support from LA care managers in completing self- or joint assessments;^{(26) (27) (54) (120) (135)}
- Brokerage services, independent of the LA;^{(17) (40) (47) (59) (75) (92) (101) (135)} but see also the discussion of their limits by Duffy;⁽¹⁴⁵⁾
- Accountancy support;^{(19) (21) (84)}

- Support and training about employment issues,^{(27) (29) (84) (111) (118) (151)} to address user concerns ⁽¹⁰⁷⁾ and the threat of legal challenges about unfair terms and breaches of contract.

5.19 It is important to note that these are sometimes referred to in combination but rarely are the costs and benefits outlined. Who pays for such support is not clear – and the literature does not generally discuss whether this might be the end user and the implications of this.

5.20 There is some evidence that users with strong **social networks** find it easier to benefit from SDS.^{(49) (54) (61) (71) (75) (77) (83) (98) (124) (137) (148) (155) (175)} This may make it easier for schemes that are embedded within the community (seeking to include disabled people within wider society) to make the most of SDS.^{(12) (15) (33) (50) (56) (75) (77) (83) (164) (175) (176)}

5.21 In relation to choice and control and the use of social networks, there are many reports that users often want to be able to **employ family members**. This works best if the process is straightforward or an automatic entitlement.^{(72) (78) (79) (85) (118)} The perceived advantages of this are that:

- It may solve staff recruitment problems;⁽¹⁵⁴⁾
- It is a matter of choice, is culturally appropriate; and is especially desired among BME users, reflected by the relatively high take up of DPs by this group;^{(41) (42) (177)}
- It is effective, particularly when supported by clear employment contracts.⁽¹¹⁹⁾

5.22 Others consider that SDS works best if there are **brokers and advocates who are independent** of LAs and of providers.^{(17) (20) (29) (56) (75) (77) (84) (92) (104) (109) (128)} This might also work well for staff facilitating the planning process, because social workers/care managers may be wedded to traditional services and require some additional input or persuasion to think creatively.^{(45) (64) (162)} There is no evidence of a move to regulate these brokerage and support services, little information about the costs of such services, and not much debate about who should pay for them. Notwithstanding this, there is a view that LAs should be prepared to pay for advocacy (imprecisely defined) services for those users whose families or carers cannot or do not wish to take on this role. For example, Clements⁽¹⁶¹⁾ says that without that without this, carers may feel pressurised to take on heavy workloads. Leaders from the voluntary sector⁽¹⁵⁹⁾ suggest that service users need rights to representation to ensure that they benefit from newly personalised support.

5.23 Many studies suggest that **emergency plans** should be established for users with episodic health conditions,^{(21) (27) (34)} or for all users should unforeseen problems arise (through the use of a contingency fund, or back up staff).^{(21) (30) (57) (79) (118)}

Processes and procedures

5.24 It is widely observed that the Resource Allocation System (RAS) determining the sums entitled to by a service user should be **clear and transparent**^{(63) (75)}

(127) (129) but there is little yet on the systems of appeals, complaints, and discretion, that might underpin the procedural justice of this.

Practitioner perspectives

5.25 Not surprisingly, there are widespread calls that **training** should be available for the following:

- Frontline staff – in general (16) (17) (27) (34) (56) (90) (91) (92) (95) (97) (103) (105) (116) (117) (127) (128) (132) (152) (169) (177)
- Specific staff - some studies have identified training needs among practitioners such as people working in mental health services (89) where communication skills are said to need improvement in one report (29) (
- Among LA social work staff at all levels including people working in areas not traditionally seen as 'front line or direct care, such as administration (1) (3) (22) (32) (52) (71) (93) (94) (102) (105) (122) (125) (128) (129) (131) (150)
- For support workers and voluntary groups;(22) (103)
- For support brokers;(43) (123)
- For carers and PAs, to cover various subjects such as: lifting and handling; (39) (120) (177) support planning; (151) care skills and communication skills; (73) or more generally (93) (97) (123) (142)

5.26 Some of this training relates to changes of professional culture. For example, it is argued that social workers need to be prepared to take risks because things may go wrong, but in order to do so they will have to:

- Be confident that there will be a move away from the 'blame culture' affecting professional practice;(9)
- Benefit from LA support for risk taking, for example, through a 'risk enablement panel' allowing frontline practitioners to consult with others (69) (120) (there is little evidence of how this works in practice);
- Encourage users to be aware of and manage their own risks (with training if necessary). (47) (49) (53) (116) (139)

5.27 While there are suggestions that small, local provider agencies may be able to provide better care, more appropriate for the users they serve, (9) (50) (51) (94) (164) it is noted that they may operate in isolation. **Networks** may help these agencies share best practice. (123) (164)

Summary

5.28 The facilitators identified often draw on material related to pilot projects and innovations and so the evidence that they provide needs to be interpreted in this context. Few are backed up by cost-benefit or cost-effectiveness analyses. There are frequent observations that communications with services users, carers and frontline staff enhance confidence and clarity. There appear to be substantial features in common with the roll out of DPs and wider SDS systems, and local solutions to problems with Direct Payments may be very applicable to SDS. The implications for research on SDS are that there is a focus on implementation and less on sustainability. While there are many

general points made about take-up, there is strong evidence that performance management is a lever to enhancing take up of SDS in the form of DPs. We have very little information on facilitators around blended funding streams or about the most effective ways of sustaining the positive outcomes of SDS over the long term.

6 OVERALL SUMMARY

- 6.1 In this summary we reflect on some of the main points that have emerged in this review that may be relevant to the development of SDS in Scotland and the key aims of such changes.
- 6.2 There is significant agreement about the perceived barriers to the development of SDS. There are also numerous comments about ways in which SDS may be facilitated. Many of these relate to DPs and there is very little evidence about other forms of deployment. Some barriers and facilitators are linked – for example, lack of information is a barrier and good or accessible information appears to be a facilitator. Similarly, lack of legal clarity is a barrier, while clarity about legal responsibilities appears to assist users, carers and staff alike.
- 6.3 Other areas are not so simple. This is exemplified by concerns about risk and cost-effectiveness, and what is regarded as the proper or legitimate use of public money. In the longer term, barriers or limits to an individual user's choice may be affected by the choices of other users (such as the viability of day centres). These are not simple trade-offs. None of the research scrutinised for this review took place in the context of the current recession. This is an important point that may affect the art of the possible. We have very little evidence about the best ways to monitor SDS but there are suggestions that what is across the board 'light touch' monitoring may enhance risks at a number of levels. These are matters for wider public debate in Scotland and beyond.
- 6.4 The theme of the desirability of reduced bureaucracy and less red-tape occurs in several commentaries and is touched upon in a small number of studies. The matter relates to perceptions and the balance between over- and under-protection. It also relates to the intentions to blend funding streams because these may have different accounting models and systems of scrutiny.
- 6.5 Leadership is less frequently disputed as a necessity for such a change process, however, most of the commentary and experiences reported around leadership are in the context of SDS as an innovation rather than mainstream activity. Moreover, while leadership might be called for, it is sometimes lacking in specificity about where this responsibility lies. When talking of 'local authority leadership', for example,⁽¹⁷⁸⁾ who is being seen as responsible? Councillors? The director or his/her delegates? The precise parameters of leadership are unclear. Uncertainties about legal and risk management responsibilities need to be addressed at national levels; other leadership responsibilities at local level may relate more to communications and workforce development.
- 6.6 Finally, the availability of transitional funding is regarded, not surprisingly, as a helpful spur for innovation by those who are likely to be the beneficiaries, but there is little evidence about the long term effectiveness of this and its impact on other areas, parts of the system, or other groups of users that might have similarly welcomed any or extra resources. All these comments support the importance of a system wide approach to the roll out of SDS.

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