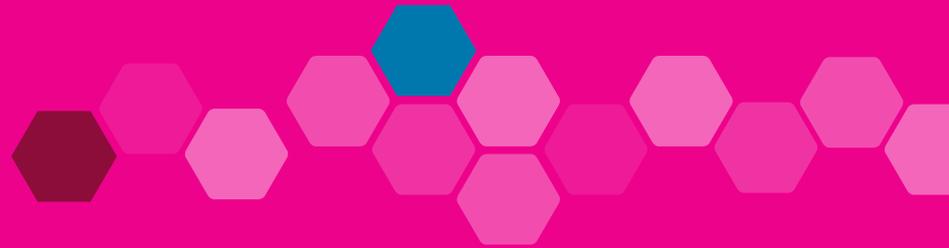




# Self-directed Support Implementation Study 2018. Report 2: Evidence Assessment for Self-directed Support



**HEALTH AND SOCIAL CARE**

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# 1. Introduction

In November 2017, the Scottish Government commissioned a consortium of Blake Stevenson Ltd, Rocket Science and the York Health Economics Consortium (YHEC) to conduct a study of the implementation of self-directed support which will contribute to and help to shape ongoing national monitoring and evaluation.

The original brief was for a commission which covered three interconnected elements:

- A: an Evaluability Assessment of self-directed support;
- B: research on the economics/resource implications of self-directed support; and
- C: research on Option 2 in practice.

It was proposed that case studies were a good approach to address research questions related to elements B and C. Through discussion at the Research Advisory Group (RAG) for this project, it was agreed that a small number of detailed case studies would explore the various ways self-directed approaches are being implemented across user groups.

Four reports, including an overview of findings across the other three, have been produced to detail the methodology and findings of this study:

- Report 1: the SDS Change Map;
- Report 2: Evidence Assessment for Self-directed Support (this report);
- Report 3: Self-directed Support Case Studies; and
- Report 4: Summary of Study Findings and Implications<sup>1</sup>

## Strategic context

The Scottish Government launched *Self-directed Support: A National Strategy for Scotland (SDS Strategy)*<sup>2</sup> in 2010. The strategy set out the Scottish Government's aim to mainstream a self-directed approach to the delivery of care and support. This formed part of a wider shift towards personalisation, co-production and assets-based thinking in social care, in contrast to the case management approach brought in by the NHS and Community Care Act 1990.

Self-directed support, and the core principles underpinning it, represented a change in the relationship between supported people, commissioners and providers, with more choice and control given to supported people and more

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<sup>1</sup> All four are published on the Scottish Government's main website: [www.gov.scot](http://www.gov.scot)

<sup>2</sup> <https://www2.gov.scot/Publications/2010/02/05133942/0>

flexibility required of providers and commissioners. It encourages more creative solutions to meet people's support needs. This has entailed a significant cultural shift for some services, from making decisions **for** supported people to making decisions **with** supported people.

Self-directed support was given a statutory footing with the Social Care (Self-directed Support) (Scotland) Act 2013 which was implemented from 2014. The legislation requires local authorities to offer individuals a range of options when they are thinking about how to meet their social care outcomes and health and social care services. These options are:

- Option 1: The individual or carer chooses and arranges the support and manages the budget as a direct payment;
- Option 2: The individual chooses the support and the authority or other organisation arranges the chosen support and manages the budget;
- Option 3: The authority chooses and arranges the support; and
- Option 4: A mixture of options 1, 2 and 3.

The Self-directed Support Strategy Implementation Plan 2016-2018 states the current priority is to “consolidate the learning from innovative practice and the application of guidance; and to embed self-directed support as Scotland’s mainstream approach to social care.”<sup>3</sup>

Audit Scotland’s progress report on the implementation of SDS<sup>4</sup> notes that not everyone who asks for social care or support is eligible to receive it. Each local authority is responsible for setting local eligibility criteria for access to social care services, based on national guidance produced by the Scottish Government and COSLA. Local authorities assess people’s needs in partnership between the assessor, the person with social care needs and, if appropriate, a family member or carer. Anyone assessed as being eligible for social care can expect to have a discussion with their social worker about the personal outcomes they want to achieve, what support they need to reach these, and how much control they would like over arranging and managing their support.

Self-directed social care applies to all user groups and age groups. This includes children and adults as well as older people, people with disabilities and people with mental health problems. The main exception is people receiving re-ablement services (short-term support to help people regain some or all of their independence). Where the person lacks the capacity to provide consent themselves, a carer or guardian can apply for power of attorney or guardianship so they can make decisions on the person’s behalf.

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<sup>3</sup> <https://www2.gov.scot/Resource/0051/00510921.pdf>

<sup>4</sup> <http://www.audit-scotland.gov.uk/report/self-directed-support-2017-progress-report>

The Audit Scotland progress report acknowledged that these changes to provision came at a time when public sector budgets were under significant pressure due to the ongoing financial constraints, while there is increasing expectations and rising demand for health and social care support, and when there are social care workforce shortages. All of these have contributed to a slower than expected speed of implementation of person-led and person-centred support and, in some cases, resulted in limited choices for supported people.

Audit Scotland<sup>5</sup> also identified that the integration of health and social care has likely further slowed the pace of self-directed approaches being mainstreamed.

## **Evaluability Assessment**

One of the main aims of the study was to produce a refreshed set of key research questions for the ongoing monitoring and potential evaluation of the move to self-directed support and the changes following from this. This assessment began with a review and refinement of existing draft logic models through a theory of change exercise. This process led to the creation of the SDS Change Map for effective policy delivery, which captures specific outcomes identified by a range of stakeholders. Report 1 details this process and the elements of the change map.

After creating the SDS Change Map, an assessment of existing evidence helped to create a revised set of research questions for future monitoring and evaluation, as well as looking at the economics/resource implications of self-directed approaches. The assessment of existing evidence included:

- a literature review of other evaluations of similar programmes;
- a review of current data collections in Scotland that potentially relate to self-directed support; and
- the production of case studies to explore the various ways self-directed approaches are being implemented across user groups and the potential for scaling up and replicating (Report 3).

## **Structure of this report**

This report sets out the findings from the assessment of evidence sources and the implications for monitoring and evaluation of self-directed support; and proposes ways forward to monitor and evaluate the policy over the next five years.

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<sup>5</sup> <http://www.audit-scotland.gov.uk/report/health-and-social-care-integration-update-on-progress>

Chapter 1 reviews the available literature, Chapter 2 presents a literature review, in Chapter 3 we assess the current data collections and evidence of self-directed approaches to care and support, and in Chapter 4 we present the evidence from the case studies.

In Chapter 5 the recommendations for future evaluation and ongoing monitoring are presented, and Chapter 6 provides an overall summary of this report.

## 2. Literature review

The purpose of the literature review was not to identify the conclusions of previous evaluations, but to identify methodological approaches and limitations from evaluations of similar policies, strategies and programmes to inform the options appraisal.

The key questions for the review were:

- What quantitative indicators have been/are being collected?
- What qualitative questions have been asked?
- What quantitative and qualitative methods have been employed?
- What challenges and limitations have occurred?
- Have any key areas emerged that should be considered for a future evaluation of self-directed support?

### Methods

Whilst the approach was not a formal systematic literature review, many of the principles of systematic reviewing were followed – notably for the searches. The methodology for the literature review is described in Appendix 1. Appendix 2 contains a list of the references extracted and Appendix 3 provides further details of the studies included in the review.

### National evaluations of established programmes

Of the ten national evaluations of established programmes, nine were in England (1-8, 10) with all looking at individual budgets or direct payments covering their impact on all supported people or the following groups:

- LGBTQI+ disabled people
- People with dementia
- Older people
- Carers
- Front line practitioners
- Managers
- Councils.

An Australian study (9) evaluated Individual Funding – a similar scheme to self-directed support or portable funding packages – and its impact on supported people, services and government agencies.

The methodologies for all evaluations used a mixture of surveys, interviews and routinely collected monitoring data. Data extracted from each study is shown in Tables A3.1 and A3.2 in Appendix 3.

### **Local evaluations of established national programmes**

Two studies were extracted providing methodological evidence from local evaluations of established national programmes (11-12).

One study from Essex (11) looked at the impact over a three-year period of individual funding on the same group of carers, supported people, families and providers using a longitudinal methodology. A study from Illinois (12) evaluated the Home-Based Support Services Programme for Adults (HBSSP) using a one-off survey. Data extracted from each study is shown in Tables A3.3 and A3.4 in Appendix 3.

### **National evaluations of pilot programmes**

Of the six evaluation reports/published studies extracted, five were in England covering pilots of individual budgets (13, 15-18) and their impact on older people and other adults, carers, disabled children and their families, and people in long term residential care, as well as services engaged with these people. One study from Germany (14) looked at the impact of personal budgets on people with long-term care insurance. Data extracted from each study is shown in Appendix 3 (Tables A3.5 and A3.6).

### **Local evaluations of pilot programmes**

One study evaluated a pilot project of support, advocacy and brokerage in three local authorities in England (19). Data extracted from the study is shown in Tables A3.7 and A3.8 in Appendix 3.

## **Summary of issues from review for evaluability assessment**

### **Economic evaluations**

There was a paucity of studies that undertook full or partial evaluations of self-directed support-type policies or interventions with only six attempting to address any aspect of economic impact [2,14-17,19]. Of these six studies, only one was a national evaluation of an existing programme [2], four only dealt with estimating the costs of delivering individual budgets or direct payments [2,14,15,19] with the evaluation of the national existing programme [2] only providing a point estimate of costs and not considering change (as the programme was already in place no data could be gathered on costs of support before the programme). Collecting high quality cost information that is reliable was frequently raised as a challenge across evaluations whether collected from families or practitioners.

One study calculated the cost per satisfied family [17] (as judged by a survey) but the authors acknowledged this could not be compared to any other policy or intervention or even a 'before' scenario. As no a priori assumption had been

made on what would be an acceptable cost per satisfied family the analysis was of no real use to evaluators or decision makers.

A further study calculated cost-effectiveness ratios based upon responses to the General Health Questionnaire (GHQ) and the Adult Social Care Outcomes Toolkit (ASCOT) [19]. This was undertaken as part of the Individual Budgets Pilot Programme which had a comparator cohort not receiving individual budgets. As such the methodology is not replicable to self-directed support in Scotland which is already established nationwide.

The evidence from the literature review shows the difficulty in evaluating self-directed support economically, at least in terms of whether it is a better way of allocating resources in social care than other methods. What the literature highlights is that identifying the costs associated with delivering care with choice and control and individualised outcomes has either not been considered in previous evaluations or has proven challenging to the point that the evidence is not robust and meaningful. We were not able to identify any economic evaluation of existing national programmes or policies, which is understandable given it is difficult to isolate the change in resource use that has occurred once a programme has been established.

### **What is a 'good conversation'?**

A key component of self-directed support is the good conversations that take place between social workers and supported people to ascertain what is the right option for delivery of social care to them. Whilst this can be in qualitative descriptions of the assessment process in pilot evaluations identified in the literature review, no attempt was made in any evaluation to try to understand quantitatively whether options had been fully explained by social workers, or qualitatively in national evaluations of established programmes. In any case, whether just explaining options would constitute a 'good conversation' which was enabling rather than directing choice is unclear. The literature review therefore did not provide evidence on how a good conversation should be evaluated or monitored or how the quality of assessment can be captured.

### **Quantitative vs qualitative evaluation and the role of a control group**

Of the ten national evaluations of established policies or programmes identified only one - of Personal Health Budgets (9) - involves a form of ongoing national evaluation or monitoring (using a bi-annual survey of supported people). The remaining evaluations were ad hoc of specific groups of supported people or stakeholders, or focused on specific issues.

Where national data on supported people receiving personalised social care (which is similar to the Scottish approach) is captured routinely – as in Australia and England – the data has either only appeared in audits or ad hoc evaluations and in both cases has been criticised because of a lack of standardisation at a local authority or state level as to how personal budgets are recorded.

The methodological focus of nearly all national evaluations of established policies or programmes was qualitative. Outside of the POET data collection described below, where quantitative data was collected it was either through a targeted survey of the group of interest for the evaluation (such as Directors of Social Services) or from nationally available sources to address very specific questions (such as the percentage of people with personal budgets). No national evaluation considered or attempted to construct any form of control group. The lack of a quantitative counterfactual necessarily limits the conclusions that can be drawn from quantitative data around impacts. In any case, with national level existing policies programmes it is not clear how a control group could have been constructed. This may explain why evaluations of existing national level policies and programmes have focussed on qualitative research on specific issues or for specific groups.

### **Evaluation of high-level outcomes**

Evaluations of both existing and pilot programmes have attempted to capture high level outcomes on patient wellbeing and satisfaction. In only one case – again the evaluation of Personal Health Budgets (9) –this is an ongoing evaluation using the bi-annual Personal Outcomes Evaluation Tool (POET) produced by In-Control.

In pilot evaluations, several other existing tools to measure outcomes in social care and health have been tried – such as the Adult Social Care Outcomes Tool (ASCOT), GHQ-12 or EQ5-D – as well as bespoke survey questions, usually including simple self-reported responses on a Likert scale.

The tool chosen to capture outcomes may be less important than the approach to administering the tool itself. Whilst census-type surveys of local authorities have been shown to have some success, in the case of supported people and services the results, in terms of return rates, have often been disappointingly low. There is a danger in assuming a blanket approach to surveying will result in a meaningful sample size because even if the absolute numbers returned are large, the likelihood of self-selection bias in those completing the surveys is high. Several different approaches to survey distribution have been trialled in the published evaluations including telephone and online surveying. These would seem to suggest that purposeful sampling - whilst more expensive per completed form - is likely not only to result in higher response rates but also a more representative sample than a blanket survey.

### **Supported people with different characteristics**

A key theme arising from evaluations was the different challenges faced by supported people and how these vary not only in relation to underlying need (such as dementia) but also in relation to characteristics such as sexuality. Similarly, the impact on carers can depend on the relationship the carer has with a supported person. Any ongoing monitoring therefore needs to capture important characteristics of both supported people and carers to ensure that self-

directed support is working for everyone and a focused evaluation may be required to understand how the characteristics of people and carers impacts on the choice and control they are able to exercise.

### **Need for a longitudinal approach**

Several of the evaluations identified highlighted the need to be able to monitor change over time – not just at a population level but for individual supported people, their carers and families and service providers. This would enable evidence to be gathered of how the choice and control offered by initiatives such as self-directed support results in changes in long-term outcomes and how the ability to exercise choice and control adjusts over time as circumstances change.

### 3. Data collections and evidence of self-directed approaches to care and support

#### Current and proposed data collections

Data is being collected on aspects of self-directed support as part of the Social Care Survey and the Health and Care Experience Survey (HACE). An initial SDS User Experience Survey has also been piloted. An assessment of the effectiveness of using evidence from each of these collections for monitoring and evaluation against the SDS Change Map is given below.

Representatives from the Care Inspectorate were contacted as part of the assessment of data collections and evidence that could aid an evaluation of self-directed support. Whilst the Care Inspectorate does not routinely collect data or evidence that could feed into an evaluation of self-directed support, any future evaluation should seek to make contact with the Care Inspectorate to identify what evidence was available at that time.

#### **Social Care Survey (Scottish Government national survey)<sup>6</sup>**

**Strengths:** An established census gathering information on everyone in Scotland who receives self-directed support. The survey questions include the self-directed support option chosen, gross budget and who contributes to it, for example, social work, housing, and what it is spent on, for example, personal care. The data collected each year is read-through indexed which means that it can be linked to other data sources, such as health data (subject to approval).

**Weaknesses:** As highlighted by the case studies reports, there is inconsistency in the way self-directed support is implemented across the country and, as a result, it can be difficult to compare data across Scotland and there is no indication about the extent to which supported people have ‘good conversations’ during their assessment which reflects what matters to them and the support they need.

#### **Health and Care Experience Survey (Scottish Government national survey)<sup>7</sup>**

**Strengths:** A large scale bi-annual survey that gathers information about health and care service users’ experience of care, including their awareness of the help, care and support options available to them, whether they had a say in how their help, care or support was provided and whether they felt treated with respect and compassion.

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<sup>6</sup> <https://www2.gov.scot/Topics/Statistics/Browse/Health/Data/HomeCare>

<sup>7</sup> <https://www2.gov.scot/Topics/Statistics/Browse/Health/GPPatientExperienceSurvey>

Weaknesses: The survey is not targeted specifically at people eligible for social care and does not ask people directly about social care. The sample is drawn from all adults in Scotland registered with a GP practice. As a blanket survey there is significant chance of self-selection bias.

### **SDS User Experience Survey (SDSS) 2016<sup>8</sup>**

Strengths: Contains quantitative data about whether supported people are having their options explained to them and qualitative data about users' views of the conversations they have had with social care workers.

Weaknesses: This was an ad hoc survey originally piloted with a sample of supported people from three local authority areas and now involving eight more authorities.<sup>9</sup> In the pilot, the low response rates meant that insufficient data was collected to enable statistically significant conclusions to be made about supported people's experiences across Scotland.

### **Summary of current evidence against the SDS Change Map**

The Health and Care Experience Survey of the Social Care Survey currently collect limited information that directly evidence or provide proxy data for the SDS Change Map.

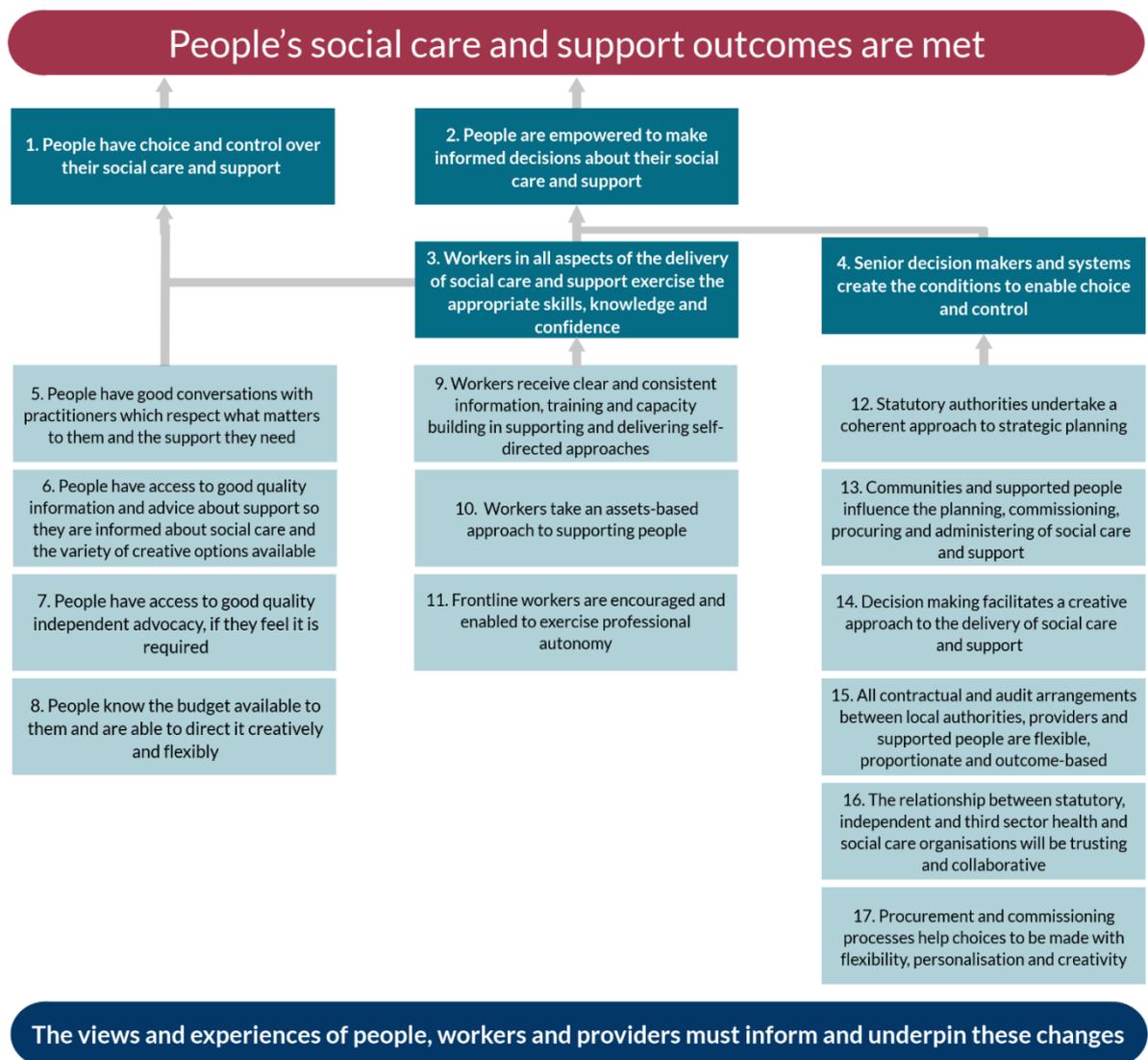
In the SDSS User Survey, there were questions that, in their current form, would provide evidence against the following changes from the SDS Change Map:

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<sup>8</sup> <http://www.sdsscotland.org.uk/wp-content/uploads/2016/09/SDS-User-Experience-Survey-Report-Full-version-2-4.pdf>

<sup>9</sup> At the time of writing, the SDS User Survey was being re-run across a number of local authorities, with a new set of questions.

## SDS Change Map



## **Outcome 5 People have good conversations with practitioners which respect what matters to them and the support they need**

The following questions from the SDSS User Experience Survey are relevant:

- I had a say in how my help, care or support was arranged (extent to which the respondent agrees).<sup>10</sup>
- Did the person you met discuss the four options with you?
- The person who I met to discuss my support needs explained things clearly to me (extent to which the respondent agrees).
- The person took notice of the things that matter to me (extent to which the respondent agrees).<sup>11</sup>
- The person understood what I wanted (extent to which the respondent agrees).

## **Outcome 6 People have access to good quality information advice about support, so they are informed about social care and the variety of personalised options available**

The following questions in the SDSS survey would be appropriate to use as a proxy for impact in this area:

- Did you know there was a new way to arrange your support (called self-directed support)?
- Did you feel you understood the options well enough to choose which option you wanted?
- Did you get help or information about choosing how to arrange your support from someone or somewhere apart from the professional you met to discuss your support needs?
- What source did you go to for information? (included family member etc., and professional advocacy organisation).

## **Outcome 7 People have access to good quality independent advocacy, if they feel it is required**

The following questions in the SDSS survey would be appropriate to use as a proxy for impact in this area:

- Did you get help or information about choosing how to arrange your support from someone or somewhere apart from the professional you met to discuss your support needs?
- What source did you go to for information? (included family member etc., and professional advocacy organisation).

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<sup>10</sup> This question is also in the Health and Care Experience Survey

<sup>11</sup> This question is also in the Health and Care Experience Survey

## **Outcome 8 People know the budget available to them and are able to direct it creatively and flexibly**

The following questions in the SDSS survey would be appropriate to use as a proxy for impact in this area:

- Have you been told the amount of money you can spend on your support?
- Option 1 - I can spend my money as I want in order to meet my support needs (extent to which the respondent agrees).
- Option 1 - I can do what I want to do, and when I want to (extent to which the respondent agrees)
- My support package is tailored to my needs (extent to which the respondent agrees).
- I can choose what support I receive (extent to which the respondent agrees).
- I have control over who provides my support (extent to which the respondent agrees).
- Option 2 – Were you able to choose who manages your budget?

For Outcome 9 – Outcome 17 there are no questions in any of the current surveys that could be used as proxies for impact against those changes.

In the next chapter, the evidence from the case studies is considered.

## **4. Evidence from the case studies**

As part of the wider research conducted around self-directed support, thirteen case studies were produced to highlight how self-directed approaches were working in practice across a sample of six local authorities in Scotland.

The case studies were not evaluative. Neither was their primary focus to inform the national monitoring. In their design and delivery, they instead provide useful context and information that have implications for future national evaluation and research on social care in Scotland.

### **Case study approach as an evaluation activity**

The aim was to undertake case studies exemplifying social care, accessed under the four options across a diverse population. This ambition was tempered slightly by the ability to identify and secure the participation of individuals. The individuals within the case studies are predominantly older or middle-aged people with degenerative diseases, neurological conditions, people who experienced a life changing critical incident and some individuals with a genetic disorder.

Undertaking the case studies was resource intensive and took several months to complete, which is important to be aware of when considering a case study approach as part of future research and evaluation of social care. Each case study involved working with local authority officials to identify individuals and gaining informed consent and then liaison with the individuals, their families/carers, their social worker and providers to arrange face-to-face and telephone interviews. The discussions were followed up with further email exchanges or telephone calls to clarify facts and details and for participants to check the written case study account. The involvement of all these contributors provided the detailed insight into the experience of self-directed support and, if this had been an evaluation, this would help us to understand the extent to which self-directed support is meeting its policy outcome in this small number of cases. However, only individuals who wanted to be involved with the research were the subject of case studies which potentially increases significant bias to those who have had positive or negative experiences they wish to share – neither of which may be representative of the experiences of most people.

Given the depth of information provided, case studies could be a valuable option for evaluation of specific aspects of social care but the resource intensity required for case studies means they would be difficult to include as part of ongoing evaluation and monitoring.

### **Local authority engagement**

Whilst some local authorities were keen to engage with the case study research, in other areas it was challenging to get full engagement and considerable effort was required by researchers to gather sufficient information to construct a case

study. The case studies were voluntary, not designed to be evaluative and did not require the level of challenge and evidence as evaluation would. It was, however, difficult to obtain sufficient information for some of them, largely because it was not easily accessible or in some cases not available at all. This is exacerbated by the time pressures on local authority staff, and an inevitable disadvantage of case studies is that they rely on individuals' recall of events and some details might therefore be missing. This highlights how difficult evidence gathering and engagement for evaluation may prove to be.

### **Variation of delivery between and within local authorities**

Choice and control were not uniformly embedded in statutory care services across the case study areas. This would be expected and would be explored in an evaluation, especially if the approach used a robust change map.

What is potentially more challenging for an evaluation, is the varying implementation of choice and control within local authorities.

In some case study areas, this variation was because choice and control and personalisation were more readily available to some groups, such as younger adults with disabilities or parents of children with disabilities. In such local authority areas, evaluation would need to ensure that the focus is not only on where the authority is doing well, but also on understanding why choice and control is not being offered to all.

In other case study areas, the variation in the degree of choice and control available is not only between client groups but there is variation at individual social work team or worker level. The individualisation, choice and control a supported person experiences is shaped by their social worker and how that professional can operate within the system.

An evaluation needs to have sufficient depth to be able to unpick issues of variance in the offer of choice and control that may both explain but also be masked by aggregate statistics currently collected or potentially collected in the future.

### **Resource allocation panels**

Resource allocation panels were not in use by all authorities but where they were they were seen as a crucial part of people being able to direct their social care support. In the case study areas with panels, these involved social workers and budget holders and meetings at least fortnightly. There were two main reasons for their use. Firstly, to ensure that overall budgets for social care were not being exceeded at a local authority level. Secondly, the panels were seen as a means to test and develop creative solutions to people's needs and provide social workers with the confidence to move from a quality conversation to a care plan that was truly bespoke to meeting an individual's outcomes.

The constraint with such panels is time. They require considerable investment in social worker and management time to attend. Currently, resource allocation panels identified in the case studies predominantly consider social care support under Options 1, 2 or 4. It is unclear whether there would be sufficient capacity to hold such meetings for every social care assessment which identifies the need for support (for example, in North Lanarkshire home care for the elderly, a significant proportion of all social care is provided under Option 3 and does not currently go to the resource allocation panel) and there are indications that the lack of local authority capacity for such panels may be limiting how self-directed support is implemented for all groups of service users in an authority.

An evaluation needs to consider how panels are used in the process of individual decision-making, if they are not being used for decision-making related to individual funding requests. For an economic evaluation, the resources dedicated to these processes needs to be considered.

### **The need for review and changing circumstances**

Several of the case studies highlighted how changing circumstances altered not only the support needed for individuals to achieve their outcomes, but also which outcomes they wanted to achieve, the priority of those outcomes and/or how much responsibility they wanted in terms of managing their support. Whilst social workers need to be pro-active to address changing circumstances as they arise and maintain ongoing relationships with supported people, the need for reviews to be conducted in such a manner that individuals can speak freely about how their support needs and desired outcomes change should not be overlooked. Several case studies also highlighted how circumstances in terms of funding available and priorities for funding can also change rapidly within an authority. The rapid changes that can take place for individuals and authorities highlight the importance of regular monitoring, not only of a random sample of individuals in an authority to provide a snapshot, but also of the need for longitudinal studies with regular monitoring points with a cohort of individuals followed over time.

### **Sufficient supply and ensuring quality of supply**

Challenges in the social care market in terms of the supply of care workers are well documented and reported. The case studies provided further evidence of the impact of supply of the care workforce on the outcomes individuals are trying to achieve. Even where a budget was provided for individuals to recruit people to provide support, it was not always possible to find suitable people. It is also potentially concerning that non-traditional methods of recruitment are being used and it is unclear how appropriate checks and balances on the quality of care a person can provide (as opposed to basic safety through criminal records checks and registration with the Scottish Social Services Council) are being undertaken. In addition, it is not clear how people employed through Option 1, or in some cases Option 2, receive ongoing training and support in their role to ensure the quality of support they can offer is - at a minimum - maintained and ideally

improves over time. Whilst aspects of this were picked up in the SDS Change Map, the case studies reinforced the importance of an evaluation to gather information on how local care markets are being managed and developing and how quality and stability of provision is assured.

## **Does the use of the four options to access social care reflect full implementation of self-directed support?**

The case studies highlighted the different ways that local authorities interpret, deliver and record the four self-directed support options. Some authorities only record as having 'self-directed support' those individuals who went through their full process (an assessment including the good conversation, a resource allocation calculation and then a decision process on the care package from a range of provider options). In other authorities essentially anyone accessing social care or support is assumed to have made an informed choice and recorded as having 'self-directed support'. This has significant implications for the collection and comparison of high-level statistics on self-directed support from across local authorities in Scotland.

Although the four options are explained within the legislation, translating them into practice has varied across local authorities. For instance, within the case studies, there are examples where Option 1 does not offer the same degree of choice and control in different places. The case studies also exemplify where Option 1 can reflect a removal of choice for individuals who would rather not have to manage their own budget but for whom this option maximises their personal budget. The boundaries between the options were not always clear across the different authorities.

## **Evaluating the economics of self-directed support**

Understanding the difference in local authority resource use and costs associated with implementing self-directed support requires an understanding of the current difference in resource use compared to previous social care practices. The case studies highlighted that the additional administrative and social work resource needed for choice and control is predominantly in the assessment process and in resource allocation panels. Ascertaining resource use in either panels or in the assessment process proved difficult to gather, with only one site (North Lanarkshire) providing information that allows the costs of both the assessment and allocation process to be estimated.

A full evaluation of the economic and resource implications of self-directed support would ideally include a comparison of current estimates of local authority resource use on assessment and allocation activities compared to previous practice. In the absence of any established system for recording relevant data, such a comparison would require research into time spent on assessment and allocation processes before 2014 and an understanding on a case-by-case basis

of how much the local authority was already engaging in practices to support choice and control and personalisation. It is likely to be challenging to involve local authorities in such work and they may not be in a position to provide the necessary data.

Furthermore, any attempt to evaluate whether the shift to self-directed support has led to health and social care system-wide costs and benefits will inevitably run into potentially intractable difficulties, not least those arising from the range of services and support that contribute to an individual's personalised outcomes and well-being. In addition, compared, for example, to many medical interventions or narrower service interventions with less diverse target populations, it is extremely difficult to monetise social care and social care outcomes or estimate returns on investment – and this has become even more so the case with the move to self-directed support.

The case studies therefore reinforced how challenging it will be to undertake an economic evaluation of self-directed approaches to social care.

## 5. Recommendations for future evaluation and ongoing monitoring

Building on the findings from the literature review, the case study research and the appraisal of existing evidence collected, this chapter presents options and recommendations for modifying and adapting existing data sources for ongoing monitoring (and potentially to feed into future evaluation) as well as recommendations for future ad hoc research and evaluation(s).

### Ongoing monitoring

The **Health and Care Experience Survey** is not currently a useful mechanism for collecting data on self-directed support. The questionnaire is largely about people's experience with GPs. Additional questions would be required rather than re-phrasing of current questions to ensure that people were aware that they were responding in relation to social care only. As the target audience for this survey is the general public, it may be difficult to ensure that a sufficient number of those using social care would answer this survey.

Similarly, the **Social Care Survey** does not provide a useful mechanism to gather information on self-directed support. The question on implementation can be considered as a proxy for the percentage of supported people who have had a 'good conversation' but it will not be as good as the kinds of information that was collected in the Self-directed Support User Experience Survey.

In addition, as evidenced by the case studies there is an inconsistency in the way the questions are interpreted across local authority areas and it is not a reliable indicator as to whether a conversation actually took place and was truly helpful. Who is included in the denominator may be different in different areas because of either interpretation or local need profile. There is no indication about the quality of the assessment, for example, if the merits of different choices for the individual were discussed in an open and unbiased manner. As shown by the case studies, it is not clear that a focus on option choice is in any case meaningful where the case studies showed that in some areas many people on Option 2 had very limited choice and control whilst in other areas those on Option 3 had substantial choice and control.

The **Self-directed Support User Experience Survey** provides a more targeted and robust opportunity to explore the same issues and to evidence the outcomes in the SDS Change Map. However, the survey has previously focused on the numbers receiving various social care supports rather than the quality of that care.

Given the availability of the Self-directed Support User Experience Survey and a willing organisation in SDS Scotland, we would recommend that the key information on the **Outcome 5** to **Outcome 8** be drawn from a social care user

experience survey modelled along those lines – rather than adapt the Health and Care Experience Survey or the Social Care Survey. To do this, we recommend that the following questions are added to a user experience survey in the future to provide a fuller picture of change in terms of **Outcome 5** to **Outcome 8**:

- Were there any questions you had that they couldn't answer? (**Outcome 5**)
- Were you satisfied with the outcome of the meetings you had with staff? (**Outcome 5**)
- Was this information helpful in understanding your options and what would work best for you? (**Outcome 6**)
- Were there any questions that you were unable to find answers to? (**Outcome 6**)
- Were you aware of the availability of independent advocates to support you? (**Outcome 7**)

As the case studies highlighted, the circumstances of both supported people and local authorities can change rapidly and we would recommend the survey should be undertaken annually with a longitudinal element following a sample of people over several years. Analysis of the responses against individual characteristics should be undertaken to ensure that self-directed support is working for all groups.

Given the move to personalised outcomes that could potentially be hard to collate and monitor in an aggregate form over time, questions on high-level outcomes such as those found in ASCOT should be added to the user experience survey.

## Options for addressing the data gaps

Currently, the key gaps for ongoing monitoring against the SDS Change Map are in the availability of information on:

- **Outcome 9-Outcome 11** which require the views of workers to be captured; and,
- **Outcome 12-Outcome 17** which require the views of Statutory Authorities – in particular, heads of services in local authorities.

To address the gaps for **Outcome 9-Outcome 11**, and **Outcome 12-Outcome 17** we recommend there are several activities that need to be undertaken.

### Survey of workers across social work and providers of social care

The survey should ask questions around the quality of the conversation workers feel they can have with people (evidence for **Outcome 9**), how they can work with people to develop a suitable package of support (**Outcome 10**) and the extent to which they are able to act creatively and with autonomy (**Outcome 11**).

## Suggested worker survey questions

- To what extent do they feel they have clear and consistent information and time to provide appropriate support? (**Outcome 9**)
- How confident are they in discussing Self-directed Support with service users and in helping service users to make informed decisions? (**Outcome 9**)
- How adequate is the training and support they receive to implement self-directed support? (**Outcome 9**)
- To what extent are they able to identify people's experience, knowledge and connections and draw on this to help each person create an appropriate package of support? (**Outcome 10**)
- To what extent do they have clear delegated authority in making decisions? (**Outcome 11**)

## Reporting by all local authorities

Routine reporting by all local authorities needs to be more robust and comprehensive than is currently occurring, and should also include an assessment of:

- **Their approach to strategic planning and engagement with supported people and the community**

Reporting should evidence how strategic planning creates the conditions to enable choice and control at a systems level by, for example, co-ordinating support and developing and implementing appropriate needs assessments. Evidence should also be gathered on how strategic planning has improved the quality of and choice on offer in social care, and how it improves the ease of decision-making for both workers and supported people (**Outcome 12**).

The extent to which – and how - communities and supported people are able to influence the planning, commissioning, procuring and administering of social care and support should also be gathered (**Outcome 13**).

- **How they are facilitating creative solutions**

Reporting should evidence the extent to which decision-making approaches facilitate creative approaches in the delivery of social care and support, both with the individual and with service providers (**Outcome 14**). The extent to which the contractual and audit arrangements between the commissioner, provider and supported people are flexible, proportionate and outcome-based should be described and evidenced (**Outcome 15**) as well as the extent to which procurement and commissioning processes help choices to be made with flexibility, personalisation and creativity (**Outcome 17**). From an economic perspective, the roles of social workers, senior social workers and team leaders, management and local authority finance officers in assessing individual cases is required. Information

therefore should be collected on who is involved in these decisions, the process (for example, whether panels are involved) and how much time is spent on the process by those involved.

### **Engagement with independent and third sector providers providing support through self-directed support**

We recommend that a voluntary survey circulated by a separate body – such as SDS Scotland or the Scottish Government - of all service providers commissioned by statutory services (primarily the local authorities), is required to cover several aspects of the SDS Change Map. The survey should consider the support providers can offer to individuals and their relationship with commissioners of their services.

#### **The individual perspective**

The survey needs to evidence how providers are able to plan in a way that encourages person-centred and person-led social care support, improves the quality of and choice in the offer, improves the ease of decision-making for both workers and supported people. Barriers to choice at an individual level should also be captured, such as the ability to find staff, but any question should be open to allow providers to articulate the challenges they experience rather than leading them to state barriers that the survey writers could anticipate (**Outcome 12**).

#### **The commissioner relationship**

The survey should cover the extent to which providers feel they can operate in a way that facilitates creative approaches in the delivery of social care and support and evidence of where this has occurred (**Outcome 14**). This should cover the extent to which they feel that contractual and audit requirements are flexible, proportionate and outcome-based (**Outcome 15**), how far procurement and commissioning processes help choices to be made with flexibility, personalisation and creativity (**Outcome 17**), and the extent to which relationships between statutory, independent and third sector health and social care organisations are trusting and collaborative (**Outcome 16**).

### **Ad hoc evaluation studies**

Improving national level monitoring as described above will provide a rich evidence base to understand the extent to which self-directed support is generating the changes and outcomes it was intended to achieve, and how this develops over time. However, both the case studies and the literature review highlighted that the implications and challenges of introducing choice and control are many, varied and potentially unforeseen. There are potential challenges for specific groups or areas of specific delivery – such as market management – where national monitoring may only ever be able to give a partial picture. Ad hoc evaluation or research in specific areas as stand-alone activities (or, for example, as part of other activities such as thematic inspections by the Care Inspectorate)

will be required to understand and report in more depth on specific issues in the SDS Change Map. The methodologies employed in the existing evaluations identified in the literature – surveys and qualitative interviews – should be the focus of such evaluations.

Case studies may also have a role for deep analysis of specific issues, but our experience of the difficulty in undertaking them suggests they would be very resource intensive and so therefore should only be considered if they provide information against the SDS Change Map that cannot be addressed through more routine qualitative collection such as ad hoc surveys and interviews or through the routine monitoring data collection proposed, including any longitudinal surveys.

### **Economic evaluation**

Economic evaluation requires information on both resource use and outcomes, evidence that is currently entirely lacking in a form that could be used in evaluation or monitoring. It was challenging to locate relevant information in previous studies identified in the literature review.

Collecting data on outcomes through an annual staff survey as suggested previously will start to plug this outcomes gap in evidence. When considering the use of resources, the case studies showed – albeit in a small sample - that there were differences across authorities in the methods employed to enable supported people to identify the outcomes that are important to them and identify the support needed to meet those outcomes and also in the means to assess whether that support package would be funded. The case studies also showed that not all areas were readily able to provide resource use information so any questions asked should take into account potential difficulties or sensitivities around providing this information. We think that these questions are best answered through asking workers simple questions about time spent on assessment, and social care partnerships asking about the processes and time involved in allocating resources – either through panels or some other mechanism.

For social workers, we suggest asking the following questions in the proposed worker survey to assist with economic evaluation:

- How long do you normally spend undertaking an assessment that involves a quality conversation? What is the shortest and longest this can take? Which parts of the assessment take the longest?
- How long would you spend undertaking an annual review? What is the shortest and longest this can take? Which parts of the assessment take the longest?

Asking social workers for this information will provide direct information on the time actually involved in assessment and review. It will also allow differences to be explored within and between authorities as well as between different types of social care (e.g. Children's and Adults' services).

Reporting by all local authorities needs to include information on the roles of social workers, senior social workers and team leaders, and management and local authority finance officers in assessing individual cases. Information should be collected on who is involved in these decisions, the process (eg whether panels are involved) and how much time is spent on the process by those involved.

## **Resource implications**

The proposed additional evidence gathering has funding and other resource implications.

Continuing a slightly expanded version of the Self-directed Support User Experience Survey will require resource for SDS Scotland or another body for the survey's dissemination, promotion, analysis and reporting.

The addition of a survey of staff who administer self-directed support in local authorities will require input from:

- local authorities through staff time to help with the distribution and to encourage staff participation; and
- an organisation to design, administer, promote, analyse and report on the survey .

There are marginal resource implications of collecting the data proposed if a social worker survey is undertaken and additional questions are added to reporting by local authorities. This should be minimal although these questions – as indeed all changes to collection proposed – should be trialled to ensure not only that they are clear and unambiguous but also that they are not overly burdensome in terms of the time they take to complete.

If a survey is conducted of independent and third sector organisations which hold service contracts with statutory services. This will require input from:

- independent and third sector organisations; and
- an organisation to design, administer, promote, analyse and report on the survey .

A reporting requirement should be introduced for local authorities to evidence and self-assess their performance against **Outcomes 12-17**. This will require input from:

- local authorities, through staff time to complete this assessment and buy-in from senior management to hold themselves accountable to their assessment and actions.
- An organisation to design, administer, promote, analyse and report on the survey .

## 6. Conclusions

The assessment of the evaluability of self-directed support looked at published previous evaluations of similar system-wide policies and strategies, reviewed data currently collected in Scotland against the SDS Change Map, and considered evidence from the case study research on potential issues for future evaluation,

The evidence from the literature review highlighted that evaluation of similar systems-wide policies or strategies is challenging - particularly economic evaluation - and almost entirely qualitative. The literature review found no evidence that anyone had ever evaluated 'good conversations'. Several of the evaluations identified highlighted the need to be able to monitor change over time for individual supported people, their carers and families and service providers, and the need for longitudinal research.

The case studies revealed many of the same issues as the literature review, notably challenges associated with economic evaluation, and the need for longitudinal research. They also identified that measures of uptake of the different options in a local authority is not a suitable proxy for genuine implementation of self-directed support and fidelity to its principles.

Current routine data collections are not sufficient to monitor or evaluate against the SDS Change Map and it is recommended that:

- longitudinal research is undertaken with people receiving social care starting from the time of initial assessment;
- a survey of staff who administer social care in local authorities is introduced;
- a slightly expanded version of the Self-directed Support User Experience Survey is used to include a high-level question on social care outcomes;
- a survey is conducted of independent and third sector organisations who hold service contracts with statutory services; and
- a reporting requirement should be introduced for local authorities to evidence and self-assess their approach to strategic planning and how they are facilitating creative solutions to achieve individualised outcomes.

Economic evaluation will remain a challenge with no quantitative counterfactual<sup>12</sup> possible and as such should focus on the time taken by staff in local authorities to deliver choice and control and compare this to the outcomes collected in the expanded SDS User Experience Survey.

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<sup>12</sup> That is, data that compares the outcomes of those having benefitted from a service or programme with those of a group similar in all respects but who have not received the service (a control group).

# Appendix 1: Literature review methodology

## Literature search

Given the wide range of terms that can and are used to describe schemes similar to self-directed support in Scotland, a broad search strategy that was designed to have high sensitivity was developed. As many of the terms also relate to personalised health care, the strategy was expected to have low specificity which would mean a large number of erroneous results that would need removing at the study selection stage.

The reference list from a literature review from 2016<sup>13</sup> was used as a means to check that the strategy was performing adequately and identifying expected studies. The final search strategy is presented in Table A1.1 below.

**Table A1.1: Search strategy**

### HMIC Health Management Information Consortium <1979 to November 2017>

- 1 (individual adj3 service fund\$.ti,ab. (5)
- 2 individual budgets/ (256)
- 3 (individual\$ adj3 budget\$.ti,ab. (127)
- 4 (personal\$ adj4 budget\$.ti,ab. (303)
- 5 ((personal\$ or individual\$) adj3 care planning).ti,ab. (50)
- 6 ((personled or person led) adj3 commissioning).ti,ab. (0)
- 7 (individualised care or individualized care).ti,ab. (139)
- 8 ((care or commissioning) adj5 (intermediary or intermediaries)).ti,ab. (7)
- 9 flexible commissioning.ti,ab. (0)
- 10 ((personalisation or personalization) adj4 (care or commissioning or budget\$)).ti,ab. (82)
- 11 ((selfdirected or self directed) adj3 (care or support or commissioning or budget\$)).ti,ab. (85)
- 12 ((selfmanaged or self managed) adj3 care).ti,ab. (4)
- 13 independent support.ti,ab. (9)
- 14 (cash adj3 care).ti,ab. (74)
- 15 or/1-14 (854)

The search strategy was translated so that it could be run in Medline, Embase and Social Policy & Practice and HMIC.

<sup>13</sup> (Pike B, O’Nolan G, Farragher L. Individualised budgeting for social care services for people with a disability: International approaches and evidence on financial sustainability. Dublin; Health Research Board, 2016)

## **Eligibility criteria for inclusion in the review (PICOS)**

### **Population**

Any person eligible for support from social care, their carers or their families; social care service providers; the social care workforce; and government (local, state or national).

### **Interventions and comparators**

Any interventions that enabled choice or control over the social care provided to a supported person was eligible for inclusion. This included (but not exclusively) interventions that were described as:

- Self-directed support;
- individual funding plans;
- personal budgets;
- direct payments;
- cash-for-care; or
- brokerage or advocacy services.

### **Outcomes**

Any evaluation outcomes were eligible for inclusion (quantitative or qualitative).

### **Study design**

Evaluations of local or national interventions either at a pilot stage or already implemented were eligible for inclusion. Studies that did not state they were evaluations but reported research that was evaluation in nature were also eligible. Studies that just described an intervention were excluded as were simple audits of data.

Studies published as abstracts of conference presentations were not eligible for inclusion. Literature reviews were used only as a source of references to primary studies.

Only papers published in English were included.

**Table A1.2: Summary of eligibility criteria**

|                                      | <b>Inclusion Criteria</b>  | <b>Exclusion Criteria</b>   |
|--------------------------------------|--|---|
| <b>Population</b>                    | Supported people of any age and with any need, their carers or their families<br>Service providers<br>Service brokers<br>Advocates<br>Local Authorities                  |   |
| <b>Interventions and Comparators</b> | Self-directed support<br>Individual Budgets<br>Personal Budgets<br>Direct Payments<br>Cash-for-care<br>Any intervention enabling choice and control for supported people | Interventions related to health care only   |
| <b>Outcomes</b>                      | Any outcomes   | Studies not reporting any outcome data  |
| <b>Study design</b>                  | Full evaluations or reviews of monitoring data   | Literature reviews<br>Audits<br>Descriptive case studies<br>Opinion pieces<br>Conference abstracts<br>News<br>Comments<br>Editorials<br>Letters |

## **Study selection and extraction**

The purpose of the review was not to list in detail methodological approaches taken, but to highlight approaches that could inform an evaluation of self-directed support in Scotland. The focus was on selecting evaluations of similarly embedded national programmes rather than on pilot or local evaluations although any useful learning from such evaluations was still to be captured.

As such, a pragmatic rather than systematic approach was taken to study selection for extraction. All evaluations of national interventions were extracted but only the primary evaluation report was extracted and not secondary reports covering specific issues. The exception was if there was a methodological element or

concern in a secondary report not covered in the primary report. Remaining studies of pilot or local programmes were reviewed in alphabetical order and extracted provided they gave information on methodological approaches or concerns not already extracted from a paper already reviewed.

A data extraction template was developed in MS Excel. Data items extracted were:

- Country;
- Year of research;
- Name of intervention;
- Description of intervention;
- Quantitative outcomes;
- Quantitative methods;
- Key qualitative research questions;
- Qualitative methods;
- Limitations in methods identified by author; and,
- Noteworthy elements of evaluation for evaluability assessment.

In all cases, only data of relevance to an evaluation of SDS in Scotland were extracted.

## **Results**

### **Results of the searches**

The literature searches were conducted on 11-12 January 2018 and retrieved 6,120 unique records.

### **Studies identified and selected**

As suspected, the search strategy had low specificity resulting in 5,972 records excluded at abstract screening. The full texts for 148 records were retrieved and were assessed for relevance. One hundred and twenty-nine documents were excluded at full text stage.

Of the 19 included studies (1-19), ten were extracted as evaluations of existing programmes at a national level (1-10). As self-directed support is an existing programme that is now embedded nationally, these evaluations were the most informative in understanding the issues involved in monitoring and evaluating self-directed support.

A further six studies of pilot programmes (11-16), two studies of local evaluations of national programmes (17-18) and one study of a local evaluation of a local pilot (19) were extracted.

A list of extracted references is included in Appendix 2.

## Appendix 2: Literature review: extracted references

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## Appendix 3: Literature review: details of studies extracted

**Table A3.1: National evaluations of established programmes – summary of studies**

| Study                        | Country | Year(s) of research           | Name of programme                            | Description of programme  | Client group in evaluation                            |
|------------------------------|---------|-------------------------------|--|---|---|
| Alzheimer's Society 2011 (1) | England | Survey point in 2010          | Individual budgets                           | Personal budget managed by a third party or direct payments   | Dementia  |
| Arksey 2012 (2)              | England | 2007-2009                     | 'Choice and Change' study of Direct Payments | Direct payments   | Disabled people with fluctuating or degenerative care |
| ADAS 2009 (3)                | England | Survey point of 31 March 2009 | Individual budgets                           | Personal budget managed by a third party or direct payments   | All   |
| Baxter 2016 (4)              | England | 2011-2012                     | Individual budgets                           | Personal budget managed by a third party or direct payments   | All   |
| Brooks 2017 (5)              | England | 2011-2013                     | Individual budgets                           | Personal budget managed by a third party or direct payments   | Carers  |
| Carers 2012 (6)              | England | 2011-2012                     | Individual budgets                           | Personal budget managed by a third party or direct payments   | All   |
| EHRC 2017 (7)                | England | 2017                          | Individual budgets                           | Personal budget managed by a third party or direct payments   | LGBTQI+ disabled people                               |
| Hatton 2015 (8)              | England | 2015                          | Personal Health Budgets                      | Personal health budgets are an allocated sum of money to help people meet their identified health and wellbeing needs, as planned and agreed between the person and their local NHS team. | People in receipt of a personal health budget         |

|                   |           |                        |                    |   |                 |
|-------------------|-----------|------------------------|--------------------|---|-----------------|
| Fisher 2010 (9)   | Australia | Unclear. Possibly 2009 | Individual Funding | Portable package of funds that can be spent on a range of disability support types. The elements that are portable and range of support the budget can be used for varies from state to state. Can be managed by a third party or taken as a direct payment | Disabled people |
| Woolham 2017 (10) | England   | Unclear. Possibly 2016 | Individual budgets | Personal budget managed by a third party or direct payments   | Older people    |

**Table A3.2: National evaluations of established programmes – evaluation methods**

| Study                        | Quantitative outcomes  | Quantitative methods  | Qualitative questions                                      | Qualitative methods  | Limitations | Notes for EA  |
|------------------------------|--|---|--|--|-------------|---|
| Alzheimer's Society 2011 (1) | Number offered a personal budget or direct payment   | Sample survey   | NR   | NR   | NR          | Difference in outcomes for different service user groups and different methods to capture these outcomes                          |
| Arksey 2012 (2)              | NR   | NR  | What is the experience of using direct payments over time? | Longitudinal study of 30 people in receipt or offered direct payments. | NR          | Shows importance of long term monitoring and evaluation with several key issues developing over time                              |
| ADAS 2009 (3)                | Engagement with market providers and market development, number of people in receipt of PBs, total expenditure on PBs and as percentage of all expenditure, number of authorities supporting self-assessment | Survey of all assistant directors of social care in England | NR   | NR   | NR          | High level survey of all local authorities asking for basic quantitative information on performance around personal budget agenda |

| Study           | Quantitative outcomes   | Quantitative methods                                      | Qualitative questions   | Qualitative methods   | Limitations   | Notes for EA  |
|-----------------|---|---|---|---|---|---|
| Baxter 2016 (4) | NR  | NR  | What are the experiences of front line practitioners, managers and support planners in facilitating choice and control for older people | Interviews with commissioning managers, home care agency managers and older people (30 interviews in total). Focus groups with home care agency managers. Covered three local authorities | Insufficient breadth given only three local authorities | Highlights importance of including service providers and 'middle men' in research |
| Brooks 2017 (5) | NR  | NR  | How are carers involved in support planning, resource allocation and ongoing management? How are carers supported separately?           | Survey of 16 adult social care departments and interviews with lead offices. Thematic analysis of findings  | NR  | Highlights importance of capturing impact on carers                               |
| Carers 2012 (6) | Percentage of carers receiving personal budgets, how they are assessed for PBs, the use of Resource Allocating Systems by local authorities (including fixed upper limits), what local authorities allow carers to purchase | Survey of all local authorities in England (92 responded) | NR  | NR  | NR  | Simple survey of authorities but with relatively high completion rate             |

| Study           | Quantitative outcomes  | Quantitative methods  | Qualitative questions  | Qualitative methods  | Limitations | Notes for EA   |
|-----------------|--|---|--|--|-------------|--|
| EHRC 2017 (7)   | NR   | NR  | What is experience of LBQTI+ disabled people with SDS?   | Survey (numbers unclear)   | NR          | Important to consider issues of equality in the evaluation   |
| Hatton 2015 (8) | Method of budget management, personal health (Likert scale), length of time with budget, value of budget, difficulty in process, impact on people's lives in 15 dimensions (Likert scale), how budget was used   | POET (Personal Outcomes Evaluation Tool) - a self-reported user experience survey tool used at the time the health budget is renewed. Separate tools for service users and their carer  | What works well? What does not work well? What would they change?  | Three free text questions in survey  | NR          | The surveys were deemed evaluation rather than research and so did not require research ethics approval.   |
| Fisher 2010 (9) | Monitoring information on use of Individual Funding (demographic and disability data on users). Perception of outcomes of managing risks and benefits, ability to choose their support, satisfaction with help choosing support and flexibility, frequency of community activity, service provider perception of client control over funding | Questionnaires handed out by researchers but returned by post, email or telephone interview. Managers in services were asked to identify 10 people at random that could complete the questionnaires. Questions were designed based upon what was found to be important from a | How well is Individual Funding performing from the perspective of people with disabilities, service providers and government agencies? | Face to face and telephone interviews with service users, service providers and government agencies. | NR          | Mixed methods evaluation with quite a small sample size for national evaluation where there could be marked difference in method of implementation across states. Interesting approach to questionnaire design by using a bespoke tool based upon what literature had deemed to be important. Problems in Australia about how funding is recorded and in |

| Study             | Quantitative outcomes  | Quantitative methods  | Qualitative questions | Qualitative methods | Limitations  | Notes for EA  |
|-------------------|--|---|-----------------------|---------------------|--|---|
|                   |  | literature review with responses on a Likert scale. Made use of nationally collected data sets for high level stats on usage. An 'easy English' version of the survey was also available that had simpler scales. |                       |                     |  | method of implementation meaning national routinely collected data was not especially robust which is the same in Scotland  |
| Woolham 2017 (10) | Budget amounts. Ease of using budgets and adjusting care required. Health and social care QoL. | Postal survey using bespoke questions on budget and management of care. EQ5D, ASCOT and Sheldhon Cohen Perceived Stress Scale   | NR                    | NR                  | People may not have known whether they received a managed budget. Survey was limited to three sites. Low response rate to survey | Interesting use of combination of bespoke and pre-existing surveys. Highlights importance of ensuring that difference in outcomes by different options chosen should be assessed and that evaluation should not just consider the initial choice but how easy that choice enables flexibility in adjusting care |

**Table A3.3: Local evaluations of established programmes – summary of studies**

| Study            | Country | Year(s) of research    | Name of programme  | Description of programme                   | Client group in evaluation                            |
|------------------|---------|------------------------|--|--|---|
| Ecdp 2011 (11)   | England | 2008-2011              | Self-directed support                                    | All  | Personal budgets as cash payments                     |
| Heller 2012 (12) | USA     | One off survey in 2011 | Home Based Support Services Programme for Adults (HBSSP) | Disabled adults with learning difficulties | Personal budget used to hire personal support workers |

**Table A3.4: Local evaluations of established programmes – evaluation methods**

| Study            | Quantitative outcomes   | Quantitative methods   | Qualitative questions   | Qualitative methods  | Limitations  | Notes for EA  |
|------------------|---|--|---|--|--|---|
| Ecdp 2011 (11)   | NR  | NR   | What is impact of personal budgets on service users, carers, families and providers | Three-year longitudinal study. Methods are not reported but appears to be a survey | NR   | Highlights the breadth of areas needed to be considered in an evaluation and how the impact on the same individuals over time needs to be evaluated |
| Heller 2012 (12) | Mental health and physical health of person with a disability. Satisfaction with services across 19 items on a Likert scale | Caregiver survey adapted from published survey by Matthias and Benjamin (2008). Disabled person survey adapted from SF12 | NR  | NR   | Asked primary care giver to complete survey and so maybe there was responder bias with an over representation of parents in the sample | Identifies some potential surveys and important areas for an evaluation to address about the difference in experience by type of person employed    |

**Table A3.5: National evaluations of pilot programmes – summary of studies**

| Study                 | Country | Year(s) of research | Name of programme             | Description of programme                               | Client group in evaluation  |
|-----------------------|---------|---------------------|-------------------------------|--|---|
| Arksey 2009 (13)      | England | 2006-2008           | Individual Budgets Pilot      | Carers   | The IB pilots were to experiment with different ways of managing and using IBs. As well as direct cash payments, other possible arrangements included care manager-managed 'virtual budgets'; provider-managed individual service funds; payments to third party individuals and Trusts; and combinations of these. |
| Arntz 2011 (14)       | Germany | 2004-2008           | Personal Budget Demonstration | People in receipt of long-term care insurance payments | Personal budgets made as cash payments for people on LTCI. People could choose a mix of cash payments and services with support to self-direct their home care.   |
| Ettelt 2014 (15)      | England | 2013-2016           | Residential care trailblazers | People in residential care                             | Direct payments to care home residents  |
| Glendinning 2008 (16) | England | 2005-2008           | Individual Budgets Pilot      | Older people or other adults                           | Direct payment, notional budget managed by council care manager, third party or trust fund, giving budget directly to a service provider. Support provided on how to make choices and understand budget management and service costs  |
| Graham 2015 (17)      | England | 2011-2014           | SEN&D Pathfinder programme    | SEN and disabled children and their families           | Assessment process, joined up EHC plan and personal budgets across education, social care and health for people up to age 25  |
| Prabhakar 2011 (18)   | England | 2008-2011           | Individual Budgets            | Disabled children and families                         | IB could be delivered as direct payment, through a budget holding lead professional or through a personal budget (essentially mixture of the two)   |

**Table A3.6: National evaluations of pilot programmes – evaluation methods**

| Study            | Quantitative outcomes   | Quantitative methods  | Qualitative questions  | Qualitative methods   | Limitations  | Notes for EA  |
|------------------|---|---|--|---|--|---|
| Arksey 2009 (13) | General health (GHQ-12), QoL (Bowling), ASCOT, COPE Index, self-perceived health and satisfaction with care   | Surveys completed via telephone interview with 100 carers   | Support arrangements, carers involvement in whole PB process, payments made to carers from budgets   | Semi structured predominantly face to face interviews with 24 carers  | NR   | Carers element of larger evaluation   |
| Arntz 2011 (14)  | Summary health outcomes   | Index of care needs (author developed and user completed). Self-assessed satisfaction with current health situation questionnaire | NR   | NR  | NR   | Highlights complexity in identifying differences arising from IB. Substitution between informal and formal care and types of provision important finding.   |
| Ettelt 2014 (15) | Based upon a logic model. Number offered and accepting direct payments, numbers of homes participating, payment amounts. ASCOT tool as part of survey to assess outcomes and change in outcomes over time. A separate question from | Electronic survey of service users/carers/families and providers  | What ways are direct payments offered and what challenges are faced from implementing them to all stakeholders? What are the impacts of direct payments on the care home market and service users? | Electronic survey of service users/carers/families and providers. Semi structured interviews with local authority and care home staff and service users. Case studies | Uptake of programme was very low meaning survey responses were similarly low | Stated aim was to do an economic evaluation but this did not really happen. Some costs were collected but not presented in any great detail. Only half the councils provided cost information and it appears scant. No real economic evaluation undertaken with limited data collected. Highlights challenge of evaluating SDS across different |

| Study                 | Quantitative outcomes  | Quantitative methods  | Qualitative questions   | Qualitative methods  | Limitations  | Notes for EA  |
|-----------------------|--|---|---|--|--|---|
|                       | Adult Social Care Survey on activities of daily living   |   |   |  |  | settings and if uptake of different options is very small   |
| Glendinning 2008 (16) | General health (GHQ-12), ASCOT, self-perceived health, overall satisfaction with arrangements (Likert scale), value of budgets | GHQ-12 and ASCOT questionnaire as well as survey questions in an RCT design                                   | Do IB offers a better way of supporting older people and other adults with social care needs? How have IB been implemented? What is experience of using IB on different groups of services users and carers? What are wider consequences of IB on adult social care and other services? | RCT. Semi structured interviews with service users, workers and project leads and other managers responsible with delivery and implementation. | Most people did not change the support provided. There were changes in funding occurring at the same time as implementation of IB. Cherry picking of individuals by pilot sites of people thought most likely to take up IB or require less preparation and assessment | Key national evaluation from England. Important points include concept of Resource Allocation System (RAS) to determine the value of their budget which involves assessment of need as well as how this translates into an equitable share of the local authority's overall budget (in England In Control was used). Limitations also noteworthy but excellent attempt at outcomes capture and economic analysis although may be difficult to replicate in a national evaluation of existing scheme |
| Graham 2015 (17)      | Parent reported health and QoL of self and child. Satisfaction with services   | Telephone survey of 689 families in pathfinder and 1000 in a comparator group matched with propensity scoring | What is experience of assessment and support processes? What is the experience of delivery of care?   | Baseline interviews with 77 families with longitudinal interviews with 40 of these families  | NR   | Attempt of cost effectiveness ratio on 'more satisfied' families and in trying to estimate parental and child quality of life - albeit on a Likert scale. Telephone   |

| Study               | Quantitative outcomes  | Quantitative methods     | Qualitative questions                       | Qualitative methods | Limitations              | Notes for EA   |
|---------------------|--|--------------------------|---|---------------------|--------------------------|--|
|                     |  |                          |   |                     |                          | interviews appear to have been successful in volume completed                  |
| Prabhakar 2011 (18) | Quality of life, choice available, control, satisfaction with services | Survey with Likert scale | What are families' experiences of using IB? | Focus groups        | Cost of pilot and set up | Different approaches to evaluation may be required for different client groups |

**Table A3.7: Local evaluations of established programmes – summary of studies**

| Study              | Country | Year(s) of research              | Name of programme  | Description of programme | Client group In evaluation  |
|--------------------|---------|----------------------------------|--|--------------------------|---|
| Campbell 2011 (19) | England | Not clear but appears to be 2010 | Support Advocacy and Brokerage (Independent Living Strategy) | Disabled people          | User Led Organisations (ULOs) who undertook support planning with individuals and in some cases provided brokerage services. All provided informal advocacy |

**Table A3.8: Local evaluations of established programmes – evaluation methods**

| Study              | Quantitative outcomes  | Quantitative methods   | Qualitative questions  | Qualitative methods  | Limitations | Notes for EA  |
|--------------------|--|--|--|--|-------------|---|
| Campbell 2011 (19) | Range of outcomes for individuals including Home life, employment, leisure, health participation, transport, education and security. Management information and market outcomes including LA expenditure and user characteristics. | Each pilot site agreed the data that was to be collected with each site signing up to an evidence grid so they understood why what was being collected was required. Service user outcomes and satisfaction were collected as part of the qualitative interviews on a Likert scale | What evidence is there on the effectiveness of the intervention? How satisfied are people with intervention and support received? Are experiences of the intervention positive? Do people have more choice and control in their lives? | Interviews with 40 service users (at two time points) in the intervention group and 40 in a comparator group | NR          | Mixed methods evaluation. Hard user outcomes were survey based and self-assessed. Difficulties on getting total costs of services provided by LAs due to diverse range of services used although all ULOs were able to identify total resource and so a unit cost of their activity could be calculated |



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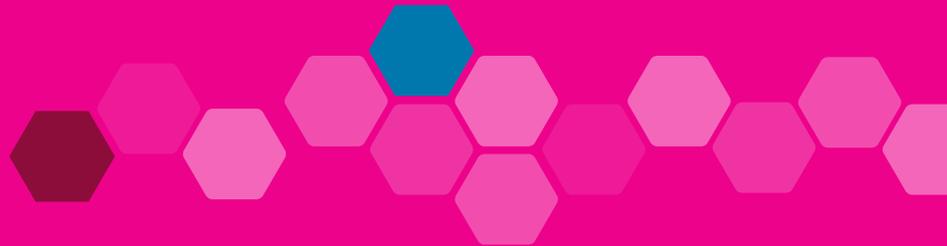
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