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# Review of Independent Information and Support Services Funded by the Scottish Government



**HEALTH AND SOCIAL CARE**



# **Review of Independent Information and Support Services Funded by the Scottish Government**

February 2018

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Lucy Robertson, Craigforth

# Executive Summary

## Introduction

This summary presents key findings from an external review of independent information and support services funded by the Scottish Government. The overall objective of this study was to provide an evaluation of services supported by the Scottish Government through the Support in the Right Direction (SIRD) Fund. It fulfils a specific commitment in the “The Implementation Plan 2016-18, for the Self-directed Support Strategy 2010-2020” (COSLA and Scottish Government 2016) to evaluate how independent information and support help and enable people to achieve personal outcomes, to be in control of their social care and to make their own decisions about social care. The findings from this review will help to inform decisions about future funding of such projects.

The research was carried out between June and November 2017 and included interviews with SIRD projects, local authorities and key stakeholders. A total of 148 supported people or carers who had used one of the SIRD projects also contributed by responding to a survey or taking part in interviews.

The study looks at the work of the SIRD projects through the experiences of those using the projects, and from the perspective of those working in the projects and other key stakeholders, including local authorities. It offers a diversity of voices shaped by individuals’ personal or professional experiences of social care and of independent support. Detailed views of local authorities on the benefits and quality of advice given by SIRD projects were outwith the scope of this review.

It is important to acknowledge that some service users had contacted a SIRD project because of concerns about the way local social services were handling their case; this is reflected in the strength of some people’s views of the process. These views should not be taken as representative of all those who have applied for, and/or are in receipt of, a social care budget. As the focus of the study is on those who have used a SIRD project, its design did not include people who may have been through assessment or review for a budget, and may have a budget, but have not contacted any of the projects. The views of this latter group may or may not reflect those who did access independent information or support through a SIRD project.

## Overview of the SIRD projects

The SIRD funding programme began in 2012. A second round of three-year funding began in April 2015 and runs to the end of March 2018. In total 36 organisations have been funded through the second round, receiving £2.96 million between them in the 2017/18 financial year. Performance monitoring of the SIRD projects is overseen by an external partner, Inspiring Scotland. They publish annual reports and provide 6-monthly overview reports of service activity.

Between them, SIRD projects are delivering direct information and support in all but one of Scotland’s local authority areas. They are working across a broad range of

client groups, with the most frequent being carers, people with learning disabilities and people with physical disabilities. There are seven projects which work across all client groups.

Compared to all social care clients who made a choice about services, as set out in the 2015-16 self-directed support statistics (Scottish Government, 2017), SIRD project service users tended to be younger. SIRD projects were working with a relatively high number of those aged 17 or under and in the 18 to 64 age group and a relatively small number of those aged 65 or over.

### **The context for SIRD**

In August 2017, Audit Scotland published its “Self-directed support: 2017 progress report” (Audit Scotland 2017). Its messages include that local authorities are experiencing pressures due to increasing demand and limited budgets for social care services. Similarly, in this review budgetary pressures were recognised across the range of participants. Projects and service users expressed concerns about the impact of local eligibility criteria on whether people are being assessed as eligible for a funded package of support.

A number of the projects had made initial assumptions, at the funding application stage, about progress in embedding self-directed support as the norm for social care in the local authorities in which they were planning to work. The reality has often been different, particularly around the number of referrals received from social work teams. Some projects have had to adapt their focus and practice accordingly.

### **Working relationships**

Overall, there was a broadly positive picture in terms of the working relationships between the SIRD projects and the local authorities in which they were operating. The strength and quality of those relationships had often built very clearly on the relationship in place prior to the award of SIRD funding.

Where working relationships have been less positive, a range of factors appear to have been at play. These have included different views on who should have choice and control over their social care budget and the types of choices that should be available.

For a number of the projects, work to build good relationships between themselves and local authority staff has been ongoing throughout the SIRD funding period. Much of this work has had a practical ‘hook’ focused on offering social work staff training on self-directed support.

### **Strategic engagement and impact**

A number of projects working in a single local authority or in a number of local authorities were involved in working groups focused specifically on the implementation of self-directed support. Strategic involvement was not always through specific groups but sometimes through regular but less formal discussions with key service planners or commissioners.

Projects had different views on the success of their attempts to influence local policy and practice. Some felt that they had had little impact, others (including some of those feeling their impact had been limited) pointed to changes in practice locally as a result of their work. A small number of projects were able to point to influence they had exercised at a national level. This included work to develop accessible information.

In addition to their own influencing work, a number of projects had been supporting their service users to have their voice heard and influence how self-directed support is being implemented in their own local authority area or more widely.

### **Direct client support**

Service user feedback suggests that people tended to have made contact with a SIRD project relatively quickly and easily. Those who said they had struggled to find independent information or support tended to be living in rural areas or be in the older age group. Unless already in contact with the project, people had most frequently been given information about it by: a social worker; another support or care worker; or family or friends.

According to the service user survey, people were most likely to be looking for advice on which self-directed support option they wanted to use or for practical support and assistance in relation to Options 1 or 4. A number of projects have been carrying out awareness-raising and community capacity-building work. This has included outreach work designed to increase general awareness of and understanding of self-directed support amongst the wider public. There has also been awareness-raising work targeting specific groups, such as carers. Overall, projects feel their community-focused awareness-raising work has been useful.

SIRD projects have also been involved in the delivery of training or personal development sessions or courses for supported people or carers covering self-directed support in greater depth. Other projects have been involved in the delivery of personal development courses, over a series of weeks or months. Their focus is on supporting people to gain the knowledge, skills and confidence to take control of their own lives and make their own choices.

Many of the SIRD projects place considerable value and importance on the work they have been doing to support people through the assessment for, or review of, a social care budget. For projects delivering what might be described as 'end-to-end' support, throughout the whole self-directed support process, there was a clear preference for engagement with clients at an early stage.

Projects were seeking to achieve a number of outcomes when working with people to prepare for a social work assessment or review. In particular, they tended to refer to trying to reduce clients' anxieties and make sure that assessments or reviews are well-handled from their clients' perspective.

A smaller range of projects were involved in supporting people at assessments or other meetings with social work. The approach taken tended to be led by the client.



At one end of the spectrum, clients sometimes simply wanted a SIRD project representative there to act as a reassuring presence. At the other end of the spectrum, and although relatively unusual, a small number of clients reported that they were looking for project staff to play an active role.

Brokerage should be understood as providing service users with the support and assistance they need to put in place and manage the arrangements which will enable them to live according to their choices. There was a very broad consensus around the value of this type of work; this consensus spanned the projects, service users, local authorities and key stakeholder interviewees.

A majority of the projects were providing some form of brokerage support. All of those were working with people with a social care budget in relation to that budget. Most were also offering a community brokerage service for both those with and without a budget.

For some projects, brokerage was the predominant focus of their work and was concentrated on working with Option 1 or 4 clients referred to them by social work once an assessment had been carried out. For others, brokerage was the latter phase of a broader package of 'end-to-end' support for people with a budget which had begun at the information provision or assessment stages.

Option 1-focused support ranged from providing further information and advice around how it works on a day-to-day basis through to support with recruiting and managing a Personal Assistant. There were also examples of projects equipping people with skills or tools which would help them manage their own, sometimes quite complex, support packages.

Although much of the SIRD projects' work has been with people who are applying for or who have a social care budget, many have also been working with other members of the community with a social care need but who are not eligible for a budget who might benefit from information, advice or support. For most of those interviewees who did not have a budget, making links into other services and groups, and community-based groups in particular, was often a key reason for being in touch with the project.

For a small number of the projects, the peer support approach has been central to their SIRD work. This has been a particular focus for user-controlled organisations, reflecting their overall philosophy and approach. The type of work that has been carried out includes assisting with setting up and running a peer support group or network.

### **Reflections on direct client support work**

A small number of projects reported meeting their original targets for working with people looking for direct client support. However, a number of projects have fallen significantly short of their target in terms of the numbers of people to whom they had provided direct client support.

A small number of the projects have concluded that the focus of their work - and in particular their client group focus - may simply have been premature given national progress on self-directed support implementation. Very much reflecting the national experience, this was most likely to be the case for projects working with people experiencing homelessness or with community justice service clients.

When faced with lower than anticipated numbers looking for social care budget-related support, many projects have looked for ways of using the SIRD funding available constructively and as part of a wider package of work around supporting the rollout of a choice and control-based approach.

Almost without exception, service users were very positive about the quality of support that they received from projects. When asked how they felt about the information and support they had received, more than 8 out of 10 survey respondents said it had made an enormous or big difference. Service users highlighted the impact that the support from projects has had on their health and wellbeing. A central theme of many of the stories shared with the study team was that the support a SIRD project gave has had a profound and life-enhancing impact.

The service user feedback also explored the extent to which people felt that support from a SIRD project had helped them to access or make the most of self-directed support. Helping unlock the potential of making choices and having control had an enormous impact for some people. Service users who had accessed a social care budget whilst working with a SIRD project felt that this positive outcome might not or would not have been achieved without the support they had received.

The findings of this review suggest that for those engaged in the self-directed support process, support at any stage can make a difference; for some people, having someone to walk alongside them for the entirety of their journey, end-to-end, has been critical.

For many, there were certain aspects of the self-directed support-related process where third sector providers could offer very real additional value. This was primarily in relation to supporting people who had chosen Option 1 or 4 and helping people access community-based opportunities and support. However, there was a range of opinion around who was best placed to provide information and advice in relation to choices about, and control of, a social care budget.

Single local authority-focused projects were often those involved in the delivery of the type of whole journey support that was much valued by clients. Where this approach looks to have been working well, projects were usually a well-established member of a network of statutory and third sector agencies with a history of working together. Projects working across a small number of local authorities across Scotland tended to face practical challenges associated with varied practice and eligibility criteria and the need to build and maintain working relationships across local authorities.

Client-group focused services sought to ensure that their specialist knowledge and skills meant clients received the right type of information and were supported in a

way which met their particular needs. Projects taking this approach have experienced similar challenges to more generalist services working regionally. Overall, however, they have tended to report that the approach has worked well; the feedback from their clients certainly suggests this to be the case.

The current SIRD funding stream has a focus on building self-directed support-related capacity in the independent information and support sector. The relationship between project independence and the source of their funding was highlighted by a number of projects and some had concerns about receiving funding from an organisation which they might need to challenge. However, other projects had no such concerns.

### **Development of self-directed support-related information**

Based on their reviewing of available information, a number of projects have sought to produce a range of materials informing people about self-directed support. For some projects this work has been their main, or a significant focus of their, work.

Information has been produced in a range of formats. Much use has been made of case studies, including in video format. There has also been some innovative work developing games and e-learning packages as tools for understanding and supporting client progression through the process.

### **Running of the funding programme**

The support commissioned by the Scottish Government from Inspiring Scotland has been very much appreciated, in terms of its quality, the commitment of Inspiring Scotland staff, and the practical networking and advice provided.

### **Concluding reflections**

The findings of this study very much echo those of the Audit Scotland “Self-directed support: 2017 progress report”. The changing environment in which SIRD projects have been looking to build capacity within their own organisations and the wider community has usually been different to that which they had expected when making their funding applications.

For the full potential of self-directed support to be achieved, members of the public need access to a straightforward but comprehensive package of information and support. The review found strong evidence that without the independent information and support received from SIRD projects, some clients would either have given up on applying for a social care budget or would have chosen a different option.

Although people’s needs will be different, information and support may be required at any or all stages of the self-directed support process. Some people may want to dip in and out of these services, but others are likely to be looking for, and would greatly benefit from, end-to-end support. This does not necessarily need to be provided by a single organisation but, given service users’ feedback on the value of continuity and strong working relationships built on understanding and empathy, this is likely to be the preference for many.

Often, end-to-end support may be most effectively provided by an organisation with a strong local presence which has a clear understanding of, and strong links into, the local community. This includes being aware of, and able to connect people into a range of informal social and support opportunities. However, there also appears to be a case for people with very particular support needs, such as families with children with multiple and complex needs, being able to access a highly specialised package of information and support from national or regional providers.

Irrespective of the type of organisation providing information and support, a positive working relationship, including a referral relationship, between them and the local authority is important. To work in the best interests of clients, this working relationship needs to be strong and mature enough to allow for challenge.

As well as building capacity within the information and support sector, there is also powerful evidence around the potential of various approaches used by SIRD projects to support individuals to develop skills, confidence and capacity. There was a broad consensus that some of the work done around peer support and involvement has been very valuable and that many other people might benefit from having access to this type of support.

Moving forward, the SIRD funding programme has delivered some useful learning about what works well or less well. In particular, it has highlighted that independent information and advice services are at their best when firmly embedded within their local context and when supported and valued by key local partners, and by social work services in particular.

Local authorities have a legal duty to assist people to make an informed choice about their support and must provide details about independent information, support and appropriate advocacy organisations. Given this legislative duty, there was a common view that local authorities need to play a central role in assessing the package of services, including independent information and support, which is required in their area. This was sometimes connected to a view that the Scottish Government should involve local authorities in discussions about any future SIRD funding plans, including the type and range of services required in their area.

Finally, the review findings point towards independent information and support as being an essential part of a well-functioning, choice and control-based social care system. This will require ongoing investment and, given their statutory responsibilities, Health and Social Care Partnerships would appear the most obvious source of that funding - in the longer-term at least- and many are already investing in independent support. There may be a case for exceptions, for example around specialist organisations delivering a service across many local authority areas. In most cases, however, the evidence suggests that it is possible for third sector organisations to have good working relationships with their local partners, including those which may fund them, whilst also providing high quality, much needed and highly valued independent information and support services.

# 1. Introduction

## Background

Independent information and support are essential for people to be informed, empowered and supported to make decisions about their social care and fulfil their personal outcomes. Activities include supporting people through an assessment for, or a review of, a social care budget; brokerage to identify the right support and creative alternatives; awareness-raising; community capacity-building; and training and personal development. This document presents findings from an evaluation of projects funded to deliver such activities under the Scottish Government's Support in the Right Direction (SIRD) Fund.

This funding has been part of a wider package of investment around the transition to self-directed support between 2011 and 2017. The implementation of self-directed support as the norm in social care practice represents one of the most significant and complex changes to social care provision for a generation and is one of the key policies underpinning delivery of the 2020 Vision for health and social care integration and the Health and Social Care Delivery Plan.<sup>1</sup>

"The Implementation Plan 2016-18, for the Self-directed Support Strategy 2010-2020" (COSLA and the Scottish Government 2016), seeks to deliver four strategic outcomes, these being that:

- Supported people have more choice and control;
- Workers are confident and valued;
- Commissioning is more flexible and responsive; and
- Systems are more widely understood, flexible and less complex.

Local authorities have a duty to assist people to make an informed choice about their support and must provide details about independent information, support and appropriate advocacy organisations.<sup>2</sup>

To ensure appropriate, high quality support is available, the Scottish Government invested in two programmes for 2015-2018:

- The Support in the Right Direction (SIRD) Fund is focused on ensuring people are supported in setting their personal outcomes and able to make informed decisions.

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<sup>1</sup> <http://www.gov.scot/Publications/2016/12/4275/downloads>

<sup>2</sup> Further detail on Local Authorities' duties is set out in the Statutory Guidance to accompany the Social Care (Self-directed Support) (Scotland) Act 2013. The relevant section of the Guidance can be found at: <http://www.gov.scot/Publications/2014/04/5438/6>

- The Innovation Fund enables third sector social care providers to deliver flexible and creative support and promote culture change through the workforce, including outcomes related to support for clients and budgeting.

The Scottish Government has made a commitment to monitor, understand, and, where needed, review self-directed support implementation and to report on progress towards intended outcomes at the national level. This independent review of the SIRD Fund is in line with this and fulfils a specific commitment in the SDS Implementation Plan 2016-2018, to evaluate how independent information and support help and enable people to achieve personal outcomes, to be in control of their social care and to make their own decisions about social care. The findings from this review are expected to inform decisions about future funding of such services.

This review builds on previous work for funders and commissioners of social care by Evaluation Support Scotland (2015a, 2015b) on what works in independent support and on ongoing project monitoring by Inspiring Scotland.

## **Study objectives**

The overall objective of this study was to provide an external review of projects supported by the Scottish Government through the SIRD Fund. The focus was on what has worked well and what has not worked well, with the original research objectives being to:

- Define and assess the effectiveness of SIRD projects, within the local context, in meeting the outcomes of clients, establishing the differences these services have made to the decisions of individuals about their social care options and, in particular, whether it helps individuals to access a budget in the first place and make better use of their allocated budget for support;
- Assess the cost-effectiveness, quality and the short-medium term sustainability of different forms of services exemplified by SIRD projects, setting out the implications in relation to future funding options for such services and for Scottish Government funding decisions in 2017/18;
- Identify characteristics, based on all of the research activities, of different kinds of successful, sustainable models for independent support;
- Gather evidence and explore ongoing challenges and barriers for impactful and sustainable independent support, and suggest ways in which they might be addressed;
- Provide an overview, based mainly on desk research, of the wider independent information and support landscape in which to contextualise SIRD; and
- Document and explain wider benefits for services and the health and social care system arising from the benefits experienced by clients (e.g. by reducing an individual's need for a formal support package and so reducing or

changing the level or nature of demand; supporting prevention; empowering people to challenge policies which do not promote self-directed support).

The primary focus of the review was on SIRD Fund projects. However, a small number of Innovation Fund projects have been involved in the delivery of information and support and hence were included within the study.

## Research approach and challenges

The research was carried out between June and November 2017. The approaches used included:

- **Review of project data and information.** This included a wide range of information supplied by the Scottish Government and Inspiring Scotland, including performance monitoring data and reports.
- **Interviews with representatives from local authorities.** Telephone interviews were undertaken with representatives from six local authority areas (Aberdeen, Argyll and Bute, East Ayrshire, Fife, Highland and Shetland). Each area was asked to nominate suitable interviewees, which included self-directed support leads and those with management responsibility for adult care, learning disability and children's services. Please note that for the purposes of this study local authorities were included because of their key role within Health and Social Care Partnerships and as the body responsible for assessing social care needs in their area. A total of 14 interviews were carried out.
- **Key stakeholder interviews:** A small number of unstructured key stakeholder interviews were carried out. Interviewees included representatives from the Care Inspectorate, Health and Social Care Alliance Scotland, Healthcare Improvement Scotland, MECOPP Carers Centre, Scottish Personal Assistant Employers Network (SPAEN), and the Self-Directed Support Practice Network.
- **Interviews with the SIRD projects.** An interview was carried out with one person or a small number of representatives from all but one of the projects.<sup>3</sup> Interviews were either face-to-face or carried out by telephone. They were semi-structured and tended to last for around 90 minutes. The themes covered during these interviews are set out as Annex 1 to this report.
- **Survey of those using services.** Projects were asked to issue an invitation to complete a short electronic or paper-based survey to service users who have an approved social care budget. Two versions of the survey were created, one for those who are responsible for decision-making about their own budget and one for those holding responsibility for someone else's budget. A total of 92 surveys were returned, 59 from those who have responsibility for their own budget and 33 from those who have responsibility for someone else's budget. The survey results are set out in Annex 2.

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<sup>3</sup> There was one project with which it was not possible to arrange an interview.

- **Interviews with clients.** In addition, the study team spoke with 88 people who had used or are using a SIRD service. Of these, 32 people were identified through the survey and a further 56 people were recruited directly through SIRD projects. The interviewees recruited directly through the SIRD projects were made up of 25 people with a social care budget and 31 people without.

A total of 148 people who had used one of the SIRD projects told us of their experiences and gave us their views. Of these, 116 people have a social care budget themselves or manage a social care budget for someone else. Around 3 out of 4 of this group have gone down the Option 1 route (see below). The remaining 32 people spoken to do not have a social care budget. Their feedback is used to inform the analysis throughout this report and as noted above, the results from the service user survey can be found at Annex 2.

When considering their views of the process of exercising choice and control and choosing self-directed support options, it is important to acknowledge that the group of service users who contributed to this research were all in contact with one of the SIRD projects. In many cases, one of the main reasons for making contact was because of concerns about the way local social services were handling their case; this is reflected in the strength of some people's views. However, these views may not be representative of all those who have applied for and/or are in receipt of a social care budget. As the focus of the study is on those who have used the SIRD project, its design did not include people who may have been through assessment or review for a budget, and may have a budget, but have not come into contact with one of the projects. The views of this latter group of people may or may not reflect those who did access independent information or support through one of the SIRD projects.

The study looks at the work of the SIRD projects through the experiences of those using the projects, and from the perspective of those working in the projects and other key stakeholders, including local authorities. It offers a diversity of voices shaped by individuals' personal or professional experiences of social care and of independent support. Service users were often very frank in their comments and had a very understandable focus on their own experiences. Project interviewees also tended to be focused very clearly on the experiences of their service users, staff and their project more widely. Very much reflecting their duties and responsibilities, local authority respondents tended to focus on wider, whole-system issues, including the overall package of advice and support required in their area.

This has been a challenging study for a number of reasons. As discussed further in the next chapters, the type of work being done and the local authority contexts in which projects are operating are both very diverse. In some instances, the operating context and the focus of the work being done has evolved during the funding period. Also, although a wider range of monitoring data and progress reports is available, as discussed further at Chapter 9, some of the data cannot be used for comparative purposes. In essence, it is not clear that all projects are



recording their activity and outcomes in the same way. There is also very limited information about the service users who have been supported by a SIRD project in project monitoring data.

As a result, it has not been possible to fully address all of the original research objectives. In particular, a robust assessment of cost-effectiveness of the work undertaken by the SIRD projects has not been possible. However, the significant body of primary and secondary data available to inform the study findings has supported an in-depth analysis of what the experiences of the SIRD projects, and critically those who use them, suggests about the provision of social care-related information and support into the future. This is the main focus of the analysis presented in the remainder of this report.

## Reporting

The terminology used in this report is in line with the standard usage unless otherwise stated. In particular, the report references the four self-directed support options for getting support. These are:

- **Option 1:** A Direct Payment (a cash payment).
- **Option 2:** Funding is allocated to a provider of the person's choice (sometimes called an individual service fund, where the Council holds the budget, but the person is in charge of how it is spent).
- **Option 3:** The Council arranges a service;
- **Option 4:** The person chooses a mix of these options for different types of support.

It is also important to note that not everyone receiving information and support from one of the SIRD projects will need a formal support package or be in receipt of a social care budget. This group of clients will be referred to as non-budget holding clients for the purposes of this report.

Please note that when the report refers to SIRD projects it should be taken as including those Innovation Fund projects which have been included in this study.

## 2. Overview of the SIRD Projects

This chapter considers the profile of SIRD projects and with whom they have been working.

### Profile of the projects

The SIRD funding programme began in 2012, with 42 organisations funded during the first three-year phase.<sup>4</sup> A second round of three-year funding began in April 2015 and runs to the end of March 2018. Over its six-year period, £12.7 million has been given to third sector organisations through the Scottish Government's SIRD fund.<sup>5</sup> In total 36 organisations have been funded through the second round, receiving £2.96 million between them in the 2017/18 financial year. The levels of annual funding to each project in the second round have ranged from around £29,000 to around £129,000.

Performance monitoring of the SIRD projects is overseen by an external partner, Inspiring Scotland, who work to build third sector capacity, resilience and sustainability.<sup>6</sup> Inspiring Scotland publish annual reports and provide 6-monthly overview reports of project activity.

Figure 1 sets out the number of SIRD projects working in each local authority area. The local authorities in which the highest number of projects is operating are Glasgow, Edinburgh and Fife (15, 12 and 11 projects respectively). Those with the smallest number - only one project in each area - are Clackmannanshire, Comhairle nan Eilean Siar and Orkney. Orkney is also the only local authority area in which there are no SIRD projects involved in the delivery of information and support to members of the public.

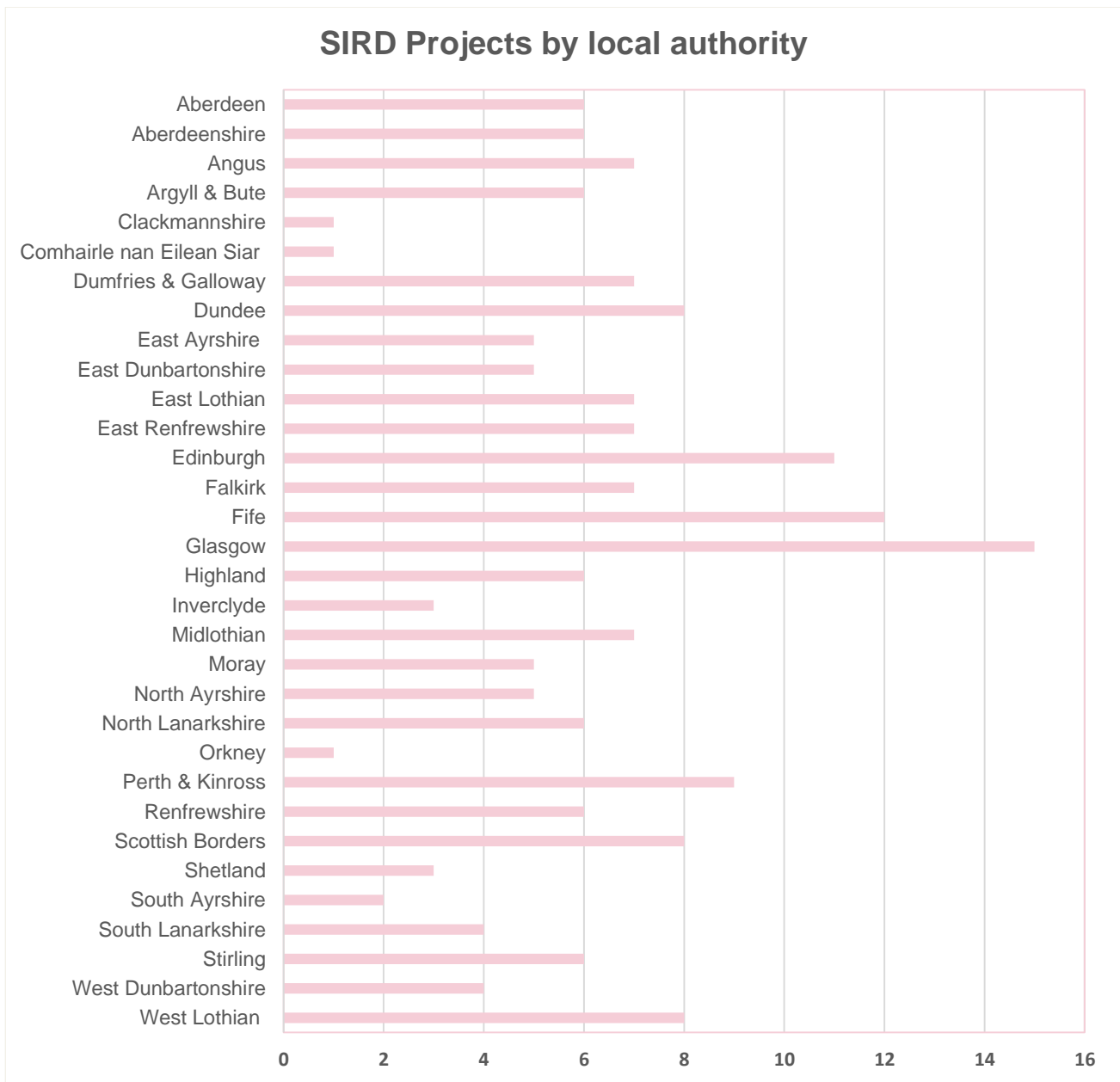
Nine of the projects which provide information or support to members of the public work in one local authority area only. The others have a regional or national focus.

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<sup>4</sup> A range of materials relating to the first funding tranche can be found on the Evaluation Support Scotland website at: <http://www.evaluationsupportscotland.org.uk/how-can-we-help/shared-learning-programmes/support-right-direction/>

<sup>5</sup> A further £8.6 million has been made available through the Innovation Fund, with 18 projects receiving a share of £1.2 million in 2017/18.

<sup>6</sup> A series of Inspiring Scotland SIRD Progress reports is available at <http://www.inspiringscotland.org.uk/our-funds/self-directed-support>



**Figure 1**

Other points to note about the SIRD projects include.<sup>7</sup>

- Seven of the projects have not been carrying out direct delivery of information and support. These have been focusing on work around capacity building, awareness raising and development of practice or materials.
- Overall, the SIRD projects have reported working with over 300 organisations and around 9,900 members of the public during the first two years of the second funding period (2015/16 and 2016/17). Further information on the particular activities undertaken is set out in the subsequent chapters.

<sup>7</sup> This analysis is taken from monitoring data provided by Inspiring Scotland for 2015/16 and 2016/17.

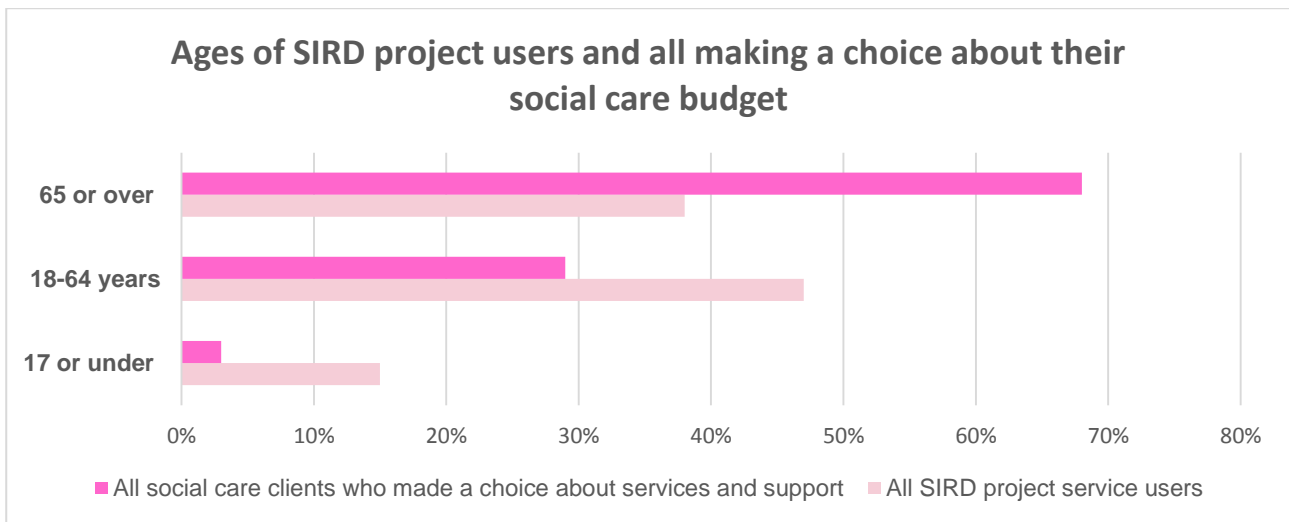
Figure 2 shows that SIRD projects are working across a broad range of client groups, with the most frequent being carers (26 projects), people with learning difficulties (20 projects) and people with physical impairments (20 projects). People who are homeless is the least frequently worked with group (three projects). There are seven projects which work across all client groups.



Figure 2<sup>8</sup>

Figure 3 sets out the age profile of the service users that SIRD projects have been working with, and provides comparative data taken from the most recent national statistics for 2015-16 (Scottish Government 2017).

<sup>8</sup> Please note that information about the three Innovation Fund projects developing information and support is included in Figure 2.



**Figure 3**

Although it should be noted that the SIRD service user group includes some people without a social care budget, the difference in the age profiles is nevertheless notable. Compared to all social care clients who made a choice about services, SIRD project users tend to be younger. In particular, SIRD projects were working with a relatively high number of those aged 17 or under and in the 18 to 64 age group, and a relatively small number of those aged 65 or over.

This younger age profile of SIRD service users may, to some extent, reflect the profile of those choosing Option 1. As noted above and discussed further below, many of those the SIRD projects have been supporting have been using Option 1. The national statistics highlight that the self-directed support options chosen vary according to client age group (Scottish Government 2017). In particular, older people are much more likely to choose Option 3 while younger people are relatively more likely to choose Option 1. Parents of young people (aged under 18), are also more likely to choose Option 1.

As noted earlier, there is very limited other information available about the profile of SIRD project service users. More granular monitoring information, for example capturing service users' gender, ethnicity, socio-economic circumstances or assessed need would allow for more detailed exploration of the profile of those who accessed support through a SIRD project. It would also allow for a more extensive comparison between this group and the overall profile of those accessing social care in Scotland.

### 3. The Context for SIRD

This chapter looks at the local context for the delivery of information and support and its impact on the SIRD projects.

#### Key Findings

Pressures from rising demand and limited budgets were recognised across the range of research participants. Nevertheless, projects and service users had concerns about the impact of local eligibility criteria on whether people are being assessed as eligible for a budget.

A number of the projects had made initial assumptions, at the funding application stage, about progress in embedding choice and control in the local authorities in which they were planning to work. The reality has often been different, particularly around the number of referrals from social work teams. Some projects have adapted their focus and practice accordingly.

#### Local context for the delivery of information and support

In August 2017, Audit Scotland published its “Self-directed Support: 2017 progress report” (Audit Scotland 2017). The report noted that self-directed support is one of a number of national policies designed to empower people and communities to become more involved in designing and delivering services that affect them. The report also highlighted the range of other legislation, including the Community Empowerment (Scotland) Act 2014 and the Public Bodies (Joint Working) (Scotland) Act 2014, that was introduced in response to the report by the Christie Commission in 2011 (Commission on the Future Delivery of Public Services 2011). The key messages from the Audit Scotland progress report included:

- Self-directed support implementation stalled during the integration of health and social care services.
- Local authorities are experiencing pressures due to increasing demand and limited budgets for social care services. Within this context, approaches to commissioning can have the effect of restricting how much choice and control people may have.
- Most people rate their social care services highly and there are many examples of people being supported in new and effective ways through self-directed support.
- Despite many examples of positive progress, there is no evidence that the transformation required to fully implement the Self-directed Support Strategy 2010-2020 has yet been made. Not everyone is getting the choice and control envisaged in the Strategy.
- Those using social care services need better information and help to understand self-directed support and make choices.

Audit Scotland's key findings very much reflect those of this study and many of the issues set out above have had a direct impact on a number of the SIRD projects.

### **Progress on embedding choice and control in social care**

Funding applications for the second round of SIRD funding were developed and submitted in the second half of 2014; this was in the fourth year of the national Self-directed Support Strategy. At the point of developing their funding proposals, a number of the projects made assumptions about progress in embedding self-directed support as the norm for social care in the local authorities in which they were planning to work. Frequently reported challenges have been that:

- Some projects had made an assumption that self-directed support would be fully implemented for managing social care budgets across the full range of client groups during, and indeed early on, in the second-round funding period. For many, their experience has been very different. A number of projects reported that the implementation of self-directed support in their area(s) has been slower than they hoped for or expected. This has tended to apply across all client groups.
- A number of the projects working with certain client groups reported seeing little if any evidence of those with a social care budget being given choice about or control over how that budget is used. These included: those with mental health issues; people on the autistic spectrum; clients of community justice services; and clients of homelessness services.
- Projects have generally found that knowledge and practice related to choice and control and the self-direct support options can vary significantly within individual local authority areas. This has included between different social work teams and individual members of staff.
- Some service users and SIRD projects reported that not all of the four options are available in their local authority areas. For example, there were suggestions that some local authorities may be seeking to avoid clients moving away from using their social care services (Option 3). Conversely, it was suggested that in some areas clients have effectively been told they will have to take Option 1.

Local authorities tended to report that implementation was on track within their area, albeit sometimes noting that it is yet to extend across all clients and client groups. They tend to suggest that the principles of choice and control were recognised as being at the heart of best practice going forward. Although sometimes acknowledging that ongoing work is required, a number of local authority interviewees highlighted that staff training is being or has been delivered.

### **Impact of Health and Social Care Integration**

Many study participants highlighted the impact of health and social care integration on self-directed support implementation. Particular issues which SIRD projects identified as being connected to integration included:

- Some key personnel, including those in posts focusing on the transition to self-directed support have moved on to integration-related posts. Also, and very much reflecting the budgetary pressures discussed below, some experienced staff have taken early retirement or a redundancy package.
- Overall, some felt that local authorities' focus has shifted away from delivering the choice and control expected and onto the very considerable body of work and system change required for integration.

Overall, some felt that integration has caused self-directed support implementation progress to stall. Some felt that it may even have had the effect of rolling back the progress which had been made.

### **Budgetary pressures on local authorities**

The Audit Scotland report notes that public sector budgets are under significant pressure owing to ongoing financial constraints, increasing expectations and rising demand for health and social care services, and social care workforce shortages. Local authority interviewees often noted the very considerable budgetary pressures on their services and that there must be a clear focus on addressing the most significant needs.

A number of SIRD projects noted that they are seeing the impact of ongoing pressures on social care budgets. This included several reporting changes to eligibility criteria in their area which meant that only those with very significant or severe social care support needs are now in receipt of a budget.

These funding pressures were also reported as sometimes resulting in service users being awarded a smaller budget than they had expected based on conversations at an assessment meeting. There was some suggestion that this has arisen when senior staff had reviewed the assessments of frontline staff with a view to making savings. There were reports of existing social care budgets (including those which had previously been taken by the client as a direct payment) being reduced at review. This was generally understood as being because new eligibility criteria had been put in place since their original assessment.

The impact of budgetary pressures was recognised across the range of research participants. Many of the projects and some clients appreciated that these are very challenging times for local authorities, but nevertheless often felt very frustrated about how this is impacting on those applying for, or already in receipt of, a social care budget. Their concerns were around both whether people are being assessed as requiring support at all and also in relation to the choice and control being offered to those who are entitled to a budget.

There were some suggestions that choice is either not being offered or is being restricted in response to financial pressures within local authorities. For example, as noted above it was suggested that some clients who are effectively on Option 3 report not having been told that other options were available to them. Some projects felt that choice is not being offered or promoted because those choices could undermine the viability of local authority-delivered services.



Local authority participants offered an alternative perspective; that some of the SIRD projects may be amongst a wider group of third sector organisations which are offering self-directed support-related information and advice that are unrealistic in the current financial climate and which risk raising expectations amongst members of the public that local authorities are not in a position to meet.

## **Impact of the local context on SIRD projects**

As noted, many of the SIRD projects have reported that they have found themselves working in a very different delivery environment to that which they had expected. In particular, a number of the projects had anticipated receiving large numbers of referrals from social work teams. In reality, this tends not to be happening to the extent expected. Where referrals are being made, they are often not at the early stages of application or assessment, as projects may have planned for, but are instead associated with the practical aspects of taking Option 1.

Projects that are experiencing fewer or no referrals tend to put this down to a lack of local progress in delivering social care services built on the underlying principles of choice and control. Combined with rising eligibility criteria for a budget, a number of projects have found there are simply fewer people applying for and being awarded social care budgets than they had expected.

Other issues which projects identified as contributing to fewer than anticipated referrals or signposting on included:

- Frontline social work staff having insufficient understanding of self-directed support requirements and options. It was suggested that not all social workers are having the required good conversations with their clients. By extension the social worker is then unlikely to refer on for independent information or support.
- Staff in a small number of the SIRD projects felt that one or two of the frontline social workers known to them did not want clients to be fully aware of their rights or supported in challenging an assessment or other decisions.
- Lack of awareness of the type of support the SIRD project can offer and to whom. This was often connected with changes in key personnel within the local authority. In particular, some projects reported that key staff who had been aware of the work they were doing, and who had sometimes been champions of the role of independent information and advice services, had moved on. Without these links into local authority services, particularly at a senior level, some projects reported finding it more difficult than expected to 'spread the word' about the work they were doing despite their often extensive efforts.

Sometimes in response to this range of challenges, a number of the SIRD projects have been reviewing and revising the focus of some of their work. This has tended to be an iterative process and has included:

- Looking to build stronger working relationships with key local services, including local authority services and other third sector providers. This has sometimes included helping to set up and run multi-agency working groups to support the further implementation of self-directed support in their area(s).
  - Increasing the amount of awareness raising work being done with professionals, including with frontline social work staff. Some projects have also been holding information giving or training sessions for social work staff and others.
  - Extending the package of awareness raising and capacity building work with local communities or communities of interest. The focus has tended to be on making connections with people who are unlikely to be assessed as eligible for a budget but who might welcome information or support in relation to other services or opportunities available.
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## 4. Working Relationships

This chapter looks at working relationships between:

- SIRD projects and local authorities, as the basis for effective practical work and strategic influence by the former.
- SIRD projects and the voluntary sector.

### Key Findings

Overall, there was a broadly positive picture in terms of the working relationships between the SIRD projects and the local authorities in which they were operating. The strength and quality of those had often built very clearly on relationships in place prior to the award of SIRD funding.

Where working relationships were less positive, a range of factors were at play. These included different views on who should have choice and control over their social care budget and the types of choices which should be available. Some projects had concerns about local budget eligibility criteria.

For a number of projects, work to build good relationships between themselves and local authority staff has been ongoing throughout the funding period. Much of this has had a practical 'hook' focused on offering social work staff training on self-directed support.

### The quality of relationships

Overall, there was a broadly positive picture in terms of working relationships between the SIRD projects and the local authorities in which they were delivering a service. In particular, a number of projects working in only one or a small number of areas reported positive working relationships. The strength and quality of those had often built very clearly on the relationships in place prior to the award of SIRD funding. Relationships which were already positive seem generally, albeit with a small number of exceptions, to have been strengthened by the SIRD work.

From both a project and local authority perspective, factors helping support good working relationships included:

- Projects having a good understanding of how social work services are structured and the appropriate and most effective routes to go through to build links and promote the work they were doing. This included which key social work staff needed to be informed about the project and what they could offer to social work clients.
- Projects having a clear understanding of the local eligibility criteria, even if they do not necessarily agree with them.

- Projects appreciating the challenges statutory services are facing and the difficult decisions they sometimes have to make.

Where working relationships have been less positive, a range of factors appear to have been at play. These have included:

- Some fundamental differences in understanding of who should have choice and control over their social care budget and the types of choices which should be available. Some projects also have very considerable concerns about the speed with which self-directed support is becoming the norm and local budget eligibility criteria.
- Working relationships which were in place being lost because key experienced personnel (usually from the local authority side) have moved on.
- There being little or no real working relationship between the organisation delivering the SIRD project and social work at the start of the funding period. National or regional projects have tended to find it particularly difficult to make the new connections they often needed to deliver their SIRD plans.

On this latter point, some SIRD projects which have been trying to carry out client group-focused awareness raising work or training have reported difficulties in getting social work to engage. They felt this related to the number of other training options which are being offered to local authorities, with authorities looking for general training on self-directed support rather than training focusing on the specific requirements of particular client groups.

Unfortunately, in a small number of instances the relationship between a SIRD project and the local authority in which they were working had broken down to the point of being conflictual. The extent of this conflict was quite marked in some cases.

From a project perspective, when working relationships were not good they tended to put this down to local authorities not accepting that their role as independent adviser would inevitably involve them in challenging poor practice. This was particularly the case where the SIRD project believed that there was a failure to adhere correctly to legislation or that local authorities were failing to offer people the choice and control they were entitled to. They saw local authorities as resenting such challenges, or as seeking to pre-emptively avoid the time and effort involved in dealing with them.

The local authority perspective was sometimes very different. Comments and concerns raised by local authority or key stakeholder interviewees included:

- Projects working across a number of local authorities may struggle to have the necessary level of understanding of the social care arrangements in each area. A number of project interviewees highlighted a similar issue as being a key challenge for those looking to work at a regional or national level.
- Not all of the current SIRD projects may have staff with the necessary skills and experience to provide self-directed support-related information and

advice. In particular, they may not have the specialist knowledge required in relation to complex cases.

- There have been instances of projects behaving naively or discourteously, for example, by arranging information sessions for a particular client group without informing the local authority that the event was being held.
- Some projects duplicating work which is either being done in-house by local authority staff or which the local Health and Social Care Partnership has already commissioned from another third sector agency.

## **Referrals and other joint working**

Projects were clear about the centrality of the quality of their relationship with local authorities to their success in engaging with sufficient numbers of clients. Some went as far as to describe themselves as *dependent* on this relationship to generate a sufficient number of referrals.

The closeness and importance of that relationship often determined whether a project would approach, meet or exceed its project targets. Where relationships had been negative or non-existent, projects had tended to fall short (relative to their original proposals) in terms of the number of people with social care budgets they had worked with.

In perhaps the most striking example, one project had had the experience of two local authorities committing to making referrals prior to the award of SIRD funding, and then not doing so once funding had been awarded. It reported that it has been unable to even make contact with one of these local authorities to gain an understanding of why this had happened.

When considering why they had received fewer referrals than expected, projects tended to highlight a similar range of issues as those which affected overall working relationships. Suggestions included local authorities wishing to avoid challenge and slow progress with the embedding of self-directed support in social care generally. Above all, however, projects presented a picture of referral relationships which could vary hugely between local authorities, between different client or geographical teams within a local authority, and between individual members of staff within a team.

For a number of the projects, work around building good relationships between themselves and local authority staff has been ongoing throughout the SIRD funding period. Much of this work has had a practical 'hook' focused on offering training on the self-directed support approach, which has included offering training for both front line or more senior staff and training which can be delivered to potential clients alongside frontline staff. Interestingly, a small number of projects noted that although they felt the overall working relationship with the local authority could be better, there was nevertheless strong demand for the training they were offering.

Beyond this very direct approach, several projects also reported on wider work around 'championing' choice and control. They cited some of their awareness raising work with members of the public and with other professional groups (such as Allied Health Professionals), and in some cases with local authority social work staff.

### **Relationships with others in the voluntary sector**

SIRD projects were generally positive about relationships with the wider group of voluntary sector organisations working in their area and other SIRD projects or other organisations working in the field of independent information and support in particular. These positive relationships were seen as important in:

- Generating client referrals.
- Creating opportunities to refer people on to other voluntary sector organisations. This included ensuring clients could receive appropriate end-to-end support when this was not provided by the SIRD project itself.
- Creating opportunities for delivering joint work, such as co-delivered training.

Projects generally reported that they were clear about their role, and where it began and ended alongside other SIRD projects or others working in the field. For a number of projects, there was a clear understanding of the work others were doing and a clear commitment not to replicate and potentially undermine their efforts.

There has been a considerable amount of partnership working between SIRD projects working in different areas to explore and share ideas. Although much of this remains in its early stages, examples of the type of work being done included:

- Exploring ideas around the provision of a payroll service.
- Mentoring support to a staff member developing the brokerage aspect of their service.

However, there were very occasional concerns expressed by SIRD project interviewees about the type of work being done by some of the other current SIRD projects. This was sometimes about whether projects have the staff with the necessary skills and expertise - a particular concern in relation to people with very specific and potentially complex needs.

## 5. Strategic Engagement and Impact

This chapter looks at:

- The strategic work projects have been doing with local authorities and other partners.
- How projects have been supporting clients to influence policy and practice.

### Key Findings

Several projects were involved in working groups focused specifically on the implementation of self-directed support. Strategic involvement was not always through specific groups but sometimes through regular, less formal discussions with service planners or commissioners.

Projects had different views on the success of their attempts to influence local policy and practice. Some thought they had had little impact, others (including some feeling their impact had been limited) pointed to changes in practice locally as a result of their work. A small number of projects were able to point to influence they had exercised at a national level (around developing accessible information).

A number of projects had been supporting service users to have their voice heard and influence how self-directed support is being implemented in their local authority area or more widely.

### Strategic work with local authorities and other key partners

Building relationships with local authorities and other statutory services was not only aimed at developing effective referral relationships, but also at making an impact on policy and practice.

Some projects had a direct presence on groups working on the implementation of self-directed support in their area. Other projects were part of organisations that were represented on such group. Similarly, some projects had a direct presence, or were part of organisations that had a presence, on other strategic working groups in the health and social care field. Examples included groups working on health inequalities or the issues affecting carers. SIRD projects also sought to feed their perspectives into planning or strategy groups through partner organisations which represent the voluntary sector on Integrated Joint Boards or other groups.

Some projects reported that their local authority had not invited them to join relevant working groups, although some had still attended at the invitation of other third sector members. These projects felt they were being excluded from these types of groups because they had been active in challenging social work practice.

Reports from projects suggested significant variation in the progress and ongoing work of strategic groups overseeing the implementation of self-directed support. Some such groups were reported as functioning effectively with wide representation from the third sector. Other projects reported that such groups had been brought to an end or placed in abeyance. In one case it was reported that the implementation group had been wound up because the local authority had taken the view that the necessary work had been completed, and by extension that the self-directed support approach was fully operational. In other cases, projects suggested that joint working had stalled because of a shift in focus onto health and social care integration or because key personnel had moved on and not been replaced.

Projects' strategic engagement was not just through formal groups but sometimes through regular but less formal discussions with key local authority service planners or commissioners

Projects had different views on the success of their attempts to influence local policy and practice. Some felt that they had had little impact, some (including, notably, some of those feeling their impact had been limited) pointed to changes in practice locally as a result of their work. Examples of the types of changes SIRD projects had been involved in included:

- The redevelopment of assessment forms.
- Being involved in the redesign of day services for young adults with learning difficulties.
- Working with a local authority around ensuring that people are able to access the equipment they need more quickly.
- Responding to a letter sent by a local authority to people on Option 1 that they considered to be problematic in tone and content and against best practice.

In the last case, the project had been supported by Self-Directed Support Scotland and Inspiring Scotland, and another organisation hosting a SIRD project, to engage with the local authority. The project has now been invited to be involved in the drafting of planned new guidance for those on Option 1. However, another SIRD project reported that other local providers, and indeed local people on Option 1, had been reluctant to challenge a shift in policy and practice by their local authority.

Some projects were able to point to influence they had exercised at a national level, in relation to:

- Clarifying and lobbying on issues around self-employment for Personal Assistants (PAs).
- Influencing, through engagement in working groups, discussions on accessible information.

Projects did report barriers to influencing national practice. For example, a project involved in the delivery of personal development courses had started with the



ambition of seeing their model replicated across the country. However, they had found it very difficult to devote sufficient time to building the necessary relationships with local authorities. Ultimately, they did not have the resources to respond to all the interest shown or to generate further interest.

### **Supporting clients to influence policy and practice directly**

In addition to their own influencing work, several SIRD projects had been supporting service users to have their voice heard and influence how self-directed support is being embedded in their own local authority area or more widely. That had, in fact, been the main focus of one of them.

Examples of this work included:

- Supporting clients to make collective representations on issues of concern to local decision makers. This involved bringing those local decision makers together with user groups or peer support groups. Some projects reported doing this collectively with other local organisations, building on their existing voluntary sector relationships.
- A similar approach, but at a national level. For example, one project had supported clients to meet with members of a Cross-Parliamentary Group at the Scottish Parliament.

Personal development projects also highlighted occasions when service users had gone on to become members of the local Integrated Joint Boards, be elected as a local councillor, or set up a local voluntary sector organisation.

## 6. Direct Client Support

This chapter looks at findings from the interviews and survey in relation to:

- The experiences of supported people and their carers of looking for information and support.
- Awareness-raising and capacity-building, including community outreach and training and development work.
- Support around applying for a social care budget, assessment and review.
- Brokerage around setting up and managing formal or informal support.
- The use of peer support, peer involvement and community development approaches within projects.

### Key Findings

Service user feedback suggests that people tended to have made contact with a SIRD project relatively quickly and easily. Those who had struggled to find independent information or support tended to be living in rural areas or be in the older age group. Unless already in contact with the project, people had most frequently been given information about it by: a social worker; another support or care worker; or family or friends.

Project users were most likely to be looking for advice on which self-directed support option to use or for practical support and assistance in relation to Options 1 or 4. A number of projects were carrying out awareness-raising and community capacity-building work, including outreach work to increase general awareness and understanding amongst the wider public. There was also a range of awareness-raising activity targeting specific groups, such as carers. Overall, projects feel their community-focused awareness-raising work has been useful.

SIRD projects have also been involved in delivering training or personal development sessions or courses for supported people or carers covering self-directed support in greater depth. Other projects have been involved in the delivery of personal development courses, with a focus on supporting people to gain the knowledge, skills and confidence to take control of their own lives and make their own choices.

Many SIRD projects place considerable value and importance on their work to support people through the assessment for, or review of, a social care budget. For those projects delivering what might be described as 'end-to-end' support, there was a clear preference for engagement with clients at an early stage. When working with people to prepare for a social work assessment or review, project outcomes tended to refer to trying to reduce clients' anxieties and make sure that assessments or reviews are well-handled from their clients'

perspective.

A smaller range of projects were involved in supporting people at assessments or other meetings with social work. The approach taken tended to be led by the client: from those who simply wanted a SIRD project representative with them to act as a reassuring presence, to a small number of clients who were looking for project staff to play an active role.

Most projects were providing some form of brokerage support. All of these were working with people with a social care budget in relation to that budget. Most were also offering a community brokerage service for both those with and without a budget. There was a broad consensus across the research participants around the value of this type of work.

For some projects, brokerage was the core of their work and focused on working with Option 1 or 4 clients referred to them by social work. For others, brokerage was the latter phase of a broader package of 'end-to-end' support for people with a social care budget which had begun at the information provision or assessment stages.

Option 1-focused support ranged from providing further information and advice around how it works on a day-to-day basis through to support with recruiting and managing a Personal Assistant. There were also examples of projects equipping people with skills or tools which would help them manage their own, sometimes quite complex, support packages.

Many SIRD projects have been working with other members of the community with a social care need who are not eligible for a budget who might benefit from information, advice or support. For most interviewees who did not have a budget, making links into other services and groups, and community-based groups in particular, was often a key reason for being in touch with the project.

For a small number of the projects, the peer support approach has been central. This was a particular focus for user-controlled organisations, reflecting their overall philosophy and approach. This has included assisting with setting up and running a peer support group or network.

## **Experiences of looking for information or support**

In a well-functioning system, anyone looking for information or support would find a possible source of information and support quickly and easily. The feedback from the service user survey (full results for which can be found at Annex 2 to this report) suggests that those who have made contact with a SIRD project have tended to do so relatively quickly after they became aware that they needed information, advice or support.

As set out in Figure 4, the largest proportion of survey respondents, around 1 in 2, had just started looking for information when they made contact with a SIRD project. However, around 1 in 4 people had been looking for information for longer than 3 months and a small number of people had struggled to find the information and support they were looking for. Those who struggled to make contact with information or support services tended to be living in rural areas or be in the older age group; and they also tended to not have easy access to, or be a user of, the internet.

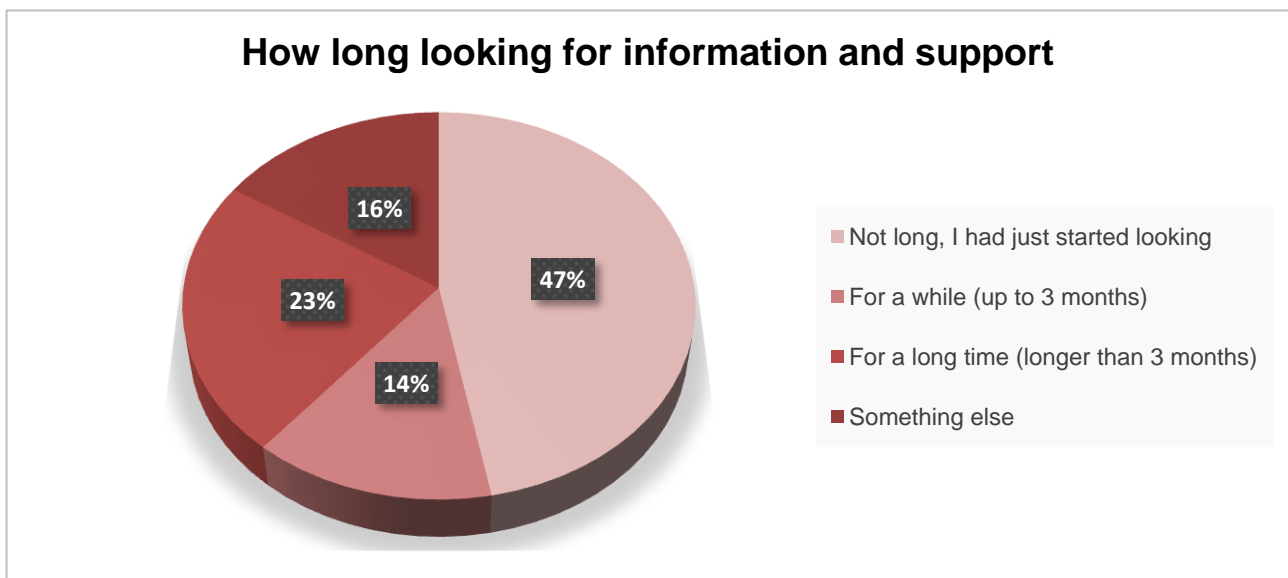
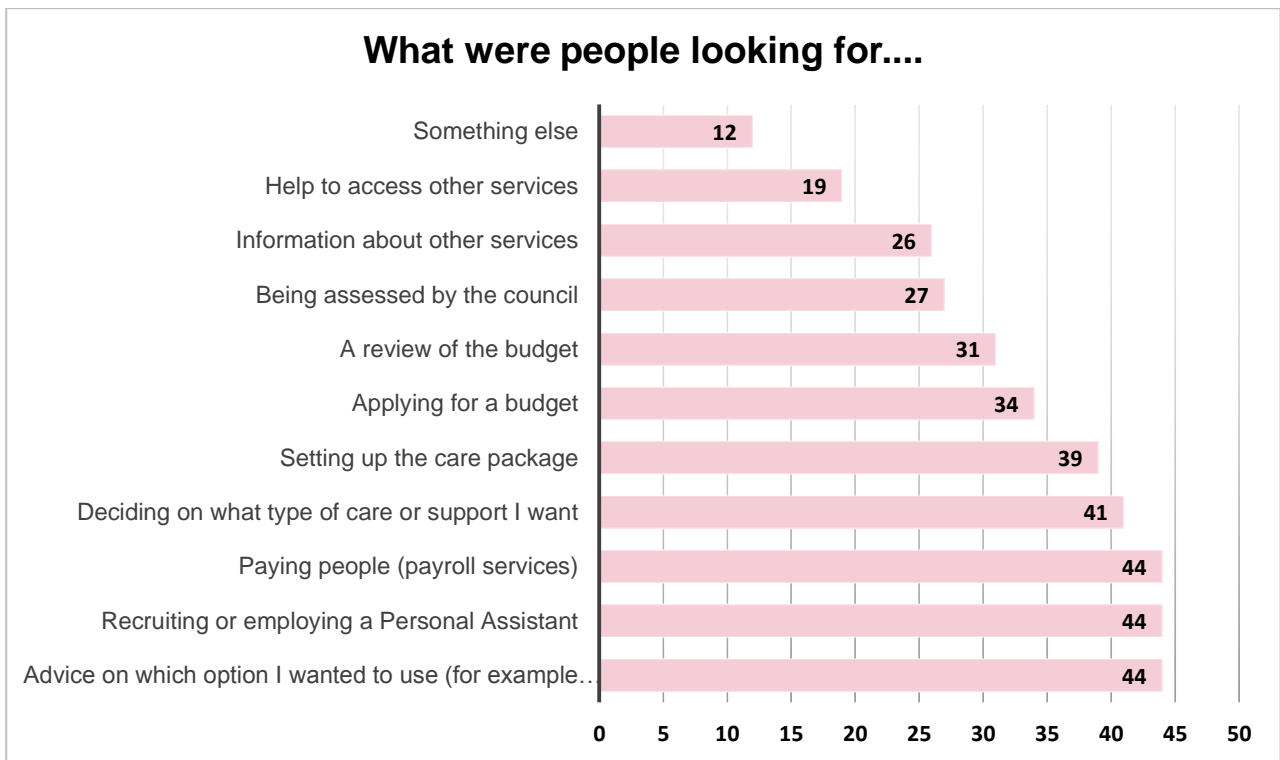


Figure 4

### Type of information or support looked for

The survey asked supported people and carers asked about the type of information or support they were looking for when they contacted a SIRD project (Figure 5).<sup>9</sup> People were most likely to be looking for advice on which social care budget option to choose or for practical support and assistance in relation to Options 1 or 4, including help with recruiting Personal Assistants (Pas) and with payroll issues. Otherwise, people were looking for a range of information, help and support around deciding what they themselves were looking for and various application, assessment and review processes.

<sup>9</sup> People were asked to identify all the types of information or support they were looking for and could select as many options as applied to them.



**Figure 5**

### **Making contact with SIRD projects**

Projects highlighted two main routes that service users had come through when looking for information or support in relation to social care: referral or signposting from social work services and self-referral.

The largest proportion of survey respondents, around 4 in 10, said they had heard about the SIRD project from a social worker. This echoed the feedback from the SIRD projects that they sometimes received referrals from social workers in relation to clients who were looking to go down the Option 1 route.

In terms of people who had made contact themselves, they had become aware of a SIRD project through a variety of routes:

- Some had accessed information or received support from the project in the past. This occasionally included support in relation to Direct Payments. Some had an existing connection through other work carried out by the host organisation. For example, a small number of the SIRD projects are hosted by organisations that are also support providers.
- Some had become aware of the support the project could offer, including but not exclusively in relation to social care budgets, through the project's awareness-raising work. This work is discussed further below.
- Others had heard about the project from friends or family, including from members of social or support groups they attended. Friends and family had sometimes attended one of the project's information sharing sessions.

Around 1 in 10 survey respondents had heard about the SIRD project from family or friends.

- Projects with a central 'high street' type location reported some 'passing trade' from people who had dropped in to find out about what they could offer or to make a social care budget or other enquiry.
- Some had responded to a SIRD project's leaflets or postcards which had been made available in local venues. Others had found out about the SIRD project through references to their work in local newsletters.

There were a number of other routes through which people had made contact with a SIRD project, including:

- Other voluntary organisations. A small number of projects reported referrals between well-established, locally-based organisations.
- Referrals from health staff. The small number of projects that had received these referrals reported that the roll out of health and social care integration had already led to an increase in the number of referrals they were receiving from health staff.
- A national helpline for carers.
- Former social workers.
- Occupational therapists.

## **Awareness-raising and capacity-building**

A number of projects have been carrying out awareness-raising and capacity-building work focused on increasing levels of understanding about the principles of choice and control and how these apply to social care.

## **Community-focused information sharing**

The work carried out can be viewed as being on a continuum which stretches from:

- Distributing publicity materials or holding information sessions which offer basic information about social care budgets and the principles of choice and control. This has generally been focused on people who currently, or at some point in the future may, require social care for themselves or their family; to
- Single sessions designed to give people facing challenges within the system or at the start of their journey more knowledge and confidence to deal with the immediate issues they face; to
- Courses designed to give people sufficient knowledge and confidence to develop a new way of thinking and generate a step change in their capacity to achieve the life outcomes they wish for.

A number of projects had undertaken outreach work designed to increase awareness of, and understanding about, choice and control amongst the wider public. The range of work undertaken has been broad and has included:

- Giving presentations to community-based groups such as: Women's Institutes; groups meeting at local places of worship; and older people's friendship groups.
- Displaying self-directed support-related information on stalls at local community events, such as local gala days.
- Having a physical presence in community-based venues such as doctors' surgeries or the premises of other voluntary organisations working in the area. One example has been the creation of computer-based 'community wellbeing points', in a number of settings, which hold a range of wellbeing-focused information, including in relation to social care budgets.
- Running drop-in information and advice surgeries in local areas where awareness about social care budgets and the principles of choice and control was expected to be particularly low. These tended to be areas of relative socio-economic disadvantage.
- Holding joint outreach surgeries in conjunction with the local social work department.

This work has tended to be undertaken by projects with a single local authority focus and often by projects that already work in the field of information and advice provision across their area beyond the SIRD funded element of their service.

In addition to the general 'whole community' focused activity outlined above, some projects have undertaken a range of awareness-raising work with specific groups of people, such as carers. The aim was to reach people with an immediate interest in accessing, or who are already accessing, social care for themselves or their family. This work may involve partners with specific expertise in delivering services to the particular client group.

Such awareness-raising work has usually been built around delivering a single information session focused on providing basic information about social care budgets and other support, and then highlighting the assistance projects can offer anyone wishing to explore their options further. Others have used an alternative approach, running a series of information events covering different issues around social care, such as benefits and transport, and targeted at specific groups, for example parents of children with complex needs, into which people can dip in and out depending on their particular interests and needs.

A number of the projects have made use of volunteers to help support their awareness-raising work. Those projects reported particular benefits associated with involving people with lived experience in presentations and other outreach work. Not only was this approach seen as improving the quality and accessibility of the information and advice being offered but it may also have helped build the skills and confidence, and by extension the capacity, of the volunteers.

Overall, projects have reported that the community-focused awareness-raising work they have done has been useful. At its simplest this has been about a generally increased level of knowledge about self-directed support as the norm within local

communities. Projects sometimes noted the potential for this knowledge to ‘ripple out’, for example by people who had found out about self-directed support suggesting that family members explore their options. The projects have reported that a small number of ‘new’ clients they are working with have come to them because a family member found out about self-directed support through their outreach work. Projects noted that such work could reap benefits going forward, with people being aware of their options if and when they or someone close to them needed them in the future.

As a counterpoint, many of the projects reported being struck by the very low level of awareness of the right to social care choice and control amongst members of the public.

Although generally positive, some projects did experience challenges in delivering their outreach work. These included:

- Projects working regionally or nationally finding it difficult or burdensome to provide appropriately locally tailored information given the variety of policy and practice in different areas. These projects noted the absolute importance of ensuring that any information they share reflects the local context and local eligibility criteria in particular.
- Where groups of people with a common interest, but living in different local authority areas, are brought together it can highlight the differences in the support available to them. This, in turn, can cause upset or even distress to those who feel they are at a disadvantage because of where they live.
- One of the national projects with a client group specialism reporting that its most natural partner organisations were sometimes reluctant to work with it around social care budgets. Their concerns related to the risk of raising expectations amongst people which could not then be met through the social care resources and arrangements in their areas.
- Projects which were intending to make a significant use of volunteers or the peer support approach in their outreach work sometimes struggling to find enough people willing and able to get involved. This was generally seen as a function of the smaller than anticipated numbers of people they were working with around assessment or the management of a social care budget. Projects tended to be optimistic that this approach would become easier to resource as the numbers of people going through the assessment process, and in particular choosing Options 1 or 4, increase over time.

Although the general awareness-raising activity may reap benefits in the future, there is limited evidence of its impact to date. Many of the projects carrying out this type of work felt that it had been of limited success, particularly relative to other work strands. A number were planning or hoping to spend less time on this activity going forward and to focus on the type of direct client work set out below.



## **Provision of basic information about self-directed support**

Although a relatively small proportion of their overall workload, many of the projects do offer basic information, and receive and respond to initial queries. A number of projects reported receiving general enquiries about social care budgets, eligibility and what someone should do if they wished to apply for a social care budget. These early enquiries may or may not then lead on to someone looking for further information and support (of the type discussed further below).

SIRD projects which form part of a wider information and support-focused organisation sometimes reported that these initial queries may come in through general advice line or drop-in routes. If further advice or support is requested, they would then tend to be referred to the SIRD project team.

## **Training or personal development courses**

A number of SIRD projects had been involved in the delivery of training or personal development sessions or courses covering choice and control in greater depth for supported people and carers.

The training sessions tended to be focused on the information that someone planning to apply for a budget, or who already has a social care budget, might want and need to know. They were sometimes run as single sessions or alternatively formed part of a wider package of training which might cover choice and control, the relationship between social care budgets and welfare benefits, and other issues relevant to the client group, including topics such as transport, self-management and self-care.

The picture has been mixed for regional or national projects which have sometimes found it difficult to get local authorities to engage with them, including to take up offers of client-group focused training for social work staff. This may have been because services simply do not have the time for client group-specific training. As noted earlier, it may also be that the client groups the SIRD projects are supporting are not yet the focus of the local authority's choice and control related work.

An attempt by one project to set up a national peer support network also proved very difficult, both in terms of recruiting peer supporters and in terms of the project resourcing work across the country.

Other projects have been involved in the delivery of personal development courses, over a series of weeks or months. These have often followed existing personal development methodologies that have proved effective elsewhere in work with carers and people with a disability or with long term conditions. Their focus is very specifically on supporting people to gain the knowledge, skills and confidence to take control of their own lives and make their own choices. Being able to make their own choices around the use of their social care budget and then, working with others if preferred or necessary, to make those choices happen is at the heart of this approach. It is also an approach which places self-directed support firmly within the broader range of challenges and opportunities which people may encounter.

The different groups for whom these personal development courses have been run include: young people at the point of transitioning to adult services; people with learning or physical impairments; and carers of children, young people or adults with significant care needs.

A number of projects have highlighted the importance of maintaining contact with people who have been on one of their courses and who might welcome or need support in the future. This has sometimes been done by making people aware that they could also receive one-to-one support as they address social care or other challenges in the future. Another approach has been to facilitate mutual support between course 'graduates', for example through a Facebook forum or meet up sessions.

A small number of projects have done work that they describe as 'one-to-one coaching', which may be seen as an individualised version of the personal development work delivered by others, or as an earlier phase of the work described in the following sections.

## **Support with applying for a budget, assessment and review**

Many of the SIRD projects place considerable value and importance on the body of work they have been doing to support people through the assessment for, or review of, a social care budget.

### **Early contact work**

A number of the projects were involved in supporting clients through the early stages of their engagement with the social care system and into the process of application and assessment.

There were a number of key aspects to this early work:

- The explanation of the choice and control principles and process to clients. This might involve talking people through each of their four options. Projects generally stressed the importance of framing these early conversations around local eligibility criteria and ensuring that they did not raise expectations that were unlikely to be met.
- Initial discussions with clients about how they feel their lives could be improved and supporting reflection on what they really want from the process.

Sometimes clients reported that this initial stage included discussion of their rights within the social care system. Examples included carers being told about their rights to a carer's assessment and siblings of disabled children about their right to a young person's assessment.

For projects delivering what might be described as 'end-to-end' support, throughout the whole self-directed support process, there was a clear preference for engagement with clients at this early stage. A number of projects, and some client

interviewees, highlighted the value of being in contact before an assessment has been carried out and, in particular, before the supported person has made a decision about their social care budget options. It was also suggested that early contact with an independent information and support service might help avoid some of the misunderstandings which can lead to later disputes.

### **Preparation for social work assessments**

Projects were seeking to achieve a number of outcomes when working with people to prepare for a social work assessment or review. In particular, they sought to:

- Reduce service users' feeling of being alone and isolated. This was often connected to building a supportive relationship with service users and giving them a feeling that there is someone 'on their side'. Projects sometimes noted that the nature of the client/social worker relationship can make it difficult to develop this type of connection.
- Make sure that assessments or reviews are well-handled from their clients' perspective. This included ensuring that service users were able to voice all of their concerns and raise all of the issues that were important to them. Older people were identified as particularly unlikely to raise issues or to as more likely to minimise some of the challenges they were facing, and this could affect their eligibility for support.

In practical terms the focus of the assessment preparation phase sometimes included the SIRD project being involved in:

- Development of plans to ensure that all the issues that service users wanted to highlight would be covered by the assessment process.
- Reflecting on service users' previous experiences of assessment or other meetings with social workers or other relevant professionals.
- Focusing on coping strategies for service users who can find such meetings challenging, for example because emotionally-charged issues are being covered and there is the potential for disagreement or conflict.
- Working, in a number of instances, with service users to develop what might be termed a 'shadow assessment' or a 'shadow care plan'. These might be used either as a prompt for further discussion or be presented to social workers to be used as a formal part of the assessment or review process.

Working with service users to consider the outcomes they would like to work towards in advance of social work assessments was sometimes a particular focus of projects working with people with learning difficulties, people on the autistic spectrum and the families of children with complex needs. Many of these service users already had a social care budget but were coming up to a review, or were in the process of applying for, a budget and there was a clear expectation that they would receive funding.

However, a number of projects also worked with people who might not have been eligible for a social care budget, to look at their future plans and hopes. The focus of this work was often around the types of community-based activities and support

which might be available. These issues are discussed further below under accessing community-based services. They highlight the added value that SIRD projects have brought by working with those without social care budgets.

### **Support at assessment or review meetings**

A smaller number of SIRD projects are also involved in activities which could be described as “independent advocacy”: making sure people’s voices are heard throughout the SDS process; enabling people to make informed choices; and upholding people’s rights (Evaluation Support Scotland 2015a).

Some projects were involved in supporting people at assessments or at other meetings between them and their social worker. Service users gave a clear sense of what such support might involve, including:

- Helping them put their points across.
- Making sure everything relevant is discussed and intervening where that does not happen.
- Taking minutes of meetings to ensure that reports of assessments are accurate, and progress is followed through.
- Where necessary, reminding social work staff of their legal and practice obligations.

The approach taken by projects at this stage tended to be very much led by the client they were supporting. At one end of the spectrum, clients sometimes simply wanted a SIRD project representative to be there to act as a reassuring presence. This was also sometimes connected with having someone who could confirm their understanding of what had been discussed and any commitments or decisions that had been made. Both projects and clients reported that SIRD project representatives might attend an assessment or review meeting but play no *active* part in it. Even where this was the case, those who had asked a project representative to be present described that simple presence as invaluable, suggesting that having someone there who they considered to be wholly ‘on their side’ had given them the confidence to articulate what they were hoping to achieve and the type of support they were looking for.

At the other end of the spectrum, and less usual, a small number reported that they were looking for project staff to play an active role in their meetings with social work. This included speaking on their behalf and replying to questions where necessary.

Although a number of the SIRD projects are offering support through attending assessment or review meetings, it was not a role that all projects felt able to play. Some felt that they were not funded to deliver this type of advocacy work, although they believed it was important.

## **Ongoing support and assistance**

For many service users, projects offered ongoing contact throughout the process of application, preparation for assessments, finding out whether a budget had been made available and then deciding how to use it. Projects sometimes noted that clients could find the 'waiting and chasing' which could be involved in applying for a social care budget difficult and at times very stressful.

Projects have looked to alleviate those pressures by:

- Monitoring the progress of applications, which sometimes included contacting social workers.
- Helping to arrange meetings required between their client and their social worker.
- Answering queries that the client may have as they are going through the process, including helping them understand written communications about their application.

This support has sometimes also extended to considering whether to challenge the outcome of the assessment or review and then providing ongoing support through that process. In occasional cases it has included providing support around making a formal complaint about how the social care assessment had been carried out or other aspects of the service received from social work.

## **Brokerage – setting up and managing support**

Brokerage should be understood as providing service users with the support and assistance they need to put in place and manage the arrangements which will enable them to live according to their choices.

Projects' involvement in brokerage includes:

- Identifying the sources from which clients might plan and access the care or support they need, and explaining, exploring, and supporting the steps they need to take to do so. This may include impartial information, advice and practical support and assistance with recruitment, employment and payroll issues.
- Identifying the sources from which service users might access a range of other non-social care budget-related support and activities, including community resources and informal support.<sup>10</sup>
- Once service users have decided on the sources from which they wish to access such support, providing them with assistance to do so.

A majority of the projects were providing some form of brokerage. This generally applied to support around spending their social care budgets and accessing

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<sup>10</sup> Also see: Evaluation Support Scotland (2015a).

services in the community that did not have to be paid for - what might be termed non-budgetary assistance and support.

There was a very broad consensus around the value of this type of work which spanned across the projects, their clients, local authorities and key stakeholder interviewees, and included a small number of SIRD projects that do not currently offer brokerage services, but which felt they were required in their area. The latter projects were often keen to explore whether they might be able to offer this type of service in the future.

For some projects, brokerage was the predominant focus of their work. These were focused on working with people who were referred to them by social work services once an assessment had been carried out and the client had chosen Option 1 or Option 4. For other projects, brokerage was the last phase of a broader package of 'end-to-end' support which had begun at the information-provision or assessment stages.

### **Work around clarifying or challenging assessment outcomes**

The focus of much of the brokerage activity has been on working with people taking Option 1 (and to a much lesser extent Option 4), to set up and then manage their package of care and support. However, many projects reported that early work has sometimes been required before the set-up phase.

Projects highlighted that their brokerage work often encompasses significant elements of advocacy, including around initial challenges about the size of the social care budget awarded or, as noted above, whether a client is entitled to a social care budget at all.

Although the number of service users involved overall was sometimes relatively low for individual projects, both projects and service users identified this as a key area in which support is required. For example, one carer for an adult child with mental health issues was clear that they would not have been able to challenge social work's decision to not award a budget without ongoing support from a SIRD project. They described feeling undervalued and defeated by the system but being given the strength to continue in their caring role by the support and understanding they had received from the SIRD project.

Other early work was around seeking to clarify the package that had been offered and any expectations social work services have around how the package is to be used. The types of issues that projects reported seeking clarification around included:

- The monetary value of their client's budget. In particular, it was reported that some local authorities only set out the social care budget as number of hours of support.<sup>11</sup>
- The acceptable parameters for any spend other than for purchasing support or care hours.
- The requirements and arrangements associated with agreeing and reporting spend.

Otherwise, for a small number of projects, and as also described by some client interviewees, the first stage had been to have a conversation around the outcomes the client wished to achieve. On a small number of occasions, projects and clients reported that these conversations - or at least 'good conversations' - had not been part of the assessment process.

### **Setting up and day-to-day management of a social care budget**

The survey and service user interviews highlighted some of the challenges people can face when taking Option 1 or 4. For many, the recruitment and management of Personal Assistants (PAs) as employees is an entirely new process and one which they can find daunting. A number of the projects have been offering support around preparing to go down the Option 1 route. This has tended to focus on:

- Providing further information and advice around how Option 1 works on a day-to-day basis. There was often a focus on legal requirements associated with being a PA employer, such as National Insurance and pension obligations. This element sometimes included a peer support element (these approaches are discussed further below).
- Discussing the options which might be available locally around the recruitment of PAs. This occasionally included providing a list of PAs working in the area.

A smaller number of projects provided direct support around employing PAs. This most commonly involved: assisting clients with recruitment, for example drawing up job descriptions and adverts and assisting with the placement of adverts; supporting PA employers in shortlisting and interviewing PAs; and providing example employment contracts. Projects which did not provide this type of recruitment-related support sometimes referred people on to other third sector organisations which were able to offer help.

Similarly, while a small number of the projects were able to offer in-house payroll services,<sup>12</sup> most made suggestions for third sector or other providers which offer

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<sup>11</sup> The Audit Scotland (2017) report highlighted that everyone assessed or reviewed as being eligible for social care can expect their social worker to discuss and agree with them a range of issues including how much money the authority will spend on their services.

<sup>12</sup> Please note that these payroll services were not SIRD funded but were otherwise being run by the project or their host organisation.

payroll services. Where an in-house payroll service was available, projects stressed that clients were made aware of their other options.

Projects which are involved in helping people set up their support packages also tended to offer ongoing support around the management arrangements. The types of issues with which projects had helped clients included: dealing with issues around holiday cover or holiday and sickness entitlements; helping make arrangements when the client had an extended period in hospital; and dealing with problems with a PA's performance. In one of these latter cases this included a project supporting someone who had decided that they needed to dismiss their PA.

There were also examples of projects equipping people with skills or tools which would help them manage their own, sometimes quite complex, support packages. One example was the provision and setting up of a software package for tracking of the delivery of care, ongoing spending and progress against outcomes.

Although much of such ongoing support has focussed on employment issues, the other issue on which projects sometimes continued to work with clients was around alternative uses of their support budget, in other words spend not associated with employing a PA. The focus here tended to be on the types of activities on which the budget could be spent. Examples included whether the budget could be spent on gym or sports club memberships or to enable someone to go to an event or on a short break. Projects reported that these can sometimes be difficult and challenging conversations, with the onus placed on their client to convince social work that the spend is reasonable. However, as with many other aspects of this review, there were reports of very positive joint-working between social workers, the SIRD project and, critically, the client themselves.

### **Advocating and supporting people to challenge decisions**

As noted above, there were reports of very positive, constructive and supportive relationships between people supported by a SIRD project and their social work service. However, a significant amount of the work of projects has involved working with, and advocating on behalf of, clients in some way unhappy with the social care process or decisions that have been taken. For some projects, this has come to constitute the majority of their work or has formed a much greater proportion of the work than they had anticipated when applying for SIRD funding.

The types of issues which projects, survey respondents and client interviewees raised included unhappiness or disappointment with:

- The pace of the application, assessment and decision-making process.
- How clients feel they have been treated and, in particular, the extent to which they feel listened to and believe that their views and wishes have been taken into account.
- Either being told they are not eligible for any social care budget or feeling that the social care budget they have been given is insufficient to meet their needs.



- Being unable to spend the budget on things that they feel will make a significant difference to their quality of life.

Given the varied local contexts, pace of self-directed support implementation and social care arrangements across local authorities, it is unsurprising that some projects reported more issues, or a different range of issues, than others. SIRD projects tended to note that they are not quick to judgement and will often seek further information on their client's behalf. This sometimes meant that, once the situation had been fully explained to the client, they did not wish to take any further action. In particular, a number of projects highlighted that it would not be in the best interests of their clients to encourage them to challenge decisions when it was clear (based on local eligibility criteria) that the decision would not be overturned.

However, many SIRD projects reported that there are occasions on which a service user does wish to challenge social work practices or decisions and looks for their support to do so. This might involve: chasing up progress; writing or supporting the client to write letters; supporting a client to make a formal complaint; challenging social workers' understanding of the relevant legislation, or established practice in their local authority area, where this appears to fall short.

As with other aspects of their work, some projects offering end-to-end support expressed frustration about the late stage at which they sometimes become involved. By the time someone comes to them the relationship between that person and their social worker may already be tense. They generally felt that, had they been able to intervene earlier, this situation, and the often-considerable stress or distress the service user was suffering, could have been avoided or been less.

Projects felt that work to challenge social workers can be difficult and is highly skilled, with the potential for conflict constantly present, and that conflict might potentially be damaging to a client's interests. Projects referred to their own understanding of the challenges facing social workers, including delivering services at a time of huge financial pressure, as being key to achieving positive outcomes. It was also seen as essential to focus on the rights of the clients as stated in legislation and expressed in practice when supporting any challenge.

A small number of SIRD projects reported experiencing difficulties because of their work in challenging the practice or decisions of individual social workers or social work teams. They felt that relationships with some social work staff, and especially with middle management, were poor as a direct consequence.

## **Accessing community-based services**

Although much of the SIRD projects' work has been with people around applying for or managing a social care budget, many have also been doing other community-based work. This has tended to focus on connecting people into groups and services within the community. Projects may have been doing this work with people who have a social care budget and with those who do not. For those without a budget, particularly reference to older people, this was sometimes articulated as

working with people who might not yet need a formal support package but who might do so in the future.

The preventative focus of this type of work was often highlighted, including in relation to 'postponing' the point at which a formal and potentially costly support package might be required. However, it is also notable that around 1 in 5 of the survey group (all of whom have a social care budget) were also looking for help in accessing other services.

For many interviewees who did not have a budget, making links into other services and groups, and community-based groups in particular, was often a key reason for being in touch with the project. The initial connections had sometimes been made through projects' awareness-raising and other outreach work, such as visiting lunch groups or other community-based events. Very often, someone attending this type of event, including carers, had suggested the project might be able to help someone known to them.

Alternatively, the person attending the event may themselves have been looking for support or might have been interested in having a conversation about choice and control. These conversations did not always lead on to any social care budget-related advice or support but generally led on to a conversation about other community-based social opportunities or support options.

In terms of non-budget related assistance, the support being looked for and received included:

- Arranging introductions into, and sometimes initially accompanying people to, social or support groups or events. These events included older peoples' lunch groups, craft groups, and walking or sports groups. People who had made these new connections sometimes referred to feeling less isolated and much more a part of their community, and some referred to a general improvement in their health and wellbeing.
- Supporting people to set up their own social groups or events and being available to provide *ad hoc* advice once the groups are up and running.
- Accessing training or employment-related support. For example, a young person and their carer have been working a project around ways of travelling to and from a local college, an example of projects working with young adults around independent living skills.
- Supporting someone to have changes made to their property which helped maintain their mobility and independence.
- Referring or signposting carers to counselling and other support designed to preserve their wellbeing.
- Also primarily for carers, providing information and advice around a range of issues such as welfare guardianship and power of attorney.

In addition to the types of support outlined above, a small number of projects had been working with small groups of people who have traditionally struggled to access social care funding, to look at ways they could pool their resources and, through coming together, could access support or other opportunities. Examples of the types of things these small pooled budgets have been spent on include photography lessons and home furnishings. This type of pooling of budgets, including to put together workable support packages, has been a focus of some of the work being carried out by projects with Innovation Fund funding.

It was also clear that for some people simply being able to make contact with one of the projects - and in particular being able to speak with someone who is known to them and who is aware of their life circumstances - gave a sense of reassurance and helped reduce feelings of social isolation. A significant majority of non-budget holders reported that they were still in contact with their SIRD project. Around 4 in 5 survey respondents also said they were still in touch although some of these were in receipt of ongoing support around Option 1.

## **Peer support and peer involvement**

Peer support or involvement should be understood as people using their own experiences to help and support each other. It aims to help both those giving and receiving support.

Projects' involvement in peer support work included: helping to set up and support peer groups or networks; involving people with lived experience in delivering awareness-raising or training courses; and setting up a Community Brokers approach, in which peer mentors support others to access community-based services.

For a small number of the projects, the peer support approach has been central to their SIRD work, particularly for user-controlled organisations, reflecting their overall philosophy and approach. Other projects have included peer support elements within the broader work they have been doing. It was sometimes an approach which projects had expected to use more widely but found challenging.

The type of work that has been carried out includes:

- Assisting with setting up and running a peer support group or network. The ongoing support offered might include: arranging meeting venues and travel arrangements; arranging speakers for meetings based on areas of interest identified by the group; and supporting members to access the technology required to participate in events or discussions. Choice and control has often been one of the main issues groups have wanted to focus on. However, feedback from members of one of these groups made clear that the social aspect, including being able to spend time and talk with those with similar lived experience, was truly valued.
- Helping to set up ongoing mutual support networks between those who have attended a personal development or other training courses. This included

course 'graduates' supporting or hosting ongoing on and offline communities. Facebook has been an important mechanism for this work, with some well-functioning and well-used Facebook groups.

- Developing an email network which allows people to post questions and concerns anonymously and receive answers or other support from network members.
- Involving people who have been through the social care budget application and assessment process, in particular people with experience of Option 1, in delivering focused awareness raising or training sessions.
- Involving 'graduates' of personal development courses as future contributors.
- Training and supporting people with lived experience around speaking to working groups, committees or commissioners about their social care and other life experience.
- Setting up a Community Brokers system, with former clients, and in particular people who are or have been carers, supporting others to access community-based activities and support.
- Employing peer educators.
- Using peer support approaches to deal with the risk to young people at the time of transition from child to adult services that their social networks will fray and they will become dependent on parents and other adults in their family for their social lives.

More generally, a number of projects noted that it is important effective peer support approaches obtain adequate funding, and that they cannot be delivered at no cost. Irrespective of the skills and commitment of those involved in delivering peer support, funding will always be needed for their set up and day-to-day running. Also, a number of projects noted that many of those willing to take on a peer support role had attended one of the training or personal development courses or had otherwise received help and support from the project. In essence, therefore, SIRD funded activities had become the recruiting ground for peer support work.

As noted above, some projects have found the setting up and running of peer support approaches challenging. For example, one project had hoped to create a group of Option 1 Mentors, people who had been through the set up and running of Option 1 and were prepared to share those experiences with others and support them in their journey. However, until very recently they simply had insufficient Option 1 clients to make this approach sustainable. They now have a small group with experience of Option 1 and are testing peer support approaches with some of them. Other projects reported being unable to recruit sufficient people to take part in peer support work; this was sometimes related to the relatively small group of people with lived experience within a particular client group.

## 7. Reflections on Direct Client Support Work

This chapter looks at:

- The numbers and types of people who have been accessing direct support.
- Clients' views of the quality of the service they have received from SIRD projects and the impact it has had on their lives.
- What the review findings suggest is good support and the added value which the SIRD projects have delivered.

### Key Findings

Although small number of projects reported meeting their targets for working with people looking for direct client support, a number of projects have fallen significantly short of theirs. A small number of the projects concluded that the focus of their work may simply have been premature given progress on embedding self-directed support as the norm in social care. Projects working with people experiencing homelessness or community justice service clients were most likely to be of this view.

When faced with lower than anticipated numbers of people looking for budget-related support, many projects have looked for ways to use the SIRD funding constructively as part of a wider package of work around choice and control in social care.

Almost without exception, service users were very positive about the quality of support received. When asked how they felt about the information and support they had received, more than 8 out of 10 survey respondents said it had made an enormous or big difference. Service users highlighted the positive impact that SIRD project support has had on their health and wellbeing - a central theme was the profound and life-enhancing impact.

Support from a SIRD project had helped users to access or make the most of social care. Helping unlock the potential of choice and control had an enormous impact for some. Project users who had accessed a social care budget whilst working with a SIRD project felt that this positive outcome might not or would not have been achieved without the support received.

For those engaged in exercising choice and control in social care, support at any stage can make a difference; for some, having someone to walk alongside them for the entirety of their journey has been critical.

For many, there were aspects of the self-directed support process where third sector providers offer very real additional value. This was primarily in relation to supporting people who choose Option 1 or 4 and helping people access community-based opportunities and support. However, there was varied opinion

around who was best placed to provide information and advice in relation to choices about, and control of, a social care budget.

Single local authority-focused projects were often those involved in the delivery of the 'end-to-end' support that was much valued by clients. Where this approach has been working well, projects were usually a well-established member of a network of statutory and third sector agencies with a history of working together. Projects working across a small number of local authorities across Scotland tended to face practical challenges associated with varied practice and eligibility criteria and the need to build and maintain working relationships across local authorities.

Client-group focused services sought to ensure that their specialist knowledge and skills meant clients received the right type of information and were supported to meet their particular needs. Such projects have experienced similar challenges to more generalist services working regionally. Overall, however, they have tended to report that the approach has worked well; the feedback from their clients certainly suggests this to be the case.

The SIRD funding stream has a focus on building self-directed support-related capacity in the independent information and support sector. The relationship between project independence and the source of their funding was highlighted by a number of projects. Some had concerns about receiving funding from an organisation which they might need to challenge; other projects had no such concerns.

## **Numbers and types of people accessing direct client support**

A small number of projects have reported hitting their targets for working with people looking for direct, independent support. Where numbers have been high, and they report working at close to, or at, capacity, projects were often the established providers of information and advice in their area or for that client group. This sometimes meant that they already had an existing client group with social care budgets and have continued to work with them through a transition to using self-directed support options. These projects also sometimes reported very well-established working arrangements, including referral arrangements, with their local authority. They have tended to be working with carers, older people or people with learning difficulties.

However, as noted earlier, many projects have found the environment within which they have been delivering services very different to that which they had anticipated. This may be one of the reasons why a number of projects have fallen significantly short of the targets set out in their original application in terms of the numbers of people they expected to provide with direct client support. More specifically:

- In some cases, the shortfall was put down to the varied pace of progress on embedding self-directed support more generally in the geographic area(s)

covered by the project. This was sometimes across the board but in other instances related to particular client groups.

- A number of projects highlighted that they had received fewer formal referrals than anticipated and that referral arrangements were either not used as much as they had hoped or were not in place. This applied particularly in relation to referrals from social work.

A small number have concluded that the focus of their work - and in particular the client group focus of their work - may simply have been premature given national progress on implementation. Projects which were focusing on people experiencing homelessness or on community justice service clients were amongst those taking this view; there were associated reports of finding it very difficult to engage homelessness or community justice services around choice and control.<sup>13</sup> They had concerns that, in addition to barriers resulting from more general cutbacks in services, they were also coming up against a working culture which had not fully bought into people making their own choices; projects sometimes felt this was connected to a perception that certain people or groups would waste their budget or that the risks associated with giving someone choice and control were too great.

This reluctance to 'risk' the misuse of a budget was also one which some projects reported as being common to mental health services and some services working with people on the autistic spectrum. Projects often did note, however, that this reluctance was often associated with concerns about the overall wellbeing of the client. Nevertheless, some projects have been working with people with mental health issues to consider which social care budget option they would like to choose. Echoing a common theme running through this research, projects tended to report that being able to have an open and constructive dialogue with social work tends to depend on the individual social worker in charge of the case.

When faced with lower than anticipated numbers being referred for social care budget-related support, many projects have looked for ways of using the SIRD resources constructively and as part of a wider package of work around supporting self-directed support implementation. Examples of this type of work include:

- Working with those experiencing homelessness or clients of community justice services around personal development work, including work on identifying personal outcomes. Three projects sometimes used other non-SIRD funding to give individuals access to small budgets which could be used to help them work towards meeting their outcomes.

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<sup>13</sup> The Audit Scotland report also identified that different groups of people receiving social care services are experiencing different levels of choice and control. The groups they identified as possibly being affected included: people who do not have carers, personal assistants or friends and family to support them; people aged 85 and over; and people with mental health problems.

- Exploring the travel-related issues young disabled people face and looking to develop innovative approaches around online peer support which could help young people overcome the barriers they face.

Although questions might be asked about whether some of this is the type of work which the SIRD Fund was designed to support, it has often been valuable and has offered the opportunity for broader learning; for example, projects suggested some of the work they have been doing could hold lessons for those looking to take forward Housing First approaches to tackling homelessness, or for those managing the Scottish Welfare Fund. Projects also noted that taking forward other useful lessons and activity could help build and sustain the working relationships needed to facilitate work in the future.

## **Clients' views on quality and impact**

### **Overall views on quality and impact**

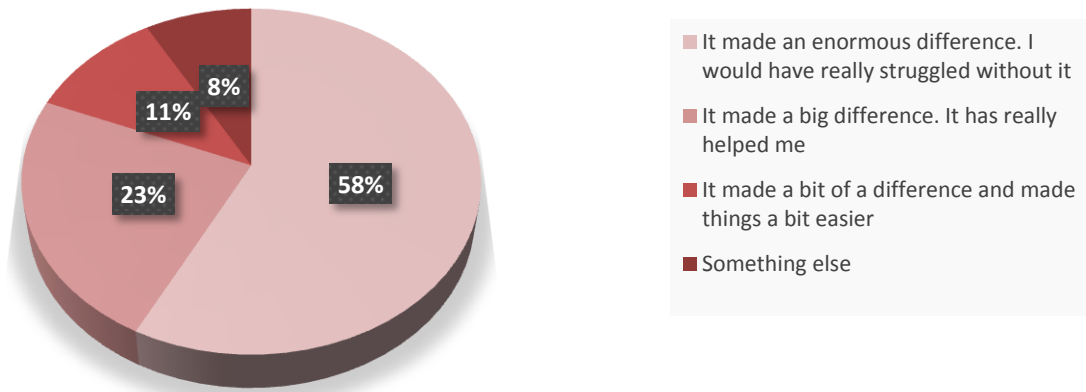
Almost without exception, clients were very positive about the quality of support that they received from projects. Elements which they particularly appreciated included project staff having:

- Technical knowledge relating to social care practice, policy and legislation.
- Empathy with the stresses and pressures they were under.
- Commitment and devotion of time and energy to supporting them, with a number of clients referring to project staff going 'above and beyond' for them or suggesting that 'nothing was too much bother'.
- Responsiveness when they raised concerns or issues.
- Perceptiveness, to the point of being able to anticipate questions and issues they would raise.
- Being 'on their side', with one client describing project staff as being '100% us and not them'.

This very positive feedback was echoed through the client survey results. As set out in Figure 6, when asked how they felt about the information and support they had received, more than 8 out of 10 survey respondents said it had made an enormous or big difference. Although there were response options for the project having 'not made much of a difference' or 'no difference at all', no respondents selected either of these options.



## Difference made by the SIRD project



**Figure 6**

As noted earlier, it does need to be remembered that the people involved in this research had needed or wanted support other than that provided by their social worker and that there may be many others who would not feel that need. There may well be others who might have appreciated or benefited from support but were not willing or did not feel able to go in search of that support.

Bearing in mind that this is the perspective of only a proportion of those accessing a social care budget, SIRD project service users often contrasted the service they had received from their SIRD project with that they had received from social work. Overall, project staff were seen as:

- Having more time than social workers to work with clients. Supported people or carers felt this enabled them to develop a real understanding of their situation and that this, along with the working relationship formed, helped achieve better outcomes. They were also sometimes very understanding that their social worker might like to give them more time but that other work pressures meant this was not possible.
- Being open and informative around the options someone might have.
- Not looking to encourage someone to go down any particular route but wanting to support the client in making their own decisions.

### **Impact on wellbeing and health**

The feedback from clients highlighted the impact that the support from projects has had on the health and wellbeing of those involved. The positive psychological impact projects have had often appeared to be very closely linked to clients feeling valued as individuals and supported emotionally as well as practically. In fact, some clients suggested that this emotional support was as, if not more, important than the range of practical assistance they had received. That emotional support might be provided through:

- Services being open, available and accessible, with clients able to drop in, pick up the phone or make contact online at any time.
- Having a named person within the project who leads on providing support to that client. This approach, and the continuity of service it fosters, allows staff to develop a real understanding of the challenges someone is facing, and to tailor the support offered accordingly. As one client expressed it, the thing they most valued about their SIRD project was 'Them understanding ME!' It was clear that for some their usual experience was not necessarily one of feeling valued or listened to.
- Being present alongside clients at stages they might find difficult or stressful, such as assessments or reviews. Clients described projects' services as being like a 'security blanket', as holding their hand all the way through the process and as providing 'total reassurance'.

The potentially transformative power of giving people choice and control was highlighted in Chapter 3. It is important to recognise here that many felt the support their SIRD projects provided had an equivalently powerful and positive impact. Examples included clients saying that the support had been lifesaving and 'literally a lifeline'. A carer described her transformation from being seriously depressed, having lost her sense of self, having resigned from jobs, and feeling exhausted and as if she could not go on, to someone who was in a better place, was coping much better and who could continue in her caring role. Another carer highlighted that a project's referral to a counselling service had helped her turn a desperate situation round.

These were just a few of the very many examples which client interviewees kindly shared with the study team. The central theme of all their stories was that the support a SIRD project gave has had a profound and life-enhancing impact.

### **Impact of having choice and taking control**

The service user feedback in interviews and survey responses also explored the extent to which people felt that support from a SIRD project had helped them to access or make the most of their social care budget. In particular, helping unlock the potential of making choices and having control had had an enormous impact for some people.

For example, those who had graduated from personal development courses were clear about what they saw as a transformative impact on their ability to make the process work for them or their family member. These courses, and other personal development work that projects have been doing, had often given people greater clarity about their or their family member's potential, and about how they could use a social care budget and other support services or opportunities to make the best life possible for themselves. People also reported having raised confidence and self-esteem.

Other benefits which these clients reported included:

- Having a level of understanding of self-directed support legislation and practice which allowed them to engage with professionals in a different way and based on an equivalent (or in some cases they felt greater) level of understanding. This included being able to challenge their social worker if necessary.
- Having an understanding of the language and jargon which might be used, along with the terminology and presentation of a social care budget.
- Developing strategies for dealing with difficult situations without being confrontational; in the words of one client, 'how to become a leader not a fighter'.

More generally, many clients who had accessed a social care budget whilst working with a SIRD project felt that this positive outcome might not or would not have been achieved without the support they had received. For some this was a matter of the project helping them to navigate a complex system with which they were unfamiliar and something that they did not believe they would have been able to manage themselves.

In particular, clients highlighted the role of their project in unblocking progress, or in dealing with situations that they had found difficult. This was often associated with getting the assessment carried out and then being told of the outcome. Other areas in which clients reported that projects had a particular impact around accessing a social care budget and then making decisions about that budget included:

- Helping them think through the outcomes they would like to achieve and how they could use their budget to help meet those outcomes.
- Suggesting other projects or organisations which could assist, such as a payroll service, or helping with practical tasks, such as setting up a bank account.
- Helping with other problems the client was facing which, although not social care-related, would undermine their ability to achieve their outcomes. A housing problem was given as an example.

Very much in line with the earlier observations around health and wellbeing, being and feeling supported in working through these challenges sometimes enabled people to persist when they would otherwise have walked away and to have found the process less intimidating and stressful than they would otherwise have done.

The impact of engagement with a SIRD project was slightly less clear cut for some. These clients were still very grateful for the support they had received to deal with the social care system, but felt that in its absence they would still have been able to get a package that suited them. However, they believed that this might have taken longer and been more stressful.

It was not always clear why a SIRD project had made a life changing difference for some whilst for others had (only) been a very much valued help and resource.

Social capital does not seem to provide a robust explanation. Some service users highlighted that their own social capital had not prevented them from finding the social care process extremely difficult to navigate. That social capital was described by some in terms of their general confidence, whilst others referred to their own professional background in an area related to social care. These clients had been surprised at how much they had struggled, even with those skills and knowledge.

Overall, if anything really distinguishes those for whom support was vital and life changing from those for whom it was important and very much valued, it may be the complexity of the challenges faced and, in particular, how long someone feels they have been 'battling' to get the help they need.

## **Reflections on good support and project additionality**

### **What matters in support**

Projects' face-to-face work provides emotional and practical support that their clients had not found forthcoming elsewhere. Project staff have the ability, and arguably the time, to establish a working relationship with service users, to be available to deal with problems or simply have the time to listen that social workers may not. It also appears that project staff may sometimes become more versed in the detail of the mechanics of the self-directed support process and options than their social work counterparts.

The result is that project staff, with knowledge of clients' situations, backed by an in-depth understanding of social care, often become the first port of call for clients when they wish to talk about their situation or to deal with particular problems. Practical support, accessibility and empathy are at the heart of the approach many SIRD projects have taken.

It is of course the case that, irrespective of the approach an organisation takes, the quality of the information, advice and support they offer is important. Many of the projects delivering face-to-face work also appear to have benefited from the recruitment of experienced, high quality staff at both frontline and management level. It was striking that some projects have staff members who are highly experienced former social workers; this not only means they have skills around assessing clients' needs but also means they have a real understanding of, and empathy with, the challenges faced by their former social work colleagues. This is not to suggest that these staff will not do everything they can to support their clients, but it does mean they have an understanding of the pressures faced by those they may need to challenge.

### **End-to-end provision**

This review has found that, for those engaged in directing their own social care, support at any stage can make a difference; however, for some people, having someone to walk alongside them for the entirety of their journey, end-to-end, has been critical. As discussed in Chapter 6, although some projects have focused on

delivering specific elements of an information and support service, others have been looking to deliver end-to-end, or virtually end-to-end, support.

There have been a range of reasons why projects have not offered end-to-end support. This was sometimes because they had set the project up to meet a specific 'gap' in the provision available in their area, for example in relation to advocacy. They may also have been aware of, or have existing joint working relationships, with other organisations which were providing information and support in their area and have sometimes sought to avoid replicating work being done by others. On a very pragmatic level, some projects noted simply that they were not funded to provide end-to-end support although they would consider expanding the range of support they provided if the necessary resources were available.

### **Focus of support needed**

As discussed above, clients who had received end-to-end service valued the whole package of support they had received. Projects that provided such a service also tended to see each component as being required and as benefitting from being delivered by an independent, third sector organisation.

Irrespective of views on other elements of the service, there was a very broad consensus, including among local authorities and key stakeholders, around two elements where SIRD projects, or other third sector providers, offer very real additional value. This was primarily in relation to:

- Supporting people who had taken Option 1 or 4 to set up and possibly manage their care package and their social care budget spend. Many interviewees suggested that this is not work that statutory services are well equipped to deliver and nor are they resourced to do so.
- Helping people without a social care budget to consider the life outcomes they would like to achieve and then, if necessary, supporting them to access community-based opportunities and resources. Also helping those with a social care budget to access other community-based options.

Beyond this broad consensus, there was a range of opinion around who was best placed to provide information and advice in relation to choices about, and control of, a social care budget. Some were clear that the local authority is best placed to: inform someone about their options, support them through the assessment process, and support them to make a decision about which self-directed support option they wished to take.

Those of this view tended to suggest that referrals to an independent information and support provider might be appropriate if there were particular circumstances which were making it more difficult for social work to be sure that someone was fully informed and was receiving the support they needed. An example might be if there were language or cultural barriers which need to be worked through. There were mixed views as to whether the complexity of a case were grounds for referral,

with some of the view that social workers are very much best placed to work with clients in these circumstances. Others felt that the significant time and empathetic approach required might mean that a third sector agency with the necessary knowledge and skills would be better placed to provide support.

From the project perspective, the majority view was all people applying for a social care budget should be referred, or at least signposted in the direction of, independent information and support. As noted earlier, they also thought that this should be done at the earliest opportunity. However, many also highlighted that this approach would have resource implications and that neither they nor the third sector as a whole would be in a position to support such an approach unless funded to do so.

### **The impact of working locally, regionally or nationally**

The SIRD projects are diverse in terms of their geographical coverage, the range of services they provide, and the client base.

Single local authority-focused projects were often those involved in the delivery of the end-to-end support much valued by clients. Where this approach looks to have been working well, and has been easiest to get up and running, projects were usually a well-established member of a network of statutory and third sector agencies which have a history of working together and which may have formal referral arrangements in place. If formal referral arrangements were not in place, informal referral and signposting between agencies – or at least between members of staff within those agencies - may already have been common practice. Unsurprisingly, where there were already good and positive working relationships between local partners these have tended to continue. Where these have needed to be built from scratch, and particularly where this remains a work in progress, projects may have struggled.

In terms of delivering information and support around community-based opportunities and resources (both to those with or without a social care budget), locally-focused projects appear very well placed. They tend to know their communities well and staff may very likely be members of those communities.

Projects working at a regional level, or across a number of local authorities, across Scotland tended to face different challenges. Most obviously, they have been looking to make connections and deliver a high-quality service within a number of different operating contexts. On a very practical level, the eligibility criteria for a social care budget will vary from local authority to local authority. Equally, relationships need to be built and managed within each local authority and quite possibly within a number of different services within each local authority. This has sometimes been possible but is described as extremely resource intensive.

Along with a small number of the projects working locally or regionally, all of the projects working nationally had a client-group focus. Although not all were involved in the direct provision of support, those that were sought to ensure that their specialist knowledge and skills meant clients received the right type of information

and were supported in a way which met their particular needs. Projects taking this approach have experienced similar challenges to more generalist services working regionally. Overall, however, they tended to report that the approach has worked well; the feedback from service users certainly suggests this to be the case. In many ways that success has been built on having both an established reputation as a client group specialist and an often-substantial pool of existing clients who could benefit from receiving information and support.

### **The value of independence**

The SIRD Fund has a focus on building self-directed support-related capacity in the independent information and support sector. The nature and importance of that independence was explored with the projects, local authorities and other key stakeholders.

At its most basic, some projects felt that their independence, and particularly having no formal reporting arrangements with social work services, was essential to their value. They felt it gave them the ability to challenge social workers' decisions and practice where necessary and was one of the key reasons why clients felt able to trust the service they provided. Those clients who raised this issue supported this view.

The relationship between project independence and the source of their funding was highlighted by a number of projects. This was often connected with ongoing funding arrangements and any plans they had for after the end of the current SIRD funding round. Projects tended to take one of two positions, these being that:

- Their independence would be compromised if they were reliant on future funding from their local Health and Social Care Partnership. Their specific concern was that they would be compromised when challenging the policy or practice of a key funder. There were also concerns that making such challenges could jeopardise future funding.
- Health and Social Care Partnerships are responsible for ensuring that there is appropriate provision of independent information and advice in their area. They should be and are capable of recognising and respecting the need for external challenge and receiving funding from the Partnership would not affect the independence of the provider. Some projects also noted that this approach is already established practice across other policy areas.

Both positions may be valid, but it is worth noting that the position taken was sometimes connected with the project's expectation as to whether the Health and Social Care Partnership was likely to make funding available, as well as whether they were the most appropriate source of any funding.

It should also be noted that some projects had no concerns about receiving funding from their local Health and Social Care Partnership and did not feel that such funding would in any way compromise their independence or cause them to step away from making a challenge if necessary. The local authority interviewees who

commented on this issue also did not see Health and Social Care Partnership funding as in any way compromising the independence of an information and support provider in the third sector. Some also noted that this type of funding approach is common across a wide range of commissioned services.

Finally, on the issue of independence, a small number of the SIRD projects are part of wider organisations which provide other social care budget-related services, and most obviously are providers of either care or payroll services. Although a small number of others felt this created a conflict of interest, the projects involved were clear that they had 'ring-fenced' the information and support element of their service and that its independence was in no way compromised. Some even reported challenging decisions and practice in other parts of their organisation. Service users of these projects did not raise any concerns nor was there any other research evidence to suggest this has created any problems.



## 8. Development of Information

This short chapter looks at the range of information resources developed by the SIRD projects.

### Key Findings

Based on reviewing available information, a number of projects produced a range of materials informing people about self-directed support. For some this work has been the main, or a significant, focus of their work.

Information has been produced in a range of formats. Much use has been made of case studies, including in video format. There has also been innovative work developing games and e-learning packages as tools for understanding and supporting client progression through the social care process.

A number of the projects have been developing information, materials and tools relating to social care and choice and control. For a small number this has been the primary focus of their work. Others have been doing this alongside the delivery of direct support.

Before moving forward, projects usually reviewed the information already available and generally saw the potential for significant improvement, including around content and presentation. This work was not confined to projects working in one local authority but was undertaken by some regional or national projects who identified shortcomings in some of the information provided by local authorities and others targeted at specific groups of people.

The focus of such work has been on providing information that is easily accessible both in its content and its format. This latter requirement has meant that materials have been produced in a range of media and formats including:

- Leaflet or booklets made available to pick up at a range of locations, giving a brief overview of how choice and control of social care budgets works and the next steps someone should take if thinking about their options. These are likely to include contact details for projects, including SIRD projects, which can offer independent information and support.
- Longer and more detailed, but still accessible, materials, in a range of formats including hard copy and web-based information, often including video and audio materials. This has included case study videos of people telling others about their experiences, including the process they had been through and the benefits they are now seeing. One project had developed web-based materials designed for people with literacy problems based around picture stories with text and sound add-ons.

- A game aimed at young people as part of which they can produce a scrapbook which they can use to support their engagement with social workers.

Projects have often worked with a range of partners when developing these materials, including other third sector organisations and design companies. As would be expected, people with lived experience, including SIRD clients, have often played a key role in developing and testing these products.

In addition to these more widely available resources, some projects had also put together information packs or resources to support their training and personal development work. In one case this was in the form of an e-learning package.

In terms of both these and other materials, projects were clear that the information they produced was not only for use by members of the public but could also be of value to professionals, including to social workers. In particular, projects suggested they could be of use to social workers when having first conversations with a client about the principles underpinning self-directed support and the choices available.

Although the focus of much of the work has been on providing information for people who might be about to embark on their own social care journey, there has also been work to produce awareness-raising information for other groups. For example, one project produced campaign-style materials aimed at encouraging people to consider becoming a PA, highlighting the value of the work, the support the organisation could give and how working as a PA could be part of a career development plan.

Projects have come up against some challenges when developing information materials. For regional or national projects, it has sometimes proved difficult to produce materials which work across more than one local authority area. Nevertheless, the investment of time and resources was generally considered worthwhile. For these and other projects, the information materials they have developed are a very tangible product of their SIRD funding and one which will continue to offer a legacy of real value into the future.

## 9. Running of the Funding Programme

This chapter looks at:

- The support provided to projects by Inspiring Scotland and other stakeholders.
- The monitoring system used to capture the outcomes generated by the projects.

### Key Findings

The support commissioned by the Scottish Government from Inspiring Scotland has been very much appreciated, in terms of its quality, the commitment of Inspiring Scotland staff, and the practical networking and advice provided.

The performance monitoring approach has evolved over time and is effectively a coming together of approaches developed by a small number of first round SIRD projects. While the data gathered is indicative of the work projects have been doing, it does not tell the full story of project activity or impact.

### Support from Inspiring Scotland and other stakeholders

During the second round of the SIRD Funding Programme, Inspiring Scotland has overseen the performance monitoring of the projects. They have offered projects a range of practical advice or support, if requested, and have organised meet up sessions which give SIRD projects the opportunity to come together, share learning and discuss a range of issues affecting them.

Projects were very positive about both the quality and practical usefulness of the support they had received from Inspiring Scotland. Inspiring Scotland were seen as:

- Positive and supportive. This included being sympathetic to projects' concerns.
- Responsive, accessible and providing a continuity of support, even when experiencing staffing changes.
- Not having the Central Belt focus that some national organisations can have.
- Focused on positive outcomes rather than bureaucratic procedures.

SIRD projects appreciated the considerable efforts they felt Inspiring Scotland staff had gone to in offering them support including, for example, by travelling some distance to be alongside them at key meetings. These types of efforts, combined with taking a realistic and open approach based on listening to projects' experiences and the challenges they were facing, has been much appreciated. Also, projects tended to feel that having a monitoring partner like Inspiring Scotland in place made relationships with the Scottish Government, as funder, much easier.

This included because Inspiring Scotland was able to present the common experience of the group of SIRD projects rather than each having to raise any issues or concerns with the Scottish Government separately.

In addition to the overall approach taken, projects appreciated the range of practical support from Inspiring Scotland, including:

- Organising practice-sharing and other events where projects could come together and share learning and ideas.
- Working with projects to review progress and develop a plan of action in response to challenges faced. Of particular importance to a number of projects had been practical advice and support when initial ideas or plans had proved difficult to implement and projects were seeking other ways of using their funding constructively.
- Supporting projects at meetings with key local strategic partners.
- Support to help projects facing challenges in securing their funding for core costs.
- Making introductions to other organisations which could share useful experience and learning.
- Other *pro bono* support they had received from the wider Inspiring Scotland organisation, for example advice around communications and the use of social media.

Although many projects reported having worked quite closely with Inspiring Scotland, a small number said their contact had been limited mainly to the submission of monitoring information. However, these projects were aware that Inspiring Scotland could have offered further support if they had wanted or required it.

The feedback on other key stakeholders was also positive, including in relation to the Scottish Government. The relevant policy team was seen as supportive of, and genuinely interested in, the work the SIRD projects have been doing. There was also a view that introducing Inspiring Scotland as an external partner had made it easier to have frank and open conversations with the Scottish Government, including in relation to the funding of independent information and support.

A number of projects also highlighted the support they had received from Self Directed Support Scotland who were described as very helpful, supportive and accessible, and as providing a source of information and lobbying that had credibility with key decision makers. The support they had provided to projects included:

- Access to a wider range of information about self-directed support through their website.
- Assistance in challenging a local authority on intended changes to their social care policy.

- The provision of practical support and second-tier advice when clients presented with complex cases.
- Support in developing ideas relating to the provision of assistance to people looking to use Option 2.

## **Monitoring procedures**

As noted, Inspiring Scotland have taken an external monitoring role for the second round of SIRD funding. They have received monitoring data and reports from each of the SIRD projects. The monitoring approach, and in particular the structure and format in which performance data is recorded, has evolved over time and is effectively a coming together of approaches developed by a small number of first round SIRD projects.

Given its genesis, it is perhaps unsurprising that some projects feel that the monitoring approach is not particularly well suited to their needs. In particular, some highlighted that the recording categories do not necessarily reflect the subtleties of the work they are doing and that they can sometimes find it difficult to properly represent both the activity undertaken and the outcomes achieved. This was perhaps typified by projects reporting frequent use of the 'other' recording categories in returns.

A review of the monitoring data, and the reflections from Inspiring Scotland staff, support this conclusion. The data gathered is certainly indicative of the type of work the projects have been doing and the outcomes they hope to have achieved, but various issues with the gathering of the monitoring data mean it should not be seen as a source which can tell the full story of project activity or impact.

Projects tended to see the bi-annual reports they produce for Inspiring Scotland as the more useful record of the work they have been doing, not least because they afford the opportunity to include qualitative information and an overall assessment of progress made and challenges faced. A small number of projects noted that developing the reports provided a useful opportunity to reflect on their work. One project went so far as to say that they enjoyed the process, as it reminded them of the extent and impact of the work that they were doing. However, some projects did have concerns that producing these reports, along with the ongoing collection of the basic monitoring data, can be time consuming and onerous.

Overall, projects appreciated the effort that Inspiring Scotland had made to adapt the monitoring approach so that it works for all of them but felt that there is still room for further improvement. Projects suggested that the approach should:

- Allow projects to showcase the work they are doing and should provide a useful source of information to support any possible applications for funding.
- Be sufficiently flexible to allow projects to record the work they are actually doing rather than having to 'shoehorn' their work into pre-determined categories that may not reflect the activity they are carrying out or the outcomes they are looking to achieve.

- Capture longitudinal information on client progress whilst recognising that this information can be difficult to obtain.
- Be as light-touch as possible, recognising that there is a clear and reasonable requirement to satisfy funders, as guardians of the public purse, as well as the public who ultimately fund these services.

### **Considering cost effectiveness**

An initial expectation of this evaluation was that it would explore the value for money of the projects supported through the SIRD Fund. From the early stages of the study, it was clear that a meaningful and robust assessment of this would not be possible.

Such an assessment would need to be informed by a set of data covering the characteristics of those receiving support from a SIRD project and the type and amount of support received. Information on the short-term outcomes that can be ascribed, in part at least, to receiving support from a SIRD project would also be required. This would allow a model for estimating the impact of people's use of independent information, advice and support on their accessing of more effective and personalised social care to be developed. Moving forward, any assessment could also draw on longer-term information on the outcomes achieved for those who accessed choice and control-related support. This value for money assessment could use the framework for analysis provided by the "4E approach", referring to economy, efficiency, effectiveness and equity.

Although useful in itself, an assessment of the value for money offered by independent information and support, would be of greater value if informed by evidence around whether the choice and control offered by self-directed support offers wider value to the social care system. The Scottish Government has recently commissioned research which will contribute to ongoing national monitoring and evaluation thinking and help to provide a strategic overview of progress in the implementation of self-directed support.

Although a robust value for money assessment has not been possible, there is some relevant, though limited, qualitative evidence, in terms of feedback from projects and service users. Those who raised this issue generally felt that a more personalised, choice and control-based social care system could help reduce overall social care costs. This view was often connected with the preventative power that giving people choice could have and in particular on the potential to avoid or postpone people's need to access other social care or health services. For example, one project and service user referred to the overall cost savings to the public sector of a young person with autism and a learning disability being able to stay at home rather than needing a costly care place. A service user with mental health problems reported that the flexibility that her Option 1 package gave her, along with other changes she had made in her life, had significantly reduced the number of times she engaged with health services. This service user had not used all of her personal budget, such had been the improvement in her health and wellbeing.

Equally, and as noted elsewhere within this report, many project users reported what to them had been life changing support from a SIRD project. This support was sometimes connected with a social care budget but may also have been around tackling other problems or reconnecting with their local communities. Project users sometimes felt that they would need to use other public services less as a result.

While this type of 'softer' evidence may point to possible benefits to be gained by investing in preventative work which the SIRD projects are arguably carrying out, the performance data collected by the SIRD projects (along with the absence of other data on the benefits of a choice and control driven social care system) makes it difficult to take this analysis further.

As noted above, the regular SIRD monitoring data is of limited value for making an assessment of whether the costs associated with running a SIRD project offers good value to the public purse in terms of impacts achieved.

## 10. Concluding Reflections

In this final chapter we reflect on the key messages and learning to emerge from this independent review.

Our initial observation would be that the findings very much support those of the recent Audit Scotland (2017) progress report. The context in which SIRD projects have been looking to build capacity within their own organisations and the wider community has usually been different to that which they expected when making their funding applications. The embedding of self-directed support in social care has not been as far advanced as some projects expected, albeit the picture varies across the country. The budgetary pressures on local authorities have had an impact, particularly with regard to eligibility criteria for social care budgets, and there may be some challenges, or even resistance, to working in a way that affords people greater choice and control. A number of projects and their clients have voiced concerns about some social work practice, including whether it is in line with either the spirit of the policy or the legislation on self-directed support.

While there have been some very real challenges, which have sometimes led to strained relationships between SIRD projects and local authorities, the transformative power and considerable further potential of the choice and control-based approach has been emphasised by many. From a service user perspective, flexibility in the use of a budget and particularly continuity of care emerged as key benefits from using Option 1 or 4. Client interviewees have spoken of the transformative power of having choice and control.

For effective implementation, members of the public need access to a straightforward but comprehensive package of information and support. The review has found strong evidence that without the independent information and support they received from their SIRD project, some service users would either have given up on applying for a social care budget or would have made a different decision about which self-directed support option they wished to take. This was not because of any lack of persistence or commitment but was because of the very considerable and, on occasions, longstanding challenges that people were dealing with. People are most likely to be looking for social care support at a difficult and stressful time in their lives. This means that they are likely to be at their least able to cope alone with a potentially complex application and assessment process or with making decisions about how they would like to use any budget they receive.

People's needs vary, and information and support may be required at any stage. This encompasses: basic information about social care; help in identifying the outcomes someone would like to achieve; support in applying for a social care budget and through the assessment or review process; support to challenge decisions if need be; help in deciding which self-directed support option to take; and shaping a package of support for those who wish to take this on. Some people may want to dip in and out of these services, but others are likely to be looking for, and would greatly benefit from, end-to-end support, throughout the whole self-directed



support journey. This does not necessarily all need to be provided by a single organisation but, given clients' feedback on the value of continuity and being able to develop strong working relationships built on understanding and empathy, this is likely to be their preference. This also suggests that, while local authorities clearly have a role to play in providing information about social care, people need at least the opportunity to access this information elsewhere if that is their preference.

Often, this end-to-end support may be most effectively provided by an organisation with a strong local presence, which has a clear understanding of, and strong links into, the local community. This will include being aware of, and able to connect people into, a range of informal social and support opportunities. There is also a clear case for some people being able to access a package of information and support that is focused on their very particular needs as opposed to where they live. For example, parents of children with multiple and complex needs were clear that their preference was to work with an organisation that fully understood the reality of their lives.

Irrespective of the type of organisation providing information and support, a positive working relationship, including a referral relationship, between the local authority and organisations providing independent information and support in their area can only be a positive. To work in the best interests of clients, this working relationship needs to be strong and mature enough to allow for challenge, on both sides. Where SIRD projects have this type of very constructive relationship with their local authorities, they have often been able to use the SIRD funding to further develop capacity within their own organisation, and sometimes within the wider system, and they are optimistic about the role they can play in the future. This may include being optimistic that their Health and Social Care Partnership will wish to support and fund their services.

As well as building capacity within the information and support sector, there is also a powerful body of evidence around the potential of various approaches used by SIRD projects to support individuals to develop their skills, confidence and capacity. There was a broad consensus that some of the work done around peer support and involvement also has considerable potential, although projects were clear that this should not be seen as a low-cost way forward. They highlighted that peer support work needs to be properly resourced to maximise its potential to transform people's lives.

Moving forward, the SIRD Funding programme has delivered useful learning about what works well or less well. In particular, it has highlighted that independent information and advice services are at their best when firmly embedded within their local context and when supported and valued by key local partners, and by social work services in particular. Where this has not happened, SIRD projects have sometimes struggled to make a real difference; this is not to say that they have not often gone to considerable efforts but sometimes those efforts, particularly around awareness-raising amongst the general public may have had little impact.

There will be various reasons why working relationships have not always been as might have been hoped. In some cases, for example, local authorities have felt that SIRD projects were simply replicating work that was already being done, sometimes in-house but also services already commissioned by the authority from other third sector organisations. Local authorities do have a duty to assist people to make an informed choice about their support and must provide details about independent information, support and appropriate advocacy organisations. Given this duty, there was a common view that they need to play a central role in deciding on the range of services required in their area. This was sometimes connected to a view that the Scottish Government should involve local authorities in discussions about any future funding plans, including the type and range of services required in their area.

Finally, the review findings all point towards independent information and support being an essential part of a well-functioning, choice and control-based social care system. This will require ongoing investment and, given their statutory responsibilities, Health and Social Care Partnerships would appear the most obvious source of that funding - in the longer-term at least – and, indeed, many are already investing in independent support. There may be a case for exceptions, for example around specialist organisations delivering a service across many local authority areas. In most cases, however, the evidence suggests that it is possible for third sector organisations to have good working relationships with their local partners, including those which may fund them, whilst also providing high quality, much needed and highly valued independent information and support services.

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# Annex 1 - SIRD Project Interview Themes

## Initial Bid:

What was the initial focus of your bid?

What did you think you would be able to achieve for your organisation? For clients?

Were you looking at exploring a particular way/ model of working?

What was the bidding process like?

## Client Facing Work

Who makes referrals into the project? How do you encourage referrals?

Do you get self-referrals? How are self-referrals encouraged?

At what points in the process do people come to you?

What support do you provide?

What have been the challenges in delivering the client facing work? Have any of those barriers been unexpected? How have you sought to overcome these challenges?

Has the balance between the different elements of client facing work been as expected?

What overall impact has the work had on clients? What has the impact been of the different elements of the work you have done?

## Strategic Work

What work have you done at a strategic level? What difference has this made?

Has the balance between your strategic work and your client facing work been as expected?

How (if at all) can your strategic work be delivered better in the future?

## Working with Partners

How would you describe relationships with the local authority in the areas in which you work? What determines the nature of those relationships?

Which other partners do you work with? How important are those relationships? What determines the nature of those relationships?

What do you try and do to build these relationships? What barriers (if any) have you faced to doing so? If you have been looking to improve relationships, how successful have you been?

### **Support and monitoring**

What internal support do you get (if any) from your wider organisation?

What support do Inspiring Scotland provide? How helpful has this been?

Are there any other peers/organisations that have been helpful in supporting the work funded by the SIRD Fund?

What are your views on the monitoring framework? Is it clear, proportionate, usable? Can you use it to improve and develop your work or to demonstrate its value to others?

### **The Future**

What case would you make for continued funding for the work done by SIRD projects, local and nationally? In the short term. In the long term?

What would the weak points of that case be? What needs to change to strengthen that case?

What do you think SDS independent information and support will look like in 5 years? What should it look like?

## Annex 2 – Service User Survey Results

### Total number of responses

	N
People who hold/manage their <b>own</b> budget	59
People (Third Party) who hold/manage someone else's budget	33
<b>TOTAL</b>	<b>92</b>

Please note that not all respondents answered all questions and some questions gave respondents to select multiple answers, so the base number of respondents / responses varies from question to question.

### Please tell us your relationship to the person whose individual budget you have responsibility for. (Please tick the one that fits best)

	Own	Third Party	Total	
	N	N	N	%
They are a child and I am their parent or guardian		5	5	5%
They are an adult and I am their parent or guardian		15	15	16%
They are my spouse or partner		1	1	1%
They are an adult and I am a relative (other than their parent) or friend		10	10	11%
Something else		2	2	2%
Manage Own Budget	59		59	64%
<b>TOTAL</b>	<b>59</b>	<b>33</b>	<b>92</b>	<b>100%</b>

**Did the person you act for already receive care and/or support paid for by the council before they got their current individual budget? (Please tick the one that fits best)**

	Own	Third Party	Total	
	N	N	N	%
Yes	24	19	43	49%
No	29	9	38	43%
Not sure	3		3	3%
Other	2	2	4	5%
<b>TOTAL</b>	<b>58</b>	<b>30</b>	<b>88</b>	<b>100%</b>

**Which option do you use for the individual budget? (Please tick the one that fits best)**

	Own	Third Party	Total	
	N	N	N	%
I get my budget as a direct payment and buy care and/or support with it, for example by employing a Personal Assistant (Option 1)	48	14	62	70%
The council or an organisation of my choice holds the budget but I am in charge of how it is spent (Option 2)	2	3	5	6%
The council arranges the service (Option 3)		3	3	3%
I use a mix of the approaches above (Option 4)	4	9	13	15%
The final arrangements aren't in place yet	3	1	4	4%
I have a budget but I don't feel I've been involved in decisions about it	1		1	1%
Not sure	1		1	1%
<b>TOTAL</b>	<b>59</b>	<b>30</b>	<b>89</b>	<b>100%</b>

**When you first contacted the support project, how long had you been looking for information or support? (Please tick the one that fits best)**

	Own	Third Party	Total	
	N	N	N	%
Not long, I had just started looking	32	9	41	47%
For a while (up to 3 months)	7	5	12	14%
For a long time (longer than 3 months)	10	10	20	23%
Something else - please write in	9	5	14	16%
<b>TOTAL</b>	<b>58</b>	<b>29</b>	<b>87</b>	<b>100%</b>

**How did you hear about the support project? (Please tick all that apply)**

	Own	Third Party	Total
	N	N	N
Social worker	25	10	35
Another support or care worker	16	2	18
Internet	2		2
Advert/ poster/ leaflet		1	1
An event	3	4	7
GP			
Health worker (like a health visitor or CPN)	2		2
Family member or friend	6	4	10
Other advice or information project		4	4
They had helped me in the past		2	2
They were helping me about something else at the time	1	1	2
Something else	7	5	12



**What did you know about individual budgets when you contacted them? (Please tick the one that fits best)**

	Own	Third Party	Total	
	N	N	N	%
Nothing at all	27	11	38	44%
A little	24	12	36	41%
A lot but was looking for help with something	7	5	12	14%
Something else		1	1	1%
<b>TOTAL</b>	<b>58</b>	<b>29</b>	<b>87</b>	<b>100%</b>

**Roughly how long have you been in contact with the support project about an individual budget? (Please tick the one that fits best)**

	Own	Third Party	Total	
	N	N	N	%
Only a few weeks or months	10	8	18	22%
Up to a year	8	3	11	13%
More than a year	33	14	47	57%
Not sure	4	3	7	8%
<b>TOTAL</b>	<b>55</b>	<b>28</b>	<b>83</b>	<b>100%</b>

**What type of things have you been getting help with? (Please tick all that apply)**

	Own	Third Party	Total
	N	N	N
Applying for a budget	21	13	34
Being assessed by the council	14	13	27
Advice on which option I wanted to use (for example whether I wanted a direct payment)	27	17	44
Deciding on what type of care or support I want	25	16	41
Setting up the care package	26	13	39
Recruiting or employing a Personal Assistant	33	11	44
Paying people (payroll services)	33	11	44
A review of the budget	19	12	31
Information about other services	13	13	26
Help to access other services	12	7	19
Something else	9	3	12

**How do you feel about the information and support you received? (Please tick the one that fits best)**

	Own	Third Party	Total	
	N	N	N	%
It made an enormous difference. I/we would have really struggled without it	29	20	49	58%
It made a big difference. It has really helped me	16	4	20	24%
It made a bit of a difference and made things a bit easier	6	3	9	11%
I don't think it made much of a difference			0	0%
It made no difference at all			0	0%
Something else	5	2	7	8%
<b>TOTAL</b>	<b>56</b>	<b>29</b>	<b>85</b>	<b>100%</b>

**Is there anything you would have liked help or support with but the project wasn't able to help?**

	Own	Third Party	Total	
	N	N	N	%
Yes	7	5	12	15%
No	40	18	58	73%
Not sure	6	4	10	13%
<b>TOTAL</b>	<b>53</b>	<b>27</b>	<b>80</b>	<b>100%</b>

**Are you still in contact with the support project?**

	Own	Third Party	Total	
	N	N	N	%
Yes, they are still supporting me or giving me information and advice	42	24	66	79%
No, I'm not getting support or advice from them at the moment	13	5	18	21%
<b>TOTAL</b>	<b>55</b>	<b>29</b>	<b>84</b>	<b>100%</b>

**Have you also been receiving advice or support about the individual budget from anyone else?**

	Own	Third Party	Total	
	N	N	N	%
Yes	25	7	32	40%
No	24	21	45	56%
Not sure	4		4	5%
<b>TOTAL</b>	<b>53</b>	<b>28</b>	<b>81</b>	<b>100%</b>

**Who else have you also been receiving advice or support from?**

	Own	Third Party	Total	
	N	N	N	%
Social worker	19	2	21	62%
Another care or support worker	2		2	6%
Family member or friend	2		2	6%
Other advice or information project	1	3	4	12%
Someone else - please write in	3	2	5	15%
<b>TOTAL</b>	<b>27</b>	<b>7</b>	<b>34</b>	<b>100%</b>

**What are the main reasons why the person who has a budget needs care and/or support?  
(Please tick all that apply)**

	Own	Third Party	Total
	N	N	N
Alcohol or drug dependency			0
Autism	6	6	12
Being a carer	17		17
Being younger and needing support starting out		1	1
Deafness/hearing loss	3		3
Dementia	1	6	7
Learning disability or difficulty	12	17	29
Long term / chronic health condition	17	6	23
Mental health problems	11	7	18
Physical disability or mobility issues	30	13	43
Problems connected with ageing	4	3	7
Terminal illness	1		1
Visual impairment	4	7	11
Other type of disability or health problem	10	7	17

**Do you act as a carer for someone other than the person whose individual budget you have responsibility for?**

	Own	Third Party	Total	
	N	N	N	%
No, I am not a carer	23	10	33	<b>43%</b>
Yes, I am a full-time carer for someone I live with	16	4	20	<b>26%</b>
Yes, I am a part-time carer for someone I live with	3	2	5	<b>6%</b>
Yes, I am a full-time carer but I do not live with the person I care for	1		1	<b>1%</b>
Yes, I am a part-time carer but I do not live with the person I care for	3	2	5	<b>6%</b>
Something else - please write in	7	6	13	<b>17%</b>
<b>TOTAL</b>	<b>53</b>	<b>24</b>	<b>77</b>	<b>100%</b>

**Please tell us which of the following best describes how you use the internet?**

	Own	Third Party	Total	
	N	N	N	%
I don't use the internet	4		4	<b>5%</b>
It's easy to get online and it's easy to look for information	32	23	55	<b>68%</b>
It's easy to get online but I don't find it easy to use	8	1	9	<b>11%</b>
Someone helps me find things online if I need to	8	2	10	<b>12%</b>
Something else	2	1	3	<b>4%</b>
<b>TOTAL</b>	<b>54</b>	<b>27</b>	<b>81</b>	<b>100%</b>

## Annex 3 – SIRD Projects

- Advocacy Aberdeen
- ARC Scotland
- Argyll Voluntary Action
- Ayrshire Independent Living Network
- Borders Independent Advocacy Service
- Cantraybridge
- Carers Trust
- Carr Gomm
- Ceartas
- Children in Scotland
- Circles Network Inverclyde
- Community Brokerage Network
- Deaf Action
- Direct Inclusive Collaborative Enterprise
- Diversity Matters
- Dundee Carers Centre
- Enable
- Encompass
- ENeRGI
- Fife Disabled Person's Housing Service
- Glasgow Centre for Inclusive Living
- Glasgow Disability Alliance
- Grampian Opportunities
- i-Connect North East
- In-Control Scotland
- IRISS / Scottish care
- Kindred Advocacy
- Lothian Centre for Inclusive Living
- MECOPP
- PAMIS
- Penumbra
- RNIB
- Self-directed Support Forum East Renfrewshire
- Self-directed Support Scotland
- Simon Community Scotland
- VOCAL

### Innovation Fund Projects included in study

- The Advisory Group
- Thistle Foundation
- Turning Point



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