



HEALTH AND SOCIAL CARE

Research Findings 140/2018

Review of Independent Information and Support Services

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 assessment or review of social care budgets; 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 Support in the Right Direction (SIRD) Fund.

Key Findings

- Almost without exception, users were very positive about the quality of support.
 A central theme was that the support had a profound and life-enhancing impact.
 This review found that support at any stage in the social care process can make
 a difference; for some having someone to walk alongside them for their entire
 journey has been critical.
- Although much of the SIRD work has been with people who are applying for, or already have, a social care budget, many projects have been working with people with social care needs who are not eligible for a budget but who would benefit from information, advice or support.
- Many projects place considerable importance on the work they do to support people through the assessment for, or review of, a social care budget. Projects delivering 'end-to-end' support had a clear preference for early engagement.
- There was a broadly positive picture in terms of the relationships between projects and local authorities. Factors supporting good working relationships included projects understanding local eligibility criteria and how social work services are structured.
- 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.
 The closeness and importance of that relationship often determined whether a project would approach, hit or exceed its targets.
- 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.

Introduction

The Scottish Government's Support in the Right Direction (SIRD) fund has been part of a wider package of investment since 2011 to facilitate the transition to self-directed support - the principle that people have informed choice about the way that their social care and support is provided. SIRD is focused on ensuring people are supported in setting their personal outcomes and able to make informed choices by funding projects, across Scotland, to deliver independent information and support services.

This mixed methods study looked 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.

The data gathered and analysed includes: project reporting data and information; 14 interviews with representatives of six local authorities; interviews with representatives of key national stakeholder organisations; interviews with all but one of the SIRD projects; a survey of SIRD project clients (92 responses); and interviews with 88 people who had used or are using a SIRD service. A fuller description of the methods and evidence used is in the main report.

Profile of the projects

The SIRD funding programme began in 2012, with a second round of three-year funding beginning in April 2015 and running 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. The levels of annual funding to each project in the second round have ranged from around £29,000 to around £129,000.

Seven of the projects have not been carrying out direct delivery of information and support, focusing instead on work around capacity building, awareness raising and development of practice or materials. The other projects have been focusing on offering information or support to members of the public.

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¹ For more information on self-directed support and the 4 options available to people see the Scottish Government's SDS website: http://www.selfdirectedsupportscotland.org.uk/

² More information about what is independent information and support can be found on the Inspiring Scotland website (https://www.inspiringscotland.org.uk/what-we-do/thematic-funds/self-directed-support/) and in two 2015 reports by Evaluation Support Scotland ("The Value of Independent Support. How it can help people understand and make informed decisions about Self-Directed Support. Information for funders and commissioners"; "What Works in Independent Support: an analysis of what Scottish Government funded projects providing Independent Support for Self-Directed Support have learned."

The SIRD projects are working across a broad range of client groups, with the most frequent being carers, people with learning difficulties and people with physical impairments. There are seven projects which work across all client groups.

Overall, the projects 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). These members of the public may or may not have been in receipt of a social care budget.

The local authorities in which the highest number of projects are operating are Glasgow, Edinburgh and Fife (15, 12 and 11 projects respectively). Nine of the projects which provide information or support to members of the public work in one local authority area only. The other projects have a regional or national focus.

Operating context for the SIRD projects

In August 2017, Audit Scotland published its "Self-directed support: 2017 progress report"³. Its key messages included that local authorities are experiencing pressures due to increasing demand and limited budgets for social care services. Audit Scotland's findings very much reflect those of this study.

Progress on embedding choice and control

At the point of developing their funding proposals, a number of the projects made assumptions about the pace of the transition to self-directed support being normal practice. Although local authorities tended to report that implementation was on track within their area, many projects had experienced challenges which they associated with slower than anticipated progress on introducing choice and control.

Impact of Health and Social Care Integration

Particular issues which SIRD projects identified as being connected to the integration of health and social care included key personnel moving to integration-related posts. 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.

Budgetary pressures on local authorities

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 financial pressures on local authorities, including changes to eligibility criteria for social care budgets in their area.

Impact of the local context on SIRD projects

Many projects reported finding themselves working in a very different delivery environment than expected. A number of the projects are receiving fewer referrals from social work than they had planned for. Referrals are often not at the early

³ Available at: http://www.audit-scotland.gov.uk/report/self-directed-support-2017-progress-report

stages of application or assessment but instead are associated with the practical aspects of people taking Option 1.

In response, 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, involving looking to build stronger working relationships with local services, including local authority services, and increasing the amount of awareness-raising work with professionals, including frontline social work staff.

Direct client support work

Awareness raising and capacity building

A number of projects have been carrying out awareness-raising and community capacity-building work. This has included outreach work to increase general awareness and understanding of the self-directed support approach amongst the wider public. There has also been awareness-raising work targeting specific groups of people, such as carers. Overall, projects believe 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 choice and control and the self-directed support process in greater depth. Others have been involved in the delivery of personal development courses, over a series of weeks or months, 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.

Assessment-related support

Many SIRD projects place considerable value and importance on the work they do to support people through the assessment for, or review of, a social care budget. For projects providing support throughout the whole process, there was a clear preference for engagement at an early stage.

Projects were seeking to achieve various 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 to making 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, although relatively unusual, a small number of clients reported that they were looking for project staff to play an active role.

Brokerage

A majority of the projects were providing some form of brokerage support. All of the projects offering brokerage were working with those 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 social care budget. There was a very broad consensus across projects, service users, local authorities and stakeholder interviewees around the value of this type of work.

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

Option 1-focused support ranged from providing further information and advice around how this option 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 the skills or tools that would help them manage their own, sometimes quite complex, support packages.

Non-budget related support

Although much of the SIRD projects' work has involved working with people who are applying for, or who have, a social care budget, many have also been working with people with a social care need who are not eligible for a budget but 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, a peer support approach has been central to the SIRD work they have been doing. Examples include assisting with setting up and running a peer support group or network. This has been a particular focus of the work being done by user-controlled organisations, reflecting their overall philosophy and approach.

Client experience

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 the project by: a social worker; another support or care worker; or family or friends.

People were most likely to be looking for advice on which option they wanted to use or for practical support and assistance in relation to Options 1 or 4.

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 social care 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 exercising choice and control, 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.

Reflections on direct client support work

Some projects concluded that the focus of their work - in particular the client group focus of their work - may simply have been premature given national progress on embedding of self-directed support as our mainstream approach to social care. Projects working with people experiencing homelessness or community justice services were most likely to be of this view.

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

For many, there are certain aspects of the process where third sector organisations offer very real additional value. This was primarily in relation to supporting people choosing Option 1 or 4 and helping people access community-based opportunities and support. However, opinion varied around who was best placed to provide independent 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 in a way that met their particular needs. Such projects experienced similar challenges to more generalist services working regionally. Overall, however, they tended to report

that the approach has worked well; the feedback from their clients certainly suggests this to be the case.

The SIRD fund has a focus on building self-directed support-related capacity in the independent information and support sector. The relationship between project independence and their funding source 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 information

Based on their reviewing of available information, a number of projects have produced a range of materials informing people about their right to choice and control of their social care budget and how to exercise that right using the options available. For some projects 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 been some innovative work developing games and e-learning packages as tools for understanding and supporting client progression through the process of exercising choice and control.

Working 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. The strength and quality of those relationships had often built very clearly on the relationship 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 supporting good working relationships included projects having a good understanding of: how social work services are structured; local eligibility criteria; and 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 have been at play. These have included: fundamental differences in understanding around who should have choice and control over their social care budget; key personnel (usually from the local authority side) having moved on; and there having been little or no real working relationship between the organisation delivering the project and social work before the SIRD funding period.

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. The closeness and importance of that relationship often determined whether a project would approach, meet or exceed its project targets.

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 self-directed support.

There has been a considerable amount of partnership working between SIRD projects to explore and share ideas. Although the majority of this remains in its early stages, examples include: exploring ideas around the provision of a payroll service; and mentoring support to a staff member developing the brokerage aspect of their project's service.

Strategic engagement and impact

A number of projects were involved in working groups focused specifically on embedding self-direct support as the mainstream approach to social care. However, strategic involvement was not always through specific groups but sometimes through regular but 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 felt that they had had little impact, others (and in fact 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, including work around developing accessible information.

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

Concluding reflections

The findings of this study very much support 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 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 has 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 vary, information and support may be required at any or all stages of the process of exercising choice and control in social care. 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 their preference.

Often, end-to-end support may be most effectively provided by an organisation with a strong local presence and with a clear understanding of, and strong links into, the local community. This includes being aware of, and able to connect people into, informal social and support opportunities. However, there is also 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 the local authority and organisations providing independent information and support is important. 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.

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 skills, confidence and capacity. There was a broad consensus that some of the peer support and involvement work has been very valuable and that many other people might benefit from having access to such support.

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.

Local authorities have a legal duty to assist people to make an informed choice about their social care 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 services, including independent information and support, 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 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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