Scottish
Independent
Advocacy
Alliance

Directing your own Support?

A report examining the value of independent advocacy in supporting people through the Self-directed Support journey

November 2014

Promoting Supporting Defending

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1. Introduction

In 2010 the Scottish Government published a ten year strategy to implement Self-directed Support as a way of giving people receiving social care services more choice and control over the way in which their services are delivered.

The Self-directed Support strategy is part of the wider concept of Personalisation which puts people at the heart of the decision-making process. It represents a major cultural shift in the way in which people who access social care services are recognised in society.

“Personalisation envisages a shift in the culture of public bodies and professionals from viewing service users as passive recipients of care to genuine partners in making decisions over the services they need.” [1]

In 2013, Scottish Independent Advocacy Alliance was allocated Scottish Government funding to carry out an Advocacy and Self-directed Support project. The aims of the project are:

- To raise awareness and understanding of the role of independent advocacy throughout a person’s care and support journey. In particular, in helping people to be actively involved in their assessment and support, to have control, to have genuine access to the choices available under social care laws and to make informed decisions about the support they receive.

- To raise awareness and understanding of the role of Self-directed Support advice organisations in local areas and develop a shared understanding of the role of advice services and of advocacy organisations in the supported person’s journey.

- To help build capacity primarily within the advocacy movement.

- To produce research on the impact of the role of independent advocacy in relation to Self-directed Support.

This report examines the value of independent advocacy to a person’s Self-directed Support journey and makes recommendations for the future development of independent advocacy in relation to Self-directed Support.

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[1] *SPICe Briefing; Social Care (Self-Directed Support) (Scotland) Bill, Scottish Parliament, P10*

2. Background

2.1 The Social Care (Self-directed Support) (Scotland) Act 2013

The Social Care (Self-directed Support) (Scotland) Act 2013 places a duty on Local Authorities to give people a range of options as to how their care is provided, allowing people to make a choice as to how much control they want to have over their own care.

"The fundamental principles of SDS are choice and control. Choice is evident where people are able to choose how they live their life, where they live and what they do. People have control of their support by determining and executing the who, what, when and how of the provision." [2]

2.2 What is Self-directed Support?

Self-directed Support is a new way of planning and delivering support for people who access social care services ensuring that people have choices in what care they receive and how they receive that care, by offering four options:

- Option 1 – Direct Payments – Receive the funds to allow people to arrange and purchase their own support
- Option 2 – Choose services from a provider and ask the Local Authority to arrange this and handle the financial side
- Option 3 – Ask the Local Authority to arrange your care from their own staff or a preferred provider
- Option 4 – A combination of any of these three options

There is also a duty on Local Authorities to give support to unpaid carers who have a carer's assessment, where they are assessed as eligible for support, offering the four options. Self-directed Support aims to provide opportunities for individuals to think about their support in terms of outcomes which are important to their health and well-being, thereby giving people more choice, more freedom and more opportunities to participate fully in community life.

2.3 What is Independent Advocacy?

Many of us find it difficult, at times, to get our voice heard about decisions or actions that affect our lives. Some people have family, friends or other carers to help them to speak up. Others do not have people in their lives to do that, and sometimes, if they do, family members may have their own ideas about 'what is best' for the person involved. Paid carers may have a duty to defend the actions of the organisation that they work for. This means that they have a 'conflict of interest'.

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[2] *Self-Directed Support, A National Strategy for Scotland, Scottish Government, P7*

Independent advocacy is as free as possible from conflicts of interest like these, is completely separate from service providers and funders and does not provide services other than advocacy.

Independent advocacy aims to help people by supporting them to express their own needs and make their own informed decisions. Independent advocates support people to gain access to information and explore and understand their options. They speak on behalf of people who are unable to speak for themselves, or choose not to do so. They safeguard people who are vulnerable or discriminated against or whom services find difficult to support.

Advocacy is about broadening horizons and widening the options that people have. It is about speaking up if you notice that something is wrong. An effective advocate will observe the whole person and all aspects of their life. They will notice what is wrong in the person's life, things that the person tolerates perhaps because they do not know any different, and tries to address them. [3]

2.4 Who Can Access Advocacy?

The Mental Health (Care and Treatment) (Scotland) Act 2003 gives a legal right of access to independent advocacy to anyone with a mental disorder. This includes mental health problems, dementia, learning disability and acquired brain injury. There are other pieces of legislation which mention advocacy but which do not provide a direct legal right of access to advocacy.

Advocacy provision in Scotland varies between Local Authority areas and in some areas, there is little or no provision for particular client groups. The Advocacy Map produced biennially by SIAA details current advocacy provision across Scotland as well as gaps in provision.

For example, while there is currently no legal right of access to advocacy for older people, an older person experiencing dementia has a legal right to independent advocacy under the Mental Health (Care & Treatment) (Scotland) Act 2003.

Similarly, there is no current legal right of access to independent advocacy for people with physical disabilities, however if the person also has a learning disability, they have a legal right of access to independent advocacy under the terms of the Act.

Advocacy organisations are funded by Local Authorities and NHS Boards, and some receive additional funding from non-statutory sources. As such, there are a number of advocacy organisations across Scotland who provide independent advocacy to groups of people who do not have a legal right to advocacy, however access to advocacy depends on what is available in each area.

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[3] *The Principles and Standards for Independent Advocacy, SIAA, P4*

Unfortunately the Social Care (Self-directed Support) (Scotland) Act 2013 does not give people a legal right to access independent advocacy. It does make reference to advocacy; however responsibility falls on to the Local Authority to decide when to signpost people to advocacy.

"(2) The authority must give the person—

(d) in any case *where the authority considers it appropriate to do so*[4], information about persons who provide independent advocacy services (within the meaning of section 259(1) of the Mental Health (Care and Treatment) (Scotland) Act 2003"[5]

2.5 Independent advocacy and Self-directed Support

A recent report published by the Stroke Association highlighted the value of independent advocacy in relation to stroke survivors being assessed for Self-directed Support.

"Independent advocacy can help people find out about Self-directed Support, prepare for assessments, explore the SDS options and weigh up the pros and cons of each option."[6]

The report points out that independent advocacy could help people who were being assessed for Self-directed Support by:

- providing information about Self-directed Support
- supporting people to understand their rights and choices
- helping people to make informed choices
- ensuring that the person is able to communicate their needs and wishes at the Assessment
- Supporting the person to challenge a decision, if necessary.

"Advocacy and SDS both have individual choice at their core…Advocacy support can help to ensure that the stroke survivor is in control and is the central focus of the SDS support arrangements." [7]

This report explores the value of independent advocacy in supporting people from all walks of life who are currently being assessed for Self-directed Support. The report looks at some of the challenges people encounter along the Self-directed Support journey and examines how independent advocacy has supported people to address some of these issues, have their voices heard and make informed choices about their care and support.

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[4] *Italics added*

[5] *Social Care (Self-directed Support) (Scotland) Act 2013, Scottish Government, Section 9, Provision of Information about Self-Directed Support, P8*

[6] *Stroke, Advocacy and Self-directed Support, A guide for health and social care professionals, The Stroke Association, P5*

[7] *Stroke, Advocacy and Self-directed Support, A guide for health and social care professionals, The Stroke Association, P4*

3. Methodology

In Spring 2014, a survey was carried out of 60 advocacy organisations across Scotland to determine which organisations had received referrals for Self-directed Support. The survey generated a 60% response rate.

From the results of the survey, organisations were approached and asked to identify advocacy partners and advocates who would be willing to be participants in the research. We also contacted Local Authority care managers and other professionals who were willing to contribute.

Interviews were informal and unstructured which allowed people to share their experiences in their own words. From these interviews, case studies were prepared. All names included in the case studies detailed in this report have been changed to protect identities.

4. Scope and Limitations of the Report

This report was prepared from case studies which were identified through responses to a survey of advocacy organisations across Scotland. This report has attempted to gather evidence from a wide number of Local Authority areas in Scotland however it should be noted that not all organisations responded to the survey and therefore it was not possible to gather information from all the Local Authority areas.

The interviewees were identified by the advocacy organisations, and each reported a positive experience of using advocacy. This report has not examined situations where this was not the case. This research therefore focusses on the ways in which advocacy has had a positive impact for people accessing Self-directed Support.
In view of this, the report cannot provide a comprehensive guide on the potential impact of independent advocacy on everyone going through Self-directed Support in Scotland. However this research does demonstrate how advocacy has been effective in helping people exercise choice and control; the fundamental principles of Self-directed Support.

5. The Self-directed Support Journey

Each stage of the Self-directed Support journey may vary slightly from one Local Authority area to the next; paperwork or terminology used by one Local Authority may be different from another, for example, a person may be offered a Self-Assessment Questionnaire, a Supported Self-Assessment or a Lifestyle Planning Questionnaire.

However, in general, there are a number of key stages:

5.1 Identifying a need and making first contact

People who are already in receipt of social care services should be re-assessed by the Local Authority and offered the four Self-directed Support options. However, where an individual is not currently receiving social care services but they have a need for support, the person can contact their Local Authority themselves, or have someone contact the Local Authority on their behalf, and ask for an assessment.

Our research highlighted cases where people had been completely unaware of Self directed Support and did not have accurate information about what Self-directed Support actually is and how it works. Having an advocate at the initial stage of the process helped people get access to information about Self-directed Support and to understand exactly how it works and what they should expect from it.

Case Study

Anna has mental health problems. Until last year, she had been attending a local drop-in centre. When Anna received news that the drop-in centre would close, she contacted an advocacy organisation to help her get more information about Self directed Support.

For over a year, Anna had been attending a local drop-in centre. At the centre, Anna participated in a creative writing group, a knitting group and attended support groups and nights out with other members.

Last September, Anna received a letter from the drop-in centre confirming that the Local Authority had withdrawn funding for the project and that all members would now have to pay to use the service. The letter explained that the Local Authority intended to assess all the members for Self-directed Support, so that they could apply for a budget, to pay to attend the centre. However, as none of the members had been assessed for Self-directed Support when the funding was withdrawn, each member would have to make interim payments from their own money, until such time as they could be assessed for Self-directed Support.

Anna did not know anything about Self-directed Support except rumours she had heard from friends who had gone through an Assessment and who had ended up paying for services through their Disability Living Allowance. Anna was unable to make the payments from her Disability Living Allowance so she was unable to continue using the service.

Anna did not want to lose such a valuable source of support in her life; however she was very concerned about the whole process of Self-directed Support. She did not want to go through an Assessment until she had more information.

The Local Authority wrote to Anna asking her to attend an appointment where she would be assessed for Self-directed Support. She did not want to attend the appointment by herself. Anna was becoming more and more anxious about the appointment, which affected her well-being.

"The Social Work department wrote to me twice and said the appointment has been made for you to attend here. I thought I'm not going along there myself, I don't know what I'm getting into here. So initially I just freaked out and I never even phoned them to say. Then another letter came in and that was another appointment to come in and see them and I thought 'no'." Anna

Meanwhile Anna continued to receive letters from the drop-in centre urging members to make interim payments in order to keep the service from closure. This only added to Anna's anxiety.

The Local Authority did not make Anna aware of independent advocacy; however, fortunately she had worked with a local advocacy organisation in the past and was still in touch with them. She contacted the organisation and met an advocate, Henry.

"I had a few meetings with Henry about the whole situation, and talked about my mental health, how it affects me, what areas I need help with, kind of what I would use the money for." Anna

Over the next few weeks, Anna and Henry continued to meet, and Henry was able to access information about Self-directed Support for her. During their meetings, Henry supported Anna to fully understand the information about Self-directed Support and think about her options.

"Henry and me were meeting and he was saying; 'I'll go and look at this and see what's happening with SDS, I'll look it up', and I would say, 'well I'll go back and read the assessment thing'. He gave me the assessment form to look over and so we both had a wee time to think and that was good for me." Anna

After several meetings with Henry, Anna felt more informed about Self-directed Support and more confident about attending the appointment with the Local Authority. At Anna's request, Henry attended the appointment with her. Anna felt that having Henry there reassured her that someone was on her side, and gave her more confidence to speak up for herself.

"..If I dried up or went off at a tangent, Henry would be there. He had enough background to realise if anything was going badly." Anna

In the end, Anna decided not to go through the Assessment for Self-directed Support. Anna is glad she made contact with Henry. She feels he was able to help her get the information she needed to make an informed choice about Self-directed Support. Before Anna met Henry, she felt out of her depth and unable to make a decision and the constant letters from Social Work and the drop-in centre were adding to her anxiety. Having Henry on board allowed her to clarify things in her mind and gave her the confidence to attend the appointment with Social Work, where she was able to express herself and put across her wishes.

5.2 Assessment

Once first contact has been made with the Local Authority and it has been determined that there could be a need for support, an assessment process is carried out to establish what care is needed. The Local Authority Social Worker or Care Manager should provide the person with paperwork which may take the form of a Self-Evaluation Questionnaire or similar. Every Local Authority has their own paperwork. However in each case, the person should be asked to think about their goals and outcomes and how they think this can be achieved.

This research has highlighted cases where people were not given an opportunity to have an assessment, or think about their goals and objectives. Having an advocate during the assessment process ensured that people had this opportunity.

Case Study

Raymond is in his early twenties and has a learning disability. He currently lives with his Mum, Kirsty. Raymond is going through the Self-directed Support journey, supported by his advocate, Eileen

Raymond lives at home with his Mum and like most young men his age, would like to move into his own flat. Raymond decided that the first step would be to spend some time in a respite service, to get some experience of living independently, with a view to having a place of his own one day.

Last year, Raymond approached his Local Authority Care Co-ordinator to talk about getting an assessment for Self-directed Support to help him to access a respite service. He did not get the response he had hoped for.

"..she patted Raymond's knee and said 'you just stay here with your mum, you're better off.' Raymond asked about respite, he asked about a place of his own and that was her response. I really didn't appreciate that and I did say to her, and she told me it would take years, so I told her 'well the quicker you get started the better' but she didn't do anything at all." Kirsty

At that point, Raymond no longer wanted to engage with this Care Co-ordinator. Raymond's Community Learning Disability Nurse told him about advocacy and asked if he would like to be referred. Raymond was referred to his local advocacy organisation and put in touch with an advocate, Eileen was able to source the relevant paperwork for Raymond, so that he could begin his Essential Lifestyle Planning.

"Eileen has really been good giving Raymond the information…and forms to fill in and we can take our time. I feel Eileen's really helping." Kirsty

Raymond wanted to change to a different Care Co-ordinator and refused to meet with her again. Until this could be arranged Eileen continued to support Raymond with his Essential Lifestyle paperwork, planning for the future, thinking about his long-term goals and outcomes.

"It's very important to get all these things down so that when the time comes when Raymond has his own budget and is thinking about moving on he can look at getting staff in to support him." Eileen

Eileen helped Raymond to think about the support that his Mum gives him on a day-to-day basis, and what support he will need if he is going to live independently.

"Eventually Raymond's aim is to move into his own accommodation with staff coming in to help him with bills, help him with accessing finances, things like that. Mum is doing that at present. He will continue to need that support." Eileen

Working with Eileen, Raymond had an opportunity to plan for his future and to think about his goals and outcomes. Raymond is now optimistic about his future.

"My dream is to be a singer, to get respite, to get a place of my own and to be in a band."

5.3 Plan

Once the Assessment has been completed, and the person has had an opportunity to think about their goals and outcomes, the next step is a discussion between the person and their Care Manager or Social Worker, to discuss what options are available to meet the person's goals and objectives and to talk about an estimated budget to meet these needs.
Having an advocate on board helped people to put across their needs and wishes to their Care Manager and allowed them to get a care package which was most suitable to their needs.

Case Study

Sara lives with her partner Trevor. Sara has a debilitating illness and uses a wheelchair. Trevor is her main and only carer. Sara and Trevor had been working with the Local Authority Social Work team to set up care for Sara using Self-directed Support. Sara and Trevor had researched Self-directed Support themselves and had identified outcomes which they felt would improve and enhance their lives.

Sara and Trevor were told that the Local Authority's eligibility criteria meant that only critical needs could be met. Sara was assessed as having a critical need, but her Care Manager stressed that the only support Sara could have was with personal care.

Because Trevor can provide personal care for Sara, the couple asked if the allocated hours could be used to meet Sara's outcomes related to health and well-being. The Care Manager said this was not possible.

Sara felt that she had become socially isolated and hoped to employ a personal assistant to support her in activities such as attending the Opera, visiting Museums and Art Galleries, Painting, Genealogy, Photography and Poetry which she felt would improve her well-being and confidence. Sara was also keen to take the pressure from Trevor and hoped that if she could get out independently this would allow him to have some life away from full time caring.

The local Carers' Centre told Sara and Trevor about advocacy and asked if they would like to be referred.

Sara and Trevor were referred to their local advocacy organisation in September 2013 and were visited by Harry, the advocate.

Sara told Harry that she felt that her Care Manager had not listened to anything she had said. Sara recognised that Self-directed Support was about more than personal care and was keen to re-build her life after being so unwell. Harry's involvement made Sara feel relieved that someone was at last listening to what she wanted.

**A few days later Sara received an indicative budget. She was very angry as she had not fully completed the Self-Assessment Questionnaire because there had been a disagreement and the couple had refused to sign the paperwork. The couple felt that they had no trust left in their current Care Manager as they felt that important paperwork had been processed without their permission.
Sara was extremely frustrated and angry so she contacted Harry.**

Harry was able to support Sara to think about her options. Sara decided to make a formal complaint to the Local Authority and asked Harry to help her with this. Harry supported Sara to compose a letter of complaint.

Sara's complaint was upheld by the Local Authority and she was soon allocated a new Care Manager. Sara was somewhat apprehensive about meeting the new Care Manager so she asked Harry to attend the meeting. Having Harry at the meeting gave Sara a confidence boost, knowing that she had someone on her side.

The new Care Manager spent time with Sara and Trevor to establish exactly what type of support they would like. They were delighted that their new Care Manager was actually listening to what they wanted.

Sara's Care Plan was completed a short while later. She had applied for a Direct Payment and was allocated a budget which allowed her to employ two Personal Assistants. The Care Manager also arranged for an organisation providing support in relation to administration and legal requirements for employment of Personal Assistants to meet with Sara and Trevor.

Sara began to realise that she could decide for herself again what she wanted to do with her time, and with assistance, return to some of the things she always gained pleasure from, without adding extra pressure on Trevor. Trevor was finally able to leave the house on his own without worrying about Sara's wellbeing.

Sara has gone out on nature trails, accompanied by her Personal Assistant, for photography and inspiration for her artwork and poetry. Sara said that she no longer feels 'like a second class citizen', closed off from the rest of the world. She has thoroughly enjoyed feeling "alive" again.

Having Harry in their corner gave Sara the strength and confidence to make a complaint. Without Harry on board, she may not have been able to get the care package they wanted, which has totally transformed her life and Trevor's.

5.4 Budget

Once the plan has been agreed with the person and their Social Worker or Care Manager, it is passed to the Local Authority for approval. The Local Authority will normally have a Resource Allocation Panel or similar. This is a team of staff which can include Social Work and finance staff. At this stage, the person's plan is looked at to determine if the care package is appropriate and to finalise the budget. Most Local Authorities use a points system whereby certain needs are allocated points based on the level of care required.

Having an advocate at this stage helped people to have confidence to speak up for themselves or where required the advocate spoke up on their behalf. Supporting some people to make their wishes and voice heard ensured that they got the service which best suited their needs.

Case Study

Denise has experienced mental health problems. Last year, Denise was assessed for Self-directed Support, however she was not able to choose the care provider she wanted. She was put in touch with an advocacy service who helped her to challenge the Local Authority.

Denise has been supported by a mental health support service for some time. Last year she was assessed for Self-directed Support and decided that she would like to use her budget to continue to get support from the same service.

Initially Denise was told that she could not continue to use her preferred service due to the cost. She contacted her local advocacy organisation to help her ask for the service that she preferred.

Denise's advocate, Frances, was able to explain what Denise should expect from Self directed Support and what her rights are.

"Frances explained SDS to me a lot clearer than it had been before. When Frances came she explained it all and how it should have been going, I was shocked because I was going through a lot of hassle. It was so much clearer and things started to move a lot faster and a lot easier than what they were." Denise

Denise and Frances met with Denise's Care Manager to discuss Denise's budget. Having Frances there gave Denise the confidence to explain that she wanted to continue working with the same service because they understood her needs and were able to support her to achieve her outcomes. Denise's Care manager agreed to speak to the Resource Allocation Panel about her case. A short time later, Denise's Care Manager contacted her to say that her budget had been approved, however she had been put on a waiting list and could not access her budget straight away.

Denise waited for several weeks to hear about her budget, however nothing was forthcoming. She was becoming more frustrated and thinking about giving up.

"The waiting was beyond a joke. Every time I phoned all I got was 'you're on the list'". Denise

Denise felt that she was getting nowhere on her own so she contacted Frances to discuss her options. Frances wrote a letter to the Local Authority on behalf of Denise, to find out why her budget had not been forthcoming. A week later, Denise received a phone call to say that her budget had been finalised and her money had been paid.

"One week later I got the phone call, I was shocked, surprised it had been approved." Denise

Since April, Denise has been getting the support she wanted and is very happy with the way things have worked out.

"I think that it's been absolutely fantastic. To think how much I would have regretted it if I had just scrapped it…, Frances has made it so much easier to understand. She has been great."

5.5 Support

Once the Care Plan has been reviewed by the Local Authority and the budget approved, the person should receive their money and begin getting their support.
When the person has chosen their option, our research shows that an advocate can be valuable at this stage in supporting the person with making arrangements, working alongside Centres for Independent Living and other support organisations, but having a very different role.

Case Study

Jack has Cerebral Palsy. Last year he was assessed for Self-directed Support. Jack chose to take a Direct Payment and asked his advocate to support him to recruit a team of Personal Assistants.

Jack has known Jerry, his advocate, for over ten years and they have a good working relationship. Jack originally lived in a residential care unit for seven years, and in 2011 he moved into his own accommodation.

In 2012 Jack's Social Worker told him about Self-directed Support and helped him through the process. Jack decided to choose Option 1 and take a Direct Payment, so that he could employ a team of Personal Assistants.

Jack asked Jerry to get in touch with the local Independent Living Centre. The Independent Living Centre was able to give Jack information about becoming an employer, as well as placing an advert for him in the Jobcentre. The Independent Living Centre gave Jack a list of questions that he could use as a template for his own interviews.

Jack wanted to interview the Personal Assistants himself. Jack communicates in a unique way and often people do not speak directly to him because of his disability, so sometimes he has to repeat himself in order to be heard and understood, which is very frustrating for him.

"..a lot of people who are not comfortable with disability and communicating with people who have disabilities, tend to talk to somebody else about the person.." Jerry

Because Jerry has such a good relationship with Jack, Jerry understands the unique way Jack communicates and is able to support him to communicate with others.

"Because of Jack's communication difficulties, it's really important for him to have people that he feels comfortable with, because if he feels uncomfortable it affects his speech. It is also important to have people who are good listeners, so that Jack doesn't feel frustrated, trying to remember what he means." Jerry

Jack asked Jerry to read the questions at the interviews and ask the candidates to respond directly to himself. Having Jerry beside him at the interviews made it easier for Jack to communicate with the candidates and candidates to communicate with him.

This helped Jack to feel more comfortable and confident not feeling that he had to struggle to be understood or have to repeat himself.

"Jack asked me to read the questions out… We deliberately said, "I'm Jack's advocate, he has asked me to ask the questions today but he will be your employer, so if you could direct your answers to him." Jerry

Eventually, Jack chose two Personal Assistants that he felt had the qualities that were most important to him. Jack has been supported by his Personal Assistants since last year.

Jack and Jerry have known each other for a long time and Jack feels that Jerry knows him really well and can communicate with him in the right way. Having Jerry on board has given Jack the confidence to express himself fully, and ensures that people communicate directly with him.

5.6 Review

Once a care package is up and running, it should be monitored by the Local Authority and reviewed periodically to ensure it continues to meet the person's needs. Having an advocate involved in the review process, can help people to think about their ongoing needs. Should they change then an advocate can support them to put this across.

Case Study

Caroline is 21 and lives in her own home, supported by a team of Personal Assistants. A member of her family has financial and welfare Guardianship. Since moving into her own home, Caroline has been supported by a local advocacy organisation. Caroline's care package was recently up for review. Caroline's advocate made sure that her wishes were taken into account at the review meeting.

In 2012, Caroline was assessed for Self-directed Support and, together with her family, filled out a Self-Evaluation questionnaire. Caroline and her family decided to choose option 1, and take a Direct Payment to employ a team of Personal Assistants. Stephanie, Caroline's advocate, has been supporting her for the last six months, and during that time Caroline has decided that she would like to be more independent.

Some months ago, a meeting was arranged between the Social Work department and Caroline's family, to review Caroline's care package. Caroline was not invited to the meeting. Caroline was extremely frustrated at not having been invited, as she would not be consulted about decisions that were being made about her care. She asked Stephanie to attend the meeting on her behalf, and gave Stephanie a number of issues that she wanted her to raise.

One issue which was particularly important to Caroline was the way in which people involved in her care would communicate directly with her family and not her, because a family has Guardianship. This meant that quite often, other people were making decisions about what was best for Caroline, without her having a say.

Stephanie attended the review meeting, and was challenged by the Social Worker as to why she was there. Stephanie explained that Caroline had asked her to attend on her behalf, in order that she could have some choice and control over the decisions made about her care.

Stephanie was told that Caroline had not been invited to the meeting, because a family member has Guardianship. Stephanie told the panel that although Caroline's family member has Guardianship, Caroline does not wish to be excluded from discussions.

At the review meeting Stephanie told the panel that Caroline wanted the care team to communicate directly with her and not go through her family. It was agreed at the meeting that all future communications would go through Caroline directly and not through her family.

Caroline is striving to become more independent. Stephanie is currently supporting Caroline to investigate the Guardianship arrangements and the powers that are contained within it.

"We've already looked at situations with the Social Worker with regards to how she changes it, because she's not happy with the extent of the power at the moment."
Stephanie

Before she met Stephanie, Caroline did not have the confidence to speak up for herself and she did not think that anyone was listening to her. Having Stephanie on board means that Caroline has more confidence to speak up for herself, and when necessary, ask Stephanie to speak on her behalf. Caroline believes that people are now listening to her and taking her wishes into account.

6. The principles which underpin Self-directed Support

The Scottish Government Guidance which accompanies the Social Care (Self-directed Support) (Scotland) Act 2013 highlights four key principles which underpin the Act. Local Authorities have a duty to take into account the key principles when assessing people for Self-directed Support.

6.1Involvement

The supported person should have as much involvement as they want in the assessment and provision of their care.

Our research shows that an advocate can be valuable in supporting a person to think about their Self-directed Support options, making sure that they have an opportunity to be involved in the planning of their care.

Case Study

Sarah is a young woman with physical and learning disabilities. She is currently going through the Self-directed Support journey and her advocate, Elaine, is helping her to think about her goals and outcomes.

Sarah has some difficulties communicating her views and wishes to people, her advocate, Elaine has spent a lot of time getting to know Sarah and supporting her to communicate her needs and wishes.

Sarah has been living in a residential Care Home for six months, where she has been receiving excellent care however she has told her advocate that she would like to move out of the care home and into her own accommodation. Elaine has been helping Sarah to think about her support needs if she is going to move into her own home, and to communicate this to her Care Manager.

Sarah's family are unhappy about her moving into her own accommodation, however she is clear that this is what she wants. Elaine has been supporting Sarah to communicate her wishes to her family.

"Sarah wants to move on. She is happy about this, her family are not." Elaine

Elaine has spent time building up a close relationship with Sarah based on trust and has been able to help Sarah communicate her wish to move into her own accommodation. Having Elaine's support ensured that Sarah was involved in the planning of her care, and ensured that decisions made were based on what Sarah wants, rather than based solely on what other people believed was best for Sarah.

6.2 Informed Choice

The person must be provided with assistance that they require to enable them to express their views and make an informed choice when choosing a Self-directed Support option

During the course of this research, we came across cases where people had not been fully informed of their rights and choices and had been pressed into pursuing a particular option, without being fully informed of the situation. Having an advocate at this point meant that people had the information they needed about the choices available to them, and ensured that people did not feel pressured into choosing an option which was not appropriate for them.

Case Study

Anthony receives care at home. When his care package was re-assessed, Anthony contacted an advocate, Carol to help him get the outcome he wanted.

Anthony has Multiple Sclerosis, and had been receiving care at home provided by the Local Authority. In January 2014 he was admitted to hospital to have a medical procedure carried out, and at that time, he was assessed for Self-directed Support.

He was assessed as needing two care workers at home, however the Local Authority could no longer provide his care. Anthony was told that he could not return home unless he took a Direct Payment to employ Personal Assistants. At that stage he was not told about the four Self-directed Support options.

Anthony believed that his Social Worker did not have enough knowledge or expertise about Self-directed Support, and was pushing him into doing something he did not want to do. He did not want the responsibility of becoming an employer, so he made a complaint to the Local Authority. He did not receive a response.

Anthony had heard about advocacy from a family member and through the local Citizens Advice Bureau. He decided to refer himself to his local advocacy organisation.

The advocate, Carol, visited Anthony in hospital. At that time Anthony had received a letter from the Local Authority, confirming he had been assessed for Self-directed Support and a new indicative budget for his care had been worked out. Anthony had not been involved in any part of the assessment. He had not been asked to fill out a self-assessment, or think about the outcomes he wanted to achieve.

Carol was able to give Anthony information about Self-directed Support and talk to him about what his rights are and what he was entitled to. She was also able to discuss Anthony's options with him.

"He wasn't offered the four options; he had no idea about the four options. He did not know that he could go home….He was very vocal that he didn't want to be an employer, he gets very stressed out and he didn't want to put himself under that kind of stress. He told me that his stress has a direct effect on his MS and he wasn't willing to put his health at risk"

Carol helped Anthony write a letter of complaint to his Local Councillor. Following the complaint Anthony's care package was reviewed and it was decided that he could return home and continue to receive care provided by the Local Authority.

Without Carol, Anthony could have been pressed into taking a Direct Payment which would have burdened him with a huge responsibility that he was not prepared for. Anthony was not given enough information to make an informed choice; he was not given any choices or consulted about the Assessment. Having Carol's support meant that Anthony was able to find out more about his choices and his rights. He was able to understand the Assessment and choose Option 3. Having Carol on board also gave Anthony the confidence to write to his local Councillor to challenge the Local Authority's decision.

6.3 Collaboration

The Local Authority must collaborate with the person in the assessment of their needs for support and services, and the provision of their support and services.

Our research has shown that in some cases, in certain Local Authority areas, decisions have been made by the Local Authority to reduce or withdraw vital support services, without consultation with the supported person, and without taking their needs and wishes into consideration. In these cases, having an advocate on board ensured that the person was informed of their rights and choices, and was able to speak up for themselves, to ensure that the Local Authority listened to what they wanted, and took account of their needs.

Case Study

John has Cerebral Palsy. He had been receiving 24 hour care from his Local Authority for some time. Last year, he was re-assessed for Self-directed Support and told that his care package would be reduced.

Until last year, John had been receiving 24 hour care from the Local Authority. Last year John's Social Worker told him that he would be assessed for Self-directed Support and that his care package would be reduced by 75% and there would be no overnight care.

John had never spent a night alone in his life. He was extremely anxious about the reduction in his care package. John was told that his 24 hour care would be replaced with a Telecare system which monitors people remotely and alerts support workers if the person needs help.

John was given a Self-Evaluation Questionnaire, however he was not given any information about the four options. John was aware of a local advocacy organisation that he could contact for support. He contacted the advocacy organisation himself and was put in touch with Lorna.

When John first met with Lorna he explained his concerns about being left alone at night. Lorna was able to give John information about Self-directed Support and how it works. She was also able to support John to think about his goals and outcomes.

John was adamant that he did not want to lose his overnight care. This was one of his biggest priorities. With John's consent, Lorna contacted the Social Worker and expressed that John was very concerned about being left alone at night time. The Social Worker then agreed that John's 24 hour care would be left in place, while Telecare facilities were installed at his flat, to give him time to get used to using the new remote system, without putting him at risk.

Telecare facilities were installed at John's home, including sensors under his bed which would alert them if he left his bed during the night and did not return after 20 minutes.

John was concerned that a lot could happen in 20 minutes, and if something happened while he was out of bed, he felt 20 minutes was too long to wait to raise the alarm.John expressed this concern to Lorna, who took the matter up with his consent. The Care Team agreed to reduce the alarm time to 10 minutes, so that if something happened to John when he was out of bed, the alarm would be raised more quickly.

John submitted his Self-Evaluation Questionnaire, and a short time later, was asked to attend a meeting with his Social Worker. John asked Lorna to attend the meeting with him. At the meeting, John was told that he would no longer be receiving 24 hour care and that he would have to spend some nights alone, using the Telecare facilities.

At first, John did not say anything. Lorna had spent a lot of time with John and during their time together John had made it very clear to Lorna that he was very unhappy about being left alone at night. At the meeting, although John did not speak, Lorna could see from his body language and his emotional state that he was very unhappy.

At this point, Lorna asked John if there was anything he wanted to say or would like her to say. This gave John the confidence to speak out and tell the panel that he was very unhappy and extremely distressed at the thought of being alone at night.

The meeting was adjourned with an agreement that John could keep his overnight care for the time being, if he agreed to spend some time alone in his home, during the day, in preparation for spending a night alone. It was agreed that it would be a gradual process.

"I said..I'll try staying myself but now I'm getting older I feel somebody needs to be with me all the time." John

For the moment, John continues to receive 24 hour care, however this is due to be reviewed. Following the meeting John asked Lorna to help him write a letter to the Local Authority to express his dissatisfaction about the way he has been treated, and to challenge the decision to remove his 24 care.

Without advocacy support it is likely that John's overnight care would have been immediately withdrawn. John told us that he is not very confident communicating at meetings and he does not want to upset anyone. Having Lorna on board meant that John had the confidence to speak up at the review meeting and tell the Local Authority how concerned he was about losing his 24 hour care. Having Lorna also gave John the confidence to write his letter to the Local Authority, to challenge their decision.

"I feel Lorna helped me quite a lot over the past month or two... Lorna is good, we get on well together"

6.4 Participation and Dignity

The Local Authority must take steps to ensure that the person's dignity is respected, as well as their right to participate in the life of the community

During this research we came across cases where people reported feeling that they had been treated with a lack of respect during the assessment process, where the official carrying out the assessment did not fully understand or respect the person's needs, and failed to take into account their right to participate fully in community life.

Having an advocate in these cases allowed the supported person to speak up for themselves, express their dissatisfaction at the way they have been treated during the assessment; and to challenge the Local Authority to provide them with support to allow them to participate fully in the community.

Case Study

Derek has experienced mental health problems for a number of years. When Derek was assessed for Self-directed Support, he felt that his Care Manager was not listening to him, so he made contact with an advocacy organisation to help him get a new Care Manager.

Derek has OCD and experiences depression and anxiety which means that he is often unable to look after himself and his home and finds it difficult to get out and about in the community. For the past few years David has had weekly visiting support from a mental health support organisation.

Derek was assessed for Self-directed Support and his Care Manager asked him to complete a Self-Assessment Questionnaire. One of Derek's priorities was to continue to receive support from the organisation he was accustomed to because he felt that this gave him support to cope with day-to-day life and gave him confidence to socialise and participate in the community.

Derek felt that his Care Manager was not listening to him, or taking into account his needs and wishes.

"Although I gave certain answers, there were different answers recorded on the form. The Care Manager said "oh no, they won't accept that". So it wasn't actually a self evaluation, it was the answers that she wanted, despite the fact that there are two boxes; one for my view and one for the assessor's view." Derek

After Derek completed his Self-Assessment Questionnaire, he heard nothing further until he began receiving letters from the Local Authority asking him to pay £25 per week for the weekly support visits.

"The letter I got from the Local Authority said that because the assessment hadn't been completed, they wanted to charge me interim payments." Derek

Derek had not been given a copy of the Self-Assessment Questionnaire from his Care Manager, and was not clear what information it contained. He contacted the Social Work Department several times to ask them to send him a copy.

“I kept asking to get a copy of the Assessment from Social Work but it was never actually provided.” Derek

Derek was unable to make interim payments and his support was withdrawn.

Derek wrote a letter to the Social Work Department explaining the issues that he had been having with his Care Manager. He did not receive a response. Derek had no further contact with his Care Manager for several months and during that time he was not receiving any support at all. As a result, his mental health deteriorated, he was unable to look after his home or get out and about in the community. He contacted an Advocacy organisation where he was put in touch with an advocate, Gerald.

Derek met with Gerald and was able to explain to him about his situation. Gerald was able to give Derek more information about Self-directed Support. Derek was relieved that someone was finally listening to him.

“I felt that I was getting nowhere on my own..” Derek

Derek asked Gerald to contact his Care Manager to see if he could get a copy of the completed Self-Assessment Questionnaire. After Gerald made contact with the Care Manager, Derek finally received a copy of the Self-Assessment Questionnaire. The Self-Assessment appeared to show that the service was in place, when, in fact, Derek was not receiving any support whatsoever.

Derek asked Gerald to accompany him to a meeting with a solicitor from Legal Services Agency (LSA). In previous meetings with the solicitor, Derek had become more and more frustrated and angry about the situation and had found it difficult to put his point across. Having Gerald at the meeting helped Derek to stay calm and put his point across concisely.

“At the time I was completely irrational and highly aggressive..” Derek

“We went along together because (Derek was) under so much pressure and not able to put his views across in a rational way...” Gerald

At the meeting it was agreed that Derek’s solicitor would contact the Local Authority and request that he be allocated a new Care Manager. A short time later, Derek was allocated a new Care Manager.

Derek was concerned that, because he had a difficult relationship with his previous Care Manager, this may have an adverse effect on the new relationship, however he did not feel able to put this across. Derek discussed this with Gerald and asked Gerald to attend the first meeting with his new Care Manager and speak on his behalf.

“I strongly said that Derek wanted to start afresh, to start from the beginning, to not have any preconceived ideas or views about Derek but to treat him on the day like he had just met him and he agreed to that.” Gerald

Derek’s journey has been a long and difficult one. However he does feel that now he is making some kind of progress. Derek is glad that he made contact with Gerald, as he did not feel that he was getting anywhere on his own.

“I think that without Gerald.. I probably would have given up one way or the other.” Derek

Derek told us that he had felt very distressed by his experiences and at one point he had considered taking his own life. Now he feels more optimistic about his future but believes that, without Gerald, he may have given up. Having someone on his side who was actually listening to him make Derek feel more confident and able to pursue his case, rather than giving up.

“I had pretty much given up hope. I had spent most of last year fairly intent on checking out. I even went so far as to say goodbye to people. A weight was lifted when the old Care Manager was no longer involved. Without the assistance of Gerald..I don’t think that would have happened.”

Case Study

Barry has experienced alcohol addiction. Twelve years ago he had a stroke which left him with some mobility issues. In April, Barry was assessed for Self-directed Support and felt that his Social Worker did not fully take his needs into account when filling out her part of the Assessment. As a result, his support was withdrawn. Barry and his advocate intend to challenge this decision.

Following an admission to hospital Barry was referred to his local advocacy organisation and met Elizabeth, an advocate.

On his discharge from hospital he moved into a flat and had visiting support to help him with practical tasks and with social interaction in the community. Barry was allocated support from a local provider for ten hours per week, over three days.

Barry had stopped drinking and, as his health gradually improved his care was transferred from the local Addictions team to the Community Care Department. He was assigned to a new Social Worker who felt that he no longer needed visiting support. Barry explained to the Social Worker that this was not the case and that he still needed support with personal care, housework and shopping, due to his mobility issues. Barry did not feel that the Social Worker listened to him, and made assumptions that Barry could do things that he did not feel he could do.

Barry also told the Social Worker that he wanted support with social interaction, as most of his friends and acquaintances were still drinking alcohol and he was concerned that distancing himself from these previous contacts had led to increasing isolation.

Barry did not feel that the Social Worker was listening to him and that she did not fully take into account his long-term support needs, particularly support with getting out and about in the community.

"She is putting far too much pressure on me. It's fair to say I am a changed person, two years ago, I wouldn't be sitting here; but she seems to think that I have overturned my life. She thinks I can do everything and I can't." Barry

In April 2014, Barry was assessed for Self-directed Support. Barry was given a Self Evaluation form however his Social Worker did not fully explain the four options.

Elizabeth was able to give Barry more information about Self-directed Support and help him to think about his options. Barry was certain that he still needed support with personal care, housework and shopping, as well as support with socialisation and participating in community life.

Over the next few weeks, Barry met with his Social Worker and they completed his Self-Evaluation. Barry asked Elizabeth to attend some of the meetings with him. At some of the meetings, Barry spoke up for himself and told the Social Worker that did feel that he still needed support, in particular, to get out and about in the community. At other meetings, Barry asked Elizabeth to speak on his behalf.

Unfortunately the Social Worker did not agree that Barry still needed support, and Barry felt that she was not listening to him or Elizabeth, and not taking his needs and wishes into account.

"Barry would say what he felt and the Social Worker would say, "No, I think you're more capable than that." Elizabeth

Over the following weeks, Barry's care package was gradually reduced, from ten hours per week to three until he was finally told it would be completely withdrawn.

Barry intends to challenge the Local Authority's decision to withdraw his care package and he has asked Elizabeth to support him with his challenge.

Elizabeth has made Barry feel that at last someone is listening to him which has given him the confidence to speak up for himself, and insist to the Social Worker that he does need support. Having Elizabeth on board has also given Barry the courage to challenge the Local Authority's decision to withdraw his support.

7. Good Working Relationships

The task of implementing Self-directed Support is a learning curve for organisations as well as people accessing services, and organisations are often constrained by time and budgets.

Social Workers and Care Managers are often faced with the added task of trying to reassure their clients and deal with their doubts and fears about the process, whilst trying to make sense of a myriad of information themselves. Most of those participants who had an advocate involved from the beginning of their Self-directed Support journey felt that the whole process appeared to run smoothly.

Case Study

Katie is a Care Manager and has a good working relationship with the Self-directed Support Worker at the local advocacy organisation. Katie explains advocacy to her clients and if the client wants to have an advocate, Katie refers them to the advocacy organisation.

Katie's task is to review all health and social care services in her division, to make sure that people who are eligible are assessed for Self-directed Support and offered the four options.

"I work with the learning disability services and transitions team; very much working with bringing in the new budgets and Self-directed Support." Katie

The task of implementing Self-directed Support comes with significant challenges, not least in making sure people have access to good sources of information in order to make an informed choice.

"There's a lot of information…but some of it contradicts itself, you've got providers who put out their own guidance on Self-directed Support and its different to where the Government is, it's just all worded differently. It can be confusing." Katie

As well as trying to make sense of the multitude of available information, there are other challenges including addressing people's anxieties and uncertainty about the process and fear of change.

"A lot of people are scared. They see it as a cut." Katie

Katie feels that having an advocate involved at the beginning of the Self-directed Support Assessment has been very positive for many of her clients, and has helped them to better understand the process.

"A lot of my clients have services in place and to them it's a change, and it's almost an enforced change, that's the way they feel. …someone that is independent, they're giving a different side of it, showing people that they have the choice.." Katie

Katie has a good understanding of the role of an advocate and appreciates the value that it can bring to her clients.

"…someone that's there to ensure that people are being heard and being listened to. I'd love to be able to do that for all my clients…having someone else there that's working on behalf of the client." Katie

Katie understands that having an advocate on board can help clients who are going through Self-directed Support have all the support they need to make an informed choice about their care.

"If we know that one of our clients has an advocacy worker, we will ask the client if they want their advocacy worker to come to the meeting and come to the support planning and get them involved, because they know the person from a different angle and that's the whole point." Katie

Katie continues to tell her clients about advocacy, and offers them the opportunity to have an advocate involved, if they want one. She makes regular referrals to the advocacy organisation and they have a very positive relationship.

Case Study

Deirdre works as an Adviser with a local advice agency. She has a good working relationship with the local advocacy organisation.

Deirdre's organisation provides advice and assistance to local people on a range of issues, including Self-directed Support. Deirdre's role is to provide advice and assistance to local people about Self-directed Support and Direct Payments. She has worked with a number of people going through Self-directed Support. The task of guiding people through the process and making sure they have all the information and support they need to make informed choices about their care is a challenge.

"Some people have explained that they have felt pressure to take up Direct Payments as there does not appear to be any other choice for them." Deirdre

The advice agency and the advocacy organisation both have very different but equally important roles to play in the community and Deirdre understands the unique role that the advocate plays.

"I am of the opinion that people should be able to progress through their life. Some people are not able to put their message across. Advocacy is a key role in assisting them to make their voices heard." Deirdre

Deirdre has developed a good relationship with the advocacy organisation and is able to make referrals.

"I was recently working with a lady and I recommended (advocacy organisation) for her and her family.

I was concerned for the family's welfare and their ability to put across what they wanted and needed to the people at the Local Authority responsible for providing (their) services." Deirdre

The relationship between the two organisations works well and Deirdre has been able to call on an advocate on more than one occasion, to support clients going through Self-directed Support, to ensure their voices are heard in the decision-making process.

"I had one lady who felt fine speaking one-to-one with people but when she went into a Review Meeting she felt bewildered by all the people who were there and found it difficult to express herself in any way. With her consent, I asked the advocacy organisation to meet her and to assist in attending such meetings in future." Deirdre

The working relationship has been successful in supporting people through Self directed Support and Deirdre is confident that an advocate will ensure that the client can speak up for themselves and have their voice heard.

"When you refer people to advocacy you know that they are in safe hands. When I go to close a case that I have referred to advocacy, I know the person will be well supported and that the advocate is going to be in their corner." Deirdre

Deidre continues to tell her clients about advocacy, and offers them a referral to an advocacy organisation if they want one.

"When I speak with the advocates, they are so passionate about the people they are supporting, they really do care so much for the people they are supporting. Advocacy, in my opinion, is an invaluable service for a lot of our clients." Deirdre

8. Summary of Findings

Choice and Control

While the principles of Self-directed Support aim to offer people choice and control over the care they receive responses from participants have shown that, in practice, the extent to which people actually have choice and control varies considerably from one Local Authority area to the next. The findings of this report demonstrate how advocates have supported people to speak up for themselves, make their wishes known and, in some cases, challenge Local Authority decisions.

"My advocate, Lorna helped me to write a letter to the Social Work Department explaining on my behalf how I feel, saying that I want my freedom, I want my independence back and I've got a right to speak up for myself."
John

Information and Making Informed Choices

The findings highlight how, for those people interviewed during the course of this research, advocates have been effective in making sure that people had access to the right information about Self-Directed Support and the four options. Some people felt they were pushed towards taking an option, perhaps because of financial considerations, in those situations they reported that advocates ensured that they had all the information they needed to make an informed choice about their care and to choose the option which was best for them.

"It wasn't as easy as that to start with but Frances made that go a wee bit smoother..they were saying we can get this cheaper..but it's not what I wanted. I wanted to choose. I wanted to have a choice. So I did, after Frances got involved."
Denise

Soft' Outcomes

For those people interviewed in the course of this research independent advocacy has been effective in achieving measurable hard outcomes such as helping to access information and empowering people to speak up for themselves. However, in addition to these hard outcomes, our research also highlights soft outcomes which add to the value of advocacy and can have a lasting positive effect on people.

Almost all of the people we interviewed told us that they experienced stress and anxiety about the whole process of Self-directed Support. Having an advocate on board helped to clarify the process and alleviate some of their anxieties. As a result, some felt more optimistic about the future.

“Going to these meetings its quite anxiety producing. Anxiety can cause blocks.. I just feel like recovery from mental health is flying without a safety net and Henry is like a safety net, having him there, going through things to start the process or investigate the process with a safety net…”
Anna

““It’s been about six weeks now, since my SDS started and it’s been fantastic. It’s been a huge weight off my shoulders… My experience has been fantastic.”
Denise

Some interviewees reported that their advocates made them feel that someone was listening to them when previously they had felt that they had not been listened to by a Care Manager or a Social Worker. This gave them a renewed confidence to speak up for themselves.

“Elizabeth supports you when you’re going to these meetings, you know, the review meetings or any meetings considering my wellbeing, so Elizabeth would be there but I did most of the talking. She’s been a lot of help, just being there … I couldn’t have done it without her.“
Barry

“I’m feeling confident now.”
Denise

Interviewees also told us that at times the challenges they faced with Self-directed Support had made them feel hopeless and that they were getting nowhere. They reported that having an advocate, someone who was on their side, gave them the strength and courage to carry on and not give up.

“Gerald has always been as helpful as possible, always followed through.. If it weren’t for Gerald.. I certainly would not have got as far as I have. I would have given up.”
Derek

“It was getting really frustrating and at one point I thought about packing it in. Just scrap it because it’s just taking too long…because of all this carry on I’ve had has just been a pain… I really was so close to just saying forget it. Then after I met Frances I was feeling confident.”
Denise

9. Conclusion

The principles of Self-directed Support are choice and control. However, findings from this research suggest that people's experiences of Self-directed Support can vary significantly from one Local Authority area to the next. For some what they experience in reality is not always in line with the legislation and the principles behind it.

For our interviewees independent advocacy has been effective in upholding the core principles of Self-directed Support by helping them to access information, to consider options and to make informed choices. This helped to ensure that people had more control over their own care and support. Furthermore advocacy had a positive effect on these individuals by helping to reduce some of their anxieties around Self-directed Support and by helping them have the confidence to speak up for themselves and have their voices heard.

The findings of the research suggest that having an advocate at the beginning of the Self-directed Support journey can be valuable in helping people to access the right information and make informed choices right from the start. However, the results of our Advocacy and Self-directed Support survey (See Appendix) show that only 21% of referrals came in at the beginning of the process. Furthermore, 75% of the people we interviewed told us that they were not told about advocacy by their Social Worker or Care Manager at the beginning of the process. Instead, they had accessed advocacy because a problem arose, and that they had made contact through a friend, family member or other professional, or referred themselves, because they had prior knowledge of advocacy. Indeed, evidence from the survey shows that almost 50% of referrals in respect of Self directed Support were self-referrals and only 25% were referred by a Social Worker or Care Manager.

The results of our survey show that 21% of people were referred or self-referred themselves to advocacy because of a lack of information or inconsistency of information about Self directed Support. 20% of Self-directed Support referrals were in relation to people's anxieties and lack of understanding about Self-directed Support.

It is clear that there is a need for Independent Advocacy in supporting people through the Self-directed Support journey, to help people access information and understand the process, and to address anxieties or misunderstandings about Self-directed Support. What is also clear is that having an advocate at the beginning of the journey can be effective in helping people to make sense of the process, ensure they have access to the right information in order to make informed choices and have someone on their side to support them to speak up for themselves and make their wishes known.

10. Recommendations

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1. Local Authorities should consider making referrals to advocacy at the beginning of the Self-directed Support journey to ensure people are fully informed from the outset as to what their rights are and what they should expect from SDS, rather than waiting until problems arise which then need to be addressed.

2. The Scottish Government should provide additional funding to advocacy organisations across Scotland, to allow them to make provision for people who are being assessed for Self-directed Support.

11. Appendix

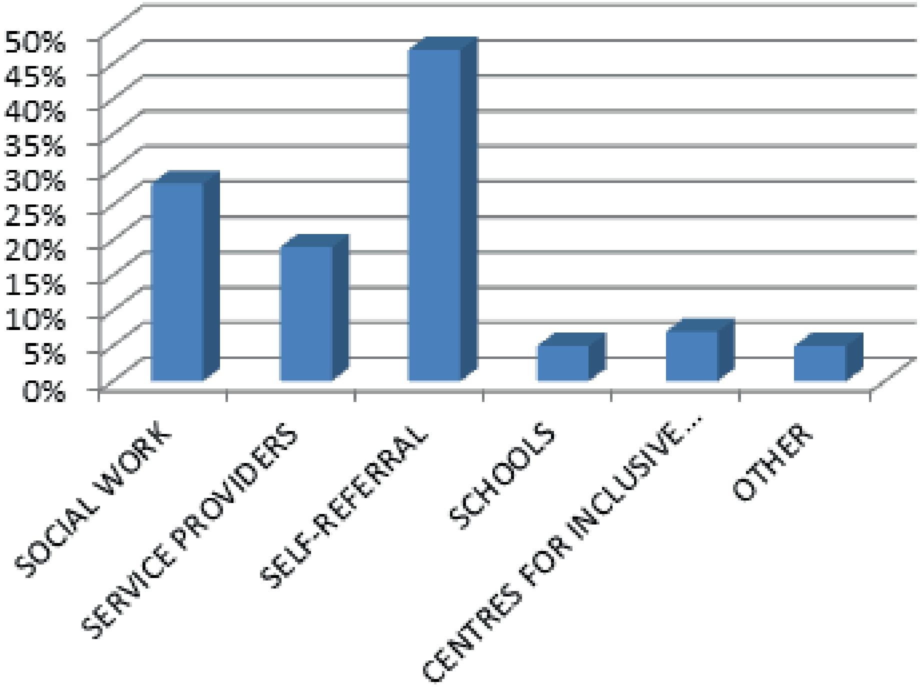
Results of Self-directed Support and Advocacy Survey

The survey generated a 60% response rate from organisations across all Local Authority areas in Scotland.

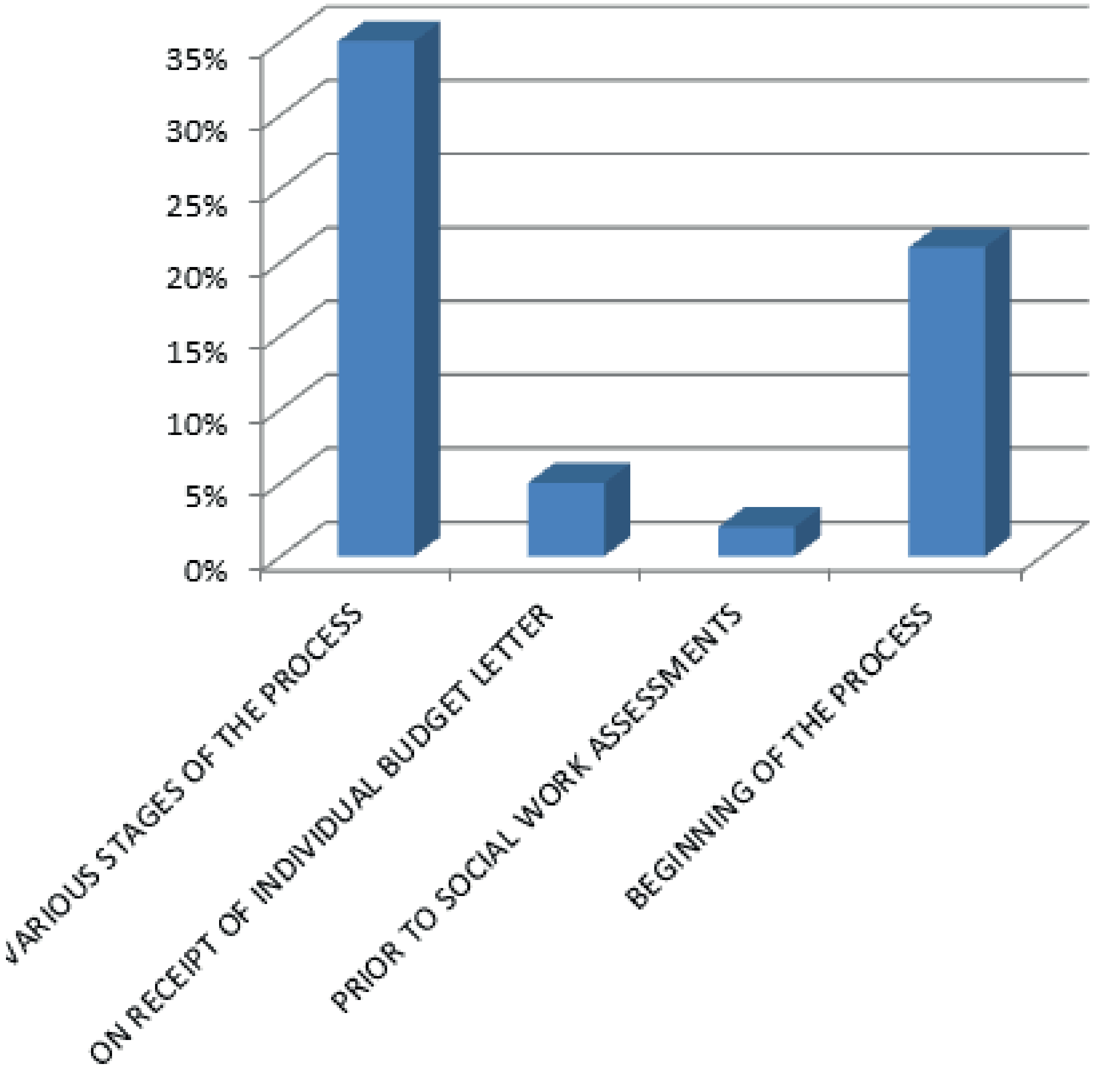
Of the organisations who responded to the survey, 66% said that they had received referrals in relation to Self-directed Support. 34% said they had received no referrals. Of these,14% reported that Self-directed Support had not yet been rolled out in their area.

(i) Referrals in respect of Self-directed Support

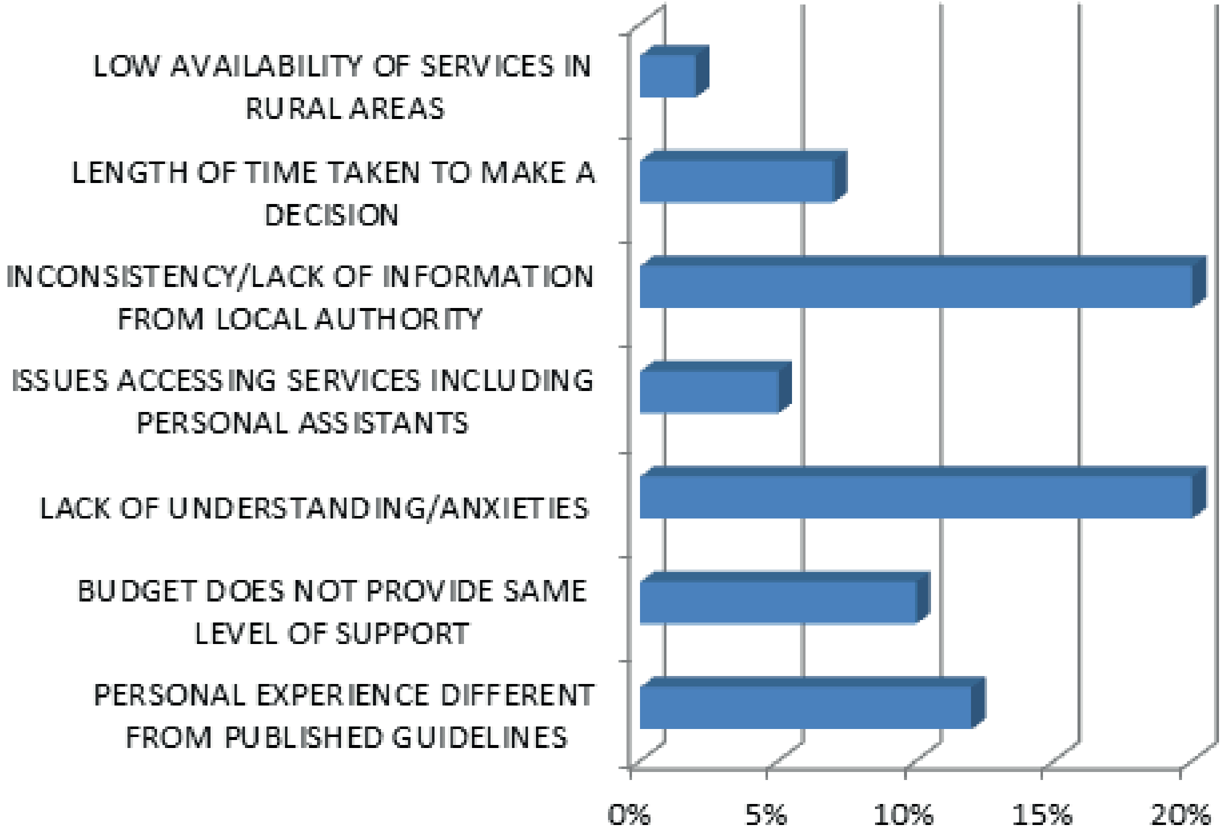
The largest number of referrals came from people self-referring to independent advocacy or being referred by a family member or friend. Only 25% were referred by a Social Worker or Care Provider.



The 66% of organisations who had received referrals in respect of Self-directed Support were asked at what point in the journey the referrals had come in. Only 21% reported that referrals came in at the beginning.



Organisations were asked the reasons for people referring themselves or being referred to independent advocacy. 20% of organisations reported that people had a lack of understanding about Self-directed Support and 21% told us that people had received no information or conflicting information about Self-directed Support.


LOW AVAILABILITY OF SERVICES IN RURAL AREAS
LENGTH OF TIME TAKEN TO MAKE A DECISION
INCONSISTENCY/LACK OF INFORMATION FROM LOCAL AUTHORITY
ISSUES ACCESSING SERVICES INCLUDING PERSONAL ASSISTANTS
LACK OF UNDERSTANDING/ANXIETIES
BUDGET DOES NOT PROVIDE SAME LEVEL OF SUPPORT
PERSONAL EXPERIENCE DIFFERENT FROM PUBLISHED GUIDELINES
0%
5%
10%
15%
20%

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