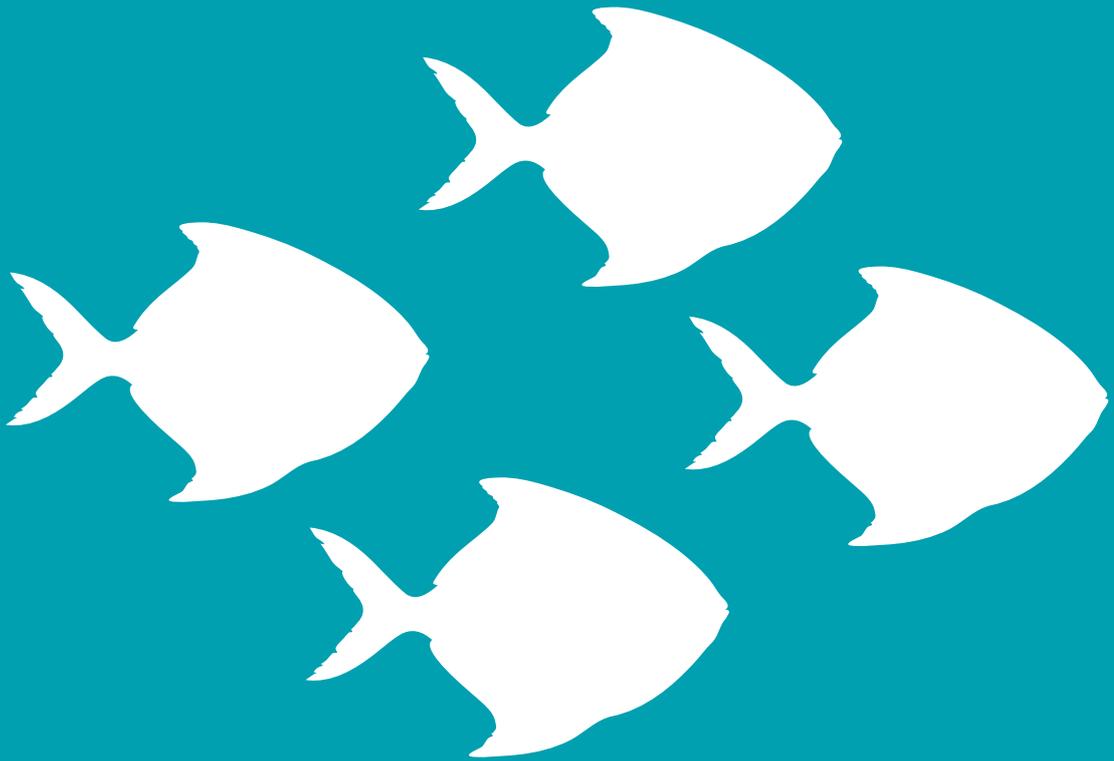


Support in the Right Direction



The value of Independent Support

How it can help people understand and make
informed decisions about Self-directed Support

Information for funders and commissioners
(and others working in the field of Self-directed Support)

Something happened that could have happened months before, but didn't happen because there was an issue about 'Is it ok? Who's taking it forward?' ... A broker who didn't have all that just came in and it happened within a couple of weeks. It's not that people haven't thought about that, sometimes it's just somebody else thinking differently and challenging it.

Social worker, East Ayrshire

I don't think that lady would have let anyone from the local authority through her door. There would have been no engagement at all.

Local authority professional

I have witnessed the positive impact [independent advocacy] has had and the rapid progress made to situations that have become static and appeared to be at a standstill.

Depute head teacher, Glasgow

"[Independent Support is] a vital service to support us in our jobs."

Local authority professional



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Foreword

The Scottish Government has a vision of a flourishing, nurturing and optimistic Scotland in which everyone has control of their lives, equality of opportunity and is empowered to make choices at home and work, in education and in their social and civic lives.

In line with the Health and Social Care integration and the National Health and Wellbeing Outcomes, *The Social Care (Self-directed Support) (Scotland) Act 2013* places a statutory duty on local authorities to provide support to those who need it in order to accomplish Scotland's vision. For this to be achieved, we also strongly encourage the public, third and private sectors to form positive partnerships.

The Self-directed Support national implementation programme aims to help people who need support, their carers, local communities, health and social care services, third sector organisations and the private sector to work together in two ways. Firstly, by creating vibrant opportunities for learning, working and socialising that are accessible to people who need support. Secondly, by using the statutory framework to empower people who need support to exercise choice and control in order to meet their personal outcomes and thus participate as fully and independently as possible in society.

Independent Support has a very important role to play within the Self-directed Support programme. By providing high quality, accessible advice and support, it can help to ensure that people can make informed choices and realise the full benefits of directing their own support.

This document, *The Value of Independent Support*, is key for those making decisions about how people are supported. It explains how Independent Support can enable people to realise their rights such as informed choice and participation. It shows how Independent Support can help with the transfer of power and control to the individual and be central to establishing positive working partnerships. Furthermore, it illustrates how Independent Support has already proved vital to many individuals' experience of health and social care.

We hope this clear guidance will be invaluable to funders and commissioners, as well as others involved in the design and implementation of Self-directed Support.

I would like to thank Evaluation Support Scotland, the working group and those people who shared their experiences for their contribution to this very important work.

Mr Jamie Hepburn MSP

Minister for Sport, Health Improvement & Mental Health



The background to this document

Support in the Right Direction

The Scottish Government wanted to find out more about Independent Support, what role it can play in the successful implementation of Self-directed Support (SDS) and how to evaluate it. The Scottish Government therefore funded a three year programme (2012-15), *Support in the Right Direction*, which was managed by [Evaluation Support Scotland \(ESS\)](#) and involved 42 funded organisations.

Working Group

A key part of this work involved a group of organisations meeting throughout the three years to focus on:

- **Explaining** Independent Support (what is it? What difference does it make?)
- **Measuring** Independent Support (how can it be evaluated?)
- **Demonstrating** what works (what evidence has been generated from evaluating Independent Support?)

This group produced two documents:

› **The value of Independent Support** (this document): intended primarily for funders and commissioners, explains the different types of Independent Support, what difference Independent Support can make, and what evidence there is for this, including some case studies.

› **Measuring the difference Independent Support makes:** intended primarily to help organisations providing Independent Support evaluate their work but likely also to have value for those who fund or commission Independent Support. Case studies describe projects' experiences of using a range of information collection methods.

Both documents can be downloaded from:

www.sdsscotland.org.uk/guide-self-directed-support/support-right-direction



The aims of Self-directed Support

Self-directed Support (SDS) is new and requires a **significant cultural change** – giving people the right to choices in how their care is provided. The following values and principles underpin the Scottish Government’s *Social Care (Self-directed Support) (Scotland) Act 2013* (the SDS Act) and current strategy:

Our values

Our established ideals, the things that we regard as fundamental:

- Respect
- Fairness
- Independence
- Freedom
- Safety

Our principles

The principles of **Collaboration, Dignity, Informed Choice, Involvement** and **Participation** are drawn from the SDS Act; Innovation, Responsibility and Risk Enablement have been added to reflect the opportunity for creative and flexible approaches to care and support.

The table describes how we will put the five values into practice.

Principle	This means...
Collaboration	Individuals are supported to achieve better outcomes in their lives.
Dignity	A person’s right to dignity is facilitated throughout the support they receive.
Informed choice	People are supported to make informed choices based on impartial information about their eligibility for support, the choices available to them and their aspirations.
Involvement	Co-production enables people to be involved in a genuine and active way at all stages of their support, to be supported to know their rights; to participate in the development of local policies and practices; to articulate their personal outcomes and to plan, manage and deliver their support; and play an active part in their communities.
Participation	Everyone has the right to participate in decisions which affect their lives. Therefore, people are supported to participate freely and equally in their community and wider society.
Innovation	People are supported to develop creative and flexible solutions in order to meet their personal outcomes.
Responsibility	People are supported to take responsibility for the choices they make and the control they take over the activities to meet their agreed outcomes.
Risk enablement	People are empowered and trusted to set the parameters of their own risks and make the choices which will impact on their lives.

Excerpt from *Scottish Government Care and Support in Scotland Statement of Values and Principles*
www.scotland.gov.uk/resource/0045/00453891.pdf

To uphold these values and principles it is important to **ensure good communication and create positive working partnerships between everyone involved**: people and carers eligible for SDS, health and social care services, third sector

organisations, the private sector and the local community. Fundamental to this is the **transferring of power and control to the individual**, in which Independent Support also has a role.

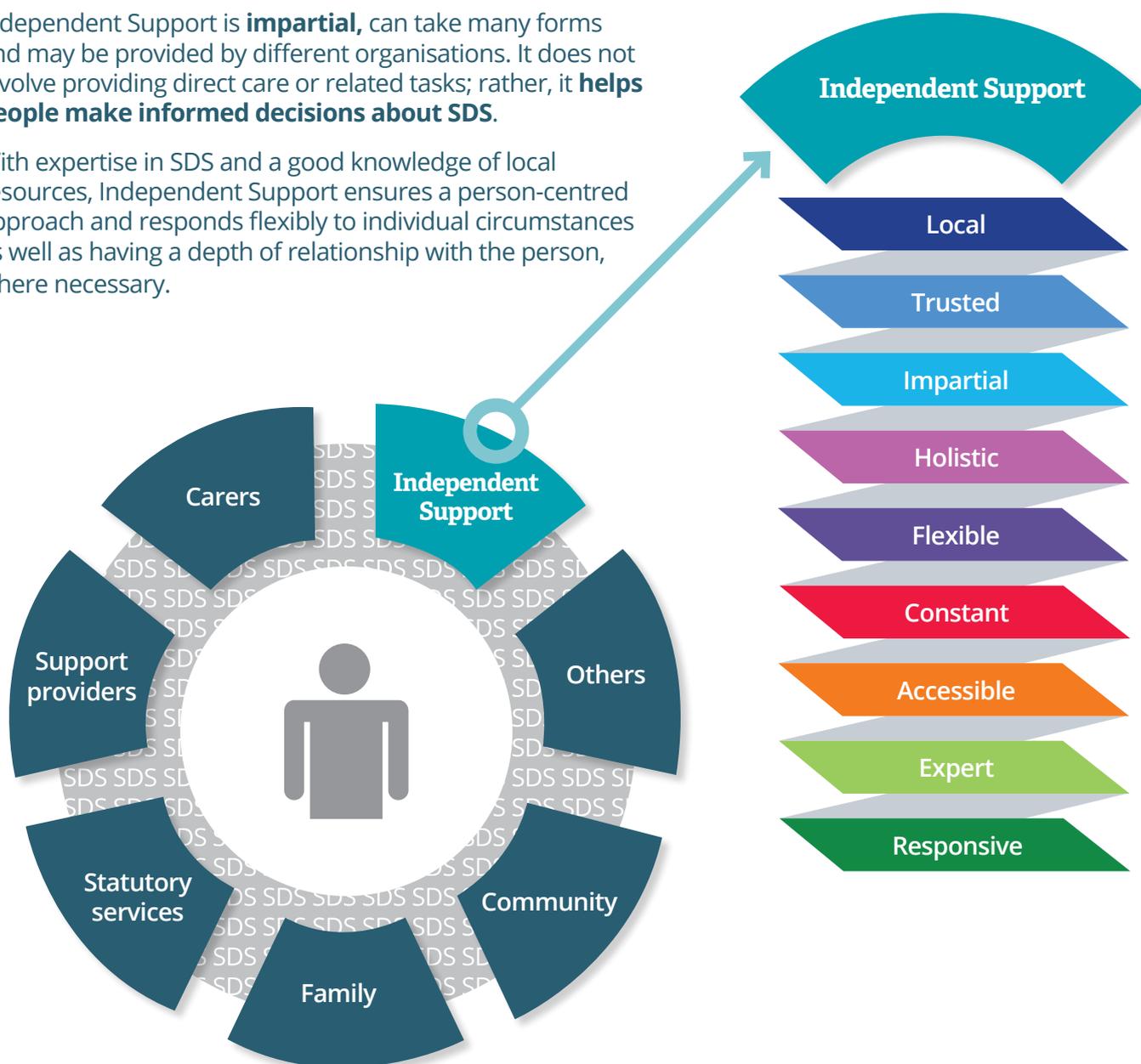
The need for Independent Support

The availability of and access to Independent Support is crucial to the success of SDS. For many individuals this ensures they have access to impartial support and information to enable informed choice.

What is Independent Support?

Independent Support is **impartial**, can take many forms and may be provided by different organisations. It does not involve providing direct care or related tasks; rather, it **helps people make informed decisions about SDS**.

With expertise in SDS and a good knowledge of local resources, Independent Support ensures a person-centred approach and responds flexibly to individual circumstances as well as having a depth of relationship with the person, where necessary.



Types of Independent Support?

Types of Independent Support will continue to evolve and change over time; however, to make sure SDS is successfully implemented, our experience is that Independent Support in any local area should include these activities:

Types	Example activities
Awareness raising	<ul style="list-style-type: none"> ■ helping organisations embed SDS in practice ■ producing accessible information about SDS ■ sharing information through forums and networks ■ sharing good practice
Brokerage	<ul style="list-style-type: none"> ■ providing impartial information, advice and support for people to help them plan and organise their own support arrangements ■ making maximum use of community resources and informal support, helping people find creative solutions to meet their needs
Engagement and consultation	<ul style="list-style-type: none"> ■ providing opportunities for people eligible for SDS, their carers and local authorities to discuss issues ■ informing hard-to-reach groups about SDS ■ taking part in policy and planning groups
Evaluating, reporting and sharing learning	<ul style="list-style-type: none"> ■ sharing good practice, experience of what works (and what doesn't) with other organisations ■ creating networking opportunities ■ feeding evidence to policy and decision-makers
Independent advocacy	<ul style="list-style-type: none"> ■ making sure people's voices are heard throughout the SDS process ■ enabling people to make informed choices ■ upholding people's rights
Training and development	<ul style="list-style-type: none"> ■ providing training and development opportunities for: <ul style="list-style-type: none"> ■ individuals ■ organisations ■ statutory services ■ commissioners and funders
Other types of support	<ul style="list-style-type: none"> ■ helping people: <ul style="list-style-type: none"> ■ understand and access their community resources ■ participate in assessments and reviews ■ set up and manage care packages ■ employ and manage Personal Assistants ■ manage finances ■ providing peer support ■ mentoring

People's need for Independent Support will vary. Some will access one-off support at a particular stage in the process; others may use different services at different times, or may need ongoing support of one type or another. This must be underpinned by sound communication and supported by organisations funded to provide information in a range of accessible formats.

The difference Independent Support makes (outcomes)

For people and carers...

Independent Support puts people at the centre of the process, meaning that they:

- access clearer information about SDS
- are more aware of the support available to access and manage SDS
- make more informed choices about SDS
- achieve their personal outcomes and live the life they want to live
- are listened to
- are an equal partner
- have increased equality of access to SDS
- gain confidence to demand an increased range of service options
- have maximised opportunities for choice and control
- experiment, make mistakes and find ways to correct them
- contribute to local and national policy development

The provision of Independent Support ensures transparent and impartial information and the removal of conflicts of interest.

For statutory services and care providers...

Independent Support is essential to uphold the rights of individuals and ensure the principles and values underpinning the SDS Act are upheld. Locally and nationally, it helps statutory services and care providers to:

- increase their capacity to support people
- access additional information
- provide holistic and person-centred solutions
- build relationships with disengaged/isolated people
- respond creatively and flexibly to people's needs
- provide earlier interventions, therefore preventing crisis
- learn about and understand best practice
- work effectively together
- ensure local and national policy makers understand the effectiveness and value of Independent Support

For guidance on how to evaluate Independent Support, please see *Measuring the difference Independent Support makes*, which can be downloaded from www.sdsscotland.org.uk/guide-self-directed-support/support-right-direction

Evidence that Independent Support can make a difference

Here are some examples of evidence gathered by the 42 organisations funded by Scottish Government to provide Independent Support.

(Our daughter's story) shows the vital role that Advocacy workers play in implementing SDS and highlights your ability to liaise with all parties.
Supported person's family

It would have been impossible for me to keep up with things without their support.
Supported person

I believe that the service has been and still is an inspiration to me and other young people with difficulties because they do their job by giving people options, they have got determination, plus they thrive in the work they do.
Supported person

Advocacy has a very important role to play from an early stage. Collaborative working with professionals will enable outcomes.
Funder

You will see somebody who's able to give more time, who's able to sit back, who's able to say 'Well let's look at this from a different angle.' And confidently I'm saying this is great, because I would love to have the time to do that but I don't.
Social worker

It's great just to see (him) so independent and totally in control and wanting to get a broker to look at (his) next stages... And on reflection it's less work for me dealing with some of the services and knowing that (he's) the right person to be doing that.
Social worker

I wish I had known the services were available sooner... I was reluctant to request a Direct Payment because of lack of confidence in my ability to manage it.

Supported person

(Your financial management support service) gives me the confidence that I shall be able to continue to employ direct staff whom I have personally selected, to give me the degree of help I think I need, at times to suit me. It is not an exaggeration to say that the enhanced service has helped to preserve my quality of life!

Supported person

A shoulder to lean on when things have become difficult.

Supported person

Thanks for your support... our social worker said it was made very easy as I knew what it was all about!

Supported person's family

[No local Independent Support would mean a] larger workload and delay in care provision... We would be even busier.

Local authority professional

I was really negative about it and couldn't see it as a way forward. I think what prompted me to make the change to Self-directed Support was being offered support to do it. The Carers Centre were very supportive... When it all became a bit stressful they would calm me down... Through having Self-directed Support I feel as though I've got my life back.

Family carer

Following your involvement I felt listened to properly.

Supported person

If there was more choice created [for homeless people] there would need to be a commitment from staff to support people in making these kinds of choices.

Supported person

Gives the clients the confidence to arrange and manage their support.

Social worker

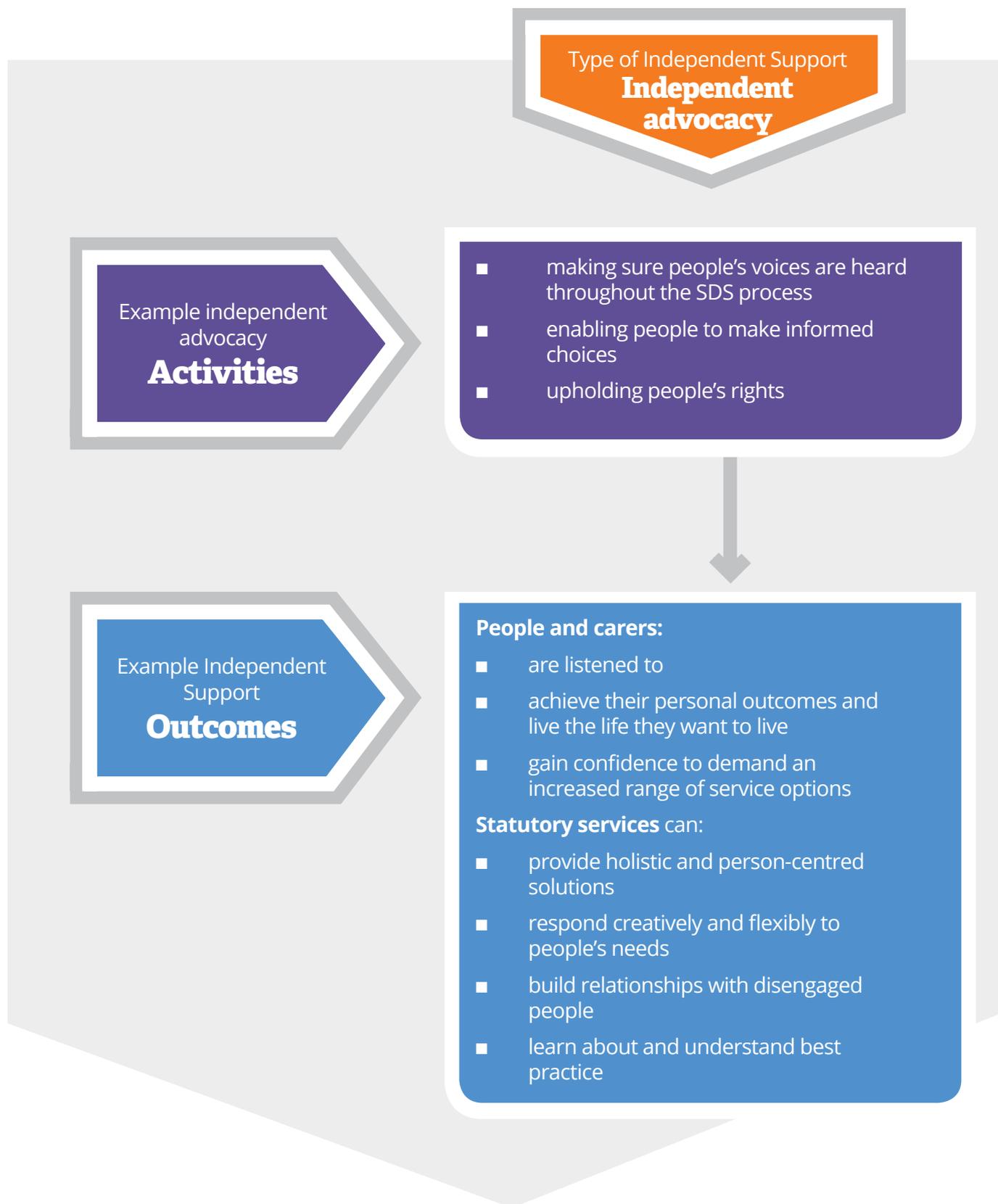
There are detailed **case studies** of the difference that Independent Support can make at the end of this document (p13-26).

Putting it all together: example 1



Direct Inclusive Collaborative Enterprise case study: *Inspiring confidence* (p14)
Community Brokerage Network case study: *Furthering talent* (p17)

Putting it all together: example 2



Borders Independent Advocacy Service case study:
[*Prioritising health and wellbeing outcomes*](#) (p20)

See **Furthering talent case study** on p17

Everyone working together [referring to brokerage].
Lewis, supported person

[Brokerage] is absolutely good.
Lewis, supported person

It has made a difference. I'm more connected to music.
Lewis, supported person

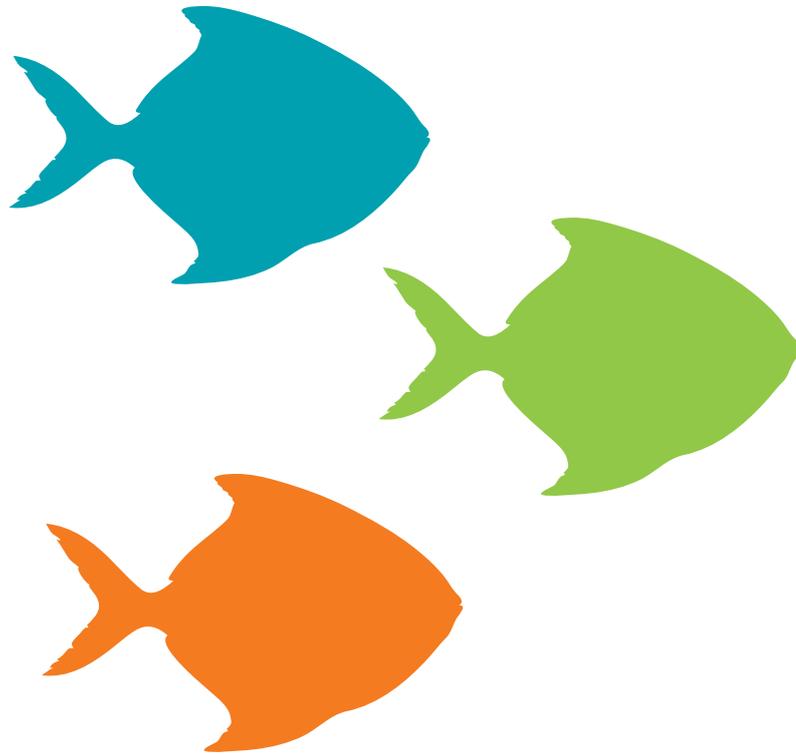
You helped me to get my accordion lessons and accordion
Lewis, supported person

Under the *Mental Health (Care and Treatment) (Scotland) Act 2003* all people with a 'mental disorder'* are entitled to free and independent advocacy. It is equally important that people have access to free and independent information and support about SDS so that they can make informed choices about the support they need.

*mental disorder' is defined as mental illness, learning disability and personality disorder
Nigel Henderson, Chief Executive, Penumbra



Lewis and his broker



Case studies

Inspiring confidence

Direct Inclusive Collaborative Enterprise (DICE) is a small, independent, disabled peoples' organisation whose vision is that everyone who wants to will be able to direct the support they need so they can live the life of their choice with dignity and as equal citizens.

DICE offers mentorship and peer support to explore how needs and outcomes can be met, how to put together a support plan, and how to put it into action using all the resources at the person's disposal. The following story about William (who has Down's Syndrome) illustrates how our outcomes are being achieved.

When William's father was told that to access future support from the local authority William would have to use Self-directed Support, he didn't know where to start:

I knew nothing about this and, when explained, felt that it was set up as another means of scaring everyone off, asking the lay person to complete lots of forms then to produce an action plan to go before the social work department.

William's father

William's father was put in touch with Sue at DICE: "She was extremely approachable and **set me at ease** that their organisation would **take me through the procedures required step by step.**"

DICE helped William do his self-assessment and support plan with input from his mum and dad. William wanted to make several changes to his life. He wanted to increase his independence, make more friends, enjoy time away from his family, join in mainstream activities, feel more confident, look for work, improve his health and the condition of his feet, and be more able to control his frustration when things don't go as planned.



William's father said that Sue: "...was able to **listen closely to our needs**, make suggestions to the way forward, and after the meeting go away and research different avenues to get what we needed, at all times **having William's best interests at heart.**"

William planned to use his budget to pay for support so he could go and watch Celtic and Queens play. He wanted to use the family caravan for respite and money towards the cost of keeping the caravan was included (after grant applications proved unsuccessful). He felt a weekly foot massage would help his feet and employing a Personal Assistant (PA) would enable him to increase his independence and work towards achieving his other outcomes.



The plan (described as “good” by the panel chair) was accepted in March and was meant to start in April. Due to administrative difficulties, however, the budget was not in place until June.

DICE helped the family prepare an advert for William’s Personal Assistant and worked with William to produce a person specification and job description. We spent time thinking about interview questions to ask and how William would be able to tell whether the candidates met his specifications.

Five people applied and DICE arranged a room for William and his mum and dad to use for the interviews. DICE supported William by sitting next to him and prompting and encouraging when necessary. **William felt listened to** and enjoyed interviewing for his personal assistant. He **gained confidence** as the interviews progressed; speaking more clearly, being more decisive about scoring each answer, finding it easier to concentrate and showing more eagerness to take part.

Ultimately, William changed his mind and chose gym membership instead of football; he loves the gym and has a personal trainer. The most important aspect of his life now, however, is his girlfriend who he met at Buddies (a local social enterprise that provides activities, support and opportunities for adults with disabilities).

The following April William and his father initiated a review of William’s plan and asked DICE for help with the Outcomes Focussed Review Form. He feels that **support from DICE was essential to enable William to access SDS:**

I feel that without the help, support and guidance from DICE a lot of needy persons will fall by the wayside and not get the support they need and deserve... **William would have been one of them.**





Providing rural Independent Support

Mary has lived in her home all her life. With family on the farm nearby, the close-knit group communicate regularly and spend a great deal of time with each other. As Mary started getting older and had increased care needs, the family stepped in to help.

It was only when Mary's mobility became impaired and her dementia progressed that her nephew and niece looked to find a solution that would allow her to **get the support she needed and still remain in the home she loves.**

The family weren't sure what the final care plan would look like, but knew they didn't want Mary going into institutionalised care for the rest of her life. They were clear in their knowledge that Mary always wanted to stay at home. **The Local Authority did not have the capacity to provide the level of step-by-step support Mary's family needed to embark on the process of employing Personal Assistants.** The solution they proposed was that she should move into a residential care placement over 30 miles away.

The family therefore approached Tagsa Uibhist for help with recruiting a Personal Assistant to live in full time and home carers who would be able to help with moving and handling at key times. They needed help with choosing appropriate interview questions, seeking references and checking applicants' qualifications.

Two candidates were interviewed by family members together with the Tagsa care manager. One person was employed as the main live-in carer and one to provide relief support.

Tagsa's input was essential to achieve the best possible outcomes for Mary. **Without their Independent Support she would have ended up living a considerable distance from her family and lifelong home.**

This would be stressful for any elderly person, but particularly so for someone with dementia. Mary has been happy and healthy at home, her family and friends can visit daily and everyone has been satisfied with the support she has received since her care package was implemented in March 2013.

The **personalised and flexible solution** found for Mary costs approximately the same as living in a middle of the range local care home and is less expensive than the closest care home. An accountant could have supplied similar payroll services as Tagsa, but at a much higher price.

This was the first SDS care plan Tagsa was involved with and there was a steep learning curve for everyone involved. For example, although Tagsa is only able to provide payroll and administrative support, it emerged that the family were under the impression that Tagsa was acting as the employer and they had not understood the full extent of their responsibilities. Terms of contract and rate of payment had not therefore been settled prior to the person starting work and these issues then had to be addressed. Tagsa is therefore now conscious of the need to **provide greater clarity** regarding the responsibilities people and their families take on when employing Personal Assistants.



Furthering talent

Lewis is a young man of 17 with a keen interest in music. He was part of a Self-directed Support pilot implemented by East Ayrshire Council. It involved a group of people who used services receiving £250 to be used to meet an outcome in their plan of support. Lewis received £250 and he opted to have an Independent Support broker from the Community Brokerage Network to help him work out how to use the money.

The broker helped Lewis (and his mum) think about what he wanted to achieve with the money. Lewis decided he wanted to improve his education and develop his musical interests. He was very keen to begin with accordion lessons and use the £250 towards that. The broker's task was to **help facilitate this**.

While it seemed fairly straightforward there were a range of challenges which quickly emerged. To be able to take accordion lessons you really needed to own an accordion! Lewis then decided to use his Christmas money and the £250 towards buying one. The broker sourced an accordion through a music shop and the owner, after much pleading by the broker, agreed to take the accordion to Lewis' house for him to try before he bought.

Lewis immediately picked up the accordion and could play it. The chap, who was an accomplished accordion player and musician, was gobsmacked at Lewis being able to do this. He explained to Lewis, his mum and the broker that Lewis had a real gift. The broker had also sourced and provisionally set up some accordion lessons for Lewis but the music shop owner suggested a friend of his, who lectured at the Royal Conservatoire. Lewis then began his lessons with this lecturer. His journey had begun and **the broker continued to keep her eye on the vision and outcomes**, which were to improve his education and develop his music. She was very keen to support Lewis in his aspirations, as was his mum.

Lewis was then granted a further £5,000 through an individual budget and he chose to purchase recording equipment. The broker sourced this

equipment and by thorough price checking helped Lewis save enough money from the budget to attend a summer school at the Royal Conservatoire. She helped Lewis and his mum with the application, forwarded video evidence of his ability, organised a reference from colleagues in education and Lewis was given the last available place. **The broker, his social worker and someone from education worked together** to facilitate Lewis attending each day. It was a huge success.

The extent of Lewis' gifts and musical talent has become clearer and clearer. He is a super composer and produced a full musical score, called "Melody on the Railway" that has been played by the Ayrshire Symphony Orchestra in Ayr Town Hall with Lewis conducting, in front of a full audience. He continues to compose music and play his accordion.

Lewis has just been given a conditional offer to do a BA in music at the Royal Conservatoire when he leaves school and, for the first time, his autism and related talent and focus are seen as a gift and not as a problem.

The broker has supported Lewis towards achieving his outcome and he continues to develop his potential.



Finding a better life together

PAMIS is funded by the Scottish Government to ensure that those who support people with profound and multiple learning disabilities (PMLD) have access to information and advice about the introduction of Self-directed Support (SDS).

PAMIS are represented on the planning group for Perth and Kinross Council's learning disability strategy on personalisation¹. This puts the organisation in an ideal position to explain the strategy to families.

PAMIS **worked with the family carers and Perth & Kinross Learning Disability and Transition teams** to help two young people achieve independence, flexibility and choice in their support arrangements. The families had been friends since their children were young and the mothers of both the young people attended PAMIS' workshop to **gain a fuller understanding of SDS**.

One of the young people had been living in her own home since leaving school, but the allocated flat was a long way from her family, making it impossible for her to keep up relationships with them. The other young person was due to leave school and move into his own home. His transition plan was appropriate for him but it was going to be difficult to identify a house, recruit and train appropriate staff in the timescale allowed.

After consultation with both families it was agreed that **PAMIS and the family carers would meet the head of learning disability services to propose that the two young people get flats next door to each other** where they could have access to day services, leisure activities, college, and could also easily maintain their relationship with their families. Their staff team, recruited by their families, would provide **flexible, appropriate and person-centred care** that would enable the young people to **maximise their opportunities for choice and control**.

Working in partnership can achieve positive outcomes for people that need SDS by making it easier to provide **holistic and person-centred solutions** and **respond creatively and flexibly** to people's needs.

Perth and Kinross family carers are actively involved and enabled to influence policy and help ensure that policy is put into practice. The **partnership working** between Perth and Kinross SDS team staff and the parent carers has helped ensure that these two young people with PMLD are successfully living in their own homes. Their present care provision has been successful partly due to both **parent carers remaining heavily involved** in the process. Through relevant feedback and reviewing case studies, including this case study, the Perth and Kinross Learning Disability Strategy will ensure that **active engagement with parents will enable the development of a strategic action plan that adequately reflects the needs of people with PMLD and their families**.

¹Perth & Kinross Council and NHS Tayside. 2012. Perth & Kinross Joint Strategy for Learning Disability Services (2012-2015). Better lives for people with a learning disability and those on the autism spectrum. August 2012 (Strategic Plan).

Over time, a number of challenges have emerged. Here is one example:

Challenge

Under the present Social Care Self-directed Support regulations and guidelines family carers can be employed and paid to provide care for their relative if this is their wish, the wish of the person being cared for and if it is the best option for the person. However, it also clearly states in section 11.23 of the guidelines:

“This is only applicable to family carers who do not also have guardianship excluding such an arrangement.”

The family carer of a person with profound and multiple learning disabilities and complex health care needs may well be the best person to provide care and, in some cases, the only person suitably skilled to provide care. However, because they have guardianship to legally enable them to make decisions for their relative, they are penalised financially by this statement.

In this case, the family carers are excluded from providing paid care for their relative even when they are best placed to provide the care. In addition, both of these family carers are single parents who, because they have welfare and financial guardianship to legally enable them to make decisions for their child, are further penalised financially by this regulation. This has placed them in the position of having to choose between providing care and support for their child (and justifiably being paid to do so), or being their child’s legal guardian.

Solution

PAMIS posed a parliamentary question (S4W-20683) to Jackie Baillie MSP through Ian Hood from Learning Disability Association Scotland. The question asked the Scottish Government what plans it has to amend *The Self-directed Support (Direct Payments) (Scotland) Regulations 2014* to prevent unintended discrimination against the carers, in particular single carers, of people with profound and multiple learning disabilities who cannot be both legal guardians and paid personal assistants.



Michael Matheson MSP, then the Minister for Public Health, responded:

“...the Scottish Government, in partnership with organisations, is carrying out on-going monitoring and evaluation during the first year of implementation of the Self-directed Support legislation. As part of this monitoring I have asked my officials to discuss this particular issue with PAMIS and Alzheimer Scotland.”

The Scottish Government is actively reviewing section 11.23 of the guidelines.

Prioritising health and wellbeing outcomes

Sara has a debilitating illness and is confined to a wheelchair. Trevor, her partner, is her main and only carer. Sara and Trevor had been working with the social work team to set up care for Sara using Self-directed Support. Sara and Trevor had researched SDS and identified outcomes to improve and enhance their lives.

After several meetings with the Social Work team, Sara and Trevor were told that the council's eligibility criteria meant that only critical and substantial needs could be met. Sara was assessed as having a critical need, but her care manager stressed that the only support Sara could hope to have was with personal care. The couple asked if the allocated hours could be used to meet Sara's health and wellbeing outcomes instead but were told this was not possible; a great disappointment.

Sara had become **socially isolated** since being confined to a wheelchair, and hoped to employ a **Personal Assistant (PA) to support her in activities** such as attending the opera, visiting museums and art galleries, and taking painting, genealogy, photography and poetry classes which she felt would **improve her wellbeing 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 a life away from full time caring**.

Sara was not made aware of advocacy by the social work team, however the Princess Royal Carers Centre told Sara and Trevor about Borders Independent Advocacy Service and, with their agreement, made a referral. Harry, the advocacy worker, visited Sara and Trevor to see how he could help.

Sara told Harry that she felt that her care manager had not listened to her. Sara recognised that SDS was about more than personal care and was keen to rebuild her life after being so unwell. Sara felt that when she asked for more than personal care, her care manager made her feel greedy given the limited resources.

Harry asked Sara if she would like him to contact social work to gain clarification of the case so far, and also explain how the couple had hoped SDS could be used.

A few days later Sara contacted Harry to tell him that she had received an indicative budget from social work. She was very angry as, due to a disagreement regarding one of the questions, she had not fully completed the Self Assessment Questionnaire and had refused to sign the paperwork. Sara had also received a copy of a completed Core Adult Assessment document which contained incorrect information. By this stage, the couple felt that they had no trust left in their care manager.

The couple discussed their options with Harry and decided to make a formal complaint. Harry helped them to compose a letter and a month later they received a response confirming that their complaint would be investigated. An investigation officer visited Sara and Trevor and compiled a report to the local authority.

A few days later the couple were contacted to confirm that their complaint had been upheld and that Sara would be allocated a new care manager. **They asked Harry to attend the first meeting as they were somewhat apprehensive.** The new care manager spent time establishing exactly what type of support they would like; Sara and Trevor were delighted that they were **being listened to.**

When Sara's care plan was completed she was allocated support to employ two PAs. Within two weeks, Sara and Trevor were able to interview and employ their staff. The care manager also referred them to Encompass (another organisation which provides Independent Support) to **discuss the administration and legal implications of becoming employers.**

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 PAs, to take photographs and find inspiration for her artwork and poetry, and she has also arranged for her PAs to help in the garden.

Sara is finally beginning to break away from feeling like a second class citizen, closed off from the rest of the world. She had missed having other females around to chat to, and she has thoroughly enjoyed feeling "alive" again.

Sara and Trevor cannot thank Harry enough. Having him in their corner gave them the **confidence to speak up for themselves and challenge the local authority to provide a new care manager.** Without Harry on board the couple may not have been able to get the care package they wanted, which has **totally transformed both their lives.**

Continuing with a chosen care provider



Penumbra is a Scottish voluntary organisation working in the field of mental health. With Scottish Government funding, Penumbra is raising awareness and understanding of SDS for those with mental health issues.

Craig had been receiving support from Penumbra for some time. As part of his SDS assessment the options were explained and he chose Option 3. This meant he could choose his support and have the local authority arrange the payment.

Some weeks later the local authority told Craig that his budget had been reduced and so he should use a different provider with a lower hourly rate than Penumbra. Social work were also worried that Craig was becoming too dependent on one particular support worker.

"I thought; it's not all about the price. For them it is, obviously, but not for me. I had been paying Penumbra myself, and I was happy... I thought I don't want someone new in whose not got a clue, I just wasn't comfortable with that." Craig

Penumbra staff suggested that an independent advocate might be able to help Craig put his case to the local authority. After a successful first meeting with Craig, David, an advocate from Borders Independent Advocacy Service (BIAS), arranged for them both to meet with the local authority.

"We had a meeting with the care manager and... she agreed to take the support plan back to the panel. This included information from Craig which evidenced that he understood the consequences of having less 'time' of support and also that he understood social work concerns about him being over reliant on one person. With support from me, Craig was also able to express more clearly why support from Penumbra was so important for him and how unhappy and concerned he was about the prospect of having a new support provider. The care manager then was able to get the panel approval for Penumbra to provide support." David, independent advocate, BIAS

Although Craig's support plan was approved he was unable to access his budget immediately.

After six weeks, he was becoming very frustrated:

"I really was close to just saying forget it." Craig

Instead, he went back to BIAS and asked David to find out what was causing the delay. David wrote to the local authority, making sure Craig had a copy of the correspondence. Within a week social work rang Craig to confirm that his budget had been approved and would be made available.

"One week later I got the phone call, I was shocked, surprised it had been approved. I think that it's been absolutely fantastic. 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." Craig

Craig has had a very good working relationship with David and is glad he went back to him for support rather than giving up:

To think how much **I would have regretted it** if I had just scrapped it. **My experience has been fantastic**, it has been made so much easier to understand. **It has been great.**

Penumbra recognised the value of Independent Support in this situation. It was important for Craig to be supported at meetings by someone who was, and would be seen to be, independent from Penumbra.

"This case shows how organisations can work together, ensuring the people we support are making truly informed decisions, and that they have the relevant independent support, to enable them to choose what's right for them." Lisa Lee, SDS manager, Penumbra

Supporting employers



Encompass is a user-led organisation offering support services to clients managing their own care. The main services offered are a comprehensive payroll service, safe recruitment and ongoing employment support, and a third party banking facility.

Cori:

"I am a 21 year old woman who has a large team of support workers whom I employ to support me in my own house. **Without the support from Encompass, I wouldn't have known how to start the employment process.**"

With the help of Encompass I have found that it is possible for me to choose which support workers to employ and to be a good employer. **This means that I can live independently**, which was a big goal for me as I became an adult.

"When any staff-related problems arise, I can also call upon my Encompass advisor to come out to visit me at home, as my house is the most suitable venue for my needs. She keeps me aware of my legal obligations."

"Without the support of Encompass, I couldn't manage to be an employer."

Nikki (PA team leader):

"As an employee for Cori (and her team leader) through a Direct Payment, I have found that Encompass **both support my employer and me.**"

"The advisor at Encompass has been there when I have raised queries or concerns and has always gave me **advice and support that enables my employment** as well as the team as a whole to run smoothly."



Responding to identified gaps

Lothian Centre for Inclusive Living (LCiL) is a user-controlled organisation which supports disabled people to live independently, including those who may have less capacity to manage their support package.

LCiL began to realise that a growing number of people, although they enjoy the flexibility and choice offered by receiving a Direct Payment, struggle with the financial management of their support package, with the risk that some people would ultimately be denied this choice altogether.

In response LCiL decided to provide the option for service users (or the local authority) to transfer Direct Payments into individually allocated client accounts. These accounts are operated by LCiL designated staff on behalf of service users, as instructed by them, through a fully transparent process. This ensures that service users have **increased equality of access to SDS and have maximised opportunities for choice and control.**

To achieve this, LCiL had to change banking provider as their existing bank did not accept that people could make decisions about how to spend their money without being able to take physical control of it, and were not willing to open a client account for multiple service users who would be out of work, on benefits and seen as vulnerable:

"Where individuals are deemed to be mentally incapable of managing their own affairs we would be looking for a Deputy Order or Power of Attorney."

However, it was clear from the outset that the Co-operative Bank were keen to work with LCiL. They were willing to start small and review the processes as demand grew and together they set up a suitable system.

LCiL came to us at the same time the Bank was **establishing its Charity and Social Enterprise team in Scotland.** It was a pleasure to work with (them) because although they knew where they wanted to go and what they wanted to do to support their service users, they were open about their understanding about banks' financial services and the **practicalities of managing accounts** on behalf of individuals.

For us no two clients are the same and we learned about their **innovative ways of working with people** too! The few teething problems were resolved easily and we have developed an **excellent relationship that is still strong today.** It seems that the care sector is changing greatly and it is important to us that we can support organisations like LCiL to adapt or even lead in their field.

Mike Grigor, Regional Manager (Charities and Social Enterprise), Co-operative Bank

LCiL is now able to **provide a service tailored to each individual's needs**. Local authorities themselves are beginning to refer existing Direct Payment recipients directly to our service as they not only see a benefit for the individual, but also for themselves with regards to the monitoring of these support packages.

Through our Financial Management Support Service LCiL can:

- enable those with less capacity to benefit from a Direct Payment and **be more in control of their support, their lives and who they want to be**
- help local authorities to allow more individuals to choose Direct Payments
- potentially assist local authorities to manage the impact of Self-directed Support Option 2 (where the local authority implements service users' choices but arranges the support on their behalf, including payments)

By developing this service, and therefore staying true to its inclusive ethos, LCiL (a relatively small organisation with about twenty staff) was forced to:

- take some limited risks as, although there was clear demand from service users, this was not initially recognised by local authorities (it is still unclear whether the need for this service will be recognised within individuals' assessments and therefore included in the calculation of their individual budgets)
- change banking provider, develop new financial procedures and learn more about financial services
- learn how to manage new responsibilities

Without it, I would probably have to fall back on agency staff, with little control over who comes or when they come, or what they are prepared to do when they come.

Supported person

"LCiL's offer of an enhanced payroll service came in the nick of time for me. It takes from me most of the paperwork and the burden of dealing with HMRC, and gives me the confidence that I shall be able to continue to employ direct staff whom I have personally selected, to give me the degree of help I think I need, at times to suit me. It is not an exaggeration to say that the enhanced service has helped to preserve my quality of life!"

Supported person

It is clear that this work has enabled LCiL to provide its service users with:

- an increased equality of access to SDS
- maximised opportunities for choice and control
- improved confidence to demand an increased range of options for services

Developing this service has given LCiL more confidence to:

- follow what service users say they need
- change its own systems in order to implement Self-directed Support fully



Working together



Self Directed Support Scotland (SDSS) is a national membership organisation actively promoting Independent Living by supporting, working with and championing the aims of Self-directed Support disabled people's organisations.

SDSS received Scottish Government funds to help local disabled people's organisations develop support services. One of the organisations that SDSS worked with is Direct Inclusive Collaborative Enterprise (DICE).

DICE is a service-user-led Community Interest Company set up to help people access and make the best use of Direct Payments and Individual Budgets in Dumfries and Galloway.

As a relatively new organisation, we were keen to build our capacity to support what we expect to be growing demand for SDS support services in our area. **We were also keen to work with our local authority to ensure that support is tailored to the needs and wants of people in the local area.**

Sue Thompson, Director, DICE

SDSS worked with DICE to:

- develop a new, accessible promotional leaflet
- develop a 'vision', learn about social media and develop their more general communications skills
- deliver peer support training
- set up a meeting with the local authority to discuss their work

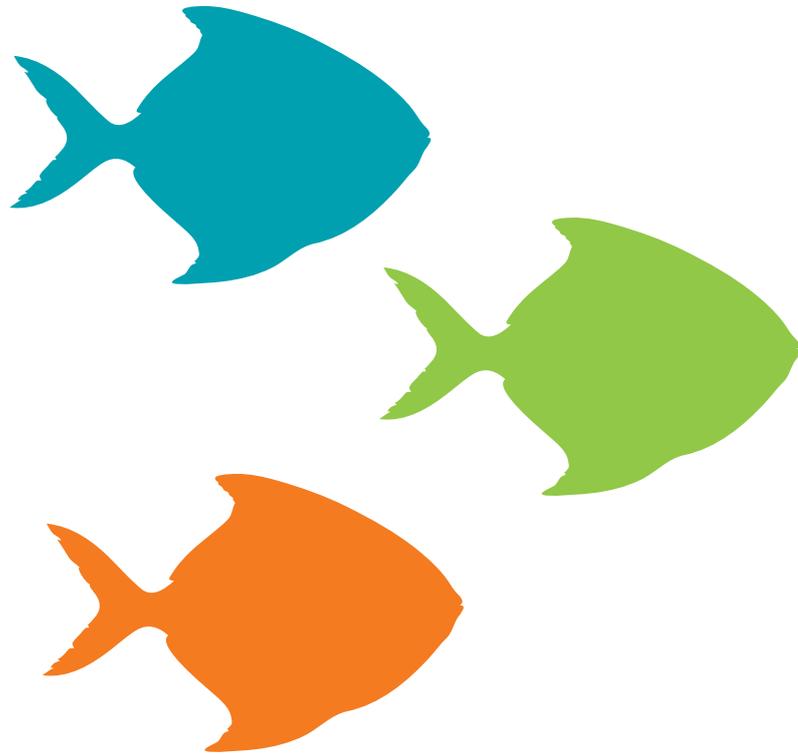
Reflecting on the partnership, Sue says:

SDSS has been helpful mediating with the local authority and getting our concerns across when we had not been able to get a meeting to discuss. DICE feels supported and encouraged by SDSS; the help, support, guidance and being on the same wavelength keeps us motivated and positive when in danger of losing heart. It is good to know you are there to talk things over and that our vision is shared by SDSS.

The partnership formed by DICE and SDSS has allowed both organisations to:

- provide clearer information about SDS
- work effectively together with their local authority
- ensure local and national policy makers know more about the value of both SDS and Independent Support

In addition, this joint work has supported the local authority to access additional information about people's situations in Dumfries and Galloway, and learn about and understand best practice.



Appendices

Appendix 1: Other resources

The Scottish Government's Self-directed Support (SDS) website

www.selfdirectedsupportscotland.org.uk

↑ This is a one-stop-shop for information about Self-directed Support for people who use social care services, and health and social care professionals.

Self Directed Support Scotland (SDSS)

www.sdsscotland.org.uk

↑ Self Directed Support Scotland is a national membership organisation which actively promotes Independent Living by supporting, working with and championing the aims of Self-directed Support disabled people's organisations.

SDSS Information and Support website

www.sdsinfo.org.uk

↑ This website is a new resource to enable anybody in Scotland to search for local Self-directed Support (SDS) Information and Support services. If you want to know more about SDS, how you can access it, and what support you can get along the way, you can search this database to find out which organisations in your area can help.

Providers and Personalisation website

www.ccpscotland.org/pp

↑ Providers and Personalisation is hosted by the Coalition of Care and support Providers in Scotland (CCPS) and funded by the Scottish Government. Our aim is to support voluntary sector support providers to prepare for Self-directed Support and influence the development of local and national policy.

Scottish Independent Advocacy Alliance (SIAA)

www.siaa.org.uk/campaignsprojects/self-directed-support-advocacy

↑ This section of the SIAA website contains information and fact sheets relating to advocacy and SDS.

Self-directed Support in your area

Each local authority is accountable for delivering Self-directed Support in their area and will have a designated officer with responsibility for its implementation. You should be able to find their contact details via the local authority's website.

Appendix 2: Contacts

Contributors

The following organisations were directly involved in developing this document:

- [Alzheimer Scotland](#)
- [Borders Independent Advocacy Service \(BIAS\)](#)
- [Community Brokerage Network \(CBN\)](#)
- [Direct Inclusive Collaborative Enterprise \(DICE\)](#)
- [Encompass](#)
- [Evaluation Support Scotland \(ESS\)](#)
- [Glasgow Simon Community](#)
- [Inclusion](#)
- [Lothian Centre for Inclusive Living \(LCiL\)](#)
- [PAMIS](#)
- [Penumbra](#)
- [Scottish Government](#)
- [Self Directed Support Scotland \(SDSS\)](#)
- [Tagsa Uibhist](#)

Thanks also to everyone who took time to comment on various drafts and versions of the document.

Funded projects

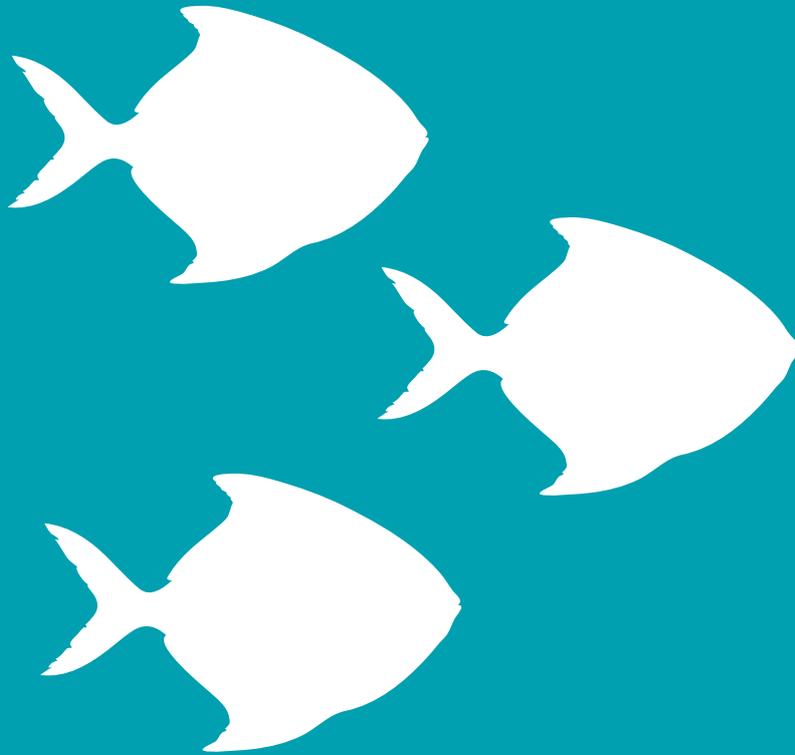
Between 2012 and 2015, the following organisations were funded by the Scottish Government as part of the *National Strategy for Self-directed Support in Scotland: Building the capacity of Support Organisations* funding stream:

- [Advocacy Service Aberdeen](#)
- [Aims Advocacy](#)
- [Alzheimer Scotland](#)
- [Angus Mental Health Association](#)
- [Ayrshire Independent Living Network](#)
- [Borders Independent Advocacy Service](#)
- [Highland SDS Consortium](#)
- [Carers Trust](#)
- [Carr Gomm](#)
- [Ceartas](#)
- [Children in Scotland](#)
- [Circles Network Inverclyde](#)
- [Community Brokerage Network](#)

- [Cornerstone](#)
- [Deaf Action](#)
- [Deafblind Scotland / Scottish Association of Sign Language Interpreters / Deaf Connections](#)
- [Direct Inclusive Collaborative Enterprise](#)
- [Dundee Carers Centre](#)
- [Dunfermline Advocacy](#)
- [East Ayrshire Carers](#)
- [Edinburgh Development Group](#)
- [Encompass](#)
- [ENeRGI](#)
- [Equal Say](#)
- [Evaluation Support Scotland](#)
- [Fife Society for the Blind / Deaf Action](#)
- [Glasgow Centre for Inclusive Living](#)
- [Glasgow Disability Alliance](#)
- [Glasgow Simon Community](#)
- [Grampian Opportunities](#)
- [Inclusion](#)
- [Lothian Centre for Inclusive Living](#)
- [Minority Ethnic Carers of Older People Project](#)
- [Outside The Box](#)
- [PAMIS](#)
- [Penumbra](#)
- [Scottish Consortium for Learning Disability](#)
- [Scottish Independent Advocacy Alliance](#)
- [SDS Forum East Renfrewshire](#)
- [Self Directed Support Scotland](#)
- [Stroke Advocacy](#)
- [Tagsa Uibhist](#)
- [Voluntary Action East Renfrewshire](#)

Download this document and the related publication,
Measuring the difference Independent Support makes, at:

www.sdsscotland.org.uk/guide-self-directed-support/support-right-direction



2015



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