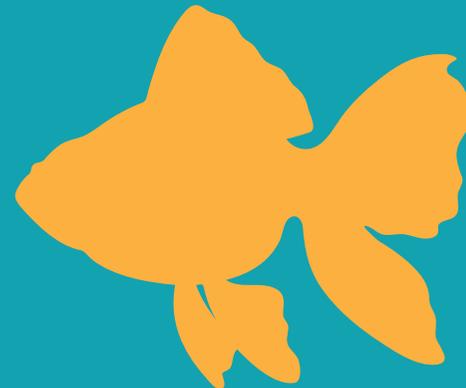
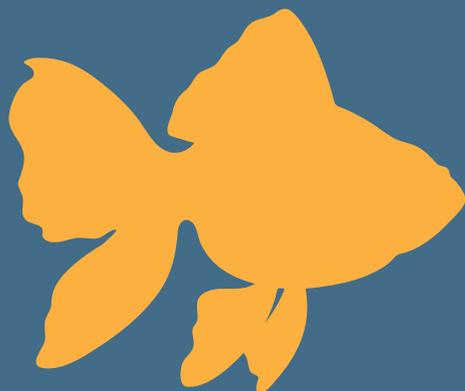


# Support in the Right Direction

Explaining, measuring and  
demonstrating the role of Independent  
Support in Self-Directed Support

**Version 1: June 2013**





More information is available at:

[www.evaluationsupportscotland.org.uk](http://www.evaluationsupportscotland.org.uk).

You can download this document (as well as a summary version):

[www.sdsscotland.org.uk/supportinrightdirection.php](http://www.sdsscotland.org.uk/supportinrightdirection.php)



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# Foreword

**The national Strategy for Self-Directed Support (SDS) aims to give individuals more choice and control over their health and social care support and is based on five key principles: respect, fairness, independence, freedom and safety. Produced in partnership with the Convention of Scottish Local Authorities (CoSLA) and launched on 23 November 2010, it sets out a 10 year vision.**

When the Social Care (Self-Directed Support) (Scotland) Act 2013 comes into force in April 2014, Local Authorities will have a firm duty to give people choice as to how they receive their support. Local Authorities will also be required to provide information and support to ensure that individuals can make informed choices.

The Self-Directed Support Strategy sets out a vision for support organisations to promote Self-Directed Support and independent living and offer high quality, accessible advice and support which enables people to make genuine individual choices. There has been significant investment by Scottish Government in the implementation of Self-Directed Support across Scotland including building the capacity of Independent Support organisations.

As the role of these support organisations continues to grow it is extremely important that we obtain a good understanding of their outcomes. To achieve this, Scottish Government is funding **'Support in the Right Direction'** - a three year programme (2012 - 15) run by Evaluation Support Scotland (ESS). ESS has been working with the funded organisations to build an understanding of the difference that Independent Support makes and to help them demonstrate the inherent value and importance of their work.

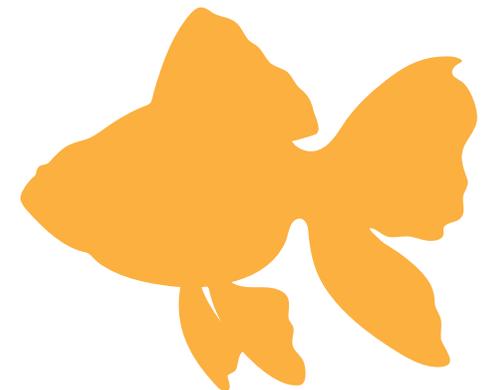
With tailored input from ESS, these organisations have been working together to create a **Framework which will help Independent Support organisations set, measure and report on their outcomes** - putting people who stand to benefit from Self-Directed Support at the heart of the process.

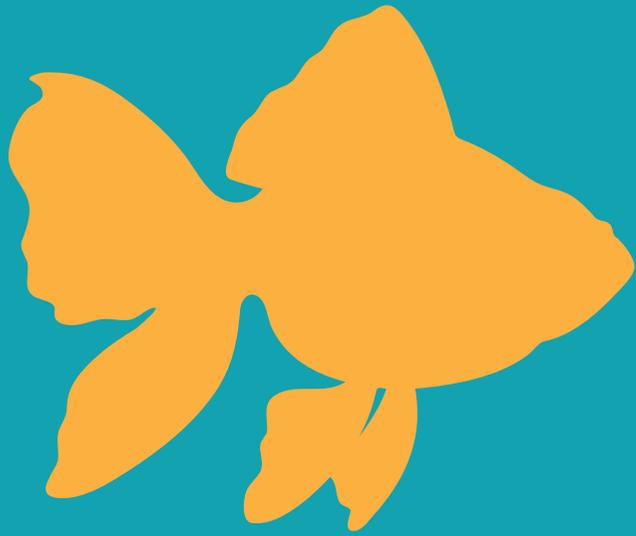
**The Framework is intended to be a living document that will evolve and change as people start to use it and share their feedback and learning with us. The Scottish Government is already using the Framework to support monitoring and evaluation activities by asking funded Independent Support organisations to report against the identified short-term outcomes and would encourage Local Authorities, service providers and funders to do the same.**

We will continue to link this work and the Framework to other strands of the Self-Directed Support Strategy implementation over the next few years. We believe this will be a vital part of improving individuals' experience of health and social care.

## **Jean Maclellan**

Deputy Director  
Adult Care and Support Division, Scottish Government





## **Part One:** Introducing the Framework

# Part One: Introducing the Framework

## About the programme

“**Support in the Right Direction**” is a three year programme (2012-15) funded by Scottish Government and managed by Evaluation Support Scotland (ESS). It is designed to **build understanding of the outcomes of Independent Support and how to evaluate them.**

More information is available at [www.evaluationsupportscotland.org.uk](http://www.evaluationsupportscotland.org.uk). You can download this document (as well as a summary version) from [www.sdsscotland.org.uk/supportinrightdirection.php](http://www.sdsscotland.org.uk/supportinrightdirection.php)

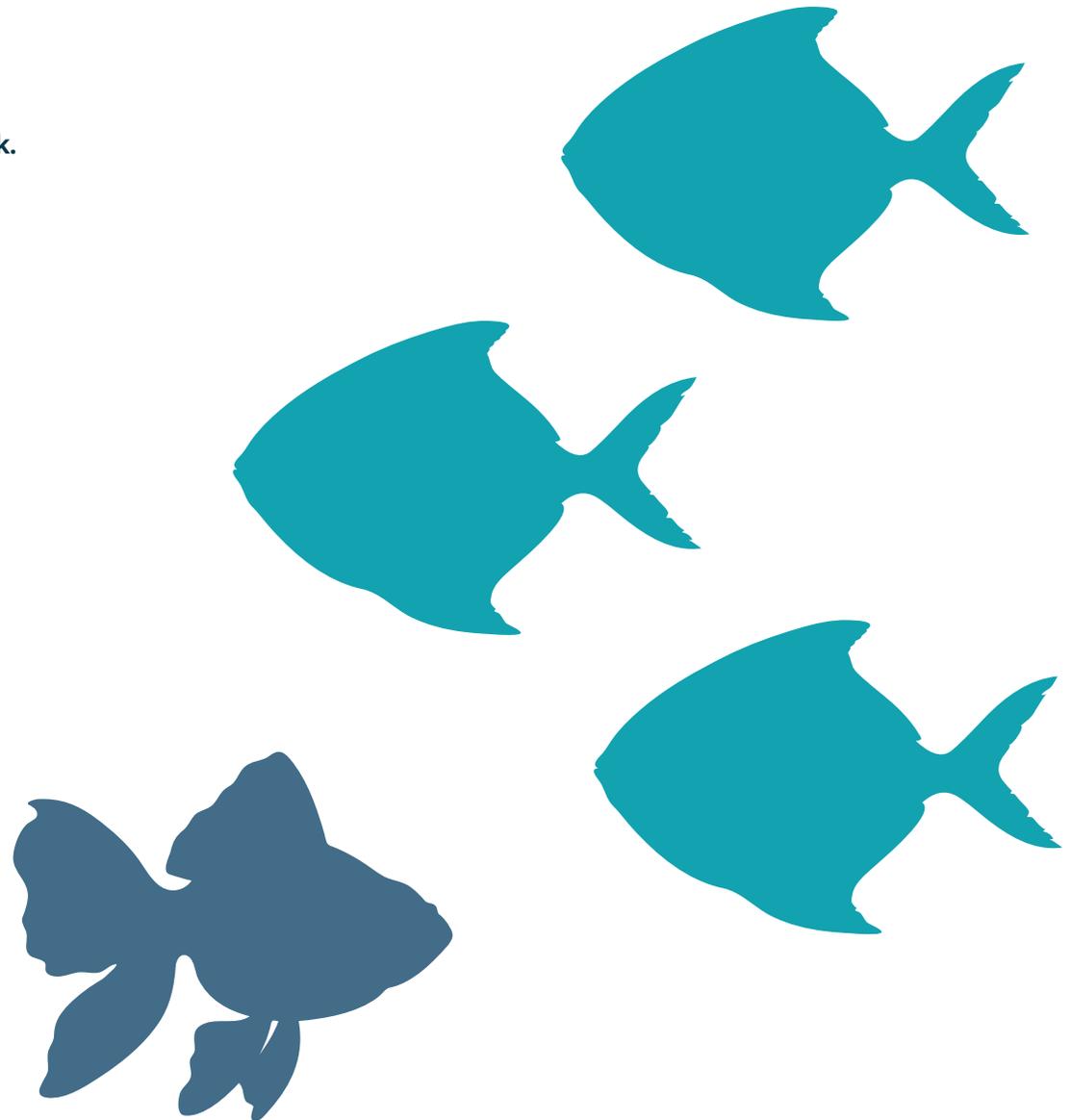
Since August 2012, seven organisations have been working together in a ‘learning set’ facilitated by ESS. The organisations are part of the wider cohort of projects being funded to increase their capacity to support the implementation of Self-Directed Support (SDS).

### The members of the learning set and authors of this pack are:

- Florence Garabedian, Lothian/Glasgow Centre for Inclusive Living
- Patricia Lozano-Casal, Evaluation Support Scotland
- Anne-Marie Monaghan, Community Brokerage Network
- Fiona Munro, Borders Independent Advocacy Service
- Derek Oliver, Alzheimer Scotland
- Maureen Phillip, PAMIS
- Graeme Reekie, Evaluation Support Scotland
- Sue Thompson, Direct Inclusive Collaborative Enterprise
- Jess Wade, Self Directed Support Scotland

### We also thank the members of a wider reference group who contributed to the pack’s development:

- Adele Donald, Dundee Carers Centre
- Niccy Kershaw, Encompass
- Maria Smith, Ayrshire Independent Living Network



## Overview

This Framework has been produced by and for organisations that provide Independent Support to help people make sense of Self-Directed Support (SDS).

### It aims to:

- Explain Independent Support and its importance for helping people gain increased choice and control in the Self-Directed Support process.
- Support evaluation by showing the outcomes that can be expected of Independent Support.

**The Framework can be found in Part Two of this document (page 16)**

### If you are an organisation that provides Independent Support

The Framework should be a good starting point for you to plan and evaluate your outcomes, i.e. the difference you make. You can also use it to explain to other organisations how your work contributes to their outcomes. Start with **Sections One (page 10)** and **Two (page 10)**.

**If you are funded under the Scottish Government's Self-Directed Support capacity building programme, the outcomes in Sections One (page 10) and Two (page 10) are those you will be asked to report against.**

### If you work for a Local Authority or provide care services

The Framework can help you understand the role of Independent Support and organisations that provide it throughout the Self-Directed Support process. **Section Three (page 13)** describes some indirect outcomes of Independent Support that might be relevant for you, and **Section Four (page 15)** shows how these are connected to the wider context.

### If you have a policy or strategy role

You might find it helpful to start with the overview in **Section Four (page 15)** to see how Independent Support contributes to the Self-Directed Support Strategy.

## Explaining 'Independent Support'

**Independent Support is provided by impartial organisations that have no vested interest in promoting any particular options. It enables people to make informed decisions about how they wish to use Self-Directed Support. Examples include independent advocacy, brokerage, mentoring and peer support.**

To help explain what we mean by Independent Support we have included a number of **case studies** in **Part Four (page 22)**. These highlight how the work carried out by Independent Support organisations contributes to achieving the outcomes in this **Framework (page 16)**.

### Please note:

- The Framework is not meant to be exhaustive or prescriptive.
- We don't expect any one organisation to achieve or measure all the outcomes. Use the Framework selectively to find the right outcomes and approaches for your context.
- We intend this to be a living document. It is designed for Independent Support organisations and others to use and test during 2013 - 14.

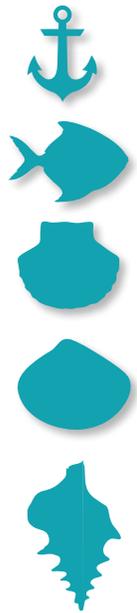
There will be opportunities throughout 2013 -14 for you to give feedback on the Framework and what you are learning about 'what works' when providing Independent Support. In the meantime please share your comments with Patricia Lozano-Casal, Evidence into Policy and Practice Manager at Evaluation Support Scotland, via [patricia@evaluationsupportscotland.org.uk](mailto:patricia@evaluationsupportscotland.org.uk)

## How to use the Framework

This pack is designed to be read in a way that builds up the individual elements of a comprehensive outcomes framework for Independent Support. You can dip into the most relevant sections by using the **contents page**.

### How to read the diagrams

To help you make sense of our diagrams, here are the conventions we have used:



The need / situation to be addressed

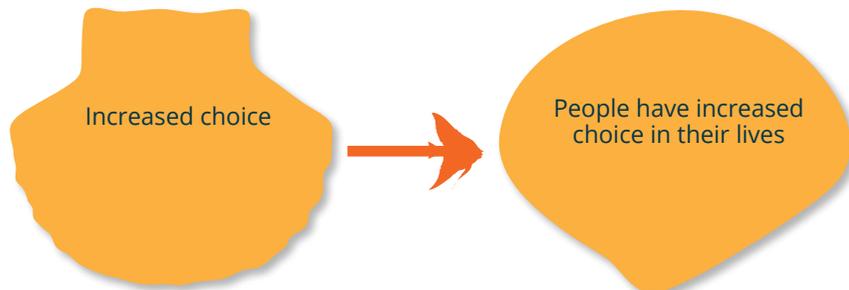
Independent Support activities

Short-term outcomes

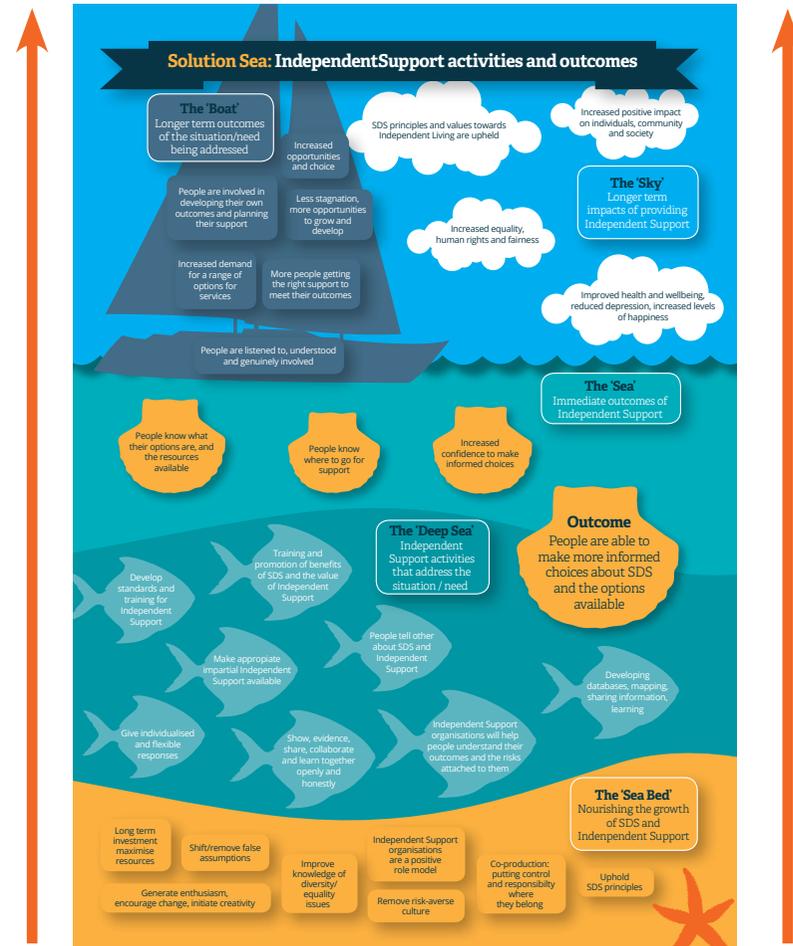
Medium-term outcomes

Longer-term outcomes (3+ years)

- The diagrams are designed to be read from left to right



The exceptions are the **'Problem Sea'** and **'Solution Sea'** in **Appendix 4**, which should be read from the bottom up. (If you think visually, you might find it helpful to start by reading these).



### Note on terminology

Throughout this document we refer to 'People eligible for Self-Directed Support' as this is the easiest way we have found to describe the people who are affected by our work.

## Explaining Independent Support

In the context of Self-Directed Support, Independent Support is provided by impartial organisations that have no vested interest in promoting any particular option. It enables people to make informed decisions about how they wish to use Self-Directed Support.

Independent Information and Independent Support are two different things although often provided by the same organisations. (They are not about providing direct care or related tasks for someone).

Independent Information is information which is provided by an organisation to an individual or group on a particular issue, in an impartial, comprehensive, digestible and accessible way, without that organisation having a vested interest (financial or otherwise) in promoting any particular options.

### Independent Support is support which:

- Enables the person to make an informed decision about how they wish to use Self-Directed Support funding;
- May assist them to manage such funding and how it is used on a day-to-day basis; and
- May provide related support services, such as training or peer support opportunities; but which
- Does not provide 'hands-on' care or related tasks as a 'care provider' and
- Which does **not** have a vested interest (financial or otherwise) in how the person chooses to use their Self-Directed Support budget.

A range of organisations provide Independent Support. We hope this pack contributes to discussions about what Independent Support is, and to the development of standards for services.

Independent Support will take many forms and be provided by a range of different organisations. But we believe that to achieve Self-Directed Support outcomes, Independent Support in any local area should include the following activities:

### Brokerage

#### For example:

- Supporting people to plan, procure and implement their support arrangements making the best use of community resources
- Offering creative, flexible and sustainable solutions to identify and manage care/support

### Communication support

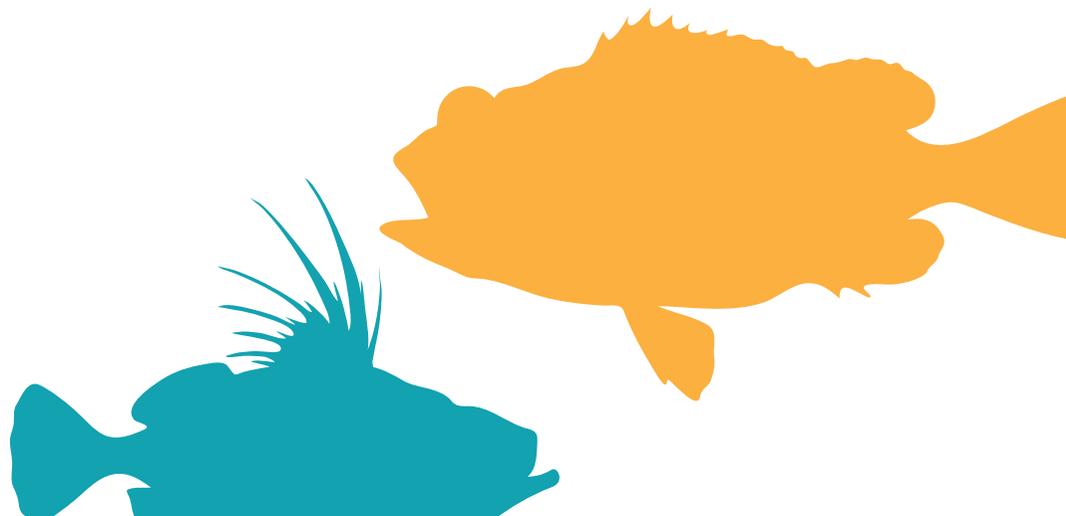
#### For example:

- Providing British Sign Language interpreters
- Advising other organisations on making communication, information and support accessible
- Coordinating production of accessible information

### Engagement and consultation

#### For example:

- Proactively engaging with Local Authorities and other agencies, while involving disabled people, people with Long Term Conditions and their supporters
- Working in co-production with Local Authorities
- Reaching out to different groups including those who have not historically related to Self-Directed Support
- Actively engaging in policy and planning groups



## Evaluating, reporting and sharing learning about what works

### For example:

- Disseminating project learning for use by other organisations
- Providing creative and relevant opportunities to share learning

## Independent advocacy

### For example:

- Providing independent advocacy to make sure people's voices are heard (individually and/or collectively) during all stages of the Self-Directed Support process

## Mentoring

### For example:

- Mentoring for support planning; what local resources can contribute to people's outcomes; managing support, managing Personal Assistants (PAs)
- Building mentoring networks

## Peer support

### For example:

- Employing people with personal experience of Self-Directed Support
- Facilitating peer support groups for those using Self-Directed Support
- Peer support for carers, who can value this as a trusted source of information

## Promotion (raising awareness of Self-Directed Support)

### For example:

- Working with user-led organisations to grow and develop Self-Directed Support work
- Using case studies to show how Self-Directed Support works and what it can be like for people
- Coordinating production of accessible information
- Disseminating information through forums and networks

## Support

### For example, supporting people (including carers) with:

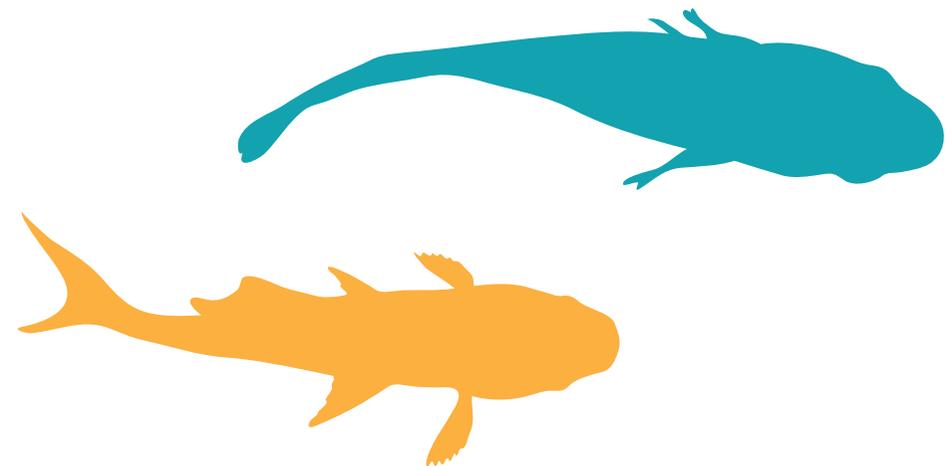
- Understanding and using local processes
- Assessment and review
- Setting up and managing care packages
- Employing and managing PAs, including payroll and related administration
- Person Centred Planning/Person Centred Support Planning
- Financial management

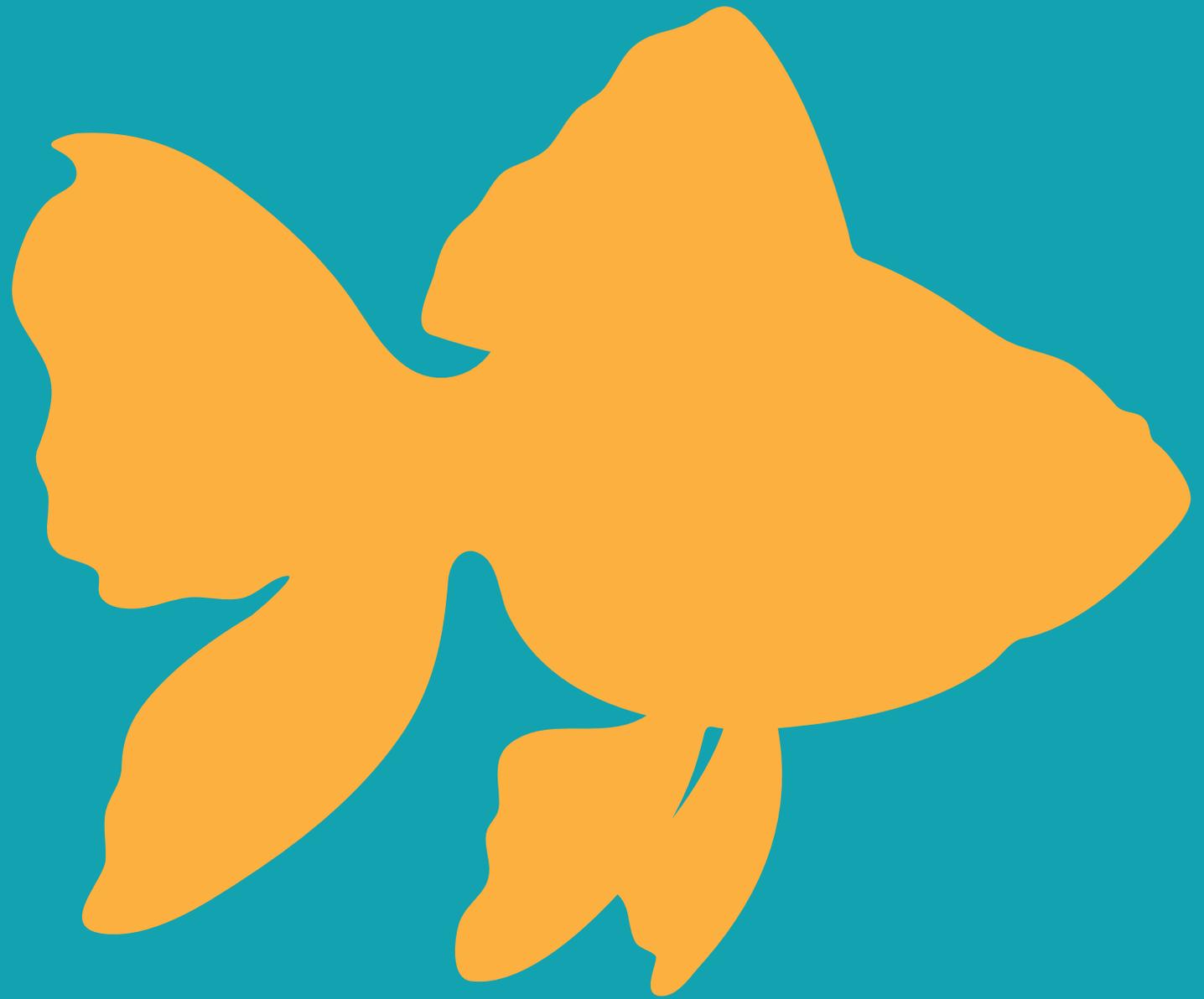
## Training

### For example, training individuals and organisations (voluntary, statutory, independent and others) in:

- Disability/Diversity/Equality
- Employing PAs/becoming a PA employer
- Confidence and assertiveness
- Supporting and caring for individuals choosing Self-Directed Support

At the time of writing, a quality standards framework is being developed for Self-Directed Support activities. Future drafts of this outcome framework will make clear links to these standards.





**Part Two: the Framework**

# Part Two: the Framework

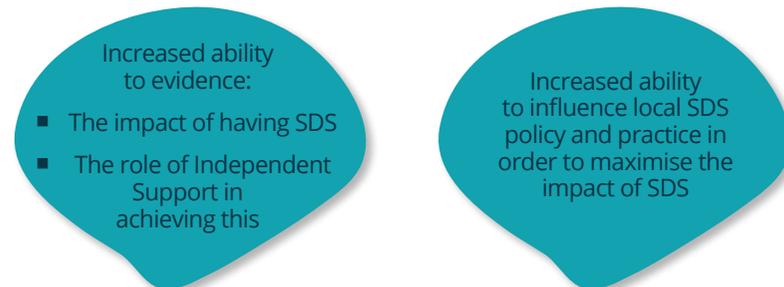
## Section One: Outcomes for Independent Support organisations

The Scottish Government's Self-Directed Support Strategy identified the need for Independent Support organisations to have increased capacity to support Self-Directed Support.

**We therefore developed these short term outcomes for Independent Support organisations:**



**We expect these to lead to medium term outcomes for the organisations (i.e. from years 2 and 3 of the funding cycle):**



Together, these outcomes are about generating learning and insight into the activities for, and impact of, effective Independent Support.

**In terms of the Self-Directed Support Strategy, the measures of this increased capacity will be:**

*'A sustainable network of advocacy and peer support organisations that support individuals to exercise choice and control';*

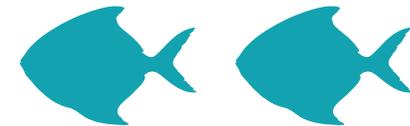
and:

*'A sustainable Self-Directed Support national network of Independent Support organisations, which is recognised as an authoritative source of expertise and proficiency in the training and support of personal assistant employers, by both local and central governments'. (Self-Directed Support, a National Strategy for Scotland, p63)*

## Section Two: Outcomes for people eligible for Self-Directed Support (including carers)

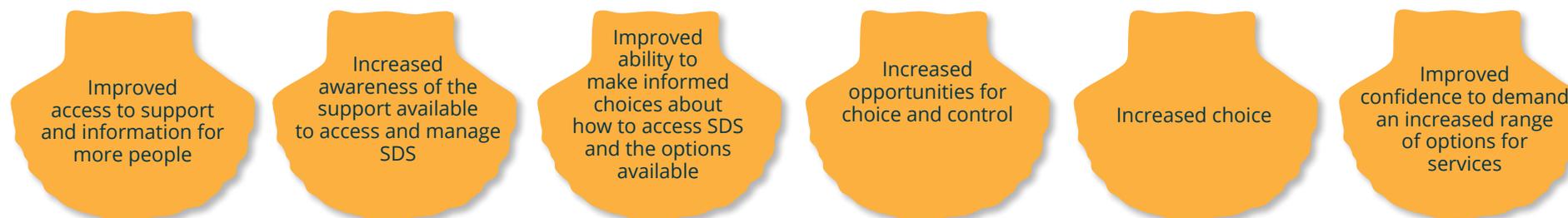
**Independent Support organisations provide a range of activities. These are described more fully on page 16, but include:**

- Raising awareness of Self-Directed Support
- Providing support during and after the assessment process
- Peer support
- Mentoring
- Communication support
- Brokerage
- Advocacy



We expect these activities to lead to some core outcomes for people eligible for Self-Directed Support and their carers.

### In the short term these will include:



These are the outcomes that are within the direct sphere of influence of Independent Support organisations. That is, **they are the ones that can most easily be achieved and therefore measured**. For those who receive funding under the Scottish Government's Independent Support funding stream they are the ones you will **report against**.

**Part Three (page 19)** includes some examples of indicators that could be used to measure these outcomes in practice.

These outcomes will be important links in the chain towards increased control and independence for people eligible for Self-Directed Support and their carers.

### In the medium term these will include:



### Longer term we believe these lead to better health and quality of life:



For people eligible for Self-Directed Support\*, we can now summarise the links between the need for Independent Support, different activities and relevant outcomes as follows:

### Situation/ Need

People are not able to make informed choices about SDS or the options available

Peer support

Engagement and consultation

Evaluation, reporting, sharing and learning

Brokerage

Support

Communication support

Independent advocacy

Mentoring

Promotion (raising awareness of SDS)

Training

## Outcomes for people eligible for Self-Directed Support (including carers)

### Medium Term Outcomes

- Increased equality of access to SDS
- More people getting the right care and support
- People are more likely to achieve their outcomes
- People have increased control in their lives
- Increased opportunities for growth, development and learning
- Greater independence and interdependence
- Improved physical and mental health
- Improved quality of life

### Short Term Outcomes

- Improved access to support and information for more people
- Increased awareness of the support available to access and manage SDS
- Improved ability to make informed choices about how to access SDS and the options available
- Increased opportunities for choice and control
- Improved confidence to demand an increased range of options for services
- Increased choice

\*This is easiest way we have found to describe the people who are affected by our work. We have included carers in this section because many of the outcomes relate to them too. See page 16 to see how this diagram fits into the bigger picture of outcomes for a range of stakeholders.

## Section Three: Contribution to other services' outcomes

The outcomes for people eligible for Self-Directed Support won't come about if there are not changes in other services.

These can be difficult to achieve, but we believe that Independent Support will contribute to this process by contributing to the following **short term outcomes for statutory services and care providers**:



These will lead to longer term outcomes for services and society:



 **Note the emphasis on contribution:** we do not think Independent Support activities will bring about these outcomes on their own. The results will be achieved by statutory services, service providers and Independent Support organisations working together.

# Summary of how we think this fits together

## Situation/ Need

People are not able to make informed choices about SDS or the options available

Peer Support

Engagement and consultation

Evaluation, reporting, sharing and learning

Brokerage

Support

Communication support

Independent advocacy

Mentoring

Promotion (raising awareness of SDS)

Training

## Outcomes for services and society

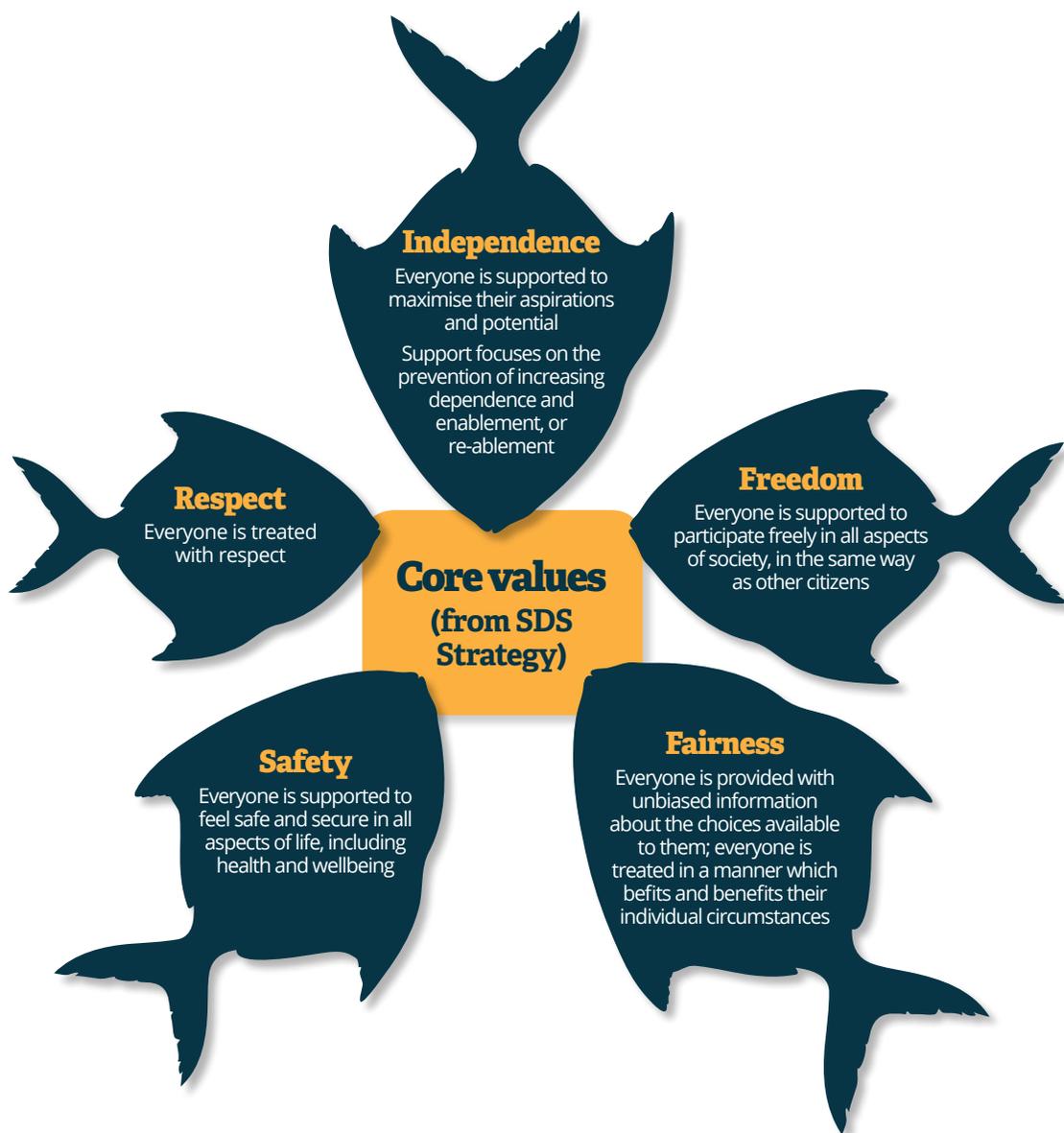
- Service and support models are better adapted to people's needs and aspirations
- Increased community capacity around SDS
- Policy and decision makers have increased knowledge of the sustainability of SDS and Independent Support
- Increased person centred practice with realistic and achievable outcomes
- Increased knowledge of SDS and links with other community resources

## Outcomes for statutory services and care providers

- Increased awareness of people's needs
- Improved understanding of standards for effective SDS and Independent Support
- Increased collaborative transparent working - 'coproduction'
- Improved creative thinking and flexibility
- Increased range of support options

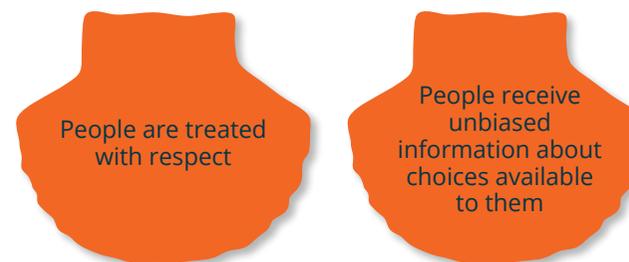
## Section Four: Self-Directed Support Strategy values and outcomes

The final set of outcomes we include are related to the core values in the Self-Directed Support Strategy. Again, they reflect the **long term impact that Independent Support contributes to.**



When we translate these values into outcomes we see a similar logic to the one set out in our Framework.

### Short term outcomes from the Strategy:



### Longer term outcomes from the Strategy:



Nevertheless, this Framework doesn't attempt to describe the outcomes of Self-Directed Support overall. It focuses on Independent Support. **The overview below links together the different levels of outcomes we have looked at, culminating with a contribution to the Self-Directed Support Strategy, and through this, to other relevant strategies.**

# Overview of the activities and outcomes of Independent Support

## Situation/ Need

People are not able to make informed choices about SDS or the options available

## Independent Support Activities

- Engagement
- Evaluation, reporting, sharing and learning
- Peer support
- Promotion
- Training

## Organisational outcomes for organisations

Independent Support organisations have increased capacity to support SDS

An improved support service better suited to the needs of people using SDS

- Brokering
- Communication support
- Engagement and consultation
- Evaluation, reporting, sharing and learning
- Independent advocacy
- Mentoring
- Peer support
- Promotion
- Support
- Training

## Outcomes for people eligible for Self-Directed Support

Improved access to support and information for more people

Increased awareness of the support available to access and manage SDS

Improved ability to make informed choices about how to access SDS and the options available

Increased opportunities for choice and control  
Improved confidence to demand an increased range of options for services

## Outcomes

- Short Term
- Medium Term
- Longer Term

- Promotion
- Training

## Outcomes for statutory services and care providers (page 13)

Increased awareness of people's needs

Improved understanding of standards for effective SDS and Independent Support

Increased collaborative transparent working - 'coproduction'

Improved creative thinking and flexibility

Increased range of support options





## Outcomes providing Independent Support (page 10)

Increased ability to evidence:

- The impact of having SDS
- The role of Independent Support in achieving this

Increased ability to influence local SDS policy and practice in order to maximise the impact of SDS

## Outcomes for Self-Directed Support (including carers) (page 11)

Increased choice

Increased equality of access to SDS

More people getting the right care and support  
People are more likely to achieve their outcomes

People have increased control in their lives

Increased opportunities for growth, development and learning  
Greater independence and interdependence

Improved physical and mental health  
Improved quality of life

## Outcomes for services and society (page 13)

Service and support models are better adapted to people's needs and aspirations  
Increased person centred practice with realistic and achievable outcomes

Increased community capacity around SDS  
Increased knowledge of SDS and links with other community resources

Policy and decision makers have increased knowledge of the sustainability of SDS and Independent Support

## SDS Strategy values and outcomes (page 15):

**Respect**  
**Fairness**  
**Independence**  
**Freedom**  
**Safety**

## Notes

1. Independent Support organisations can directly influence the short term outcomes for people eligible for Self-Directed Support. Evaluation should focus on these **(Part Three, page 19)**

2. It is important to understand how Independent Support relates to other outcomes, so we have shown how these links can be made.

3. We have placed 'Outcomes for people' below 'Outcomes for organisations' solely to make the diagram easier to read.

4. The outcomes in the diagram contain many assumptions and are dependent on a range of external factors, detailed in **Appendix 3**.



Contributions to other strategies



## **Part Three: Evaluating the outcomes of Independent Support**

# Part Three: Evaluating the outcomes of Independent Support

In this section we give some examples of **indicators** that could be used or adapted by local services to **help them evaluate Independent Support outcomes**.



## Read this first!

We want to note three important principles:

- **No organisation can be expected to achieve or evaluate all the outcomes in our Framework!** Rather, the Framework gives local services the chance to select from a range of outcomes, and/or to see where their own outcomes connect to the 'bigger picture'.
- **One size does not fit all:** Local services can select from the outcomes and indicators we have developed, but they will still need to set their own indicators. This is because the outcomes will look different in different settings and need to be evaluated accordingly.
- **We have not tried to identify indicators for every individual.** Again, the outcomes will mean different things to different people. We believe that individuals are the best people to tell us what success would look like for them.

The process that we used to develop indicators is the same process local services can use to help people plan outcomes and review progress, e.g. as part of everyday person-centred planning and review.

**First, we took each outcome and asked: "Imagine the outcome was achieved...What would that look like?"**

In other words, what does it mean, specifically, when we say "Improved access to support' or 'Increased opportunities for choice and control?" What would be happening that isn't happening now? What would have stopped happening? What can people do, or do differently, as a result?

We applied this process to the short term outcomes for people eligible for Self-Directed Support, since these are the outcomes most Independent Support organisations will want to achieve and measure.

### Outcome

**Improved access to support and information for more people**

### Example Indicators

- People tell us they have the information they need to make an informed choice
- People know where to go for help to make sense of Self-Directed Support
- Self-Directed Support materials are available to people in a variety of formats e.g. websites, DVDs, posters, leaflets, languages (including British Sign Language), Easy-read
- Someone is available to help people to make sense of the information if they need it
- People tell us they are happy with the support and information we provide

### Outcome

**People are more aware of the support available to access and manage SDS**

### Example Indicators

- Number of referrals to Independent Support organisations, level of contact throughout the Self-Directed Support process (this could be before or after assessment by a Local Authority)
- Carers understand what Self-Directed Support means for them
- People who have a caring/supportive role feel able to support (or make) decisions
- People understand what's involved in managing the budget and the help available to do it
- People are able to plan their own outcomes and support
- People request Independent Support and a change to their care

**Outcome**

**Improved ability to make informed choices about how to access Self-Directed Support and the options available**

**Example Indicators**

- People can access Self-Directed Support, including the assessment process
- People are confident that the option they choose is the one which is suitable to their circumstances
- People use the options (e.g. Personal Assistants (PA) or Direct Payments) as they become aware of the support available
- People know they can change their support if they choose
- People are actively involved in picking their care provider

**Outcome**

**Improved confidence to demand an increased range of options for services**

**Example Indicators**

- Level of enquiries from other organisations to Independent Support organisations to respond to the increased demand they have from people
- There will be a shift from Local Authority provision and placing, to people doing it themselves
- Some providers will no longer exist (if they are not good enough or won't offer what people want)
- People review their support as and when they want to
- New services are developed to fill gaps identified by people – e.g. micro enterprises and disabled people's organisations

**Outcome**

**Increased opportunities for choice and control**

**Example Indicators**

- People report they have more choice in their care due to help from an Independent Support organisation
- People are able to plan their own outcomes and support
- People use a range of Self-Directed Support options to have the life they want
- People review their support as and when they want to
- Professionals attend reviews when invited

**Outcome**

**Increased choice**

**Example Indicators**

- People use the options (e.g. Personal Assistants or Direct Payments)
- People can spend their money as they see fit – with limited restrictions
- People can get up when they want to, go to bed when they want to and go out to do things when they want to thanks to being able to direct their own support, use a Personal Assistant (PA) etc.
- New services are developed to fill gaps identified by people
- Level of enquiries from other organisations to Independent Support organisations to respond to the increased demand they have from people
- People change their support arrangements as they choose, including changing providers

## Evaluation plan template (with worked example)

We encourage you to make your own plan for evaluating the outcomes that are relevant for you and the people you work with. You might find it helpful to use a template like this, to link the outcomes with the evaluation methods you can use to collect information (remember these are just examples).

Outcome	Example Indicators	Method to collect information
 <p><b>Increased opportunities for choice and control</b></p>	<ul style="list-style-type: none"> <li>■ People are able to plan their own outcomes and support</li> <li>■ People use a range of Self-Directed Support options to have the life they want</li> <li>■ People report they have more choice in their care due to our support</li> </ul>	<ul style="list-style-type: none"> <li>■ Client action plan/support plan</li> <li>■ Collate information from action plans/support plans</li> <li>■ Records of client review meetings</li> <li>■ Questionnaire</li> </ul>

Outcome	Example Indicators	Method to collect information
 <p><b>Your outcome here</b></p>	<ul style="list-style-type: none"> <li>■ <i>Your indicators here</i></li> <li>■</li> <li>■</li> </ul>	<ul style="list-style-type: none"> <li>■ <i>Your information collection methods here</i></li> <li>■</li> <li>■</li> <li>■</li> </ul>

# Part Four: Case Studies

## 01 A Better Life Together

PAMIS is a Scottish charity established in 1992 to provide support for people with profound and multiple learning disabilities (PMLD), their family and carers and interested professionals. PAMIS is funded by the Scottish Government to ensure the families they support have access to information and advice about the introduction of Self-Directed Support (SDS).

To achieve this more effectively, PAMIS works in partnership with others, including the statutory sector, to develop networks to share information and reduce duplication of work.

in the document refers to the “personalisation” of services and the development of Self-Directed Support.”

**This case study highlights how good partnership working can achieve positive outcomes for people that need Self-Directed Support when their views and needs are taken into account.**

When asked about how this partnership works, Maureen happily illustrates by saying, “PAMIS has been working in excellent partnership with the family carers, Perth & Kinross Learning Disability team and the Transition team, to ensure that two young people with profound and multiple learning disabilities living in Perth and Kinross are being enabled to achieve outcomes that will allow them to have independence, flexibility and choice in their support arrangements.”

In 2012 Perth and Kinross Council published their excellent three year strategy “Better lives for people with a learning disability and those on the autism spectrum”<sup>1</sup>, which clearly records how the Council will achieve personalisation of community health and social care through service improvement and development. PAMIS are part of the strategic planning group and, because of this involvement, can inform and advise families of the strategy and what it means for their daughters/sons. Maureen Phillip, Tayside Co-ordinator at PAMIS, explains that “The strategy contains a number of pledges that will enable improvement to happen and pledge number ten

PAMIS has a dedicated staff member to develop, organise and deliver a workshop programme that enables family carers to familiarise themselves with the legislation and what it means for them. These workshops are on-going and are designed and developed according to national and local developments of Self-Directed Support. “The mothers of both the young people attended the PAMIS, Self-Directed Support workshop in Perth. The workshop enabled both families to **gain a**

**fuller understanding of Self-Directed Support**, the process and what it meant for the lives of the individuals they cared for.”, Maureen explains.

Looking back at when PAMIS got involved in this case, Maureen says, “One of the young people mentioned above had been living in her own home since leaving school in the summer of 2012 but unfortunately the allocated flat was in a village a considerable distance from her family home, making it impossible for her to maintain relationships with her family. The other young person is leaving school in summer 2013 and will be moving into his own home. Both families have been friends since their children were young.”

The developed final transition plan for the young man leaving school captured all aspects of the young man’s life but it was clear that for the outcomes recorded to be realistically achieved, it was going to be difficult to identify a house, recruit and train appropriate staff in the timescale allowed. A newly appointed transition team had to undertake the planning.





Following a period of uncertainty and after consideration and consultation with both family carers, it was agreed that PAMIS and the family carers would arrange to meet with the head of learning disability services. Maureen explains, “PAMIS produced a proposal suggesting that both young people get a flat in a nearby village where they could live next door to each other, have access to day service provision, leisure activities, college and they could easily maintain their relationship with their families. The young people would be able to have a staff team recruited by their families and that could offer flexible,

appropriate and person centred care that would **enable the young people to live the life they wanted to live.”**

Once the housing was identified the rest of the planning could take place, including a referral to occupational therapy to enable any assessment for adaptations to be carried out; an outcomes based assessment and a proposal for financing the care package submitted.

Both young people will reside in their own homes supported by their own innovative, flexible and

competent support staff. The houses allocated are within a three mile radius of amenities in Perth and close to the family homes of both young people. This allows **independence** for the young people but also enables contact with their families to be more easily maintained.

Reflecting on what the designed care package will mean for the two young people, Maureen says, **“The opportunity for young people with profound and multiple learning disabilities to have access to this type of independence, flexibility and choice within service provision means they will benefit from a range of available options that are financially sustainable but more importantly; that are personal to the individuals accessing services and amenities in and around Perth and Kinross.”**

In relation to PAMIS’s experience entering this partnership, Maureen says, “The family identified what would be their ideal and by working in partnership through the strategy and following the principles of Self-Directed Support; the , including the Transition Team, PAMIS and the parents achieved **independence, flexibility and choice to enable the two young people to have access to the same opportunities as everyone else.”**

*<sup>1</sup>Perth & 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]*



## 02 Creating Awareness Together

Borders Independent Advocacy Service (BIAS) is an independent advocacy organisation working throughout the Scottish Borders area. It provides a range of advocacy services free of charge for a wide variety of people, including one dedicated to Self-Directed Support.

Fiona Munro, Advocacy Worker at BIAS explains, "With Self-Directed Support being in its infancy much of our work at the current time has been focused on the promotion of Self-Directed Support and increasing knowledge and awareness of Self-Directed Support, rather than supporting clients through the Self-Directed Support process. As such, we have made the most of as many joint working opportunities as possible so we can provide as much accurate information as we can to our clients."

For example, Sylvia Crick, Project Manager for the Self-Directed Support Providers Consortium, explains that "We worked very closely with BIAS to run 4 events aimed at front line staff, to give them some basic information about the national and local contexts for Self-Directed Support. Val and Fiona [two members of BIAS staff] spoke about their project and the support they can offer to individuals and families. This information was very well received with comments from participants such as *'I found out a great deal today, including various organisations we can sign post to and the basic information on Self-Directed Support and how to access more.'*"

When reflecting on the Consortium's partnership with BIAS, Sylvia says, "The Self-Directed Support Providers Consortium has developed a very good working relationship with BIAS, which gives us the opportunity for good collaborative working, sharing information on what we are all doing and ensuring we avoid duplication." She continues to

say that "This has been particularly important in terms of ensuring we are clear who is doing what to support the building of capacity within provider organisations, and I believe BIAS and the Consortium have complemented each other in the work we have done around this aspect."

For Sylvia, evidence indicates that **"The four events increased awareness amongst the 94 participants about the support that is available to people going through the process of getting an individual Budget. They also offered an opportunity to explore people's concerns and challenges, and BIAS staff were very helpful in addressing many of these in their question and answer sessions and as part of the general discussion."**

**BIAS have fed into the Consortium the issues they have been experiencing about:**

- Awareness of Self-Directed Support within provider organisations
- What more might be needed to support provider staff to respond more effectively to people with Individual Budgets looking for support services
- Other aspects of people's needs.

Sylvia says, "We have used the information from BIAS to put together some helpful questions/issues for providers to consider as part of an information pack

we are compiling for them. Round table meetings with the Council offer us all the opportunity to discuss these issues and identify collaborative ways to improve the experiences people have of the overall process. BIAS has fed information to each of these meetings about people's experiences, which has been of enormous benefit as we do not currently have anyone other than BIAS and Encompass [another charity that supports disabled people in the Scottish Borders] representing the voice of people who use services and families within the working group."

Karen, BIAS Manager, says, "This exciting opportunity not just helps our clients have real choice and control over their support needs but also allows BIAS to improve the quality of our service and raise the awareness and importance of independent advocacy generally. In the Borders there have already been a number of joint working opportunities and examples of good collaborative working and, ultimately, all try to develop quality services in response to the challenge Self-Directed Support represents and ensure clients have a positive experience of the Self-Directed Support process."

Overall, the partnership fostered by BIAS and the Consortium has enabled them to meet outcomes for their organisations and clients, including **Independent Support providers have increased capacity to support Self-Directed Support; increased awareness of people's needs during personalisation process; increased collaborative transparent working, and improved understanding of standards for effective Self-Directed Support and Independent Support.**



## 03 Walking the SDS Journey Together

*\*The names of the people involved in this case study have been changed to protect their identity and privacy.*



Kim\* is a young person living at home with her parents. She has a mild learning disability and is now at the stage in her life where she feels she would like to make plans for her future.



Kim's family said this case study **"Is extremely accurate and well written. It highlights in detail the case history behind how Kim has got to where she currently is and her understanding of how the Self-Directed Support works and how it will affect her in the future. It shows the vital role that Advocacy workers play in implementing schemes, such as the Self-Directed Support and highlights your ability to liaise with all parties concerned to ensure the best possible outcome for your client and their family."** In relation to how Kim's story may benefit others, her family said, "Let's hope it is of some use to others in a similar position, who are or will be going through the same anxieties and concerns as we went through to put it all into place, something we could not have done without your tireless assistance and knowledge."

Kim has very supportive parents who understand her wishes and would like to support her to lead as independent life as possible. The family also work closely with Kim's social worker, Lewis\*, who initially referred Kim for advocacy support during the Self-Directed Support process.

On receiving the referral, Sam\*, the advocacy worker, arranged a visit with Kim and her parents, as she wished for them to be present during the meetings. Sam posted information regarding both advocacy and Self-Directed Support to the family to allow them the opportunity to **gain an**

**understanding of Self-Directed Support** prior to the first visit.

During the first visit Sam explained what independent advocacy support could help Kim with. When chatting about what Kim would like to happen in her life in the next few years, Kim identified that she would eventually like a job and to move out of her parents' house and get her own place. This was the first step in assisting the client to identify possible outcomes for Self-Directed Support.

At the next visit Sam brought a self-assessment questionnaire to allow the family the chance to look this over and consider the answers. Kim was unsure where to start as she had never had to think about what type of help she may or may not need in the future. Kim's parents were concerned about filling this in, as they may either over-estimate or under-estimate Kim's abilities, subsequently leading to problems in the future with any service provided.

Sam spent time with Kim to help her to understand what a support worker was and how they could assist Kim reaching her goals and live her life. Kim and her family then spent the next few days thinking about outcomes and how she would like to live her life with support staff.

The next meeting was planned with Lewis\*, the social worker, to complete the self-assessment

questionnaire. As Kim had spent some time considering her future and some possible outcomes Kim and her family felt prepared for this important stage. Kim was able to tell Lewis four outcomes she wanted and two things she did not want for her future, therefore **having genuine choice and control** over her support. This was a successful meeting with the paperwork being completed in full. Kim now had to wait to hear how much budget she would be allocated.

The next big step was the completion of the Care Plan. Once the indicative budget was agreed Kim and her family had to consider how to use the funds to meet Kim's needs. Lewis worked closely with Kim and the family, but as Kim had never experienced any individual support, she found it too difficult to understand and to plan her care plan. Lewis agreed to slow down the process at this stage to allow Kim to gain a better understanding of how her life might look with the help of support staff. Kim and Sam looked at the internet to get information on support workers and their roles in people's lives. Kim also attended a day service activity where she asked some of her friends how they got on with their support staff and the kinds of things they did with them. Kim felt this was helpful and felt more confident that she could contribute to her care plan with the support of her parents and Lewis. Kim was now **better informed and equipped to make the choice to access an individual budget.**



At the next meeting Kim told Lewis that she had decided she would like a young person to provide her support. With the help of Lewis an independent organisation was approached to visit the family to explore what type of help they may be able to provide. Kim visited the project to see Support Staff working with their clients. Kim and her family wanted a flexible support package from the independent organisation. This was agreed and set up, giving Kim **increased choice**.

An Self-Directed Support review was carried out after 12 weeks working with the independent organisation. Sam met with Kim and her family prior to this. Kim was not very happy with the service so far. She felt that her support staff were asking her to do things that did not interest her and in fact were not included in her original outcomes. She also felt that as her travel time to attend her support was included in her service, she was losing out on active support time. Kim also wanted to receive support at the weekends and so far the independent organisation could only provide support at 8am on Sunday mornings. Referring back to the four options available for Self-Directed Support, Sam suggested that Kim and her family may wish to consider employing a Personal Assistant to ensure she was getting the service she wanted and one which would best suit her outcomes.

During the review Lewis listened to the major concerns and suggested that looking into employing a Personal Assistant may be the best option for the future. The family wished to consider this and not rush into it.

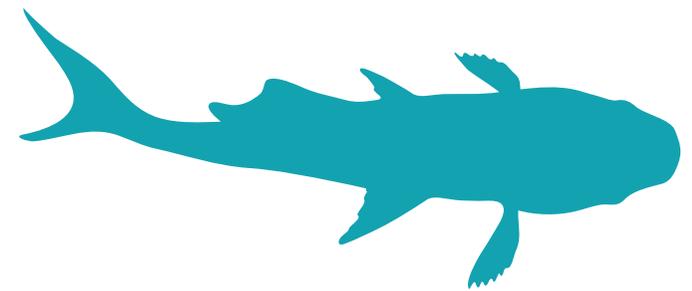
After careful consideration, Kim and her family decided that a personal assistant would be the best option. Kim had obviously **improved her confidence to demand an increased range of support options**. Encompass (a Scottish charity which provides a range of services to help people manage Self-Directed Support including recruitment, becoming an employer and payroll services) were contacted and the adverts placed in the local paper.

On the next visit Kim and her family told Sam that they were concerned as the length of time the employment of a PA was taking. Kim was bored being in the house most of the week. Kim asked if Sam could contact Encompass to see what was causing the delay. Encompass stated that due to the Christmas holiday period there had not been very many applicants for the post. Kim's family were also concerned about the amount of funds building up in her account, since the contract with the independent organisation has been cancelled.

Prior to the next visit Kim's mother contacted Sam to ask for support with the interview process. They had received 3 applications and as they had never interviewed in the past, they were unsure as to how to proceed. Sam accessed information on-line regarding the type of questions people should consider asking potential PA's. She met with Kim and her mother to help them to prepare for the interviews. Together they drew up a list of questions for the interview. Sam stressed to Kim that she was employing someone to help her live her life, so she must be sure she feels comfortable with the person.

A PA was appointed. Her name is Paula\*. At the next visit the family said they were happy with her. They did have a few concerns about how it was going to work. There were issues about where shifts would start, travel costs and additional expenses incurred by Paula. Kim has a relatively modest budget and both she and her family were keen to make sure things were run as effectively as possible. Sam contacted Lewis to ask for guidance for the family regarding these issues. Work is on-going.

When comparing the work undertaken to the Outcomes Framework for Independent Support and self-directed support there is clear evidence in this case study of advocacy assisting Kim and her family to achieve all the identified short term outcomes listed in the Framework, including **improved access to support and information for more people; people (including carers) are more aware of the support available to access and manage Self-Directed Support, and people will be better informed and equipped to make the choice to access a individual budget.**



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 - mostly Direct Payments (DP) at present rather than Individual Budgets.

Over time we've realised that a growing number of people, although they do not regret choosing to receive a DP in order to have maximum flexibility and choice, 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 took the decision in 2010 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 who facilitate the financial management on behalf of service users, as instructed by them, through a fully transparent process.

In the end we had to change banking provider in order to achieve this as our original 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. They said, "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."

From the first meeting it was clear that the Cooperative Bank were keen to engage with us.

They were willing to start small and review the processes as demand grew and together we set up a system that suits our needs and remains fit for purpose. Mike Grigor, Regional Manager (Charities and Social Enterprise) - and our partner - in the Co-operative Bank said:

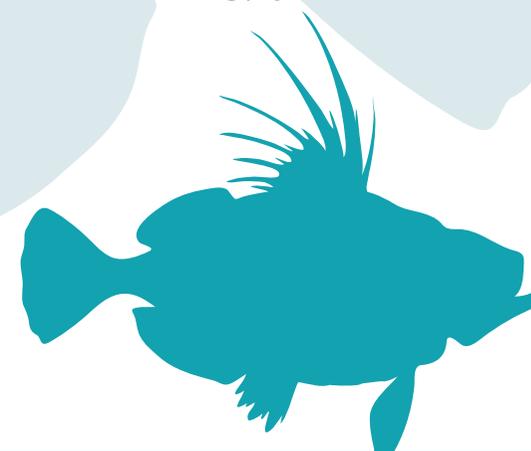
"LCiL came to us at the same time the Bank was establishing its Charity and Social Enterprise team in Scotland. It was a pleasure to work with [them] because although they knew where they wanted to go and what they wanted to do to support their service users, they were open about their understanding 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."

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

Joanne Boyle, Planning & Commissioning Officer for the City of Edinburgh Council says: **"It is very positive to work with organisations such as LCiL which are ready to explore new and creative approaches in response to the changes in health and social care policy. In an ever changing landscape we face many challenges, so being able to work constructively together to ensure that people remain at the centre of what we do, is the way forward. This relationship is essential to achieving this outcome."**

**Through our Financial Management Support Service LCiL can:**

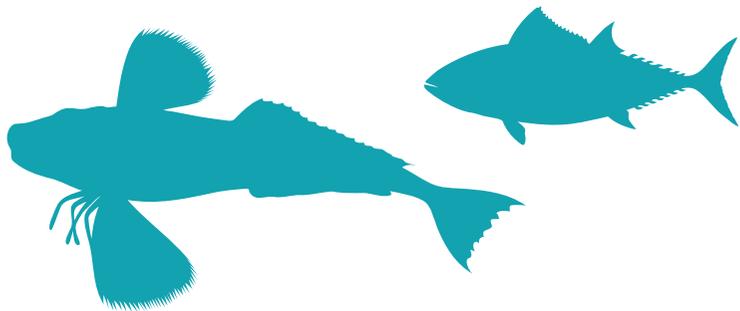
- Enable those with less capacity to benefit from a DP and be more in control of their support, their lives and who they want to be
- Help Local Authorities to allow more individuals to choose DP
- Potentially assist Local Authorities to manage the impact of Self-Directed Support Option 2 (where the Local Authority implements service users' choices but arranges the support on their behalf, including payments)



By developing this service, which has enabled us to stay true to our inclusive ethos, LCiL (a relatively small organisation with ~20 staff) was forced to:

- Take some limited risks as, although there was clear demand from our service users, this was not 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 and develop new financial procedures while increasing our knowledge and understanding of financial services
- Learn how to manage new responsibilities

It is clear that this work has **increased LCiL's capacity to support Self-Directed Support** and has also enabled LCiL to provide **an improved support service which is better suited to the needs of people using Self-Directed Support.**



#### Service users said:

"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."

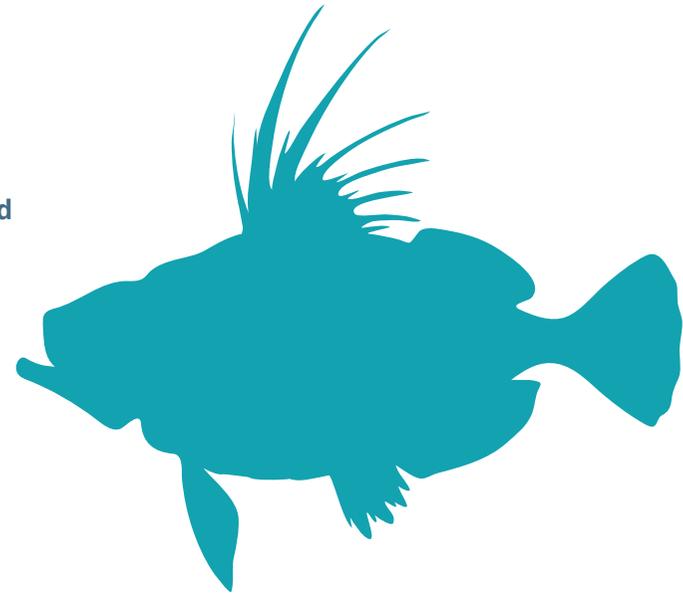
"LCiL's offer of an enhanced payroll service came in the nick of time for me. It takes from me most of the paperwork and the burden of dealing with HM Revenue & Customs, and **gives me the confidence that I shall be able to continue to employ direct staff whom I have personally selected, to give me the 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!"

In terms of the outcomes identified in this Framework, these service users have experienced **increased opportunities for choice and control and have improved confidence to demand an increased range of options for services.** There is also an **increased equality of access to Self-Directed Support.**

#### Developing this service has given LCiL more confidence to:

- follow what service users tell us they need and what we should do
- change our own systems, procedures and even practice for the full implementation of Self-Directed Support

LCiL will be able to meet the medium term outcomes identified for Independent Support organisations by gathering **evidence of the impact of Direct Payments on individuals.** We will also be able to **demonstrate our role in enabling people to manage the Direct Payment option well** and therefore reap the full benefits.



## 05 Making it Work Together

*\*The names of the people involved in this case study have been changed to protect their identity and privacy.*

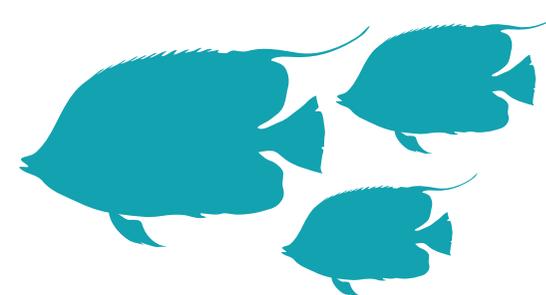


with initial payments and continued to provide on-going support with relevant payroll related queries.

Sylvia continues to receive on-going support from the Independent Living Team with all her PA employment related queries and concerns – including re-recruiting when the original PA left. Sylvia said:

**“I feel very fortunate to receive on-going ILT/ Payroll services for managing care package and it would have been impossible for me to keep up with things without their support. I am especially grateful to LCIIL for understanding my cultural, religious needs and providing me the space and opportunity to grasp things and maintain package depending on my ability.”**

Working with Sylvia taught LCIIL an important lesson; one of the key aspects of our service - advertising for PAs on behalf of the service user - didn't work well in this instance. Enabled to do so, however, Sylvia came up with the solution; to adjust our usual processes by promoting the vacancy in different places where people from BME community would be more likely to see the adverts.



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 - mostly Direct Payments (DP) at present rather than Individual Budgets.

In 2011 a social worker asked LCIIL to provide information to Sylvia\* on Direct Payments (DP) and explain how we could support her in recruiting her own Personal Assistant (PA). Sylvia's full time carer is her daughter, Annette\*, who has a mild form of Autism and other cognitive difficulties as well as her own family and children.

Annette had contacted the Local Authority requesting support for Sylvia who belongs to the Black and Minority Ethnic community, is over 65 and had recently had a stroke. LCIIL's role was to support Sylvia and Annette to find the right support, taking into account their cultural background and capacity in terms of managing the package.

The LCIIL Independent Living Officer (ILO) contacted Sylvia and arranged a joint visit with the social worker. She explained in detail about a Direct Payment and how it could be used. Annette mentioned recruiting a PA for her mother – someone who could also meet her language and cultural needs. The ILO explained in detail about all LCIIL's relevant services - especially the Independent Living Service and the Payroll Support Service. Sylvia was apprehensive about all the paper work involved, taking on employer's responsibilities and doing wage calculations. After the meeting, however, she confirmed to the social

worker that she felt confident to apply for a DP as she was now aware of the services available from LCIIL and the on-going support to manage a care package.

The ILO supported Sylvia and Annette with a care assessment, prepared a list of care requirements and drafted the job description. The DP was approved for 8 hours per week at the low rate and it was agreed that Annette would manage the package with support from LCIIL.

The ILO helped Sylvia and Annette with all the recruitment procedures including drafting the job advert and creating the application form according to Sylvia's wishes. The post was advertised but received few responses and after a month there was still no suitable candidate for interview. They decided to print the job advert in a large font on coloured paper and Sylvia and Annette distributed it in local community centres and shops. This approach generated a better response and the ILO was able to support Sylvia by collating the applications and by assisting with interviews and reference checks. The ILO offered the job to the chosen candidate, supported Sylvia to draft the induction document, draw up daily rotas and write the terms & conditions of employment. The ILO also supported Sylvia to purchase insurance. Payroll staff supported her

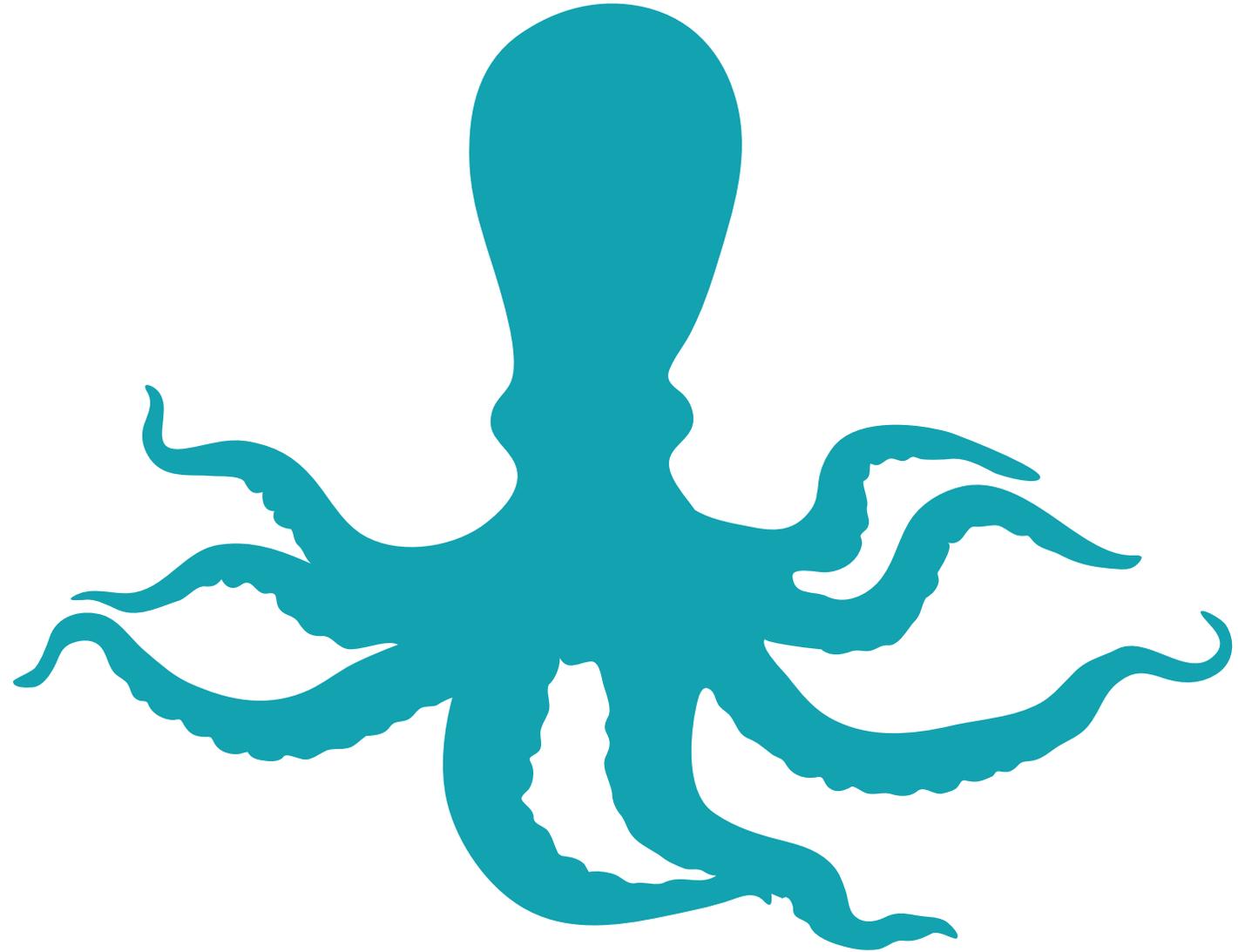
## 05

**The success of the support in this particular case is due to:**

- our standard person-centred approach which focuses on Sylvia and her carer so that our support adapts to their needs
- the full involvement Sylvia and her carer from start to finish
- the organisational commitment to the outcome desired by Sylvia i.e. a suitable PA from a BME background
- our willingness and ability to do things differently and try new ways

**This case study shows how LCiL met many of the short term outcomes for individuals through their support for Sylvia and Annette, including:**

- **Improved access to support and information**
- **Increased awareness of the support available to access and manage Self-Directed Support**
- **Improved ability to make informed choices about how to access Self-Directed Support and the options available**
- **Increased opportunities for choice and control**



## 06 “Bernard’s Story”: Pulling through the challenges together



Bernard is 69 years old and has had several strokes, the first at an early age. He has been married to his wife, Iris, for 22 years. Bernard attends a fortnightly Stroke Group and in 2011 the co-ordinator of the group suggested he got in touch with Direct Inclusive Collaborative Enterprise (DICE) to explore the possibility of accessing some personalised support. 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.

Bernard’s DICE Mentor, Ged, is also in his 60s, had a stroke 8 years ago and has directed his own support for the last 7 years.

When they met, Bernard had no knowledge of Self-Directed Support (SDS), ‘personalisation’, Direct Payments or the opportunities available to him. He had poor mobility and was frustrated at not being able to get about in his home and community. Bernard had ‘no social life’ as his driving licence had been taken away and he could no longer get to sheep-dog trials or the accordion club where he had been Master of Ceremonies (M.C.). His wife’s health was not good either.

Bernard wanted to be active again with a full social life, wanted to be able to walk from home to his local village and back and wanted to contribute to his share of household tasks to take the strain from his wife.

Bernard now employs a personal assistant. He can walk further. He goes to sheep-dog trials. He is back at the accordion club and plans to M.C. again. He has help with household tasks and feels he contributes once more. Bernard is a good employer and he and his wife have a great relationship with his Personal Assistant (PA).

After a year Bernard organised a review of his support and he and Ged gathered evidence to show how things had changed. Evidence was found in documentation such as Bernard’s self-assessment form; his support plan; emails between DICE and professionals involved in Bernard’s care; feedback from his Physiotherapist that Bernard’s ‘gait has improved’; feedback noted in a diary that Bernard has available for that purpose; his review document; photos, including two showing Bernard’s leg before and after his massage; feedback from Iris and Bernard himself; invitations to professionals to attend his review, and the responses to the invitations.

Bernard has joined the DICE Stakeholder Consultation Group and has volunteered to co-ordinate the DICE Self-Directed Support Peer Support Group in Annandale. Bernard says, “I can’t believe how straightforward it has been!”

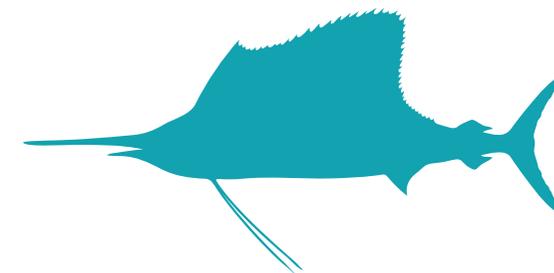
**There were several enabling factors contributing to the positive changes in Bernard’s life, including:**

- **Mentoring:** Ged worked alongside Bernard and helped identify what worked in his life, what he wanted to change and how. Bernard completed his self-assessment and he and Ged

produced the support plan with input from Iris and health professionals. Ged helped communication between Bernard and ‘professionals’ and accompanied Bernard to his ‘Panel’ meeting where Bernard’s plan was approved.

Ged also helped Bernard identify what skills, knowledge and experience he wanted his PA to have and they drew up a person specification and job description and advert with advice from the Scottish Personal Assistant Employers Network (SPAEN). Once the PA was employed, Ged helped Bernard with her supervision and payroll and they devised ways of collecting evidence so Bernard can see his progress. Finally, Ged helped Bernard prepare for and organise his review.

- The **Local Authority** agreed Bernard’s plan with no quibbles. The ‘Panel’ was a comfortable conversation between Bernard, the Lead Personalisation Officer and the Operations Manager, Dumfries and Galloway Council. There was a smooth transfer of money and the financial contribution by Bernard is manageable for him.
- **Iris**, his wife, is very supportive and was involved in all aspects of recruiting the PA, putting her previous management experience to good use.



However, not everything was a 'walk in the park' for Bernard. Making sure that Bernard understood the process and took ownership and control of his support was a challenge at first. To overcome this Ged worked at Bernard's pace and they spent time developing a comprehensive action plan based on Bernard's decisions and wishes. Ged encouraged Bernard to concentrate on himself as it is his story and his life.

The second challenge was ensuring the PA was employed by Bernard, and not self-employed, which was what the PA had assumed herself to be. To overcome this Ged sought advice from SPAEN and the Department for Work and Pensions (DWP), providing documentation to show that the PA did not fit into the self-employed criteria and carefully explained to the PA, who accepted the post under Bernard's terms and conditions.

#### **Some of the 'straightforwardness' of Self-Directed Support for Bernard could possibly be explained by:**

- The position of the Local Authority when Bernard first submitted his plan for Self-Directed Support. Dumfries and Galloway was still part of a Test Site for Personalisation. The Personalisation Team, including the Lead Officer and other professionals, were accessible and enthusiastic. It was an opportunity for the Local Authority to work with Health and show that 'personalisation' can work for people affected by a stroke; there was enough Local Authority money to resource Bernard's plan.
- The rapport built up between Bernard and his mentor and that the Independent Support Ged

provided was not influenced by anything other than Bernard's desired outcomes. Ged was diligent in communicating with all involved and ensured he asked for advice from appropriate people when necessary. Ged was flexible and fitted in with Bernard's needs and always deferred to Bernard when decisions needed to be made.

- Bernard's commitment to making changes in his life and willingness and enthusiasm to engage with the process and make the most of the opportunities available.

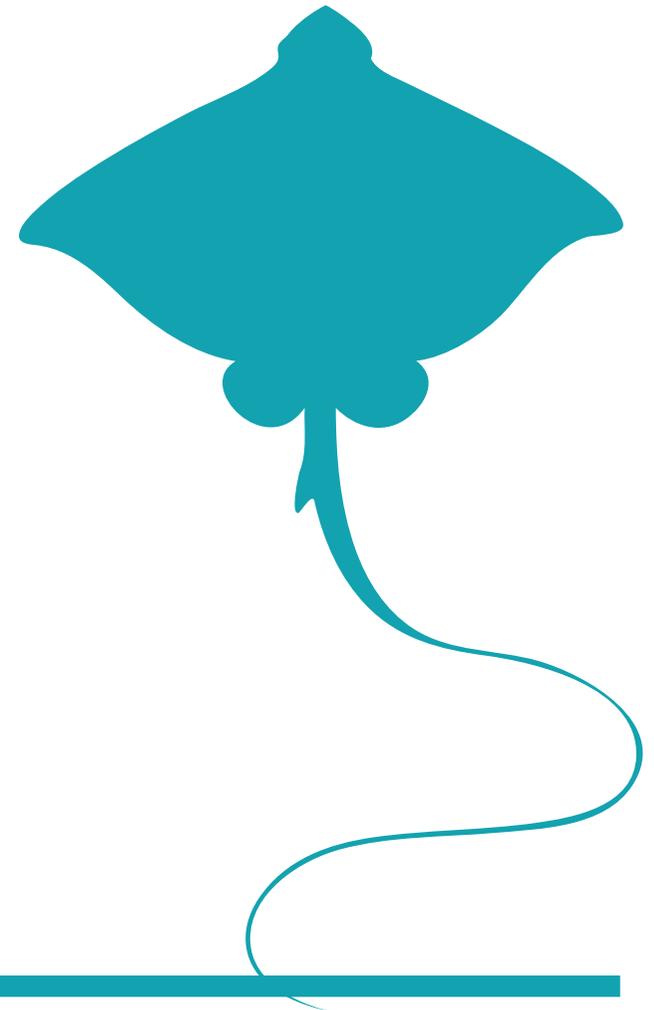
Through being part of Bernard's story DICE have learned the importance of the client understanding the process and options available. DICE have learned that co-production is key; that the individual, DICE, family members and professionals must work together for clients to achieve their outcomes. We have learned that the mentor needs to identify and work at the pace dictated by the client.

#### **This case study shows how DICE's activities, such as mentoring, have allowed the organisation and Bernard achieve the following outcomes, among others:**

- **Increased ability to evidence the impact of having Self-Directed Support and the role of Independent Support in achieving this.**
- **Increased awareness of the support available to access and manage Self-Directed Support.**
- **Improved ability to make informed choices about how to access Self-Directed Support and the options available.**

- **Increased collaborative transparent working, 'coproduction'.**

(The time taken from self-assessment to the 'Panel' accepting the plan for Bernard was 3 months. DICE supported Bernard through this time with 18 hours mentoring and provided a further 39 hours during the first year of implementing the plan, which he could use flexibly over the year).



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.

Jess Wade, Manager at Self Directed Support Scotland, says, "We are currently funded by the Scottish Government's Self-Directed Support Information and Support Capacity Building Fund to work with local Disabled People's Organisations to develop support services."

One of the organisations that SDSS has supported 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.

Jess explains, "SDSS and DICE have worked together in a number of ways in the last year, to build on the work done by DICE in Dumfries and Galloway." Sue Thompson, one of the Directors of DICE, says, "As a relatively new organisation, we are keen to build our capacity to support what we expect to be growing demand for Self-Directed Support support services in our area. **We are 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.**"

#### SDSS worked with DICE:

- To develop a new promotional leaflet, including making it more accessible.
- On communications in general, including supporting them to develop a 'vision' and gave training on social media.
- To deliver Peer Support training - this work is still ongoing.
- To set up a meeting with the Local Authority to discuss their work.

Reflecting on this 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." She highlights that, **"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 meet organisational outcomes, such as:

- Independent Support organisations have increased capacity to support Self Directed Support.
- An improved support service better suited to the needs of people using Self-Directed Support.
- Increased ability to influence local Self-Directed Support policy and practice in order to maximise the impact of Self Directed Support.

And, in addition, support the Local Authority to **improve awareness of people's needs** in Dumfries and Galloway, and **improve their understanding of standards for effective Self-Directed Support and Independent Support.**



Support in the Right Direction is a three year programme funded by the Scottish Government and administered, on behalf of Scottish Ministers, by the Self-Directed Support Branch in the Adult Care and Support Division. Elaine Black, Self-Directed Support policy lead, is responsible for the day-to-day management of the fund. Elaine embarked on the Support in the Right Direction journey together with the 24 funded organisations in April 2012.

This case study highlights the Scottish Government's commitment to making Self-Directed Support the norm and supporting Independent Support organisations to understand, through monitoring and reporting activities, the impact of their work on people's lives. It also demonstrates the funder's commitment to share learning about 'what works' and 'what doesn't' so that policy and practice can be improved.

There is a requirement on the Scottish Government funding for officials to support the capacity of funded organisations to monitor and evaluate the value of the money provided. About her role Elaine says, "I have a unique role in the programme. Working as part of the programme has given me a real insight in to the valuable role of Independent Support organisations. The challenge for me will be gaining an understanding of the outcomes all the organisations on the programme are working to achieve."

Reflecting on the drivers behind Support in the Right Direction Elaine says, "It is about being accountable in a meaningful way and showing value for money. This is only one part of the Self-Directed Support Strategy but it is a very

important part because it feeds into the Self-Directed Support Act and Self-Directed Support Strategy. It's about putting people at the centre. In order to provide flexibility, choice and control for people they need to know what organisations out there can offer and what they can do.

"At the beginning, my role in the Support in the Right Direction programme was to move funded organisations away from reporting on outputs and activities delivered to report on outcomes." For Elaine, "It is more than communicating information [about Independent Support and Self-Directed Support] but about getting a baseline of what support is about."

At a personal level, when reflecting on what drove her to get involved Elaine says, "I got involved in Support in the Right Direction because it was so interesting and inclusive. There was clear collaborative learning on outcomes, not focusing on any particular groups but as a whole."

Elaine started her journey when commissioning Evaluation Support Scotland (ESS) to deliver the Support in the Right Direction programme, "For me it started when I got involved with ESS to shape the learning in the programme. My

learning was, at the beginning, like everyone else's.", Elaine says. As the programme developed Elaine became increasingly interested in self-evaluation and saw it as a personal development opportunity but also as an opportunity to take the learning back to her team: "It is important to learn how to self-evaluate. You have a start, which is what you want to do, and an end, which is what you want to achieve, what Self-Directed Support is about. It is almost justifying what you are doing but in a good way, and helping people understand too."

Elaine attended practical workshops on evaluation and received regular support from ESS tailored to her needs, mostly around monitoring and reporting. "We [Self-Directed Support Branch] started by asking funded organisations to report on outputs and expenditure. However, soon it became clear that funded organisations were keen to share with us more than that so we moved on to reporting on outcomes. So far we had two rounds of reports. The most recent, as well as detailing financial reporting and outputs, focused on short term outcomes, giving organisations a chance to reflect and share what they are achieving."

Thinking of how she managed to make the move from asking funded organisations to report on outputs to reporting on outcomes, Elaine recalls taking into account the Scotland Funders' Forum's report, Harmonising Reporting, which sets out practical tips and templates to help funders make reporting more useful to them and less burdensome to funded organisations:

**“Moving away from the measuring of outputs and expenditure to outcomes and achieving was a very positive thing to do. You need to have a better understanding of what you have done as a whole but you also need to know why you did it and what you achieved by doing it. It is meaningful in terms of achievement.”**

However, for Elaine it goes further than that: “Organisations have to know what they are doing well to continue doing ‘what works’ and be sustainable in the future, given the current economic climate.”

Support in the Right Direction created a Framework of outcomes for Independent Support. As a funder, Elaine wanted to support the subset of organisations which took part in a learning set to produce this work: “When you are constantly questioning what you are doing and see others doing things you realise that you are not alone. It is good to see that you are part of something.” Taking a step further, into Self-Directed Support,

Elaine continues, “In Self-Directed Support you cannot work in isolation. You have to work as a team.

“I did not feel like people did not want me there. I certainly was not at the learning set meeting to make any enforcement but to enable the group and support the demonstration. I want to think that I added value by being there.” For Elaine, taking part in the learning set helped her improve her relationship with the cohort: “It was great to see how well everyone worked together with me rather than funder versus funded organisation. It helped break down the barriers and make sure that people felt they could approach me to discuss issues. It is not difficult, but it changes things.” Elaine continues to say, “People told me that they could not do what they set out to do, or needed more funding to do it. By being flexible we allowed people to understand that they have Scottish Government’s support to achieve their outcomes.”

“Once we have the next round of reports with updates on what the funded organisations have been doing and achieving in terms of outcomes, we will pull the learning together to share with the cohort. I want to give meaningful feedback because it is a way of highlighting the good, the bad and the in-between but does not replace the one-to-one individual feedback. By sharing learning in a communicative way we will give a picture of what everyone is doing. It will show that we are meeting the requirements of the fund in terms of accountability but it will also give us the necessary evidence to change projects, funding arrangements and strategy so that people who need Self-Directed Support in Scotland know about it, access it and makes use of it to live the life they want to live.”



If you would like to share your Independent Support case studies, please e-mail:

**[patricia@evaluationsupportscotland.org.uk](mailto:patricia@evaluationsupportscotland.org.uk)**

# Appendix 1: The background to this document

**In 2010 the Scottish Government published the Self-Directed Support: A National Strategy for Scotland setting out a clear message about individuals and families having real choice and control, and the key challenges that we need to work on over the next ten years to deliver that. The focus is on delivering better outcomes through focused assessment and review, improved information and advice, and a clear and transparent approach to support planning.**

The Strategy is, however, not the only step being taken to ensure that the lives of people who require support are enriched through greater independence, control, and choice that leads to improved or sustained health and wellbeing, and the best outcomes possible.

At a policy level, there is the intention for health and social care services to become more integrated; for older people to be supported to enjoy full and positive lives in their own home or in a homely setting; for improving the lives of people with dementia and their families, and for carers to be supported to manage their caring responsibilities with confidence and in good health, and to have a life of their own outside of caring.

There is therefore a recognition that, at an individual level, people's health care and social care needs are often inseparable. So, this Framework identifies the outcomes that are possible when people are supported towards increased choice and control in their lives.

**Support in the Right Direction** is a three year programme (2012-15) funded by Scottish Government, managed by Evaluation Support Scotland (ESS) and involving 24 funded organisations in 2012-13. It is designed to build understanding of the outcomes of Independent Support and how to evaluate them. By the end of the three year programme we hope this will in turn help identify 'what works' in Independent Support.

**This work came out of a strong and shared will to think strategically and effectively about Independent Support. We hope that having a shared outcome framework will:**

- Enable different Self-Directed Support stakeholders to identify with and understand Independent Support

- Allow effective evaluation of outcomes for individuals, organisations and stakeholders, but also the big picture of Independent Support and Self-Directed Support.

We recognise that the move to Self-Directed Support requires big changes for everyone involved and that this has its challenges. But our Framework represents the ambitions we have for Independent Support. We don't just want it to improve choice and control for people; we believe that better-informed choices will lead to a better life through Self-Directed Support.

**The Framework has been produced by and for organisations that provide Independent Support to help people make sense of Self-Directed Support. It aims to:**

- Explain Independent Support and its importance for helping people gain increased choice and control in the Self-Directed Support process.
- Support evaluation by showing the outcomes that can be expected of Independent Support.

In other words, this pack presents a **Framework of outcomes for Independent Support**.

However, we want this to be a living document. It is designed for Independent Support organisations and others to use and test. There will be opportunities throughout 2013-14 for you to give us your feedback on the Framework and what you are learning about what works in providing Independent Support as part of the Self-Directed Support process. In the meantime please share your comments with Evaluation Support Scotland via [patricia@evaluationsupportscotland.org.uk](mailto:patricia@evaluationsupportscotland.org.uk).

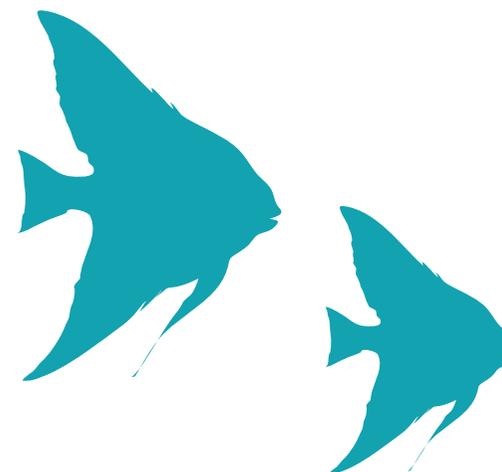
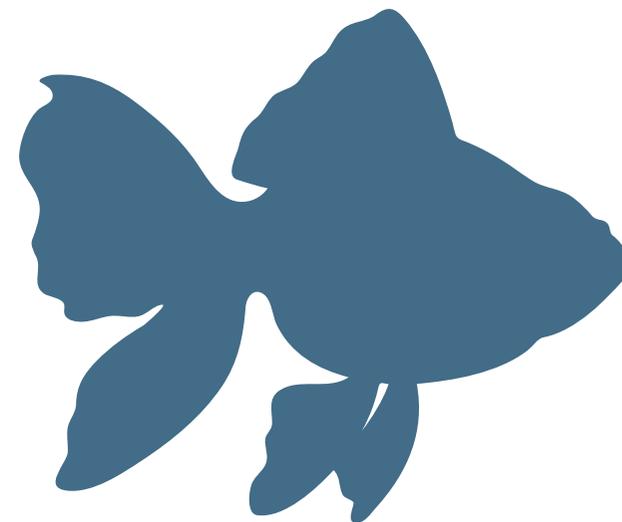
**In summary, we see the journey like this:**

- **Explain** Independent Support (the Framework tries to do this)
- **Measure** it (the Framework should help you start)
- **Demonstrate** what works (the Framework needs to be underpinned by evidence generated by Independent Support organisations and others)

## Appendix 2: Some important principles

### Our work has been informed by several principles:

1. We believe that Independent Support will help uphold and make manifest the principles of Self-Directed Support and the associated Strategy and legislation.
2. No organisation could be expected to achieve all of the outcomes shown in the Framework. Instead, we hope the Framework allows organisations of all sizes, types and locations to see where their unique work contributes to a collective aspiration - that Self-Directed Support will lead to 'individuals and families having real choice and control' (Self-Directed Support, A National Strategy for Scotland).
3. Our model is generic, as we believe the outcomes apply to a range of people. When you see the word 'people' in the pack, we mean people eligible for Self-Directed Support.
4. We have tried to record outcomes for carers as well as for those supporting decision making in Self-Directed Support, as we recognise the two can be the same, but might not be.
5. Our model is not exhaustive – or prescriptive. We recognise that different organisations will have unique outcomes so we have not attempted to list all the possible outcomes of Independent Support. Instead, we have tried to give examples of what these might be so that local outcomes can be linked to a bigger picture.
6. We won't reinvent the wheel and will work towards providing evidence of these outcomes and showing links to other relevant frameworks like Talking Points.
7. One size won't fit all: we know that to be meaningful, evaluation tools and measures must be adapted to local circumstances.
8. We have also tried to embody in our work the Self-Directed Support Strategy's principles of inclusion, dignity, equality, respect, fairness, independence, freedom and safety.



## Appendix 3: Notes on the model - assumptions and external factors

We recognise that the outcomes in our Framework won't just be achieved because we say they will! They depend on a range of other conditions. We have identified some of the assumptions in our thinking and have set them out below. This can be helpful because we don't just want to evaluate whether the outcomes are achieved or not, but to learn about the factors that help and hinder this.

### Our assumptions and other conditions:

- The outcomes apply to individuals who meet their local Self-Directed Support eligibility criteria.
- Our model is generic, but we believe the outcomes apply across different disability and age groups.
- When support is independent, it is fairer and more transparent.
- Having access to a full range of information will lead to people making better informed choices and accessing better support.
- Being included will help people understand how things work in their Local Authority area and how to deal with problems/issues.
- Co-production means ensuring that people and organisation can contribute on an equal basis – and that their contributions are valued.
- Carers trust the information they get from Independent Support organisations – more than they do from service providers.
- Improved understanding of their options will lead to people challenging their assessment/support arrangements – and more creative responses
- People will be able to experiment, make mistakes and be supported to correct them.
- Working with Independent Support organisations increases capacity for people to directly influence policy.
- Commissioners and providers will proceed with Self-Directed Support while awaiting legislation and other guidance.
- The assessment process for Self-Directed Support will not take longer than any other assessment process. The provision of accessing Self-Directed Support shouldn't delay the process of receiving care and support.

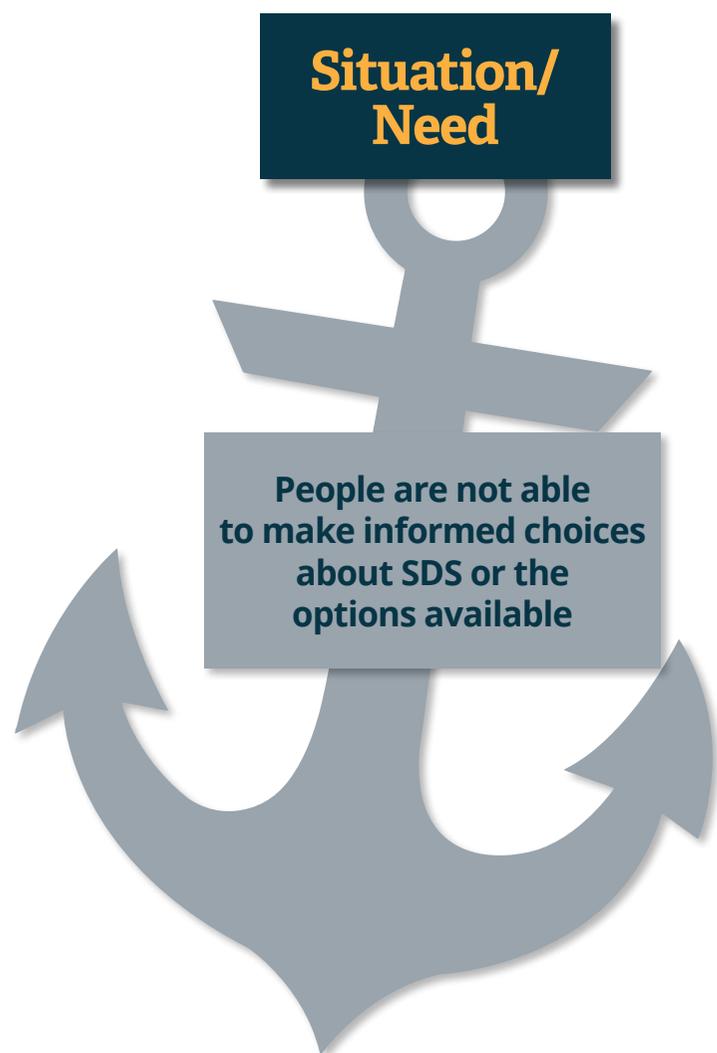
- Organisations will have the time and capacity to deliver Self-Directed Support on time and within budget.
- Commissioners (individuals and Local Authorities) will be able to afford to continue paying for Independent Support after 2015.

### External factors (i.e. not within the control of Independent Support organisations):

- Local Authority strategy/implementation of Self-Directed Support, which may vary across the country.
- Regulators' understanding of Self-Directed Support.
- Capacity of professionals and individuals.
- Legislation and the timeline for this.
- Genuine choice might be limited by Local Authorities, for example if they use an 'approved providers' list or restrict the use of budgets for certain things.
- Agency guidelines e.g. minimum staffing requirements, Health and Safety policies etc. can affect choice but are outwith the control of Independent Support organisations.
- Adequate funding of Self-Directed Support packages.
- Implications of major changes in the environment, e.g. Health and Social Care integration, welfare reform.
- The barriers to Self-Directed Support that individuals face from internal and external factors.
- If healthcare needs have to be met from Self-Directed Support budgets, people may not be able to afford the social care they need.

# Appendix 4: How we arrived at the outcomes in the Framework

When working with outcomes, it is useful to begin by understanding the need or situation that they reflect. In the case of Self-Directed Support, we identified that people eligible for Self-Directed Support were not able to make informed choices about Self-Directed Support or the options available.



In developing the model we focused on this need.

**We began by exploring the need and creating a 'Problem Sea'. This shows the potential causes and consequences of the situation. The model should be read from the bottom up.**

- At the bottom we see the **'Sea Bed', the background and environment in which the problem flourishes.**
- Reading upwards into the **'Deep Sea', we find the broad causes of, and more specific reasons for, limited or unequal access to Independent Support.**
- The situation or need is depicted as an **anchor.**
- Continuing to read upwards, we come to **the 'Sea': the immediate consequences of the situation.**
- Sailing on the 'Sea', we find **the 'Boat': the longer term consequences of the situation / need not being addressed.**
- Above them, **the 'Sky': the larger, longer term consequences of not providing Independent Support.**

We then created a 'Solution Sea', transforming the causes of the situation into appropriate activities that need to take place. The consequences of the situation become the outcomes that should be achieved once the activities are delivered.

This gave us a good place to start identifying and refining the outcomes that would be most relevant for Independent Support, i.e. the ones you can read in this Framework.

# Problem Sea: causes and consequences of a lack of Independent Support

## The 'Boat'

Longer term consequences of the situation / need

Create dependency, reduced independence

Negative mental and physical health consequences

People won't be supported in appropriate ways

It takes a long time to arrange and receive appropriate support

Prevent growth, development and learning

People are stifled and contained, denying their Human Rights

Unfairness, inequality and stigma

## The 'Sky'

Larger, longer term impacts of not providing Independent Support

Negative impact on individuals, community and society

SDS principles and values towards Independent Living are undermined

## Disempowerment

People don't know about SDS or how to plan, arrange and purchase it

People are denied the right to choice and control

People don't know where to go for support

Unequal provision geographically

## Situation/ Need

People are not able to make informed choices about SDS or the options available

Lack of capacity in the workforce to provide information and signpost for SDS

Few services offering Independent Support

Information is not available, individualised or consistent

Rural isolation and lack of resources

Power not shared with people

Communities not being aware of, or having the capacity to assert, their rights to SDS and Independent Support

Lack of clarity about the Independent Support that is necessary or available

Assumption that people don't want SDS or that it is new, expensive or risky

## The 'Sea'

Immediate consequences of the situation / need

People don't know what their options or rights are

## The 'Deep Sea'

Causes of and reasons for the situation/need that exists

## The 'Sea Bed'

Background or environmental factors

Assumption that Independent Support providers are not qualified

Health and Social Care services lacking shared vision and doing things the way they've always done them

Culture - lack of knowledge of diversity/equality issues

Injustice

Lack of imaginative support/provision

Regulation



# Solution Sea: Independent Support activities and outcomes

## The 'Boat'

Longer term outcomes of the situation/need being addressed

Increased opportunities and choice

People are involved in developing their own outcomes and planning their support

Less stagnation, more opportunities to grow and develop

Increased demand for a range of options for services

More people getting the right support to meet their outcomes

People are listened to, understood and genuinely involved

SDS principles and values towards Independent Living are upheld

Increased positive impact on individuals, community and society

## The 'Sky'

Longer term impacts of providing Independent Support

Increased equality, human rights and fairness

Improved health and wellbeing, reduced depression, increased levels of happiness

## The 'Sea'

Immediate outcomes of Independent Support

People know what their options are, and the resources available

People know where to go for support

Increased confidence to make informed choices

Develop standards and training for Independent Support

Training and promotion of benefits of SDS and the value of Independent Support

Make appropriate impartial Independent Support available

People tell other about SDS and Independent Support

Give individualised and flexible responses

Show, evidence, share, collaborate and learn together openly and honestly

Independent Support organisations will help people understand their outcomes and the risks attached to them

Developing databases, mapping, sharing information, learning

## Outcome

People are able to make more informed choices about SDS and the options available

## The 'Deep Sea'

Independent Support activities that address the situation / need

## The 'Sea Bed'

Nourishing the growth of SDS and Independent Support

Long term investment maximise resources

Shift/remove false assumptions

Generate enthusiasm, encourage change, initiate creativity

Improve knowledge of diversity/equality issues

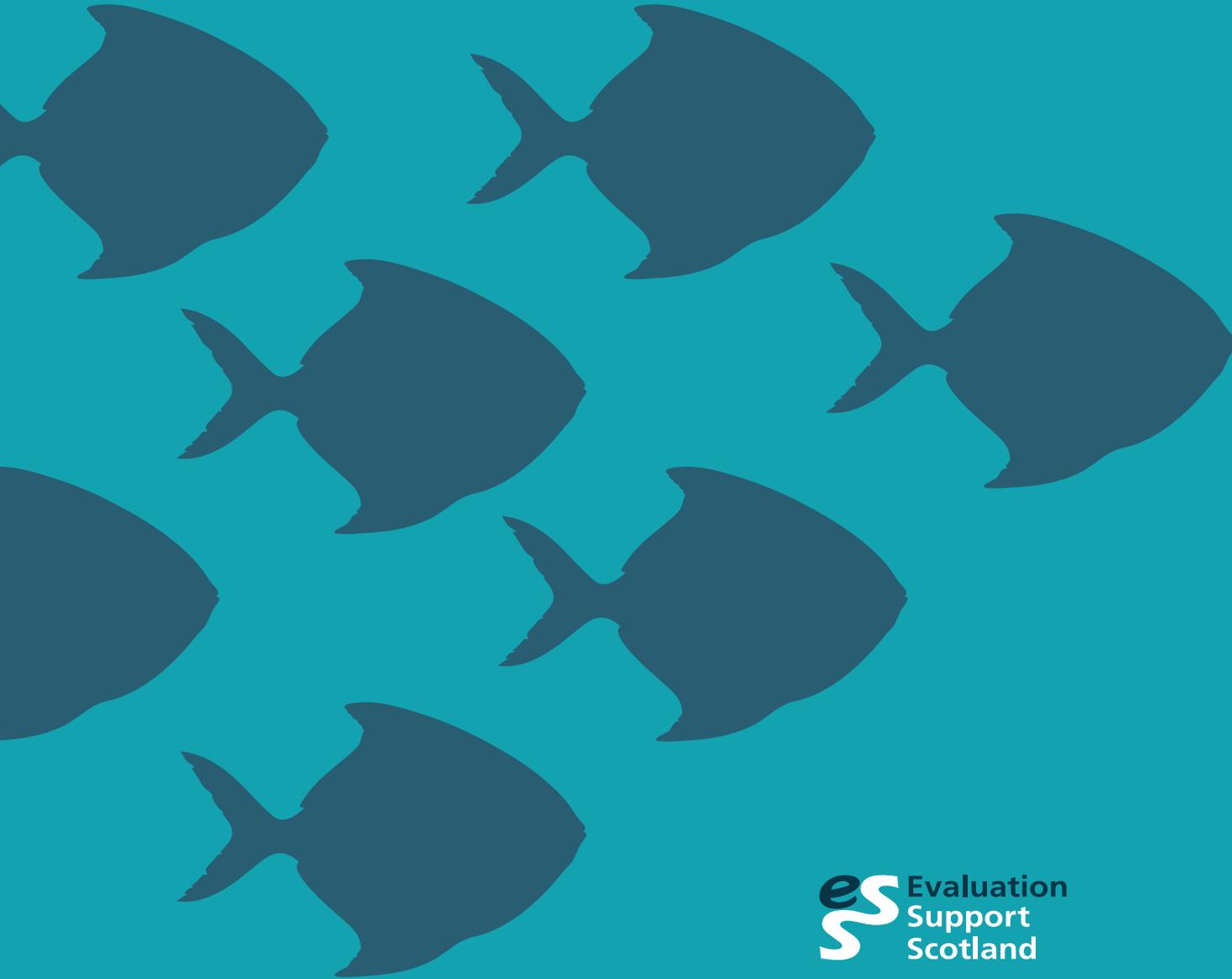
Independent Support organisations are a positive role model

Remove risk-averse culture

Co-production: putting control and responsibility where they belong

Uphold SDS principles





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