# Self-directed Support Practitioner **Toolkit**

Helpful





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## Why do we need a toolkit?

Evidence from a range of sources including the My Support My Choice report 2020, Audit Scotland SDS Progress report 2017, and IRISS Insights: SDS Ten Years On 2021 tells us that Self-directed Support is not being practised in the way that it was intended by policy and legislation.





These reports tell us that supported people, families and carers don't get the information they need about Self-directed Support (SDS) in a way that makes sense or is accessible to them, so they are unable to make choices about how much involvement they will have in decisions about their support.

Social workers tell us that they sometimes lack confidence when discussing a Self-directed Support approach and the four options with adults, children and families and unpaid carers. Social workers also tell us that they do not have dedicated time for learning or time to find relevant practice resources quickly.

Self-directed Support practice can be different in children and families, adult services and for different groups of people. Some people with mental health conditions, sensory loss, Black and Asian Minority Ethnic Communities and unpaid carers (among others) tell us that Self-directed Support is not being offered to them and that workers don't always understand their particular needs.

Keep your eyes on the outcome that you are hoping to achieve. The assessment is time consuming and a bit overwhelming but tell the social worker everything relevant. Check the draft assessment and make sure that it is accurate. For us, Self-directed Support is the perfect solution.

Around a fifth of people surveyed in 'My Support, My Choice' said that none of the SDS options were discussed with them during their assessment (21%), and around a quarter of people had their SDS option chosen for them by a social worker (24%).

We hope this toolkit will help to address some of the challenges identified by supported people, children and families, unpaid carers and practitioners encouraging both creative thinking and co-production in Self-directed Support.

This toolkit has been developed by the Social Work Scotland Self-directed Support project in collaboration with our stakeholders. It will connect you to relevant practice resources located in the Self-directed Support Library and online to support both your relationship-based practice and the implementation of the Self-directed Support Standards.

Gaps have been identified in Self-directed Support practice resources for people with sensory loss, people with mental health conditions, unpaid carers, and Black and Minority Ethnic Communities. We have developed specific resources to fill these gaps and they are contained in this toolkit.

This toolkit should be used alongside your local authority's Self-directed Support policies, processes, practice guidance and resources.

The toolkit should also help your practice when considering your statutory duties and responsibilities contained in the detailed Self-directed Support Statutory Guidance and in the implementation of the Self-directed Support Standards.

The Social Care (Self-directed Support) (Scotland) Act 2013 Statutory Guidance explains what authorities should do to make sure that people are able to get the support that is right for them. It is based on the Social Care (Self-directed Support) (Scotland) Act 2013 ('the 2013 Act'). This is the law that tells local authorities what they must do to give access to SDS in a way that supports people's rights to choice, dignity and being able to take part in the life of their communities.1

All resources listed in this toolkit are available in the SDS library and they will be regularly updated. Please contact us at <a href="mailto:sds.team@socialworkscotland.org">sds.team@socialworkscotland.org</a> if you have resources which should be included in the SDS library.

We know that when people get high quality information from their social worker it has a very positive impact:

Social worker has great understanding...she is very approachable, and I can speak to her about any concerns and suggestions. She is very informative and extremely helpful and reliable too.

<sup>&</sup>lt;sup>1</sup> Self-directed Support statutory guidance - <a href="https://www.gov.scot/publications/statutory-guidance-accompany-social-care-self-directed-support-scotland-act-2013-2/documents/">https://www.gov.scot/publications/statutory-guidance-accompany-social-care-self-directed-support-scotland-act-2013-2/documents/</a>

# The Current Self-directed Support Landscape

This toolkit has been created by people who want Self-directed Support to be the way social care is delivered in Scotland, as the <u>Social Care (Self-directed Support) (Scotland) Act 2013</u> (the Act) intended.

This legislation is supported by the <u>Self-directed Support Statutory Guidance</u>.

- Social Care (Self-directed Support) (Scotland) Act 2013: statutory guidance - summary - gov.scot (www.gov.scot).
- Social Care (Self-directed Support) (Scotland) Act 2013: statutory guidance - easy read - gov.scot (www.gov.scot).
- Statutory Guidance to accompany the Social Care (Self-directed Support) (Scotland) Act 2013 (BSL) -YouTube.

The national strategy for Self-directed Support improvement is detailed in the SDS National Improvement Plan.

The <u>Self-directed Support Standards</u> describe what good Self-directed Support looks like and we hope this toolkit will provide an easy gateway to resources to help you to deliver Self-directed Support in practice and meet the standards. Please note that at the time of publication of the toolkit, the SDS Standards are under review to make sure that they are relevant and inclusive for all.

SDS legislation is grounded in human

rights and covers all age populations, and it can be widely applied across early intervention and prevention measures through to critical support and care.

You will see reference to the Selfdirected Support Standards throughout the toolkit, where you see this logo.



# Independent Review of Adult Social Care

This review recommended improvements to adult social care support in Scotland, primarily in terms of the outcomes achieved by and with people who use services. There are three things we must change in order to secure better outcomes. These can be summarised as follows:

- 1. Shift the paradigm
- 2. Strengthen the foundations
- 3. Redesign the system

There is much about adult social care support in Scotland that is ground-breaking and worthy of celebration. The introduction of self-directed support, the integration of health and social care, and the promise of the Carers Act form the scaffolding upon which to build.

#### Getting it Right for Everyone (GIRFE)

The Scottish Government is currently codesigning Getting it Right for Everyone (GIRFE) with people with lived experience across Scotland. GIRFE is about ensuring a multi-agency approach of support and services that will support people from young adulthood to end of life care.

GIRFE will be tested and developed in local areas, with practitioners and with the people the initiative is designed to benefit, to understand how it will be interpreted and implemented in different contexts. Pathfinder teams are currently in the ideation stage of the co-design process, with prototypes expected to be developed for testing in Spring 2024.

Further information will continue to be available from <a href="mailto:gov.scot/GIRFE">gov.scot/GIRFE</a>. Self-directed Support will align with GIRFE at the heart of the new national arrangements.

GIRFE is about ensuring a person is placed at the centre of all decision making that affects them to achieve the best outcomes, with a joined-up, coherent and consistent multi-agency approach regardless of the support needed at any stage of life.



### GIRFE is being designed with the following principles at its core:

- I have the information that I need to make decisions about my own health and social care, and I am trusted to know what is right for me.
- The people who support me take the time to listen and understand me as a person and we consider my whole life when making decisions about my health and social care.
- I know that I can be clear about what matters to me, and I trust that my choices will be respected and understood by the people who support me.
- Treating everyone with kindness, dignity and respect is the foundation of my health and social care support.
- The people involved in the conversations around my health and social care support work together with me to share information and develop a clear understanding of how to support my wellbeing.

The ALLIANCE spoke to the Minister for Social Care and the four GIRFE professional leads within Scottish Government to ask them what GIRFE is all about. Watch their introductory video here.

#### **Getting it Right for Every** Child (GIRFEC)

In Children and Families social work, Selfdirected Support sits alongside current legislation and policy frameworks for Children and Families practitioners.

- The Children (Scotland) Act 1995
- The Children's Hearings (Scotland) Act 2011
- The Children and Young People (Scotland) Act (2014)
- The Education (Additional Support for Learning) Act (Scotland) 2004 (as amended 2009)
- The Promise
- UNCRC article 19: protection from all forms of abuse, neglect, exploitation, violence
- Getting It Right For Every Child (GIRFEC)
- National Guidance to Child Protection in Scotland 2021

#### **Independent Living Fund**

The Scottish Government's 2024/25 Programme for Government makes the following commitment:

Reopen the Independent Living Fund on a phased basis, with an initial £9 million in 2024-25 to enable up to 1,000 additional disabled people with the most complex needs to access the support they need and deserve to live independent lives.

The fund will open in April 2024. ILF Funding is additional to SDS funding. ILF funding is very similar in use to SDS Option 1 but has key differences outlined here.



# Key Self-directed Support Messages for Practitioners

Here are the important messages about Self-directed Support that you should keep in mind, and share with others.

- Self-directed Support is the way that Scotland delivers social care and support.
- Self-directed Support is for everyone who is eligible for social care in Scotland. It is designed to enable people<sup>2</sup> with support needs of all ages to live an independent life, and for unpaid carers to have a life outside of caring.
- Self-directed Support is a legal right under the <u>Social Care (Self-directed Support) (Scotland) Act 2013</u>. It is also a right for unpaid carers under the <u>Carers (Scotland) Act 2016</u>.
- People themselves are likely to be the most informed expert in their own life.
- Support is anything that will help people to achieve personal outcomes and have a good life.
   Relevant support should be based on what is important to people.
- Self-directed Support needs good relationship-based and rightsbased social work practice to work well.
- People should be involved at every step of the process including assessment, support planning, use of budget and reviews.
- The <u>SDS Standards</u> describe what good SDS looks like.

- People need to know what their options for support are, including what their budget is, in order to make informed decisions.
- People can take as much or as little control as they want over how their support is organised and delivered.
- People must be offered support to make decisions, ask questions and to challenge decisions.
- Social workers must make people aware of organisations that can help people to make decisions about their support (for example <u>Support in the Right Direction</u> <u>providers</u>, or <u>Community Brokerage</u> <u>Network</u> and <u>independent</u> <u>advocacy</u>).
- Practitioners must offer the four SDS options and explain what each of them mean in a balanced and impartial way, and how they would work for the supported adult or child's unique circumstances.
- Evidence suggests that there are groups of people who do not get equal access to SDS, or who have not received sufficient information, choice or support. It is important that social workers and duty bearers consider the impact of decisions on people across all protected characteristics.3

<sup>&</sup>lt;sup>2</sup> When we say 'people', we mean adults, children, young people and unpaid carers.

<sup>&</sup>lt;sup>3</sup> Self-directed Support statutory guidance Section 5 - <a href="https://www.gov.scot/publications/statutory-guidance-accompany-social-care-self-directed-support-scotland-act-2013-2/pages/7/">https://www.gov.scot/publications/statutory-guidance-accompany-social-care-self-directed-support-scotland-act-2013-2/pages/7/</a>

There are no obvious limits to the groups that benefit from Self-Directed Support, although often different groups may need some differences in approach. Groups that use some form of Self-directed Support include:

- Children with disabilities or complex health conditions
- Children in care or families in crisis
- People with physical disabilities
- People with sensory disabilities
- People with substance abuse problems
- People who are homeless

- People with dementia
- People with complex health needs
- People with mental health needs
- People with intellectual disabilities (learning disabilities)
- People with mental health problems
- People who are elderly or frail
- People at the end of life<sup>4</sup>

#### **Self-directed Support Principles and Values**

Self-directed Support is practiced according to the Self-directed Support statutory principles, practice principles and values contained in the Social Care (Self-directed Support) (Scotland) Act 2013.

#### Collaboration

The assessment and support planning must be done collaboratively with the person and relevant others.

#### **Informed Choice**

People must be provided with information and any reasonable assistance which helps them express a view and make choices on how their support is to be delivered.

### Statutory Principles

#### Participation & Dignity

People should be provided with the help they need to participate in the life of the community and practitioners should facilitate their right to dignity.

#### **Involvement**

People are encouraged to have as much involvement as they wish - in both their assessment and in the provision of any support.

<sup>&</sup>lt;sup>4</sup> Self-Directed Support – If It's So Good Then Why Is It So Hard? By Simon Duffy – <a href="https://citizen-network.org/library/selfdirected-support2.html">https://citizen-network.org/library/selfdirected-support2.html</a>

#### **Practice** Risk Enablement People must be supported to feel safe **Principles** and secure in all aspects of life - to enjoy life but not be overprotected and as far as possible free from exploitation or abuse. **Innovation** Responsibility **Develop creative** solutions together People should be able to take as to meet agreed much control over their support as outcomes. they wish, and exercise that control in a responsible way. **Fairness** It's about fairness to the Respect individual, not the group or society, treating people in We need to have a manner that befits and regard for the benefits their individual feelings, wishes and circumstances. rights of others. **Values** Independence Freedom People are supported People having to maximise their Safety choices potential, focussing on enablement rather People feel safe and secure than dependency. - to enjoy safety but not be

The statutory principles are important because they set out the spirit of the legislation and complement the social work duty to assess, and the social work duty to enable choice to meet people's needs and personal outcomes.

The statutory principles and practice principles can be considered alongside the practice statements set out in the Self-directed Support Standards.

overprotected and to be free from exploitation and abuse.

#### **Human Rights Approach**

Self-directed Support empowers people to have choice and control and to know and claim their rights. In the course of their work, social work practitioners should realise and protect people's human rights.

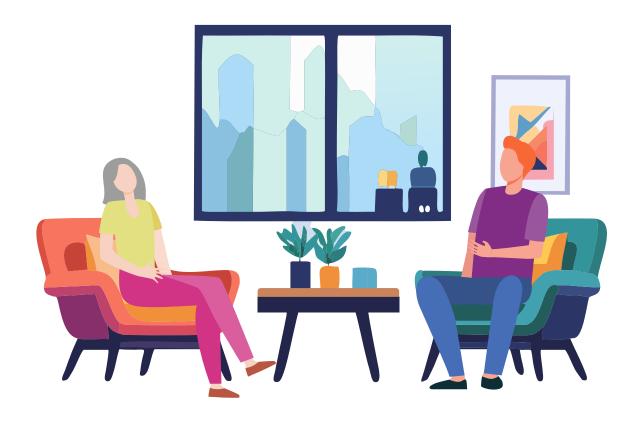
The PANEL principles can help you to apply a human rights-based approach in practice.

Participation, Accountability, Non-discrimination, Empowerment and Legality

This video tells you more about using the PANEL principles.

<u>The PANEL Principles – Taking a</u> <u>Human Rights Based Approach</u> Here are some more resources to help you to take a human rights-based perspective and approach in your practice.

- Scottish Human Rights
   Commission have produced information resources
   about Human Rights-Based approaches.
- United Nations Convention on the Rights of Persons with Disability.
- Health and Social Care Standards.
- Dementia Strategy.
- Autism Strategy.
- Independent Living Movement in Scotland.



# Understanding How to Use Self-directed Support

In the following sections, we focus on the key areas that supported people, children and families, unpaid carers and social workers have told us could be improved.

#### 1. Early Help and Support

### Signposting to Community Resources

At enquiry stage, your role in signposting to wider community support and services can have a huge beneficial impact, and is not affected by eligibility criteria.

Please check whether accessible information is needed, for example BSL interpreter, large print, easy read (go to <u>sensory loss</u> section of this toolkit) or translation into another language.



Early help and support aligns to Self-directed Support Standard 2: Early help and support

You can contact your local Third Sector Interface (TSI) organisations and use social media to help people to find local community groups, supports and services.

- A list of Third Sector Interface organisations can be found here.
- Use <u>ALISS</u>

   (A Local
   Information
   System



- for Scotland) to find local community groups and activities in your area to provide support, connect people, reduce social isolation and improve wellbeing.
- Libraries offer many activities to support wellbeing including reminiscence groups, storytelling for children, tea and blether sessions, carers' support, reading for wellbeing and craft sessions for example.
   Find your local library here.
- <u>Carers' Centres</u> offer a range of activities for young and adult carers including practical support.

Find your local Carers' Centre here.



 Children and families benefit from early help and family support too. <u>Children 1st</u> and <u>Parenting Across Scotland</u> websites offer practical early help resources.



# Early Help and Support also aligns to Self-directed Support Standard 1: Independent Support and Advocacy

#### Signposting to Independent Support Organisations

Support in the Right Direction (SiRD) are organisations funded by Scottish Government to support people to access Self-directed Support. They can support people to prepare for an assessment, or by explaining the four SDS options and by helping to arrange support. They are experts in Self-directed Support and can help you in the implementation of Self-directed Support.

- Click here to find a Support In the Right Direction organisation in your area.
- Community Brokerage Network Scotland can also help you to identify a local qualified broker who can support a person to prepare for an assessment and help with planning and organising support. Click here to see a video explaining Community Brokerage.

#### Signposting to Self-directed Support Scotland

SDS Scotland (SDSS) has developed a free online support forum that enables people to connect with each other to share information about social care options and provide peer support. Social workers can use this too and can often find useful solutions to issues that people are facing.



 <u>Click here to go to the SDS Forum</u>. This is what the page looks like and it has many helpful topics.



SDSS have also produced a helpful <u>Personal Assistant Employer Handbook</u>.

#### Signposting to NHS inform

It may be helpful to visit NHS Inform to get trusted health information about conditions such as osteoarthritis, Parkinson's disease, dementia, stroke, motor neurone disease and many more conditions.



NHS Inform gives easy to understand information about how people are affected by disease, how it may impact on their daily activities and explains how conditions are likely to develop in the long term.

NHS Inform website has a range of useful self-help guides plus links to third sector organisations who can offer early help and support, for example:

- Parkinson's UK
- Chest Heart and Stroke Scotland
- Dementia Scotland
- Alzheimer Scotland
- Macmillan Cancer Support
- Children's Health Scotland

#### 2. Assessment

The initial purpose of the assessment is to identify the person's needs with a view to determining how the person can best be supported and whether the authority has an obligation to meet those needs.<sup>5</sup>

The SDS standards describe what a good assessment approach looks like.



Assessment aligns to Self-directed Support Standard 3: Strength and asset based approach

Eligibility criteria are used to determine whether the local authority has an obligation to meet needs identified through the assessment. (Note: there is a commitment to overhaul existing eligibility criteria, and as of summer 2023 the Scottish Government has commissioned research to inform their thinking).

For good social work practice, the assessment and resource release sequence (such as the Helen Sanderson method shown here<sup>6</sup>) offers an empowering, collaborative, creative and flexible way of working out how best a person's outcomes can be achieved. A good assessment is based on a respectful relationship with the supported person. It will acknowledge and build on a person's capabilities as well as what support friends, families and carers can provide. A good assessment will also consider how technology,

<sup>&</sup>lt;sup>5</sup> pg 57, Social Care (Self-directed Support) (Scotland) Act 2013 Statutory Guidance

<sup>&</sup>lt;sup>6</sup> Helen Sanderson Associates – The Support Sequence: <u>https://www.youtube.com/watch?v=i0KwD-hbbr0</u>

adaptations and universal services can support the person, as well as identifying opportunities for people to participate in community life. All of this should be taken into account before funded support is considered. The aim of the assessment is to help the person to identity their personal outcomes based on what matters to them.

Family Group Decision Making (also known as Family Group Conferencing) is a tried and tested rights-based and outcome focused method of bringing families around the needs of a child, and this has been expanded to include adults as the focus of a FGDM process.

Find out more about Family Group Decision Making for children on the Children 1st website and Family Group Decision Making (vimeo.com), and the work done in Edinburgh Health and Social Care Partnership to make this approach accessible for adults.

#### Gemma's story

Gemma was 14 and lived with her great grandmother as her mother was not able to care for her.

Gemma was not attending school. There were significant concerns about her behaviour in the local community. She was staying out very late and there were concerns that she was starting fires. Her great grandmother's health was not good and there were concerns that she may not be able to continue to care for Gemma.

A family meeting was held to explore who within the network may be able to care for Gemma and what needed to happen to make sure that Gemma was safe.

The family agreed that Gemma would go to live with her Granny.
One of the outcomes that the family wished to achieve was to make sure

that the room that Gemma was to move to at her Granny's was freshly decorated and had all the necessary furniture.

The family also identified that Gemma needed support to help her manage her feelings. Gemma's aunty had a boxing bag. Gemma was interested in trying this sport and asked if she could have some boxing gloves.

Following the family meeting the social worker agreed an SDS payment to ensure Gemma's new bedroom was furnished and decorated. An SDS payment was also agreed to pay for boxing gloves and Gemma's Aunt took Gemma shopping for these. This SDS payment was part of a range of support that was offered to the family to ensure Gemma continued to be cared for by her family.

Outcomes that cannot be met by all of the other resources identified may be eligible to be accessed through an SDS budget. The supported person must be offered choice and control in how to use their SDS budget. The <u>Social Care (Selfdirected Support)</u> (Scotland) Act 2013 specifies four options that the supported person may choose:

- Direct Payment Option 1
- Individual service fund Option 2
- An arranged service Option 3
- A combination of the three optionsOption 4



Assessment also aligns to Self-directed Support Standard 1: Independent Support and Advocacy

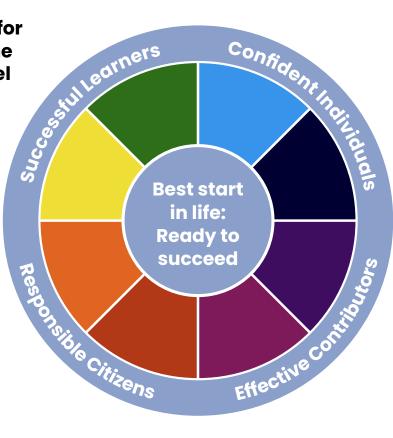
Supported people and carers are entitled to discuss their support with others, and may benefit from doing so (e.g. <u>Support in the right Direction</u>, <u>Community Brokerage Network</u>).

#### Relationship-based practice

The first step in the assessment process involves using approaches such as Good Conversations combined with the use of conversational prompt tools such as Outcomes & CO, GIRFEC wellbeing indicators (SHANARRI), or other national or locally defined outcome conversational aide-memoires. These tools are just a reminder of the things that have been identified as being important to most people, captured through many years of research. They are all very similar and focus on the following:

- Is the adult or child safe?
- What matters to the adult/child/ family?
- What communication support might they benefit from?
- How can I support the participation of the adult/child/ family and enable them to share ideas?
- Does the adult/child/family need independent support and advocacy to help them to understand the process?
- What changes does the adult/ child/family want to make?
- What can the adult/child/family do for themselves?
- What natural supports does the adult/child/family already have in their lives?
- What community supports do they already have in their lives?
- What equipment, technology or telecare could support the adult/ child/ family?
- What are the person's capabilities, needs, capacity and related risks?
- How can we build on the strengths and qualities the person already has?

Getting it Right for Every Child – The Wellbeing Wheel



#### Achieving

Being supported and guided in their learning and in the development of their skills, confidence and selfesteem at home, at school and in the community.

#### Nurtured

Having a nurturing place to live, in a family setting with additional help if needed or, where this is not possible, in a suitable care setting.

#### Active

Having opportunities to take part in activities such as play, recreation and sport which contribute to healthy growth and development, both at home and in the community.

#### Respected

Having the opportunity, along with carers, to be heard and involved in decisions which affect them.

#### **▶** Responsible

Having opportunities and encouragement to play active and responsible roles in their schools and communities and, where necessary, having appropriate guidance and supervision and being involved in decisions that affect them.

#### ▶ Included

Having to overcome social, educational, physical and economic inequalities and being accepted as part of the community in which they live and learn.

#### Safe

Protected from abuse, neglect or harm at home, at school and in the community.

#### Healthy

Having the highest attainable standards of physical and mental health, access to suitable healthcare, and support in learning to make healthy and safe choices.

In this toolkit, we acknowledge the valuable work and research of In Control Scotland and we use their graphics from the practice resource <u>Self-Directed Support as the Foundation of a New Relationship – In Control Scotland</u> to describe good practice in assessment.

Through good conversations, your job is to get to know the person; to find out their gifts and skills and the resources they have, as well as to establish what they need and what you can offer. **Mainstream & Targeted** Universal **Individual Support Person** Individual Community Support Listen and We need Allocate Plan collect funding together help! information **Decisions** Learn and Live with and change support agreement

# The things you need to consider as part of your good conversation



#### **Person**

The person at the centre of the discussion - this may be the supported person or a carer.

Establish what, who and where matters to the person, what's working and what's not, and what changes do they want to happen in their lives.

Establish what the person can do for themselves; their skills and abilities.

Utilise the local independent support for SDS project - put the person in touch with them.



#### **Targeted**

The things we might access if we have a particular need e.g. the Cancer Survivors' Group or the 'Knit and Natter Carers' Support Group.'

Is the person aware of the targeted services around them and do they know how to tap into them? How can you help them to do so?

Utilise the local independent support for SDS project - put the person in touch with them.



#### **Mainstream & Universal**

The things we all have a right to access e.g. GP services and schools.

Is the person aware of the mainstream and universal services around them and do they know how to tap into them? How can you help them to do so?

Utilise the local independent support for SDS project - put the person in touch with them.



#### Community

What does their support network look like? Do they have friends and family?

What's going on in the local community or community of interest e.g. the local history group, should the person be interested in the past or volunteering at the library because the person is interested in helping others.

Is the person aware of community opportunities around them and do they know how to tap into them? How can you help them to do so?

Utilise the local independent support for SDS project - put the person in touch with them.



#### **Individual Support**

Go to diagram on page 20.

#### 7 Steps to Self-Directed Support

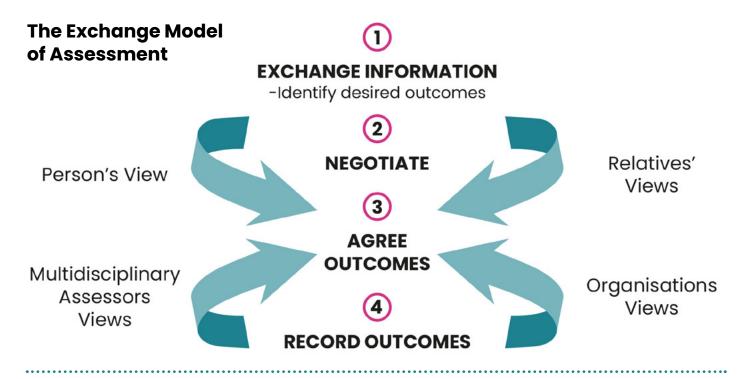
The things you need to take into account, the steps you need to take and the additional people you need to include:

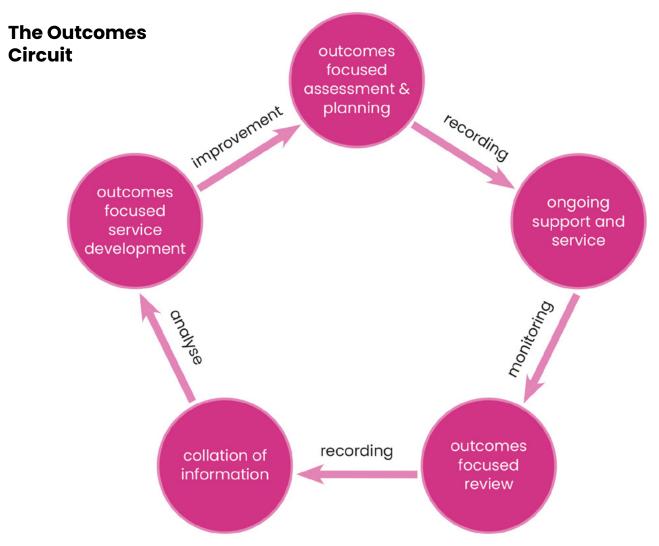
Establish what, who and where matters; what's working We Need and what's not, and what changes the person wants to Help! happen in their life. Help person consider what matters to them again and agree personal outcomes (and ensure the outcomes are 'personal' and stated in the supported person's own words). Listen & Collect Consider how equipment, adaptations and technology **Information** might help the person. Talk about finances. Make sure the person is accessing the financial (social security payments) assistance available to them. Consider how to make simple estimates of available funding that can form an individual budget. Allocate **Funding** This should be transparent, participative, and up-front. Link in finance colleagues. Discuss the 4 Options of SDS and help the person decide which option best suits them. Agree Option. Plan Together Develop a support plan with the person and work out the details of the budget and/or support arrangement. **Decisions &** Ensure the plan (including personal outcomes) is clear, developed and agreed together. Agreement Ensure the supported person knows how to get back in Live with touch if they need to. Support Listen and collect information. Learn & Consider what is and what isn't working, what needs to

change, and what have we learnt?

Change

More good practice comes from the Personal Outcomes Network and their <u>Personal Outcomes Approach</u>. A personal outcomes approach to assessment, planning and review aims to shift engagement away from service-led approaches. This involves everyone working together to achieve the best possible impact on the individual's life.





# A <u>personal outcomes approach</u> is underpinned by three core elements:

# 1. Engaging with individuals using services and carers about:

- what is important to them in life
- why these things are important (outcomes)
- Personal outcomes planning also involves engaging with people to work out:
- how to go about achieving these things
- who will be involved, including the person, other people in their life and community, and services
- when and where etc.
- extent to which their personal outcomes are being achieved, what helps and hinders

### 2. Recording of information on outcomes:

- Qualitatively in a language meaningful to the person – the personal outcomes story
- And that may then be summarised using personal outcomes scales

## 3. Using information for decision making including:

- Individual actions, care and support
- Service delivery and improvement
- Planning and commissioning
- Enriching performance monitoring
- A personal outcomes approach to assessment, planning and review aims to shift engagement away from service-led approaches.
   This involves everyone working together to achieve the best possible impact on the individual's life.

### You can find more useful assessment resources here:

- Personal Outcomes
   Network: <u>Outcome Focused</u>
   <u>Conversations</u>
- Leading For Outcomes:
   Children and Young People Iriss (2012)
- Friend Not Foe Make
   Recording Personal And
   Accessible
- My Communication Passport

#### **Support Planning**

#### An effective support plan should:

Demonstrate a shared understanding and agreement of how the outcomes will be achieved and which resources will be used to achieve them.

Be written or communicated in a format that makes sense to the person.

Describe arrangements for what happens if things go wrong or what would happen in a crisis.

Allow for a sufficient degree of flexibility to make adjustments and respond to changes in the person's life and circumstances.



Support Planning is aligned to Self-directed Support Standard 8: Worker Autonomy

#### **Key points for practitioners**

- Have you considered using support planning or personcentred tools to ensure the person is involved and encourage creative thinking?
- Does the support plan reflect the involvement of the person and evidence collaborative working?
- Is the person clear about their support plan and how this will be monitored and what to do if they wish to make adjustments?
- Have you explored all alternative supports as well as funded support to ensure maximum opportunities have been used and that the person is not dependent on only funded support to achieve agreed outcomes?
- Is the person clear about what supports will be provided, by whom, when and how?
- Is the person clear about how to raise concerns?
- Is the support right for the person and does it meet the agreed outcomes?
- Have any potential risks been explored, agreed and recorded with everyone involved?
- Does the person need independent advocacy support to help understand the process and express their views?
- Is everyone clear about their roles?



Self-directed Support Standard 6: Risk enablement is relevant when planning support

We fully recognise and value the role of social workers in respect of assessment and care management, and in changing the way self-directed support currently operates, as well as their critical role in adult support and protection.



Self-directed Support Standard 10: Early Planning for transitions is also relevant when planning support for young people

### You can find more useful support planning resources here:

- Support Planning Factsheet
- Carer Support Planning Toolkit
- SDS Add-on to Support Plan
- Principles of Good Transitions
- Risk Enablement
- In Control Scotland Thinking About Your Support Plan

#### Thinking Differently - Service Providers7

Self-Directed Support involves a series of practical changes in how funding and control is organised. It does not make community support redundant. Service providers can and do play a vital role in securing the implementation and the delivery of positive systems of Self-Directed Support and co-production.

### Community-focused provider organisations from Scotland, the wider UK and internationally, are often at the forefront of innovative practice:

- An article from Citizen Network describes the development of personalised support in Scotland.
- SDS Scotland and partners developed a <u>handbook for PA</u> <u>employers.</u>
- Citizen Network share good practice from Western Australia on <u>shared management</u>.
- The <u>Community Brokerage</u>
   <u>Network</u> support people across
   Ayrshire to access care and support.
- Community Catalysts help people and communities across the country to use their talents to start

- and run small enterprises and community businesses.
- The New Economics Foundation reports on <u>community</u> <u>microenterprises</u>.
- Connecting people in rural Scotland through <u>community</u> <u>connections</u> projects.
- Asset-based community development (ABCD) is a global organisation supporting local communities to innovate.
- A report from <u>National Voices</u> shows the benefits of peer support.

#### Recording

It is important that assessments, support plans and reviews are recorded in a meaningful and measurable way using your local recording system.

Good recording practice demonstrates how the person's lived experience and preferences have been acknowledged and expressed in their support plan, and connects personal outcomes to the subsequent review process.



Recording aligns to Self-directed Support Standard 4: Meaningful and measurable recording practices

Data that is meaningful can be used for continuous improvement and to evidence that a range of choices has been put to the person.

<sup>&</sup>lt;sup>7</sup> Self-Directed Support For Service Providers by Simon Duffy, John Dalrymple and Nic Crosby - <a href="https://citizen-network.org/library/selfdirected-support-service-providers.html">https://citizen-network.org/library/selfdirected-support-service-providers.html</a>

- Social Care Wales has produced this short video about meaningful recording practice in social care: <u>Friend</u> <u>Not Foe - Make Recording</u> <u>Personal And Accessible.</u>
- My Communication Passport is a personal communication tool that creates a person-centred way of supporting children, young people and adults who cannot easily speak for themselves.
- 24/7 Grid is a creative and visual way of mapping out a person's life and building support around it. It quickly and easily calculates the cost of current or proposed support packages.



#### 3. Explaining the Four Selfdirected Support Options

Another interviewee outlined how empowering their child, now a young adult, found it that with SDS they could do what they liked, when they liked: They can get up and go to the café, ... because they've got the support to do it. They can go to the gym because there is the support there to do it. The cinema, they can go there without us because they've got the support there to do it. It's just really good. It's wonderful and nice and worth all the worry before it. I've sat here at this table and thought are we doing the right thing? Employment and police checks and wages... But yeah, it's all been worth it. If I could turn the clock back I wouldn't change a thing.

Social workers tell us that they do not always have good knowledge of Self-directed Support and they sometimes lack confidence when discussing the four Self-directed Support options.

<sup>8</sup> p81 My Support My Choice report 2020

Here is a summary of each option.

| SDS Options   | Level of choice, control and responsibility  |
|---|--|
| Option 1  The supported person receives a direct payment.   | The supported person arranges their own support using a budget provided by the authority. The budget can be used to employ staff and/or purchase goods and services.  This option gives the supported person the most responsibility, which may include employer responsibilities.   |
| Option 2  The supported person decides on the support they want, and support is arranged on their behalf. | The supported person uses the budget provided by the authority to choose goods and services, and then the support is arranged on their behalf.  This can be arranged by the local authority, or a third party (such as a support provider) can manage the money on behalf of the supported person.  The supported person directs the support but does not have to manage the money.                          |
| Option 3  After discussion with the supported person, the local authority decides and arranges support.   | The supported person asks the local authority to choose and arrange the support that it thinks is right for them.  The supported person is not responsible for arranging support, and has less direct choice and control over how support is arranged.  Option 3 services are often traditionally commissioned, however the supported person should still be offered as much choice and control as possible. |
| Option 4  The supported person uses a mixture of ways to arrange their care and support.                  | The supported person picks the parts they want to have direct control over and what parts they want to leave to the local authority.   |

When explaining the four SDS options, you could give an example of how a person has used each option in practice.

You can find examples in the SDS Library (check the 'lived experience' topic field) or you may be able to draw from local or personal case experience.

Glasgow Centre for Inclusive Living has produced <u>Passport to</u> <u>Independent Living</u> to show what can be achieved with Option 1.

Here are some examples of personal stories of using options 1 and 2:

- <u>Joan's</u> personal story of Option 1
- Grant McTaggart's personal story of Option 1
- Norma's personal story of Option 2
- <u>Callum and Moira's</u> personal story of Option 2

# There are specific resources about SDS and children and families.

- Lothian Centre for Inclusive
   Living (LCiL) has produced this
   <u>Frequently Asked Questions</u>
   <u>Self-Directed Support for Children and Families</u> resource
   to explain how to use SDS in a children and families context.
- In Control Scotland has produced a range of <u>resources</u> <u>about SDS and children and</u> <u>families.</u>
- PAMIS has produced an <u>SDS</u> information pack for people with profound and multiple learning disabilities.

#### Communication

SDS can be difficult to understand and communicate, and it may not be the right time for the person to hear about it. It may be best to assume that people may not 'get SDS' the first time you talk to them about it, and you might have to discuss it over a few visits.



Good practice in communication would include consideration of Self-directed Support Standard 9: Transparency

For people with additional communication needs it is important to provide accessible information, and/or translated materials. Please check whether accessible information is needed, for example BSL interpreter, large print, easy read (go to sensory loss section of this toolkit) or translation into another language.

#### To make it easy to explain SDS:

- Break the information into small chunks and check for understanding after each chunk.
- Check that it is the right time and the person is okay to talk about their SDS options.
- Avoid jargon and acronyms for example HSCP, PA, personal outcomes. Explain what you mean.
- Ask them to 'teachback' or repeat back to you in their own words, what you have discussed, so you know that they have understood.

Visit the <u>Health Literacy</u>

<u>Place</u> for more assistance on communicating with people with a range of communication needs.

People can also get help from their local independent support organisation or community brokerage provider.

#### 4. Reviews

The review gives the social worker or social work practitioner and the adult, child, carer and family an opportunity to discuss what is working well and what may need to be changed.

Reviews align to Selfdirected Support Standard 4: Meaningful and Measurable recording practices

The review process follows the good conversation approach and provides time and support for the adult, child, family or carer to discuss their outcomes, their support, the option/s they have chosen and if anything needs to be changed.

The review is also an opportunity to develop relationships further, increasing people's self-confidence especially where support is working and outcomes are being achieved.

The review provides an opportunity to explore if it is possible to aim towards becoming less dependent on formal support and more engaged with communities, universal and natural supports.

The review is also an opportunity to put in place measures to prevent crisis and to adapt to any changes in a person's health and daily life.

Reviews should be carried out ideally within 6 weeks of setting up support, when a person's needs change or if they ask for a review, and routinely every 12 months.

People repeatedly referenced prompt communication and easy access to information as key to smooth communication with social work and effective SDS provision.

Two interviewees outlined that they appreciated email contact with the social work department and their regular attendance at meetings about their children's care.

<sup>&</sup>lt;sup>9</sup> p68 My Support My Choice report 2020

#### **Key points for practitioners**

- Local authorities have a duty to undertake reviews where support is provided to meet eligible needs.
- A change to the person's needs should prompt a review.
- The supported person can request the social worker to review their options.
- A review of a person's choice under the 2013 Act can take place without a detailed review of their needs. The person may decide that they do not wish to continue with the option that they have chosen, even if their needs haven't changed.
- The review should be conducted in line with the principles of collaboration, informed choice and involvement.
- Unless the person requests one sooner, a review should be conducted every 12 months to prevent crisis and to adapt to a person's life changes.
- Additional support from an advocate or independent supporter should be offered as early as possible.

#### 5. Challenging Decisions

The local authority, through the social work function, should inform the supported person that if they experience difficulties with any aspect of their engagement with social work services, they should in the first instance try to resolve matters with their social worker.

People should be supported to query and challenge decisions throughout their assessment, support planning and review processes, including their personal outcomes. It's important that the person knows from the start that it is okay to do this.



Challenging decisions aligns to Self-directed Support Standard 5: Accountability

At each stage, supported people have the right to the provision of accessible information, independent advocacy and mediation, and the right to challenge a decision and to make a complaint.

You can signpost to a local independent advocacy organisation using the Scottish Independent Advocacy Alliance website for support to challenge decisions.

If the supported person wants to complain, they should use their local authority's complaints procedure. Local authorities use feedback from complaints to make improvements to the quality of their systems and processes.

If the complainant is not satisfied with the local authority's response to their complaint, then they can escalate the complaint to the Care Inspectorate, Scottish Social Services Council (SSSC) and the Scottish Public Services Ombudsman.





Challenging decisions also aligns to Self-directed Support Standard 9: Transparency

In a recent <u>Equality and Human Rights</u>
<u>Research report</u>, suggestions for improving the process of challenging decisions about adult social care in Scotland included:

- 1. making participants aware that they could challenge decisions without fear of adverse consequences.
- 2. informing participants how they can contact an advocate and what benefits an advocate can offer, as well as providing reassurance regarding the advocate's independent status.
- clarity about how to challenge decisions using local authority and other complaints processes in the social care sector.
- **4.** maintaining regular communication during the informal stage of challenging a decision.
- **5.** providing support for individuals asked to meet a number of social workers to discuss formal challenges.
- making sources of mental health support available to those pursuing challenges.
- speeding up formal complaints processes wherever possible, and
- 8. using plain English, free from jargon.

# Making SDS Relevant and Accessible for All

Unfortunately not everyone who is entitled to social care support gets equal access to choice and control under the Act. The following sections aim to help social work practitioners to become more confident about offering SDS to people with a wide range of conditions and experiences.



Making Self-directed
Support relevant
and accessible for all
aligns to Self-directed
Support Standard 11:
Consistency of Practice

#### Supporting People with Sensory Loss

# What is accessible information? What is inclusive communication?

Accessible information and inclusive communication should meet the needs of the person so they can understand what is being shared with them, form an informed opinion, and express their opinions easily. They apply to people of all ages.

Good, inclusive communication is key to health and social care outcomes. Without the ability to communicate choices, preferences and concerns, people cannot have person-centred support planning and care.

Social workers should check what forms of communication and language people require on first contact, prior to any initial assessment. They should ensure that this information is recorded for future contacts with that person, that all necessary colleagues are notified, and they should check regularly whether people's communication requirements have changed.

Digital documents are normally most accessible in Word rather than PDF format – particularly for screen readers. Pictures and diagrams should be accompanied by text descriptions of their content.

The <u>British Sign Language (Scotland)</u>
Act 2015, the <u>British Sign Language (BSL)</u>
National Plan, and the <u>Equality Act 2010</u>
place duties on public bodies to support people to access information in the format and language they require.

Social workers should receive training on recognition of sensory loss and best practices for accessible information and inclusive communication.



#### What is sensory loss?

The term sensory loss can apply to people who are blind, partially sighted, D/deaf, hard of hearing, and deafblind. It can be acquired, congenital or a combination of the two. People can have partial sight and/or hearing and still be described as having sensory loss.

Acquired sensory loss is when someone loses sight and/or hearing after they have developed language in their early years. This can include Deaf people who lose access to BSL following acquired sight loss.

Congenital sensory loss is when someone is born with a sight or hearing impairment or develops sight or hearing loss before they have developed language in their early years.

Deafblindness is when someone has dual sensory loss. There is not yet an official definition of deafblindness in Scotland. A useful working model is the Nordic definition of deafblindness.

#### The impact of sensory loss

Sensory loss can have a significant impact on people's lives. There is a wide body of evidence on the emotional and mental health impacts of acquired sensory loss, and of the importance of communication and community engagement for all.<sup>10</sup>

Recent research indicates that people with a single sensory loss are twice as likely to experience depression as the general population, while people with a dual sensory loss are four times more likely to experience depression. People with sensory loss are also more likely to experience chronic anxiety.<sup>11</sup>

People with sensory loss can benefit from support via SDS at different points in their lives. For example, as an adult someone might have suitable support via Access to Work, but require additional support via SDS when they become a parent. A young person might have had good support at school but things change at transition. Someone with a single sensory loss may require additional communication support if they subsequently experience dual sensory loss. It is important for social workers to be aware of personal contexts, particularly during reviews.<sup>12</sup>

<sup>&</sup>lt;sup>10</sup> Andrena McMenemy and co-authors, "Mental Health and Deafness in Scotland: Exploring the Data" (deafscotland, 2021), available at: <a href="https://eresearch.qmu.ac.uk/bitstream/">https://eresearch.qmu.ac.uk/bitstream/</a> <a href="https://eresearch.qmu.ac.uk/bitstream/">handle/20.500.12289/11282.pdf</a>. S. Cosh and co-authors, "The association amongst visual, hearing and dual sensory loss with depression and anxiety over 6 years: The Tromsø Study", International Journal of Geriatric Psychiatry (33:4, 2017), available at: <a href="https://onlinelibrary.wiley.com/doi/10.1002/gps.4827">https://onlinelibrary.wiley.com/doi/10.1002/gps.4827</a>

<sup>&</sup>lt;sup>11</sup> Shahina Pardhan and co-authors, "Combined Vision and Hearing Difficulties Results in Higher Levels of Repression and Chronic Anxiety: Data from a Large Sample of Spanish Adults", Frontiers in Psychology (2021), available at: <a href="https://www.frontiersin.org/articles/10.3389/fpsyg.2020.627980/full">https://www.frontiersin.org/articles/10.3389/fpsyg.2020.627980/full</a>

<sup>&</sup>lt;sup>12</sup> For further examples, see Hazel McFarlane, Disabled women and socio-spatial "barriers" to motherhood (University of Glasgow, 2004), available at: <a href="https://theses.gla.ac.uk/1289/">https://theses.gla.ac.uk/1289/</a>. See also the ALLIANCE and Self Directed Support Scotland, My Support My Choice: Blind and Partially Sighted People's Experiences of Self-directed Support and Social Care. Thematic Report (December 2020), available at: <a href="https://www.alliance-scotland.org.uk/wp-content/uploads/2020/12/ALLIANCE-SDSS-MSMC-Blind-and-Partially-Sighted-Report-Dec-2020.pdf">https://www.alliance-scotland.org.uk/wp-content/uploads/2020/12/ALLIANCE-SDSS-MSMC-Blind-and-Partially-Sighted-Report-Dec-2020.pdf</a>

#### Diagnosis and sensory loss

Many people with sensory loss also live with additional long-term conditions. It is important that social workers establish the cause of any communications problems and do not assume that communication problems are a result of any one factor. As well as sensory loss, communication problems can result from the onset of another condition, such as dementia or cognitive decline, or another neurological condition.

Population projections indicate that Scotland can expect to see rising numbers of people living with dementia and sensory loss.<sup>13</sup>

in terms of screening and diagnosis ... it is imperative that identification of dual sensory loss is considered so that misdiagnosis of dementia is lessened.

People with sensory loss may also have "good" and "bad" days in terms of communication (such as eye strain from lip reading after a long day). It is important to follow up on any assessments and reviews to ensure common understanding and agreement, as well as highlighting any additional concerns.

### Resources to arrange communication support

This section provides some suggestions on arranging communication support, both for meetings with individuals, and for planning their ongoing care and support.

#### There are a variety of resources on good practice in accessible information and inclusive communication, including:

- Disability Equality Scotland's <u>Inclusive Communications Hub</u> Resources section.
- Deafblind Scotland's <u>Inclusive</u>
   <u>Communication Guide for</u>

   <u>Engaging with Deafblind</u>
   <u>People.</u>
- British Deaf Association's <u>Help</u> and <u>Resources</u> and toolkits.
- RNID's Communication tips.
- Scottish Government's <u>Principles of Inclusive</u> <u>Communication.</u>
- The Unseen: Blind and Partially Sighted People's Experience of Domestic Abuse.

<sup>&</sup>lt;sup>13 & 14</sup> Andrena McMenemy and Christine Johnson, "Deafness and Dementia: Predicting the future for Scotland" (deafscotland, Queen Margaret University and Life Changes Trust, 2021), available at: <a href="https://eresearch.qmu.ac.uk/bitstream/handle/20.500.12289/10647/10647.pdf">https://eresearch.qmu.ac.uk/bitstream/handle/20.500.12289/10647/10647.pdf</a>

When arranging communication support, allow plenty of time both to book interpreters and arrange Moon/Braille etc documents; and during meetings, where communication may need clarified.

Speech-to-text apps can be useful for D/deaf people and those with hearing loss (see RNID list), although hard of hearing or deafened people may prefer a lipspeaker or speech to text reporter.

Booking procedures for BSL interpreters, Guide/Communicators, lipspeakers and electronic note-takers (ENTs) will depend on your organisation's arrangements. Some HSCPs have internal booking systems.

If your HSCP does not have a contract or agency arrangement, these language service professionals can be booked through organisations such as Sign Language Interactions or SignVideo, or by searching the Scottish Register of Language Professionals with the Deaf Community or Deaf Action's database of community services. Deafblind Scotland also offer Guide/Communicator services across Scotland. Costs associated with these services need to be taken into consideration.

The Scottish Braille Press, among others, can convert documents into a range of accessible formats (large print, audio, Braille).

Social workers should not assume that a Guide/Communicator is a substitute for an interpreter during assessments or reviews; it is important to check the person's communication preferences.

### Positive Impacts of Self-directed Support

SDS can be life-changing for people with sensory loss. One blind person who took part in the My Support My Choice research summarised the impact of SDS on their life.

SDS basically is the a la carte of the care system. Previously the local authority provided this care, you had no choice. ... But now with SDS I have control. I can choose what option I want (within the rules, of course!). I find this is much more liberating. ... Basically, it has been the passport to independence. Whereas before, often times, especially if you're disabled you have to take what you get, you haven't really any choice. But to have the ability to decide for yourself is liberating. So, it makes a big difference.

Communication is essential, and a human right. Social workers should take care to ensure good information and communication practices for people with sensory loss. It is particularly important to consider people's social and communication needs, as well as their personal care requirements, when agreeing outcomes – especially with degenerative sensory loss.

Communication support can be paid for via SDS and be used to ensure people can meet their personal outcomes.

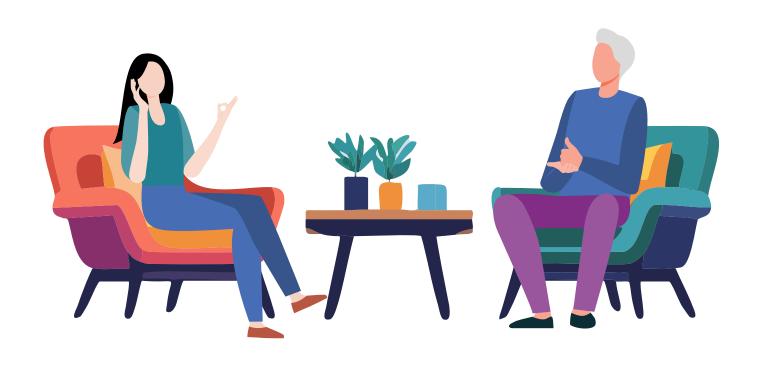
#### Christopher's story<sup>15</sup>

Christopher is in his 80s and lives alone. He lives with a variety of long-term conditions which affect his mobility, and more recently has experienced dual sensory loss. He used SDS Option 3 for several years for personal care.

However, after experiencing dual sensory loss, the only way Christopher could communicate was by writing on a small whiteboard. He was not comfortable with technology, including mobile phones, and struggled to communicate with family, friends, and his carers, leading to two years of severe isolation. Social work informed him they could not provide any support beyond personal care.

After contacting a third sector organisation, Christopher was supported to use low technology solutions to help with some of his communication problems, including a synaptic tablet. With this he was able to email and call family and friends, substantially improving his mental health and reducing isolation. With communication support, both Christopher and his carers were able to learn some BSL and communicate better with each other.

Had communication, language and technology support been included in Christopher's SDS package when he first experienced sensory loss, he would not have had two years without any ability to communicate meaningfully with people, and the ensuing social isolation and distress.



<sup>&</sup>lt;sup>15</sup> Anonymised case study provided by third sector organisation.

#### Marjorie's story<sup>16</sup>

Marjorie is in her late 60s. She lives alone and communicates using a tactile deafblind manual. She relies heavily on a specialised service to enable her to attend to her basic needs: communication, accessing everyday information, and getting out for shopping or a walk.

Earlier this year following a review, Marjorie's SDS budget was reduced by more than half. Since then, Marjorie's standard of living has deteriorated: mobility difficulties mean that she cannot go shopping by herself, and she cannot read the expiration dates on food or see that there is mould growing in her home. This has resulted in sickness, poor living conditions, and a deterioration in her mental health – particularly as she is now unable to participate in community life.

Recently a health visitor attended Marjorie at home, and an urgent transfer to hospital was required.

There was no communication

support for Marjorie through the process of transferring to hospital in an ambulance or when she arrived. This was a distressing episode which would have been mitigated if her previous access to inclusive communication support through SDS had been available.

Marjorie is now alone for 22 hours a day with no way to access the outside world. Deprived of human contact and access to basic information and communication, she is dangerously vulnerable to crisis, with little access to the specialist support she requires. A greater understanding of the specialist needs of deafblind people is required from those assessing/ reviewing SDS, to ensure that the importance of communication is understood. It is vital that people are properly assessed, and not left in isolation and distress when better awareness of the impact of sensory loss and the role of communication support could materially improve their lives.

<sup>&</sup>lt;sup>16</sup> Anonymised case study provided by third sector organisation.

## Training on supporting people with sensory loss

Social workers can access a range of training on how to better support people with sensory loss. This includes (but is not restricted to):

Deafblind Scotland run a range of free and charged training sessions on communicating with people with sensory loss, from sensory equality training courses up to and including accredited Guide Communicator training.

NHS Scotland offers e-learning modules on Sight Loss Awareness, Deaf awareness, deafblindness awareness and BSL awareness via Turas. Although Turas is an NHS Scotland platform, anyone in Scotland can create an account and log on.

RNIB provide a range of specialist training for social care professionals.

Visibility Scotland have an introduction to visual impairment awareness and making documents accessible, with practical tips and exploration of aids and assistive technologies.

British Deaf Association in Scotland have produced <u>The Deaf Dementia Experience</u> in Scotland: a Toolkit for All.

Forth Valley Sensory Centre run <u>Sensory</u> <u>Awareness Training sessions</u>.

Disability Equality Scotland's Inclusive Communication Hub – <u>Education and Training section</u>.

Most Scottish colleges and universities run BSL courses – even Level 1 provides participants with the ability to finger spell and check people's understanding.

The Scottish Human Rights Commission offers tools and training for people to better implement human rights based approaches, particularly in the delivery of care.

Every local authority should have a sensory officer. Social workers should seek out their input to better support people with sensory loss in their area. Your local See Hear partnership or lead may also offer sensory loss awareness training.

### Sources of support for people with sensory loss

It can be useful for social workers to be able to signpost people with sensory loss to sources of support. For example, these include:

- RNIB's Need to Talk counselling service, and their specialist support for children and young people.
- <u>Deafblind Scotland's services</u> (including specifically on SDS).
- Sight Scotland's information and advice services.
- RNID in Scotland's community support groups and wider services.
- <u>Deaf Action's</u> community services.
- National Deaf Children's Society local groups.
- British Deaf Association's
   Family Sign in the Home
   project, events, and advocacy
   services.
- <u>Sense Scotland's</u> information and support services.
- <u>Deaflink's</u> support services.
- The ALLIANCE's Sensory Hub.
- <u>Disability Equality Scotland's</u>
   Inclusive Communication Hub.
- ALISS (A Local Information Service for Scotland) is also searchable by keywork for local sensory loss services and support in your area.

## 7. Supporting People with Mental Health Conditions

## What is mental health? What are mental health conditions?

Everyone has mental health. Mental health describes how you think, feel, and behave. Mental health problems are when your mental health negatively affects how you think, feel, and behave for a longer period of time (more than two weeks).

Some mental health conditions will affect and impact on people's entire lives, others may only affect people for a short period of time. Some people will have returning symptoms at different points in their lives, along a spectrum of severity.

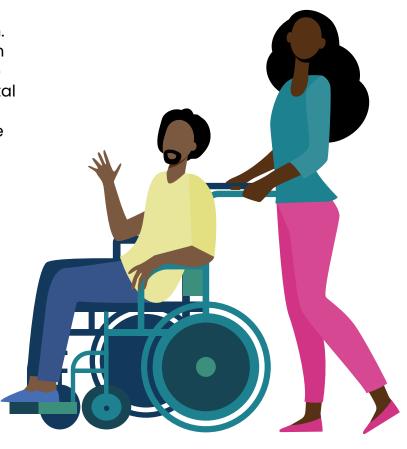
Some people fully recover from their mental health conditions. Many people consider themselves as being in recovery, and many people live well with mental health conditions.

People with mental health conditions or problems have the same right to care and support as people with any other kind of disability or long-term condition. People can access SDS to support them with their mental health, even if they do not have a diagnosis of a specific mental health condition. When a person with a mental health condition has social care needs then they are entitled to choice and control under SDS.

#### For more information on the impact of mental health problems on specific groups of people:

- Rethink mental illness website for information and advice.
- Mental Welfare Commission report on Racial Inequality and mental health.
- See Me Scotland <u>report on</u>
   <u>Mental health and Polish Men in</u>

   Scotland.



#### Key information about mental health conditions

- Around 1 in 3 of Scotland's population are estimated to experience mental illness in any one year.<sup>17</sup>
- In Scotland, it is estimated that only 1 in 3 people who would benefit from treatment for a mental illness currently receive it.<sup>18</sup> Social workers have a key role to play in providing support for people with mental health conditions and listening to their experiences and developing trusting relationships.
- People with life-long mental illness are likely to die 15-20 years prematurely because of physical ill-health.<sup>19</sup>
- There is a strong link between social inequalities and mental illnesses. There is widespread international agreement that wellbeing is intimately tied to

- structural factors such as resources, education, employment, and community support.<sup>20</sup>
- Some population groups are less likely to receive support for mental health conditions than others but are more likely to experience mental health illness; it is important to consider intersectional concerns when discussing support with people.<sup>21</sup> This includes cultural awareness and being aware of people's potential for self-stigma.
- Half of mental health problems in adulthood begin before the age of 14, and three quarters by the age of 24.<sup>22</sup>
- By the time they're 16, three children in every classroom will have experienced a mental health problem.<sup>23</sup>

<sup>&</sup>lt;sup>17</sup> Scottish Government "Mental Health", available at: <a href="https://www.gov.scot/policies/mental-health/">https://www.gov.scot/policies/mental-health/</a>. For more detailed analysis, see Sophie Birtwhistle and co-authors, "Chapter 2: Mental Health and Wellbeing", The Scottish Health Survey 2021 Edition, Vol.1: Main Report. A National Statistics Publication for Scotland (Scottish Government, Nov. 2022), pp. 37-52, accessible at: <a href="https://www.gov.scot/binaries/content/documents/govscot/publications/statistics/2022/11/scottish-health-survey-2021-volume-1-main-report/scottish-health-survey-2021-volume-1-main-report/govscot%3Adocument/scottish-health-survey-2021-volume-1-main-report.pdf">https://www.gov.scot/binaries/content/scottish-health-survey-2021-volume-1-main-report/govscot%3Adocument/scottish-health-survey-2021-volume-1-main-report.pdf</a>.

<sup>&</sup>lt;sup>18 & 19</sup> Scottish Government, Mental Health Strategy 2017–2027 (March 2017), p. 7. accessible at: <a href="https://www.gov.scot/publications/mental-healthstrategy-2017-2027/">https://www.gov.scot/publications/mental-healthstrategy-2017-2027/</a>.

<sup>&</sup>lt;sup>20</sup> Derek Ewens and co-authors, The Scottish Mental Illness Stigma Study: Final Report (The Mental Health Foundation and See Me, 2022), pp. 19-20, available at: <a href="https://www.mentalhealth.org.uk/sites/default/files/2022-11/MHF-Scotland-See-Me-SMISS-Final-Report-2022.pdf">https://www.mentalhealth.org.uk/sites/default/files/2022-11/MHF-Scotland-See-Me-SMISS-Final-Report-2022.pdf</a>.

<sup>&</sup>lt;sup>21</sup> Rethink, "Black, Asian and Minority Ethnic (BAME) mental health factsheet", available at: <a href="https://www.rethink.org/advice-and-information/living-with-mental-illness/wellbeing-physical-health/black-asian-and-minority-ethnic-mental-health/">https://www.rethink.org/advice-and-information/living-with-mental-illness/wellbeing-physical-health/black-asian-and-minority-ethnic-mental-health/</a>. See also Mental Welfare Commission for Scotland, Racial Inequality and Mental Health in Scotland: A call to action (Sept. 2021), available <a href="https://www.mwcscot.org.uk/sites/default/files/2021-09/Racial-Inequality-Scotland">https://www.mwcscot.org.uk/sites/default/files/2021-09/Racial-Inequality-Scotland</a> Report Sep2021.pdf.

<sup>&</sup>lt;sup>22</sup> https://www.samh.org.uk/get-involved/going-to-be/information-help

<sup>23</sup> https://www.samh.org.uk/about-mental-health/children-and-young-people

#### Stigma and discrimination

Stigma is negative attitudes or beliefs based on a preconception, misunderstanding or fear of mental health. Discrimination is when a person performs an action, whether intentional or unintentional, that creates barriers and inequality for people with lived experience of mental health conditions.<sup>24</sup>

People with lived experience say it's common to experience stigma and discrimination from health and care providers including primary care such as GPs, social services and other agencies including in the provision of benefits or housing. This has a negative impact and can create a pre-emptive distrust of people in those positions, so the importance of empathy and compassion cannot be underestimated.

Some people are more likely to encounter stigma and discrimination. It is important to consider a whole person approach to support when talking to people about their mental health. For example, people who are LGBTQIA+ may experience discrimination based on their sexuality, and face assumptions that their mental health conditions are a result of their sexuality.

Dealing with stigma and discrimination about mental health conditions can have a significant impact on people's lives. There is a wide body of evidence exploring how the stigma and discrimination that many people with lived experience of mental health conditions face (from family, friends, and professionals), and how this can act as a key barrier to help-seeking behaviour and accessing health and social care services.<sup>25</sup>



<sup>&</sup>lt;sup>24</sup> See Me, "Understanding mental health stigma and discrimination", See Me. See Change. Staff Workbook One, p. 10, available at: <a href="https://www.seemescotland.org/media/10912/staff-workbook-one.pdf">https://www.seemescotland.org/media/10912/staff-workbook-one.pdf</a>.

<sup>&</sup>lt;sup>25</sup> The ALLIANCE and Self Directed Support Scotland, My Support My Choice: People with Mental Health Problems' Experiences of Self-directed Support and Social Care – Thematic Report (Dec 2020), available at: <a href="https://www.alliance-scotland.org.uk/wp-content/uploads/2020/12/ALLIANCE-SDSS-MSMC-Mental-Health-Report-Dec-2020.pdf">https://www.alliance-scotland.org.uk/wp-content/uploads/2020/12/ALLIANCE-SDSS-MSMC-Mental-Health-Report-Dec-2020.pdf</a>.

### Key information about stigma and discrimination

- 50% of people with lived experience of mental health conditions in Scotland have experienced stigma and discrimination.
- 37% of people in Scotland have witnessed someone experiencing stigma or discrimination because of a mental health condition.<sup>26</sup>

## Stigma can take a variety of forms, including:

- Self-stigma is the judgement people put on themselves, which has often come from hearing and seeing external stigma and discrimination.
- Stigma by association is stigma experienced by someone connected to people with mental health conditions, e.g. a family member or friend.
- Structural stigma is when the rules, policies, and practices of social institutions restrict the rights of, and opportunities for, people with mental health conditions.
- Public stigma and prejudice is when people form an opinion before becoming aware of and understanding the relevant facts. Public stigma and prejudice can also stir up emotional responses such as fear or anger towards the people who are being stigmatised.<sup>27</sup>

## For more information on the impact of stigma:

- See Me Scotland <u>report on</u> <u>understanding mental health</u> <u>stigma and discrimination.</u>
- See Me Scotland <u>resources on</u> mental health inclusion.

## Independent advocacy, guardianship, and mental health

Some people may not be able to make decisions about their care and support as a result of mental health conditions. Mental health law in Scotland states that in certain situations, a person may have decisions made on their behalf (e.g. when the person is under a guardianship order) or may be treated or detained without their consent (e.g. where they are placed under a Compulsory Treatment Order).

Even when someone has a Guardian or has been placed under a Compulsory Treatment Order, their rights, will and preferences should still be sought and respected as recommended by the Scottish Mental Health Law Review. This means that the person can say how they prefer their care and support to be arranged.

Independent advocacy is important and useful in ensuring that people's will and preferences are respected. Social workers should be able to direct people to local independent advocacy organisations and work alongside Guardians and independent advocates to obtain the best outcomes for people.

<sup>&</sup>lt;sup>26 & 27</sup> See Me, "Mental Health Stigma and Discrimination", p. 13, available at: <a href="https://www.seemescotland.org/stigma-discrimination/understanding-mental-health-stigma-and-discrimination/">https://www.seemescotland.org/stigma-discrimination/understanding-mental-health-stigma-and-discrimination/</a>.

People with lived experience of mental health conditions can benefit from support via SDS at different points in their lives. It is important for social workers to be aware of personal contexts, particularly during reviews.

## Advance statements and wellbeing recovery plans

Advance statements are important in ensuring that people's will and preferences are respected. Social workers should encourage people to complete and share advance statements where appropriate.

Wellness recovery plans are also useful resources to aid in ensuring that people's outcomes are met throughout their recovery. Social workers should seek out the relevant resources used in their area to better support people in recovery, and draw on the expertise of relevant organisations (such as the Scottish Recovery Network).

## Children, young people and mental health

At times, children and young people will need support with their mental health.

- The Scottish Association for Mental Health (SAMH) have a lot of useful <u>resources for</u> <u>children and young people</u>.
- Public Health Scotland developed this <u>resource</u> <u>with young people</u>. It offers practitioners advice on how to support young people.
- CAMHS (Children and Adolescent Mental Health Services) or CYPMHS (Children and Young People's Mental Health Services) are available via the NHS.

## For more information on mental health self-management:

- How Lanarkshire <u>helps people</u> to take control of their own wellbeing and recovery.
- Mental Health at Work resources on <u>setting up a</u> Wellness Action Plan at work.
- Scottish Recovery Network support people at all stages of their recovery.



## Positive impacts of SDS in mental health

People with mental health conditions are entitled to choice and control under Self-directed Support in the same way as people with other conditions. A person's capacity to make decisions and keep safe should not prevent them from accessing SDS.

SDS can be life-changing for people with lived experience of mental health conditions. One person with lived experience of mental health conditions who took part in the My Support My Choice research summarised the impact of SDS on their life.

I came out of hospital and ... I was sitting there, in the house on my own. ...
Once I got my support ... it completely changed everything, because I was getting out and about. ...And I was very lucky because the two care workers the agency sent me I got on really well with, and we're still friends, you know? The fact that the people are good. I got my life back; obviously it changed, but I was back doing things.

Two participants with lived experience of mental health conditions summarised their experiences.

And then the social worker started suggesting groups that I could go to so that I wasn't on my own all the time. It would be peer support with people who also have mental health conditions; people with lived experience. So, I went along ... and it took me a wee while to settle in, but I settled in. And it was very helpful.

Support workers ... know about you and your mental health. When I went for a consultation, I probably forgot loads of stuff with my mental health. ... I might say some stuff and my support worker will be with me. ... I'll say I can't cook, and he'll say what I've been going through before all that ... and what you have been through prior to your mental health.

SDS can be used flexibly to ensure people with lived experience of mental health conditions can meet their personal outcomes. SDS has a significant role to play in preventative care and support for people living with mental health conditions, particularly in preventing crisis.

## Problems with Self-directed Support

Social workers should take care to ensure that good communication practices are used and good information is available for people, including those with lived experience of mental health conditions. One person with lived experience of mental health conditions who took part in the My Support My Choice research summarised their experience of a recent assessment.

Respondent: It must have been the social worker, the doctors, who chose a specific provider of support.

Interviewer: You didn't have a say in the decision?

Respondent: No.

Others reported experiencing stigma and discrimination.

People judge mental health. It's still happening, and it's been happening for a long time. They don't think about the person at all; if the person looks OK, they think they are OK. ... All through social workers, doctors and nurses.

Social workers should aim to provide preventative support for people with mental health problems. This includes signposting to relevant sources of support. Social workers do not have to be mental health experts in order to have judgement-free conversations about mental health, and to discuss and plan how best to support people.

#### Sharon's story<sup>28</sup>

Sharon is in her 60s and lives alone. She has lived with a complex mental health condition and a second long term condition for many years, and has attempted self-harm and suicide. Sharon has been subject to a compulsory treatment order and in the past resided in a psychiatric hospital.

The last time Sharon was discharged from hospital she was contacted by social work about arranging support at home via SDS. Her social worker visited her on several occasions to discuss different options, and they agreed a personal outcomes plan via Option 4. Some aspects of Sharon's care are arranged by the Council;

other parts of her SDS package she manages herself. This flexibility allows her to be supported in engaging with her community, including taking fitness classes that help her mental health, as well as providing her with some personal care.

Sharon reported that SDS has been life-changing for her; while she still lives with mental health conditions, which at times adversely affects her quality of life, she has good support in place, robust self management strategies, and – crucially – has built up a good and trusting relationship with her social worker. SDS has been transformative in supporting Sharon to live independently and well.

<sup>&</sup>lt;sup>28</sup> Anonymised case study provided by third sector organisation.

## Training and resources on supporting people with lived experience of mental health conditions

There are a variety of resources and training available on good practice in supporting people with lived experience of mental health conditions.

- See Me Scotland's mental health inclusion resources for people working in health and social care, including a dedicated video library and people's personal stories of stigma and discrimination.
- See Me's "See Me, Value Me" tool for improving healthcare professionals' practice and support for people living with mental health conditions.
- See Me Scotland and the Mental Health Foundation published The Scottish Mental Illness Stigma Study, which contains useful evidence to inform social work practice, especially around additional risk factors that may make people less likely to be able to access support.
- See Me Scotland mental health at work.
- <u>Rethink Mental Illness</u> has a range of resources.

- SAMH resource on <u>asking about</u> suicide.
- Mental Health Foundation's <u>A-Z of topics library</u> provides a range of resources.
- Mental Welfare Commission for Scotland's range of up-to-date good practice guidance, including on mental health and incapacity law.
- First Aid for Mental Health courses

   various levels of courses are available, in person and online.
   It is worth noting that mental health first aid aims to support people when they are in mental health crisis, rather than providing ongoing support.
- The Scottish Human Rights
   Commission offers tools and training for people to better implement human rights based approaches, particularly in the delivery of care.

#### Sources of support for people with mental health conditions

Finally, it can be useful for social workers to be able to signpost people with lived experience of mental health conditions to sources of support.

- SAMH <u>information service</u> (telephone, email and website).
- SAMH <u>Understanding Mental</u> Health Problems handbook.
- SAMH <u>How to cope when</u> supporting someone else handbook.
- SAMH mental health resources in community languages.
- Change Mental Health national information services.
- Voices of Experience (VOX)
   Scotland's mental health collective advocacy charity. Includes work on advance statements.
- Samaritans <u>24-hour helpline for</u> anyone feeling down, distressed or struggling to cope.

- Breathing Space <u>out of hours</u> telephone line for people over 16.
- Qwell <u>online and anonymous</u> <u>mental health support.</u>
- Childline a free, private and confidential service for anyone under 19.
- RNIB's Need to Talk counselling service, and their specialist support for children and young people.
- Carers Trust <u>local community</u> <u>support for unpaid carers.</u>
- Prevent Suicide app <u>designed to</u> offer support options for people in distress.
- Living Life to the Full <u>free online</u> courses on low mood, stress, and associated problems.

#### Social workers' mental health

It is vital that social workers are supported in their own mental health, particularly given the risks of burn out and vicarious trauma. Without investment in social workers' mental health, it will be difficult for them to support others in turn. Social workers should be able to discuss with colleagues what support is available to them in situations when their work negatively impacts their own mental health.

Leadership teams should foster a supportive environment where social workers' mental health is prioritised, and they feel valued. People should also be proactively signposted to workplace resources designed to support good mental health and wellbeing, including access to workplace counselling services where required.

- The National Wellbeing Hub was established in 2020 to help support the wellbeing of everyone working in health and social work and social care. Contact the National Wellbeing Helpline on 0800 111 4191.
- See Me Scotland mental health at work.

## 8. Supporting Unpaid Carers

#### What do we mean by a carer?

A carer is someone who provides unpaid support to a family member or friend. They may care for an older person, someone who is disabled, has a longterm illness, mental health problems or is affected by alcohol or drug use.

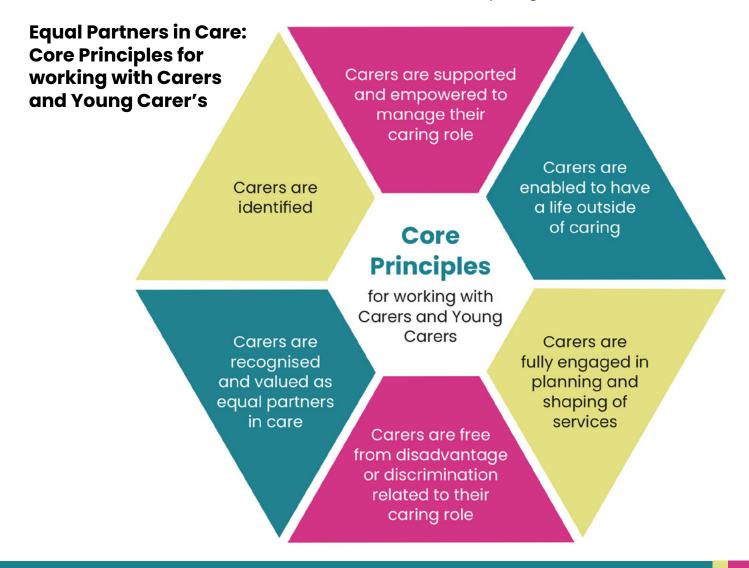
Carers can be any age, from children to older people, and from every community and culture. Some carers may be disabled or have care needs themselves. They may be parents, spouses, grandparents, sons, daughters, siblings, same sex partners, friends or neighbours.



Carers Self-directed
Support aligns to
Self-directed Support
Standard 12: Access to
budgets and flexibility
of spend

## Identifying and recognising carers

The carer may not already be known to the authority, so it is important that if you are involved in the assessment of a child or adult with support needs, that you always 'think carer' and help identify and signpost any carers to access support using the <a href="Equal Partners">Equal Partners</a> in Care (EPIC):Core principles for working with carers and young carers.



#### Carers and eligible unmet needs

Carers should be offered the options for SDS if they have eligible unmet needs.

To determine whether a carer has eligible unmet needs, they should be offered an Adult Carer Support Plan (ACSP) or Young Carer Statement (YCS) if still at school (under 18).

The ACSP or YCS will usually be undertaken by your local carers centre, but in some authorities it is carried out by the social work team. Local Authorities should still offer preventative support, including information about local advice services to carers who do not meet the local eligibility criteria. This would include services provided by carer centres.



#### Carers of a terminally ill person

There are specific timelines for supporting carers of terminally ill people as set out in the <u>Carers (Scotland) Act</u> 2016 statutory guidance.

Once an authority identifies an adult carer of someone who is terminally ill, the authority must offer that carer an ACSP within two working days. If the authority cannot do this within two working days, due to unforeseen circumstances, they must make the offer as soon as reasonably practicable.

You should have a 'substantive conversation' with the carer about urgent outcomes and needs for support within five working days of the carer accepting an offer or requesting an ACSP.

You should complete a light touch ACSP with the carer, based on the substantive conversation, within ten working days of the date when the carer originally requested or accepted the offer of an ACSP.

A light touch ACSP should focus on immediate or urgent personal outcomes and needs of the carer.

#### **Carers and Self-directed Support**

If a carer has unmet needs identified through their ACSP or YCS and they meet the local eligibility criteria threshold, then the local authority has a duty to support that carer.

The SDS options should then be discussed with the carer.

Carers can still be offered SDS even if the person(s) they are caring for does not receive social care support. This may be the case when a carer is looking after someone who refuses support themselves or when a carer is looking after more than one person and the carer's unmet needs are a result of their multiple caring role.

#### Using Self-directed Support to employ family members as Personal Assistants (PAs)

An individual can employ a close relative or family member as a Personal Assistant, with agreement from the local authority. This is in line with the statutory principles of the SDS Act and the spirit of the legislation, which includes the provision of creative and effective solutions for those receiving social care support.

This is an important consideration where more formal support may be difficult to access (because of geographical remoteness) or where a person's specific cultural needs require to be met by someone with a comprehensive understanding of those needs, and that person may be a family member.

The authority retains the power to either agree or disagree to the employment of a family member, though this should be on the basis of whether the arrangement will or will not meet the assessed needs of the supported person.

There should therefore be no blanket bans imposed by authorities on the employment of family members as PAs. However

(i) if a family member holds a power of attorney or is a guardian for a supported person, they are usually not permitted to be employed as a PA for the supported person if, as part of their role as guardian or attorney, they have the power to make decisions about the support to be provided through the direct payment.<sup>29</sup>

<sup>&</sup>lt;sup>29</sup> <u>Social Care (Self-directed Support) (Scotland) Act 2013: statutory guidance - summary - gov.scot (www.gov.scot)</u>

# Some examples of how carers have used Self-directed Support.

- A cleaner to do housework
- Buying a washing machine and tumble drier
- A short break
- Replacement care to attend a leisure activity
- Buying garden furniture
- Online courses
- Buying exercise equipment
- Buying a sofa bed (so that someone can stay over to give carer full night sleep)
- Technology
- Employing family members



#### Key messages about Selfdirected Support for carers

- SDS is a rights-based approach to supporting carers, and is good social work practice.
- Support for carers can be personalised using SDS.
- Through SDS, carers can use budgets flexibly and increase their choice and control.
- SDS supports carers to continue in their caring role.
- Social work practitioners should become confident to provide information and advice to carers about SDS, and signpost to relevant third sector organisations.

# Be aware of the barriers to carers accessing Self-directed Support

- Carers may not yet be aware of their right to SDS.
- Carers may lack confidence to use their SDS budgets flexibly, and might need support and encouragement from their worker.
- Workers may need to think about issues around employing family members.
- There is often too much bureaucracy, and it can take a long time for decisions to be made.
- Carers have a right to SDS independently of arrangements for the cared for person. The cared for person's arrangements don't have to be reviewed before the carer is offered support, and the cared for person doesn't need to have a budget for the carer to be given one.

#### Sources of support for carers

- Find your <u>local carers centre</u>
- Carers Trust Scotland



Coalition of Carers in Scotland



Carers Scotland



MECOPP





# 9. Black, Asian and Minority Ethnic Communities

#### **Anti-Racist Approach**

It is important for practitioners to adopt an anti-racist approach to social work and understand the impact of individual and structural racism on their practice to ensure they fully support people from ethnic minority communities to access Self-directed Support.

Supported people, carers, and staff from Black, Asian and ethnic minority backgrounds are at risk of facing both direct and indirect forms of racism; public service organisations need to be able to take appropriate action where this occurs.

Are staff aware of their own bias and of the organisational/structural bias that could make it more difficult for Black, Asian and ethnic minority people to access services and support?

- The <u>Scottish Social Services</u>
   <u>Council</u> has some useful links for practitioners to consider.
- In addition, the <u>Race Equality Framework 2016-2030</u>
   makes some reference to improvements required in health and social care on pages 70-79.

#### **Acronyms**

Some communities are happy with the BAME acronym, and some are not. The experiences of each sub-group within the umbrella all have their own traditions, identities, voices, and all should be recognised and heard.

### Some useful blogs on why the term BAME can be problematic

- Please, don't call me BAME or BME! By Zamila Bunglawala
- Don't call me BAME. We need a new political language By Kenan Malik
- To BAME or not to BAME Do we need an alternative term? By Cheryl Carty

# 1. Understanding your local BAME communities and identifying and building links

There is very limited national data on ethnic groups of people who access social care. In 2020/21, 72% of people receiving social care support were White, a similar proportion to previous years, but ethnicity was recorded as not known or not provided for a further 26%. Insights in social care statistics for Scotland can be viewed here.

The gathering of local knowledge and intelligence about local Black, Asian and ethnic minority communities will be invaluable in ensuring that the specific needs of those communities are captured, considered and subsequently reflected in the development of any local services and support.

Minority Ethnic Carers of Older People Project (MECOPP) put together an audit toolkit to help local authorities to identify how well they know their local ethnic minority communities.

#### You can use the toolkit to:

- Support and feed into existing auditing and improvement mechanisms.
- Identify actions which can be fed into existing Service Plans and strategy reviews.
- Support outcome measurement frameworks.
- Inform Equality Impact Assessments.

You can download the MECOPP audit toolkit from here.

MECOPP also have a <u>Briefing Sheet</u> to help practitioners to identify data sets that may exist locally or nationally about minority ethnic communities.

#### Additional helpful resources

- BME Carers in Scotland.
- Experiences of Gypsy/Traveller Women - example of engaging with a community.
- Experience of Muslims Living in Scotland - a literature review of published research into the experiences of Muslims in Scotland and the United Kingdom.
- South Asian people living with dementia.

### What we know so far from Census and health data:

- Pakistani men living in Scotland have a significantly higher risk of heart attack and of admission to hospital with asthma compared to White Scottish men.
- There are unequal patterns of psychiatric hospitalisations by ethnic groups in Scotland. South Asian and Chinese groups in particular access mental health services late or not at all.
- There are substantial ethnic differences in breast screening attendance with South Asian women having lower rates of attendance.
- The risk for all-respiratory diseases was found to be relatively low in other White British and Chinese men and high in Pakistani men and women.
- Gypsy / Travellers were twice as likely to have a long-term health problem when compared to white: Scottish group.
- Older Pakistani, Bangladeshi and Indian women reported worse health than older men in these ethnic groups.

## 2. Considering the communication needs and supports of different BAME communities and how these are resourced.

The key to good communication with supported people or carers from Black, Asian or minority ethnic communities is to ask about their communication preference rather than assume.

- Good communication is key to health and social care outcomes – without the ability to communicate choices, preferences and concerns, people cannot have person– centred care and support planning.
- Social workers should check people's preferred forms of communication on first contact.
   They should ensure that all necessary colleagues are notified, and check whether people's communication needs have changed.
- Don't assume interpretation or translation requirements – ask what they would prefer.
- The interpreter is not a substitute for an advocate.

- Being aware of the problems with using 'local' interpreters who may be part of the community that the supported person or carer belong to. There can be issues of confidentiality and stigma in close knit communities.
- The Equality Act 2010 and the Carers (Scotland) Act 2016 place duties on social workers to ensure that information and advice is available and accessible to anyone with a protected characteristic.
   This requires an adequate level of resource.
- Practitioners need to be aware that engagement and building a relationship might be more likely/ only be possible with a worker of the same gender.

MECOPP have produced a <u>briefing sheet</u> to support practitioners to develop their practice in working with interpreters.

If professional translators are not available practitioners may want to use Google Translate or technology available on phones for helping with initial conversations. While this approach can be useful it needs to be balanced against how comfortable the supported person and staff feel about using such technology.



#### Translating written information

The starting point for translating any information for someone whose first language isn't English is to start with information that is written in Plain English. If you try to translate a jargon filled document into another language, you just end up with a jargon filled document in another language!

- The average reading age in Scotland is 11 years old.
- Check readability.
- Stop and think before you start writing. Make a note of the points you want to make in a logical order.
- Prefer short words. Long words will not impress people or help your writing style.
- Use everyday English whenever possible.
- Keep your sentence length down to an average of 15-20 words.
- Use active verbs as much as possible.
- Be concise.
- Imagine you are talking to your reader.
- And always check your writing is clear, helpful, human, and polite
- Use pictures alongside words

## 3. Examples of what choices and flexibility look like for different BAME communities

While planning and providing a short break for carers which included access to swimming, a practitioner identified through engagement with Muslim women carers that swimming was not a suitable short break activity unless provisions could be made to have women-only swimming sessions. The practitioner approached leisure services and they were able to set this up.

TLAP (Think Local Act Personal) commissioned a project in 2020 to find examples of promising practice that demonstrate what good, personalised community-based care and support looks like for people in ethnically diverse communities.

Because of religious needs, food requirements, access to religious places and having family and friends around who share these beliefs, direct payments make all the difference when it comes to having the care and help that meets my needs. It allows me to get that help from different sources. But I also work as an advocate for other people on direct payments so I think there still is a lot that needs to be done by commissioners to think in a more innovative way about how these payments could be used. This would save money for those commissioners as well as make those of us using direct payments much more confident and help our wellbeing even more.

- Mohammed Patel, Research Participant.

#### Further reading in the **SDS library**



Authors Alliance Scotland, SDS Scotland  $\oplus$ 

Black and Minority Ethnic People's Experiences of Self-directed Support and Social Care - Alliance/SDSS



Authors Minority Ethnic Carers of People Project (MECOPP)  $\oplus$ 

A guide to Self-directed Support for people with dementia - MECOPP



Authors Minority Ethnic Carers of People Project - MECOPP



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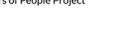
Authors Minority, Ethnic Carers of People Project (MECOPP)  $\oplus$ 

Self-directed Support and Scotland's Black and Minority Ethnic Communities - MECOPP

Self-directed Support Translation Guide - MECOPP



Authors
MECOPP - Minority Ethnic
Carers of People Project



Lost in Translation - Making SDS work for BME Communities MECOPP

## **Contributors**

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| In Control Scotland   | South Ayrshire Health and Social Care<br>Partnership    |
|---|---|
| Self-directed Support Scotland  The Health and Social Care Alliance | Shetland Health and Social Care<br>Partnership          |
| Inspiring Scotland  | Falkirk Health and Social Care<br>Partnership           |
| Lothian Centre for Inclusive Living                                 | East Ayrshire Health and Social Care<br>Partnership     |
| Coalition of Carers in Scotland                                     |   |
| 24/7 Grid   | Perth and Kinross Health and Social Care<br>Partnership |
| Minority Ethnic Carers of People Project (MECOPP)                   | North Lanarkshire Health and Social Care<br>Partnership |
| Community Brokerage Network   | NHS Highland  |
| Carr Gomm Community Contacts  | Scottish Sensory Hub                                    |
| Moray Health and Social Care<br>Partnership                         | Sight Scotland and Sight Scotland<br>Veterans           |
| City of Edinburgh Council   | Robert Gordon University                                |
| Angus Health and Social Care<br>Partnership                         | Scottish Social Services Council                        |
| West Lothian Health and Social Care<br>Partnership                  | See Me  |



#### **Self-directed Support Team**

Social Work Scotland March 2024

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