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# SELF-DIRECTED SUPPORT (SDS) INFORMATION PACK

## Helping you through the SDS journey

# Finding Your Way

2016

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# SECTION 1

# Introduction

## What is Self-Directed Support?

Self-Directed Support (SDS) is an approach to social care that puts the person at the centre of the support planning process. It enables people, carers and families to make informed choices about what their social care support is and how it is delivered.

Self-Directed Support emerged as a social care policy in the form of a ten year strategy: the Self-Directed Support Strategy 2010-20. The purpose of this strategy is to drive a cultural shift in the way that the provision of care and support is delivered in Scotland. It was further embedded into the mainstream through the enactment of the Social Care (Self-Directed Support) (Scotland) Act 2013. This piece of legislation ensures that when discharging their duty to support people in need, local authorities do so in a way which offers the person choice, control and flexibility to determine how they wish to receive support.

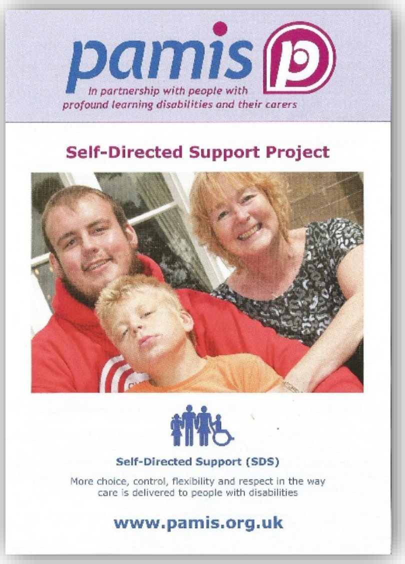
Local authorities have a legal duty to offer people eligible for social care four options about how their care is delivered. The four options are: (1) a Direct Payment (a cash payment); (2) an Individual Service Fund (a budget held by the local authority and allocated to a provider of your choice); (3) the local authority arranges support on your behalf; or (4) a mix of these options for different types of support. Those eligible for social care or carers acting on behalf of the cared-for person, should also have support to help them make informed choices and PAMIS staff are able to assist family carers with this through our Self-Directed Support Project.

The first section of this pack will introduce you to some of the key terms you will hear during your relative's SDS journey and also acts as a general guide as to how the journey through the Self-Directed Support process should look.

The second section will focus on legislation and policy which relates to both the cared-for person and the carer, with the aim of empowering you to feel more confident when negotiating with professionals involved in the care of your relative.

## Background

The origins of Self-Directed Support (SDS) can be traced back to the 1970s in which disabled people's movements campaigned for changes to the way social care was provided. Disabled people wanted to have a process which would enable them to take control over their own care and support. The personalisation agenda was borne from this aspiration and has been implemented to restructure the way social care policies are delivered. This restructure has given rise to the development of SDS as a way in which individuals are able to manage their own care and support.



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In partnership with people with profound learning disabilities and their carers

Self-Directed Support Project

Self-Directed Support (SDS)

More choice, control, flexibility and respect in the way care is delivered to people with disabilities

www.pamis.org.uk

Self-Directed Support (SDS) emerged as a social care policy in the form of a ten year strategy – the Self-Directed Support Strategy 2010-20 - which sought to achieve transformational change to the way social care was delivered in Scotland. This ambition was taken forward by the Scottish Government, who embedded SDS into the mainstream by enacting into statute the Social Care (Self-Directed Support) (Scotland) Act 2013. This piece of legislation ensures that when discharging their duty to support people in need, local authorities do so in a way which offers the person choice, control and flexibility to determine how they wish to receive support.

## That's fine but what is Self-Directed Support really all about and what does it mean for the person I care for?

Self-Directed Support is an approach to social care that puts the person at the centre of the support planning process and it is the way that anyone assessed as eligible for support from their local authority will now access social care. It is not an alternative to the way social care was once provided but rather, is now the way that all social care will be provided, with the Self Directed Support assessment being the start of the process.

In addition, it is a means by which you are able to make informed choices and have greater control over what kinds of support would best meet the social care needs of the person you care for. As a parent and/or Welfare and Financial Guardian (for more information on guardianship, please see page 8), you are able to choose and arrange some or all of the support provided to your relative. Prior to the introduction of Self-Directed Support, people had less choice as their local authority made arrangements for care on the person's behalf. There was limited choice, flexibility or control in who delivered the service, how it was delivered and where and when a service was delivered. Involvement of the person, or where relevant the family carer, in making decisions about the care and what it would involve and look like, was limited. Again it is important to highlight that Self-Directed Support is not a specific type of support but is the way services are and will be delivered in the future and one which will emphasise the importance of having carer services and support that is tailored to your relative's specific needs.

## What does Self-Directed Support mean for me as a Carer?

It should be noted that SDS is not only for the cared-for person. The Self – Directed Support Act also makes provisions for local authorities to offer SDS to carers to support them in their caring role. However, as this is only a **power** and not a **duty**, local authorities are not required by law to offer SDS to carers. However, should the person's carer be eligible for care services in his or her own right, their local authority has a duty to offer the same four options of support to the carer.

When carrying out their social care obligations, local authorities have a duty to regard five key principles which underpin the Social Care (Self-Directed Support) (Scotland) Act 2013. These principles are:

- **Involvement** – this means that you should be fully involved in the SDS process and be able to say what you think the person you care for needs from social care provision.
- **Information** and **Choice** – this is about being provided with the information you need to enable you to make real choices on behalf of the person you care for. The local authority should provide this to you before the assessment process starts.
- **Collaboration** – this involves you and the local authority practitioner e.g. social worker, working together co-productively to agree specific outcomes and what support is needed for the cared-for person to achieve those outcomes. We will look at the concept of co-production in the next section. Outcomes will also be discussed within the next section.
- **Dignity** - this means that the local authority must respect the dignity of the cared-for person throughout the SDS process.
- **Participation in the community** – this particular principle refers to the cared-for person being able to use their support to take part in community life. Local authorities must make it possible for the person to do this, 'as far as it is reasonably possible'. An example of this would be using support to attend college.

## In Summary

Self-directed support is not a daunting process, it is merely the way that social care services are now accessed. However, the four options might feel different, as prior to the introduction of

SDS, people accessing support had less choice, flexibility and control.  The four options now available are: (1) a Direct Payment (a cash payment); (2) an Individual Service Fund (a budget held by the local authority and allocated to a provider of your choice); (3) the local authority arranges support on your behalf; or (4) a mix of these options for different types of support.  The four options will be discussed in greater detail on page 10.

It is also worth noting that the local authority has a responsibility to provide, those accessing social care services, information about the options available and to signpost you to organisations, like PAMIS, who are able to offer information and support should you want it.

## Self-Directed Support Key Concepts

There are a number of terms and concepts associated with SDS which have been used interchangeably or in some cases incorrectly with the result that people are often left confused as to what the terms actually mean. It is therefore helpful to examine the following key concepts that you will encounter during the SDS journey:

- **Personalisation** - putting the person at the centre of the process of identifying their needs and making choices about how and when they are supported to live their lives as active citizens in their communities. Personalisation should also lead to services that are person-centred and which can change and adapt when needed. For children with Profound and multiple learning disabilities (PMLD), a parent is able to help identify needs and make choices on behalf of their child; however, for someone caring for an adult relative, (A person over the age of 16 years) it is essential to ensure that Welfare and Financial Guardianship has been appointed to enable you to make choices for the person you care for.

- **Co-production** – is intrinsic to SDS and although partnership working is not new, co-production means more than simply 'working together'. Rather, the professional involved in delivering a support service, works with you in a way, which enables you both to share knowledge, skills and responsibility; thus forming an equitable partnership.

- **Outcome** - is defined as a result that the person would like to achieve and how this is realised through the support provided. It could mean achieving something new or maintaining something that is already there; it also includes the end result or impact of activities.

- **Outcome Based Support Plan** – is a document created by both the social worker and the person or carer, which details the outcomes that have been agreed on behalf of the person and records how, for example in the case of option one where the person is in receipt of an individual budget, the budget will be spent to meet the identified outcomes. It is a flexible document which can be modified and updated in order to ensure that identified needs are being met.

- **Resource Allocation System** – is a system which translates identified social care needs into points, which are then used to calculate an indicative budget in which to base the Outcome Based Support Plan on. A large proportion of local authorities in Scotland use this system.

- **Equivalence Model** - is a system that relies on the professional judgement of the social worker to establish the level of budget. The social worker decides what support would normally be provided to the person with social care needs. After this is decided, the service is monetised into the form of an indicative budget.

- **Individual Budgets** – is an allocation of money that can be used to design and purchase support to meet assessed eligible needs, in line with the person's Outcome Based Support Plan and is accessed through option one and received as a direct payment. An example of using this option would be to use the allocation of funds to recruit Personal Assistants to support your relative, as opposed to utilising a social care provider. Individual budgets are accessed by choosing option one and hiring your own personal assistants. Individual budgets accessed through option one offers the greatest level of choice and control.

- **Risk Management** – is an inherent part of the SDS process. The assessment process should assess the risk that the proposed care package may imply. As a family carer of a child or guardian of an adult, carers should have the opportunity to express their views on where risks of a care package may outweigh its benefits, and potentially, where benefits to the person may outweigh the risks. Where there are concerns around the level of risk involved, a formal risk assessment should be requested.

## Guardianship

Once a person has reached the age of 16 that person is considered an adult and as such, parents are no longer legally responsible for the person and have no **legal authority** over the person's affairs or wellbeing. However, where there is incapacity and especially where the person has profound and multiple learning disabilities, (PMLD) parents/relevant others, must apply for guardianship if they want to continue to have legal authority to act on their relative's behalf.

Guardianship is required to enable you as a carer to access all of the **four options** under SDS. (Self-Directed Support will be covered in greater detail in the next section) For children who are about to reach the age of 16, a guardianship order can be applied for up to three months before the child's 16th birthday. This means that the guardianship order should be in place from the date of their birthday.

### What is a Guardianship?

A guardianship order is a court appointment which allows a person or persons to act and make decisions on behalf of an adult who has been assessed as not having capacity. Having a guardianship order in place enables the named guardians to make decisions for the person they care for. Named powers are identified and explicitly written into the guardianship order. Importantly, there are two types of guardianship and PAMIS strongly recommends that families caring for a person with PMLD apply for both and preferably at the same time.

Guardianship orders:

- **Financial Guardianship**: powers relating to the finances and property belonging to an individual including tasks such as:
    - opening a bank account on behalf of the person
    - paying bills on their behalf
    - handling ongoing and outgoing monetary commitments such as direct payment use and other financial affairs pertaining to the person being cared for.

- **Welfare Guardianship**: powers in relation to making welfare decisions on behalf of an individual. Welfare Guardianship enables decisions such as:
    - where a person stays and what type of support should be in place
    - making arrangement, and where necessary, consent or withholding of consent to any medical or dental treatment etc.

As mentioned, financial guardianship is necessary in order to access option 1 of the Self-Directed Support options as this option involves a cash payment paid directly into your relative's bank account and would require that you are able to manage the monies on their behalf. It is important to seek legal advice before applying for financial and/or welfare guardianship for your relative. It should also be noted that there are various costs involved in applying for guardianship which should be discussed with you before you proceed in applying on behalf of your relative.

To reiterate, it is strongly advised that you have both financial and welfare guardianship in place for your relative, as this will ensure that you are able to make on-going decisions about your relative's medical and social care alongside handling any financial tasks on their behalf.

It is also worth noting that although Guardianship should take approximately 3 months to have put in place the reality is that it can take longer and so it is important to apply for guardianship as soon as you can. It is also important to seek legal advice preferably from a solicitor experienced in guardianship work. PAMIS staff can also help direct you to solicitors in your area who are familiar with drawing up guardianship orders for people with PMLD.

# Self-Directed Support Options

The Social Care (Self-Directed Support) (Scotland) Act 2013 places a duty on local authorities to offer people, who are eligible for social care support, four choices as to how they would like to receive that support.  The purpose of this is to allow people to decide how much control and responsibility they want to have over their own support arrangements. This means that you must choose in what way you want the provision of support for your relative to look like and to decide how much control you wish to have over that support.  To make informed choices, it is necessary to have a good understanding of all the options and how much responsibility is involved in each.

## Option 1 – Direct Payments

This is where payments are made by the local authority to the person with disabilities. The person's legal financial and welfare guardian will be able to choose, organise and buy support on behalf of that person.

This option offers the greatest amount of choice, control and flexibility as you are able to determine and manage the support that is provided to your relative.  It is important however, to consider that with this option you will have on-going responsibilities for the arrangement and payment of your relative's social care support.  But, there is additional support available to help you as there are organisations that are able to assist you to manage these on-going responsibilities, e.g. those which offer a payroll service for a specified fee.  It is important to ask your local authority whether or not they provide for 'start up' costs within SDS budgets, as your relative may be entitled to additional funds to cover these particular costs.

If you feel that this option would be best for the cared-for person and for you, it is important to ensure that you or another close family member or relevant other has **Financial Guardianship**. Without this, you cannot choose to manage your relative's SDS budget under this option.  In addition, it is worth noting that, at the moment, a carer who is also the Welfare and Financial Guardian for the person for whom they care for, cannot also be paid to provide that care. It is rare that a local authority will allow you to employ a family member as a personal assistant and as it stands at the moment, local authorities are not legally able to pay a person to provide care for that person if he or she is also the legal guardian for that person. It is therefore wise to consider fully who or whom should be named guardians for the person.

## Option 2 – Individual Service Fund (ISF)

An Individual Service Fund is where payments are made by the local authority to a third party; this could be a specific care provider, agency or the local authority, who will manage your relative’s allocated budget and spend it on the support you want, as agreed with the local authority within the SDS assessment. This option gives you some choice and control by enabling you to decide which care provider you feel would best support your relative. It also means less responsibility for organising and arranging care provision. However, it does mean that you cannot specifically choose the people you want supporting your relative, E.G. choosing particular personal assistants.

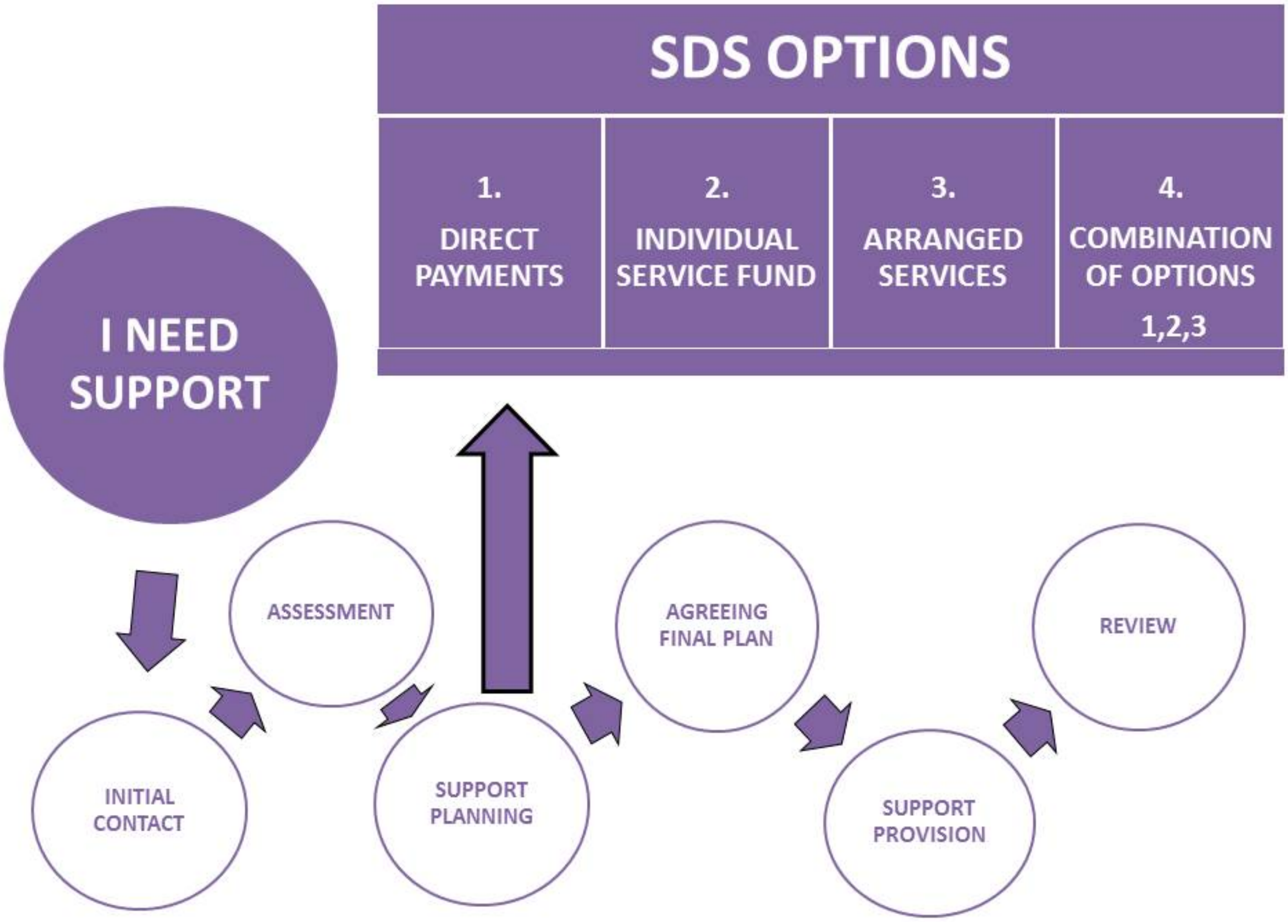
## Option 3 – Arranged Services

This means that after discussing with you, the local authority will arrange and manage your relative’s support on his/her behalf. With this option there should still be two way discussion around the best outcomes for the person but you will not have the responsibility for arranging services. However, choosing only option 3 means that you will have the least amount of choice and control over the support your relative will receive.

## Option 4 – Mix of Options

This is where you are able to choose from the combination of options above. This option may suit those who wish to have some control over certain aspects of their relative’s support but don’t want to make decisions on everything. Example: if you employed a Personal Assistant to support weekend activities and had the local authority arrange home care support during the week, this would mean you have chosen a combination of options 1 and 3.

## Self-Directed Support Process



The above diagram should be considered a general guide to what the Self-Directed Support process should look like, however the reality may be slightly different and in accordance with the way your local authority promotes and delivers their services.

# SECTION 2 MEETINGS:

# FEELING EMPOWERED

## Feeling that you are being heard: Some tips and useful suggestions

### Stress

Stress is almost certainly a constant feature of your life.  You may be juggling work with caring or have had to give up work to care full-time.  Sometimes you may feel you are not able to cope.  The suggestions below may help you.  However caring for someone with complex health and care needs is hard and we realise that some suggestions may be difficult to achieve.  Hopefully though, they may help a little.

### Ways to manage your stress as best you can

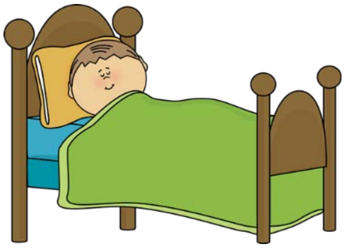
If the health or needs of the person you are caring for have changed and you feel you need some more help in your caring role, you can ask your Social Work Department for an updated **assessment of need**.  You can also ask for an assessment of your own needs (a **Carers Support Plan**).

Even though your caring role may take up much of your time, **try to take time for you** every day, even if it’s only a few minutes.  Maybe try out a relaxation or mindfulness exercise.  You can find out more about relaxation techniques from your GP or your local carers centre.

Building **physical activity** into your daily life can help bring down your blood pressure and give you more energy.  If it’s difficult to leave the person you are looking after, you could try doing some exercises in the house.

**Foods** such as porridge, chicken and turkey, bananas and nuts are examples of foods that can help reduce stress.  You guessed it, too much tea and coffee, or alcohol is not so good.  Too much fat and sugar helps mood short term but over the long term can add to feelings of stress.

**Getting enough sleep** might be very difficult if the person you care for has night-time needs which you must provide.  It might be appropriate to ask for an updated assessment of need if you are regularly missing out on lots of sleep because of this.



**Getting emotional support** is also a key part of managing stress.  Keep in contact with others as much as you can.  Support groups may be an option if you can get a couple of hours off every so often.  If your situation becomes very difficult, you may prefer to speak to a trained counsellor to help you make sense of difficult emotions and thoughts.  See www.bacp.org.uk for details of counsellors in your area, or ask your GP for a referral to an NHS service.  Telephone and even online counselling is quite common these days and is helpful if leaving the house is difficult.

## Meetings

**Do you dread meetings? Do you feel you don't get enough time to get your points across? Do you feel outnumbered?**

Many family carers have told us how emotionally drained they are and the difficulties they have, when faced with difficult conversations. This is especially so when trying to access appropriate care and support for their relative. Professionals should view you as an equal partner in care. However, it doesn't always feel like that in practice.

In order to prepare and increase your confidence when faced with such meetings the following is a useful guide with key points that may help you when faced with difficult meetings.

### Preparation: Work out what you need and what you would like

For example, you need a couple of nights' respite. You would really like a week, but you would settle for two nights, just to let you catch up a bit. Having thought about what you would really like and what you feel you must have is important as having a clear understanding of the difference will enable you to **negotiate** and when necessary **compromise.** Having clarity on what you are willing to compromise on helps to create a win/win situation with both parties leaving the meeting feeling that a positive outcome has been reached. It is helpful to write down what you would like to have and what you really must have.

### What exists that you would like to access?

**Find out everything** you can about what it is that you want. For example, finding out what respite options there are locally. Your local PAMIS Family Support Director will be aware of what exists and is accessible for people with profound and multiple learning disabilities in your area. Other organisation such as the local Carers Centre will have more general information. Write down any pieces of information you want to explore along with any questions you may have. Importantly, be clear in your own mind as to what it is you **really need** before the day of the meeting.

### When you ask for support what might be the response?

Think about the other party (e.g. Care Manager) and how he or she may respond to your request. Do you expect a positive response? Are they likely to say no or might they have to speak to another colleague before you get an answer?  Think about how you might respond depending on the other person's stance.

It is often a good idea to practice what you want to say or ask before the meeting.  You could ask a friend, family member or support person from PAMIS to take the role of the professional and practice.  It is also helpful if you are familiar with how your words sound when you say them out loud. Do you sound anxious or do you sound calm? What is your body language revealing? (More on body language can be found on page 12 ) Going through such exercises can help you gauge how you might come across and it really helps you to be prepared!

### Work on feeling more empowered

Remember, as a carer, you have the right to be treated with respect and that you are entitled to ask for the appropriate support and services to meet your needs as a carer and to meet the needs of the person you care for. Some people use affirmations to help them boost their confidence before a meeting such as "I am an expert in caring for my child' 'I am as good as anyone else' Think about the tips around becoming more empowered.

### On the Day of the meeting

Give yourself as much time as possible to get ready and travel to the meeting.  Think about what clothes are going to wear to make you feel most confident. A smart appearance can make a good impression. However, remember it is important that you feel comfortable in what you wear.

Take some deep breaths before going into the meeting or try some mindfulness techniques that can help calm you down and help you focus.  Relaxation is good too as long as you're not driving at the time!

### During the meeting or when on the phone

Take your notes and questions to the meeting. Having your jotted down notes will make you feel more confident and you will be less likely to be de-railed during the discussion.  Try and take someone with you to take notes and or for moral support.

Remember that it's OK to ask for clarification on who is at the meeting.  How do they know your child? Lots of people rattle their name and job title off! Ask them to repeat it if you haven't heard properly.

**Give yourself an opportunity to speak**. You could say at the beginning of the meeting. "I have something important to ask/say and I would like an opportunity to speak about this during today's meeting" If the other person says they haven't got time, ask for another meeting as soon as possible so you can discuss what you wanted to say.

Put your case over, using your notes and facts in front of you. Make sure you say everything necessary in order to strengthen your case, but be as succinct as possible. Be willing to listen to the response and if necessary, come back with a compromise. For example, you ask for 7 nights respite but the Care Manager says she can't meet this. Try, 6 days, 5 days etc. and don't agree anything less than the 2 days minimum you have set yourself.

**Try and keep to the facts** and do your best not to slip into an emotional response or use judgemental language such as, "you are cruel" or "this is hopeless" when referring to the other person/people in the meeting.

**If you find yourself becoming angry or anxious**, ask for a five-minute break.

**If you are not clear** about anything that is being or has been discussed don't be afraid to ask for clarification. If you don't understand some of what has been said or if jargon is used ask that it be explained.

**At the end of any meeting or discussion** be clear about what has been agreed. It is often useful if you go over any agreements as you understand them just to further clarify and avoid miss-understandings.

## When things don't go as you would like

When things don't go as planned, in difficult conversations, it is very easy to take it personally and feel that you are not being taken seriously or that no-one really understands. This is a natural response to a stressful situation. It is useful to remember that the professionals involved may not be in a position or be able to give you what you want. This could be for a number of reasons such as, funding shortfalls, availability of appropriately skilled staff, or suitable premises. Professionals often wish that they could provide more and would do so if able.

It is also useful to remember that although family carers are entitled to be treated respectfully and have their knowledge and understanding acknowledged with access to appropriate care, it can be difficult for staff working within health and social services, who may be finding their roles challenged due to economic restrictions.  On an individual level, professionals will usually do everything they can to secure the best package of care possible and appreciate good working relationships with carers in what are often difficult circumstances.

## Becoming more empowered

Being empowered is often about building up your own skills and confidence, so that you feel that you have some control in tense or difficult situations or meetings. It's also about ways you can gain good insight and understanding in a discussion so you are able to achieve the best outcome you can and feel you have done your best.

When we feel empowered we feel more confident in our ability to face the world, and in the case of accessing services for our relative, better able to negotiate successfully. Armed with knowledge and having prepared well, can also help positively influence other aspects of the process.

## Useful Tips

**Choose a time that suits you best**
If someone phones you when you are about to do something important, let it go to answer machine or ask if they can call back later.

**Choose a place that suits you best**
If possible, discuss important issues in a quiet location that makes you feel comfortable and where you will not be interrupted. That could be your own home.

**Be clear in what you want**
For example, "Lisa, I would like to discuss the issue of respite please." This removes possible confusion or miss-understandings.

**Say “I” not “we”**
Instead of saying, “We need a break by next year,” say, “I would like respite to be arranged before December.”

**Be specific**
Instead of saying, “hurry up with organising that respite for me,” say, “I would like the respite break to be organised by the 1st October.”

**Give a reason**
This enables the listener to gain a better understanding of the circumstances or difficulty involved and can open up discussion to consider different options. Be ready to further explain your statement by having a clear view of why you need respite in place by the beginning of October.

**Match your body language to emphasise your words.**
For example, “Lisa, I really need respite in place by the beginning of October.” This is an assertive statement. Sit tall and try to look confident and relaxed even if you don’t feel very confident and relaxed inside.

**Be prepared**
Good preparation and practice, around how you want to be and what you will say, will help increase your confidence on the day.

**Confirm any decisions that have been agreed**
At the end of the meeting or phone call make sure decisions are clear. Clarify any actions that have been agreed and who is to action them. Where possible, a summing up at the end of the meeting with attention to agreed details will help minimise miscommunication, truly reflect what was said, and importantly, enable decisions to be documented. If you would like the other person to document or minute agreed details explain that it would help if you both have a clear picture of what has been agreed and what happens next. Asking them to please write down important aspects of the discussion along with any agreed action(s) necessary is a reasonable request.

**Express your opinions honestly**
When you disagree with someone, do not pretend to agree. When you are asked to do something unreasonable, say that you feel that this is an unreasonable request and ask that it be re-considered. Again it's helpful to ask why and have them explain more clearly.

**Establish eye contact**
When you are in a conversation make eye contact with the other person. However, try not to stare as this can be a bit off-putting as well, but meet up with the person's eyes every few seconds.

**Ask when something is not clear**
You can explain that just so there is mutual understanding you would like to hear that again or ask if they could explain it in another way.

**Don't get personal**
It is helpful if avoid personal statements that show that you are annoyed or are criticising the person. For example:

> "Please don't talk to me that way," or even, "What kind of fool are you?"

If you find you are expressing annoyance or criticism, comment on the person's *behaviour* rather than attacking the person and try to ask them to behave in the way you would like them too. You can explain why, for example:

> "I would find it really helpful if you would talk with me rather than about me so I can feel properly included in the discussion."

**Suggest a different approach**
If appropriate, promote a different response by saying,

> "I would really like to work with you to resolve some of the issues. Can we sit down and work this out together?"
>
> or
>
> Do you think you would be able to ………………………..

**Practice is important** Changing your way of responding and speaking along with thinking about how you are coming across in a meeting can take time and takes practice. It is therefore good to try and practice how you want to be before an important meeting. Parents who attended the PAMIS Empowering Conversations events found that they, with the help of trainers from the mediation partnership, were able to reflect on what their language, including body language, said to the listener. On reflection, parents were able to consider other ways of asking and responding. Parents were able to think about small changes to behaviour that not only better prepared them for future difficult conversations but gave them good tips and suggestions to reach more favourable outcomes for themselves and their son or daughter.

**Be kind to yourself**

Think about what went well. Take time to congratulate yourself on being more empowered and move forward happy in that you did what you could in a difficult situation and feel proud. Make a note of things you felt you would like to do better and ask for help to think about a different approach.

## If a meeting has gone wrong

If you end up in tears, lose your temper with another person in the meeting or find that everything went out of the window when something unexpected was announced, don't get angry with yourself for not remaining calm and try not to berate yourself. What can you learn from this? **You're Human and so is your Listener!** Additionally, if the meeting involved a number of professionals, some of whom you did not know, and took place in an unfamiliar space this too will most likely have increased your stress levels.

PAMIS staff work with many families who have had similar experiences and we recognise that caring for a person with profound and multiple learning disabilities is intense and stressful. This is further compounded when family carers meet additional challenges when trying to access appropriate support services. It is therefore understandable when parents react to the level of stress, and associated anxiety, their caring role can produce.

**Don't put yourself down**

Instead learn from what went wrong and think of it as good learning experience for the future.

## What can you learn following a meeting that did not go so well?

The following table will help you reflect on past events, make sense of them and provide you with strategies that may help at future meetings. It is also useful if you consider what was going on for you at the time and how you communicated your needs with others.

Think about how you have said something or how you might have responded differently. Reflecting on what went wrong and how you might change responses or behaviour can help increase positive future experiences.

| | |
|---|---|
| **What happened?**<br>**Be specific** | *I said "I needed a break" in a meeting with my social worker*<br>*My social worker said "I'd be lucky to get respite in the next 6 months"*<br>*I burst into tears* |
| **How did I feel about it at the time?** | *I felt overwhelmed and angry* |
| **How might this have affected how the other person responded to me** | *They might have become defensive or withdrawn or felt defeated or angry* |
| **How do I feel now?** | *I feel disappointed now and still quite angry* |
| **What is my honest objective assessment of what happened?**<br>**Try to think of this happening to someone else and what you might say to them to help?** | *I was tired from not getting enough sleep this past week. The Care Manager couldn't come to the meeting so we couldn't make some important decisions on her revised care plan, so I was feeling a bit frustrated that there would be yet more delays on signing this off.*<br>*The Social worker is quite new in post and I think she was feeling a bit out of her depth with my Daughter as she said most of her caseload had been mild Learning disabilities. When I asked about respite I think the social worker felt a bit helpless.* |

| | |
|---|---|
| | |
| **What can you learn from this?** | *Maybe I need to give the social worker more information about what I need. I think she was thinking I wanted a long time, but I would be ok with a couple of nights.*<br>*On important decisions, I need to wait until I can speak to the Care Manager as she seems to be in charge.* |
| **How could you ask for this in a different way?** | *I could say "I want to speak to the Care Manager please, I'm feeling really overwhelmed at the moment and I've been up in the night all this month. I really need a break so I can re-charge. A few days would be fine as I know things are quite tight at the moment".* |

## Expressing things in a different way

When we are upset or angry we often want to hit out at the person we think is responsible. Using phrases like 'should' 'ought' and 'must' or strong words like "cruel" "ridiculous" and "appalling" can cause the listener to become 'disconnected' from you or defensive. This can result in the listener being less likely to respond to you favourably. Becoming disconnected or defensive also makes it harder for you to be properly heard.

- Try and leave out judgemental words such as 'ought' and "should" when speaking
- Make complaints, requests or descriptions of what has happened, non-personal
- State the facts as they would be told by an impartial observer, be specific and guard against use of 'emotional' words.
- Try not to make accusations but provide the information you have and ask for an explanation. Remember you might not have all of the information.

The following are a few examples of how you can discuss issues in a different way and reframe language to gain a more positive outcome.

"The quality of respite service was appalling"

“The respite service did not meet my Son’s needs as the room he had was too small and staff were not trained to deal with his moving and handling needs”

“My Daughter would be better looked after in Prison than she is in this flat”

“The current care plan does not make adequate provision for my daughter to have her care needs met in this tenancy and there is no option for her to have time out of the flat with others”

“The Care Plan for my Sister isn’t worth the paper it’s written on”

“I feel there are fundamental elements of my Sister’s needs that have not been addressed within the Care Plan”

### Managing feelings of anger

Anger can sometimes be useful in making yourself heard. However, unhelpful anger can be damaging and counterproductive. If you know that you tend to become angry, a useful tool to use is the following traffic light approach:

Red Light – When you are about to lose your temper. Stop. Make some space for yourself and don’t say anything just yet. Ask for a short break or glass of water to give you some breathing space. Take some slow deep breaths.

Orange Light – Think about what has triggered your anger? Are you already exhausted? Was it the way someone spoke to you? Was it the words they used? Do you feel dismissed, disrespected or ignored? If it was not happening personally to you but to someone else what might you say to help? What would a stranger observe about you if they could read your thoughts?

Green Light – Go ahead with care. Explain what has made you feel so strongly and how it made you feel. Ask for what you need in this situation. For example:

*“When you said that we are having our respite cut because other people may need it more, I felt like my Son was just being dismissed and seen as not very important. But I need you to explain to me how the new arrangements will work and how he will continue with his activities with you.”*

## A Brief Tour of Body Language

Communication isn't all about what words you say! Research suggests that between 50% and 80% of communications are non-verbal, so an awareness of your body language and vocal tone is very important. Body language is a complex area and often specific physical positions and facial expressions can be interpreted in different ways. Some reference about However, a few things are worth doing, if you are communicating with someone face to face:

- Sit square with both feed on the ground as this helps you get attention and also helps you listen to the other person.

- Try to sit in an open posture with arms and legs uncrossed, as crossed arms and legs *can* come across as unwelcoming and defensive.

- Keep an open facial expression (i.e. look as if you're listening) and respond to what they are saying with shakes or nods of the head.

- Establish eye contact with the person you are talking to, but try not to stare as this can be a bit off-putting as well, but meet up with the person's eyes every few seconds.

- Lean forwards towards the person you are talking to in a way that makes you look interested in what they are saying.

- Try to relax as much as you can. Take some deep breaths and keep your shoulders relaxed and try if possible not to fidget.

### Conclusion

Getting ready for meetings by preparing well and having a clear understanding of what you want can not only help you increase confidence but helps calm nerves too. This is turn will make you feel more empowered to ask confidently for what you want in meeting and during telephone calls. Understanding that we all speak verbally and through body language, and that how we say something and what our body language conveys, will help you to move toward more favourable outcomes when negotiating with others. Reframing what we are saying can have dramatic and positive outcomes.

It is also useful to remember that professionals may have limits on what they are able to provide so where possible thinking ahead to how a professional might respond to your request is helpful. If a meeting does not go as planned it is important that you do not berate yourself about how you might have handled something differently.  Remember how far you have come, learn from the experience and use the experience to improve future negotiation skills.

Keep this pack handy so you can refer to the tips provided.

# SECTION 3 SELF-DIRECTED SUPPORT: THE PROCESS

## What the SDS process looks like and how best to prepare for it?

Before considering what the self-directed support process should look like, it is important to be aware that each local authority was given the freedom to develop their own SDS process, which means that each may have interpreted the legislation in slightly different ways. Nevertheless, the SDS process should still be recognisable to you based upon what you will have read within this guide. If you wish to find out more about the slight differences within your area, you can review your local authorities' website for more information. Alternatively, you can contact PAMIS to speak with your area Family Support Director who can help and also put you in touch with the SDS Project Worker who will be able to advise you on differences which are particular to your local authority.

### Considering a Digital Passport

If your relative does not yet have a digital passport, it might be useful at this stage of your relative's SDS journey to consider developing a Digital Passport for him or her. Digital Passports are personalised digital guides on the health and social care needs of the person receiving support. You are able to embed videos, voice recordings, pictures and text, which creates a visual impact within a flick through resource that can be accessed on tablet devices. Digital passports are not only extremely useful digital guides for storing information about a person's needs, wants and aspirations, but they can be very helpful during the assessment stage of SDS as videos and pictures can help to evidence the complexity of need your relative has and could be useful in demonstrating why he or she needs the level of care requested. For example, if a person requires additional 2-1 support, having a digital passport that visually documents exactly why high level support is necessary helps justify the request for such support. Digital passports are also useful as training tools especially if there are short videos of procedures that must be carried out as part of the person's ongoing care.

PAMIS are able to support families through the process of developing a digital passport. For further information on digital passports, please follow the link here.

**Step 1 – Preparation:** If you feel prepared before the process begins, you will feel more confident and better able to explain the level of support that your relative needs. Below are some helpful examples of things to consider before the assessment starts:

- Consider whether the social worker undertaking the assessment is familiar with the support needs of someone with PMLD and if not, how you are best able to explain their needs to them, e.g. does your relative have a Digital Passport which details their health and social care needs? It may also be helpful to utilise training documents for care staff as these tools can be useful in demonstrating the high-level support needs your relative has and may evidence his or her need for 2-1 support during the SDS assessment. If you are unsure about this, it may also be helpful to keep a diary for at least a week which details your relative's daily support needs. Note down at the beginning of each day: (i) what task was carried out, e.g. hoist transfer to carry out personal care; (ii) how long the task took to complete, e.g. ten minutes; (iii) how many carers it took to do this task safely,
  e.g. two carers to ensure safety during hoist transfer.

- It is also useful to detail any products that you pay for on a regular basis. It is not unusual for carers to pay for items that should actually be included as a provision that is costed as an expense that comes out of the person's budget and not the carer's pocket, e.g. extra sheets due to increased laundry; specialist mattresses; or entry fees to accessible activities. Also, specialist items such as special cups etc. should be included.

- Detail all of the health needs of your relative, example: do they use a gastrostomy tube? What is involved in this, e.g. cleaning? What complications can occur if this is not done properly?

- Think about the types of equipment used and the reasons why the person needs them e.g. sleep systems to maintain body shape; hoists for safe transfer.

- A lack of suitable fully accessible changing toilets for people with PMLD is one of the most restrictive practical problems that prevents participation within the community. It is important to highlight any inaccessibility issues and/or lack of changing facilities within the community in which your relative lives as this will have an impact on both the SDS assessment and support planning stages.

PAMIS runs a national Changing Places Campaign to advocate for disabled toilets that are fully accessible and meet the needs of people who require the facilities of a Fully Accessible Changing Places Toilet. PAMIS have created a directory of all the Changing Places Facilities in Scotland which can be downloaded on our website or you can access it here. It may be helpful to have a look at this directory prior to the assessment stage, to help you consider what leisure activities are available locally to your relative, as well as being able to think about what types of support your relative would need to enable them to engage with these activities. The social worker involved in your relative's care may not be aware of local accessible activities for a person with PMLD, therefore it helps to be prepared and enables good shared discussion where both you the social worker can consider how and what must be in place in order for the person to realise identified outcomes and have access to a life worth living. Co-production (See page 6) during the assessment and support planning stages is important.

If you are still unsure of how best to prepare for the SDS assessment, contact PAMIS to speak with an area SDS Project Worker and or your Family Support Services Director who will be able to help you consider your relative's needs in more detail.

**Step 2 - Initial Contact**: If the person you care for already receives social care support, you can speak with your local social work department to discuss SDS; or if you prefer to wait until your relative's support package is reviewed, it will be at this point when the process begins.

**Step 3 - Assessment:** It is important to again highlight that the following is what should happen during a Self-Directed Support assessment, however occasionally you may find the reality to be slightly different. For the SDS process to start a **co-produced** assessment should be carried out by a social worker from your local authority who will visit you in your home. It is important that the focus of the assessment is on your relative and that you feel prepared to explain in detail the needs he/she has and the support he/she requires to ensure those needs are met safely. It may be helpful to have someone on hand to offer you support during this stage, e.g. someone who knows the person well and has a good understanding of his or her needs. You can also ask for additional support from PAMIS if you feel that this would be helpful.

It is worth noting that the co-produced assessment may take several visits to complete. During the assessment process the social worker will want to take account of what support your relative has from you and whether or not you are able to continue providing that support. The social worker will also want to know what support is needed, which if provided would make a positive difference to their quality of life. This refers to what **outcomes** your relative would like to achieve or maintain and what support would be required to ensure that the identified outcomes are realised.

**Example of what outcomes might look like:**

Lucy is 19. Mum thinks Lucy would enjoy attending a particular music therapy class, as two of Lucy's friends attend the same class. Accessing the music therapy would offer Lucy peer interaction, as well as mental stimulation which is appropriate for a young woman her age. In order to achieve this outcome, Lucy requires two hours of support to both attend and travel to and from the club. Should Lucy receive those two hours of support, she will have achieved her identified outcomes of gaining peer interaction and mental stimulus.

**Preparation** will ensure that the assessment is a strong reflection of your relative's social care needs and the amount of support required to meet those needs. It will also demonstrate the positive benefits which the provision of support would have for you, as well as any other family members within the home. Once the assessment has been completed, you should receive a copy.

In addition, a financial assessment will be conducted to establish what contribution, if any, your relative will make towards the total cost of their support. You will be notified of any charges in a letter of confirmation of support. It is a good idea to speak to an organisation, like the Citizens Advice Bureau, to ensure that you and your relative are receiving the benefits that you are entitled to. If you are unsure about whom to contact, Scotland's Financial Health Service are able to direct you to local welfare offices who are able to offer advice and income maximisation reviews. Scotland's Financial Health Service and other support organisations are listed in the 'Further Information & Useful Organisations' section of this pack. (Page 28)

At this stage, it is also worth requesting a **Carers Assessment** if you have not already had one. Local authorities have a duty to support you in your caring role and this can help to evidence the support you provide to your relative and what support is needed to enable you to continue in your caring role, should you wish to do so.

**Step 4 - Support Planning:** At this point of the SDS process, you may be given an indication of how much money could be available for the care package, in the form of an ‘indicative budget’. This sum allows both you and the social worker to work together co-productively, to develop a support plan that will meet specific outcomes. This support plan should detail the types of support needed and who will provide this support, e.g. paid support workers. It is important to consider and assess any **risks** that the proposed care package may entail and to express your views on whether you feel that the identified risks will be appropriately managed. If you are concerned about the safety of your relative, you can request a formal risk assessment.

An intrinsic part of the support planning process involves considering the four SDS options, for the purpose of choosing the best way in which the provision of support is delivered to achieve your relative’s outcomes. For a recap of the four SDS options, please refer to page 10. The social worker should discuss with you all the options and help you to weigh up the pros and cons of each, enabling you to make an informed decision on whether you want only one or a combination of options.

**Step 5 - Agreement:** By this point, you will have been informed of the **final budget** that will be used to implement the Outcome Based Support Plan (OBSP). If you are satisfied with both the budget and OBSP, you and the social worker will ‘sign off’ the OBSP and you should receive a copy of it. It will identify how the agreed outcomes will be met and how the final budget should be used. If however, you are unsatisfied with either the budget or OBSP, you can request to have either or both, considered again by social work. It is important to highlight any potential risks to the cared-for person, either as a result of an insufficient budget or because some outcomes may pose a risk to the person’s safety or wellbeing. If after doing this, you are still unhappy, you may wish to proceed with a formal complaint. On the other hand, it is best to exhaust all avenues available before to you before going down the complaints route.

**Step 6 – Support Provision:** This is the actual provision of support that your relative receives to enable them to achieve their specific outcomes.

**Step 7 – Review:** An agreed period of time will be made to check on how well the care package in place is working for your relative. This is often between six-ten weeks and if things are working well, the local authority should advise you how often they will review the outcome based support plan thereafter. If the care package is not working or you find that after the set period of time has lapsed that your relative's needs have changed, you are able to request a review at any time.

## In conclusion

It is hoped you have a better understanding of what Self-Directed Support is and what the SDS process **should** look like. It is worth reiterating that each local authority was given the freedom to develop their own SDS process and each have interpreted the legislation in slightly different ways; however, it should still be recognisable to you based upon what you have read within this pack.

The following section will offer a brief overview of some of the most important legislation and policy pertaining to both people with disabilities and their carers. Being aware of legislation and how it pertains to you and the person you care for will not only help you feel more prepared and empowered but will help increase your confidence when negotiating with professionals involved in the care of your relative.

The final section of this pack contains a list of organisations that are able to provide further information and or support to you on both Self-Directed Support and matters relating to it. It is also useful to review your local authority website for information on how they are delivering SDS or alternatively, contact them by phone to speak with your local Social Work department. For details of your local authority, please click here. Additionally, you can contact PAMIS to speak to your area SDS Project Worker or Family Support Director who would be happy to offer assistance to you with all matters pertaining to SDS.

# SECTION 4: LEGISLATION

## Legislation relevant to persons with Disabilities and Carers

It is helpful to have a general understanding of some of the main legislation and policies which offers protection for people with disabilities, as well as their Carers. This knowledge can be especially useful in empowering you, as a Carer, to feel confident when you are negotiating with professionals involving in providing care and support to your relative.

### Children (Scotland) Act 1995

Within Section 23 of the Children (Scotland) Act, disabled children are entitled to a social work assessment as requested by their parent or Welfare Guardian. The assessment should consider all the help that the disabled child needs, the needs of any other children in the family (including any care provided by a young carer) and the help that a parent may need to care for their disabled child. Parents should be actively included in the assessment process, involved in decision-making meetings and case reviews, as well as having their views taken into account by the professional conducting the assessment. There should also be clear and accessible means for families who wish to challenge decisions taken by professionals and to make a formal complaint if required.

### Adults with Incapacity (Scotland) Act 2000

The Adults with Incapacity (Scotland) Act creates provisions for protecting the welfare of adults who are unable to make decisions for themselves because of a learning disability or an inability to communicate. The Act enables carers to become Welfare and Financial Guardians, which provides carers with legal powers to make decisions on behalf of their relative about things like: arranging services through social work and choosing Self-Directed Support options; managing their finances; and making decisions regarding medical treatments. The Act also ensures that even if a carer does not have Guardianship, the carer’s views should still be taken into account by health and social work services, however **securing Guardianship is strongly advised.**

## Mental Health (Care and Treatment) (Scotland) Act 2003

The Mental Health (Care and Treatment) (Scotland) Act came into force in October 2005 and increased the rights and protection of people with mental disorders, which also encompasses people with learning disabilities. The law details how someone with learning disabilities can be given care and treatment. It also sets up a 'named person' who helps protect the rights and interests of the person receiving treatment. The named person doesn't have to be the carer, although the main carer will become the named person if no one else is asked. In addition, the Act states that the rights and views of the carer should be taken into consideration as much as possible when any decisions about the person's care and treatment are made. Carers should also be provided with information they need to provide effective care. At present this piece of legislation is being considered for review by the Scottish Government and all changes will be updated accordingly.

## Education (Additional Support for Learning) Act 2004 (amended 2009)

The Education (Additional Support for Learning) Act shifted the concept of 'special educational needs' to one which encompasses a broader range of needs, introducing the concept of 'additional support needs'. It gives parents the right to request an assessment of needs for their child and the right to appeal decisions made, as well as set in place the processes for resolving differences for families and authorities through the introduction of mediation and the Additional Support Needs Tribunal. If a child receives support from more than one service, as is the case for a child with profound and multiple learning disabilities, those involved in the provision of support for the child will draw up a Co-ordinated Support Plan (CSP).

## Equality Act 2010

The Equality Act is a substantive piece of legislation which covers a broad range of equalities related legislation and unifies them together under one Act. The act makes it unlawful to discriminate against someone because of their 'protected characteristics' such as being a disabled person with PMLD. It also offers legal protection to carers from discrimination in the workplace or harassment in public places due to their association with a disabled person and caring responsibilities.

## Patient Rights (Scotland) Act 2011

The Patient Rights (Scotland) Act states that patients should have the right to healthcare which considers their needs and promotes active participation in discussions regarding one's health; it also gives patients the right to give feedback on the healthcare they have received. For people with profound and multiple learning disabilities, the Act recognises that family carers play a key role in supporting the person they care for to have their voice heard and that their views, regarding the person's care and treatment should be taken into account when planning and providing care; however, this does not undermine clinical judgement. Included within the Act was the establishment of the Patient Advice and Support Service. This service provides free, accessible and confidential information, advice and support to patients and family carers about NHS Healthcare.

## Self-Directed Support (SDS) Strategy 2010-2020

In 2010 the Scottish Government published a ten year strategy for Self-Directed Support. The purpose of this strategy is to drive a cultural shift in the way that the provision of care and support is delivered in Scotland, with the aim being that users of health and social care experience real choice and control over the way in which they receive support from their local authority.

## The Social Care (Self-Directed Support) (Scotland) Act 2013

The Social Care (Self-Directed Support) (Scotland) Act brought into statute the ambitions of the Scottish Government's ten-year vision for Self-Directed Support (SDS) to become the mainstream way in which social care is delivered. The Act places duties on local authorities to offer a range of self-directed support options to children and adults with assessed support needs, so that social care services are delivered in a way best tailored to meet their outcomes. The four options are: (1) a Direct Payment (a cash payment); (2) an Individual Service Fund (a budget held by the local authority and allocated to a provider of your choice); (3) the local authority arranges support on your behalf; or (4) a mix of these options for different types of support. For further information on the four options, please see page 10.

As a family carers of a child or adult with PMLD, the Act therefore, enables you as a parent or Welfare and or Financial guardian to have greater choice and control over the way in which social care support is provided to the person you care for. Local authorities have a duty to provide you with the information you need to make informed choices about the options available and what the implications of each of them would mean for the cared-for person; this also includes signposting you to organisations, like PAMIS for the support you need to help you make the choices which are right for you as a family carer and which, most importantly, best meets the needs of the person you care for.

You should also be given support through an organisation that can help you with payroll and other aspects of employing personal assistants, should you chose option one, which enables you to employ your own staff to carry out identified and agreed care. Some local authorities do not have an in-house payroll service or identified organisation to assist with payroll but instead allocate a set monthly amount for you to engage your own payroll service that can make payments to employees and other associated tasks.

For Carers, the Act also provides local authorities with a 'power' to offer Self-Directed Support to the carer following a Carers Assessment. If such support is provided by your local authority, they then have a duty in which to offer you the same SDS options as your relative. Again, it should be noted that this remains a 'power' and not a 'duty', meaning that if local authorities are not providing this type of support to carers; they are as yet, under no legal obligation to provide you with SDS following an assessment of your carer needs.

However, should you as a carer need to access SDS support in your own right, you should be able to go through a similar process and access an SDS budget too, as long as your needs meet the eligibility criteria stipulated by your local authority. In this case the local authority would have a duty to provide you with a budget as long as your needs met with their eligibility criteria.

The Scottish Government has produced three guides to SDS for those involved in the process, one each for: service users, carers and practitioners.

For more information and to download visit:
http://guidance.selfdirectedsupportscotland.org.uk/

For general information on SDS visit:

http://www.selfdirectedsupportscotland.org.uk/self-directed-support

## Public Bodies (Joint Working) (Scotland) Act 2014

This Act set the framework for the integration of adult health and social care, establishing new Health and Social Care Partnerships between local authorities and NHS boards. The aim of integration is to ensure a seamless provision of care is delivered to service users. http://www.legislation.gov.uk/asp/2014/9/pdfs/asp_20140009_en.pdf

# Legislation and policies relevant to the person with Disabilities

## GIRFEC - Getting It Right For Every Child

GIRFEC is the national approach in Scotland that supports children and young people. It is a framework that is intended to make sure that the people involved in supporting your child work together seamlessly to give your child the help and support they need, at the right time, to enable them to achieve their specific outcomes.

At the heart of GIRFEC is the concept of 'wellbeing' with the framework focussing on eight specific areas, which are important for your child's development and ensures they are supported to reach their full potential. These key areas are:

- **S**afe
- **H**ealthy
- **A**chieving
- **N**urtured
- **A**ctive
- **R**espected
- **R**esponsible
- **I**ncluded

These wellbeing areas are often referred to by its acronym – SHANARRI.

Importantly, as a parent of a child or young person with PMLD, the GIRFEC approach not only promotes strong collaborative working between organisations involved in supporting your child, it also ensures that as a parent, you are fully involved and considered an equal partner in developing the right support necessary to enable your child to achieve their outcomes and fulfil their potential. This joined-up approach should facilitate a co-ordinated response from those involved with your child to tackle issues that arise before they become problematic either for you or your child. As a parent, you should expect to be listened to, have your wishes heard and taken into full consideration by those involved in supporting your son or daughter.

## Children and Young People (Scotland) Act 2014

This Act furthers the Scottish Government's ambition of improving the wellbeing of children and young people in Scotland by taking forward key elements of the Getting It Right For Every Child approach (GIRFEC).

For all children and young people in Scotland, the Act will:

- From birth to 18 years old, give children and young people a Named Person. This is someone who will be a central point of contact for you to raise any concerns you may have about your child's wellbeing or development; also, if you need information and advice; or are seeking additional support for your child. The Named Person is usually a Health Visitor or a Head Teacher. It should be noted that at present there is some controversy around the Named Person scheme, which has been subject to a delay by the Supreme Court for human rights due to concerns over information-sharing provisions. This is currently being reviewed by the Scottish Government and the scheme is expected to be fully implemented within the next twelve months.
- Put in place a single planning process known as a Child's Plan. The purpose of the Child's Plan is to provide your child with the extra support required to meet their needs and improve their overall wellbeing. The Child's Plan is the responsibility of the Lead Professional, who is generally a professional from an organisation involved in supporting your child, such as the local authority or health board. Their role is to coordinate your child's support and work with you, the Named Person and other organisations to ensure the services needed to support your son or daughter are tailored to their specific needs.
- Place a definition of wellbeing in legislation; and
- Place duties on public bodies to coordinate the planning, design and delivery of services for children and young people, with a focus on improving wellbeing outcomes and to report collectively on how they are improving those outcomes.

It is important to be aware of whom your child's Named Person and Lead Professional is, so that you can liaise with them, as and when required.

The Scottish Government have produced comprehensive factsheets which provide further information on what GIRFEC, the Named Person and the Child's Plan are and how they affect your child.

**Getting it right for every child** - http://www.gov.scot/Resource/0049/00498272.pdf

**Named Person** - http://www.gov.scot/Resource/0049/00498268.pdf

**Child Plan** - http://www.gov.scot/Resource/0049/00498268.pdf

## Adults Support and Protection (Scotland) Act 2007

This Act seeks to protect adults who are 'at risk' from being harmed and who would find it difficult to stop harm from happening to them. It places a duty on local authorities to inquire and investigate cases where harm is known or suspected. The Act also established Statutory Adult Protection Committees to increase collaboration across organisations to protect adults at risk of harm.

## Legislation relevant to Carers

### The Carers (Recognition and Services) Act 1995

The Carers (Recognition and Services) Act was the first piece of legislation which legally recognised carers. It established carers' right to have their own separate Carers Assessment during the assessment process for the cared-for person. There was however, no requirement to provide services to carers following a Carers Assessment.

### The Community Care and Health (Scotland) Act 2002

The Community Care and Health (Scotland) Act gave carers who provided 'regular and substantial care' the right to a Carers Assessment independent of the assessment process for the person being cared for. The Act placed a duty on local authorities to inform carers about their right to an assessment and to take into account both the carers assessment and the views of the carer when making a decision about the community care package for the person being cared for. It also placed a duty on health boards to develop 'carer information strategies' to improve the ways in which they inform carers about rights and services available to them.

### The Work and Families Act 2006

The Work and Families Act provides carers with the right to ask their employers for flexible working arrangements for regular or one off needs. Employers must have good reasons for denying an application and carers have the right to appeal.

### Carers (Scotland) Act 2016

In February 2016, the Scottish Government passed the Carers (Scotland) Bill, which is expected to be implemented in April 2018. Primarily the aims of this new piece of legislation is to ensure that better and more consistent support is available to carers to enable carers to continue to provide care, they choose to do so, in better health and to enable you to have a life outside of your caring role. The Act will introduce a range of provisions to identify, assess and support you. Below is a brief summary of some of the key provisions contained within the Act:

1. Carers Assessments will be replaced by new assessments called Adult Carer Support Plans and Young Carer Statements. Each local authority must offer an ACSP or YCS to anyone identified as a Carer and you can request one at any time from your local authority. The

YCS is particularly relevant for siblings under the age of 18 who provide care to their brother or sister with PMLD.

**NB: Until ACSP and YCS are introduced in 2018, you are still entitled to request a Carer's Assessment from your local authority. This assessment will look at the needs you have as a Carer and the support you require to help you in your caring role.**

2. The Act removes the need for a Carer to be providing '*regular and substantial'* care which means that ACSP and YCS are available to anyone who provides or intends to provide care.
3. The legislation places a **duty** on local authorities to provide support to those carers who meet local eligibility criteria.
4. Carers cannot be charged for any support they receive.
5. As a Carer, you must be involved and have your views and your caring role considered when determining the support needs of your relative and the services provided to meet those needs.
6. Health Boards will have a **duty** to inform and involve you in the discharge planning of your relative from hospital.
7. Local authorities are required to publish a short breaks statement.
8. Each local authority must establish its own information and advice service for carers. The service must provide information and advice on, among other things, carers' rights, emergency and future planning, advocacy and income maximisation.

To find out more information about the Carers (Scotland) Act and what it means for you as a caregiver, please see the Scottish Government's website:
http://www.gov.scot/Topics/Health/Support-Social-Care/Unpaid-Carers/CarersBill

The Coalition of Carers Scotland website also has useful information. Please see their website:
http://www.carersnet.org/carers-act-resources/

It is hoped that this brief overview of relevant legislation and policies relating to both people with disabilities and carers will empower you in your negotiations with professionals involved with your relative's care. The final section of this pack contains a list of organisations who are able to provide further information and/or support to you on both Self-Directed Support and matters relating to it. Should you need assistance with any aspect of SDS, contact PAMIS to speak with your area SDS Project Worker who will be able to help you.

# SECTION 5:

# FURTHER INFORMATION AND USEFUL ORGANISATIONS

# Charity & Independent Organisations:

## PAMIS

PAMIS (Promoting A More Inclusive Society) is the only voluntary organisation and registered charity that provides support to people with profound and multiple learning disabilities, their family carers, as well as interested professionals. PAMIS are able to offer families practical help, advice, training and information, as well as individual support. PAMIS also seeks to influence policy and services at both local and national level.

If you feel that you and your relative would benefit from speaking to a staff member at PAMIS about an issue you may be experiencing, please contact us.

**Website**: http://www.pamis.org.uk/index.php

**Telephone number**: 01382 385 154

## Self-Directed Support Scotland (SDSS)

SDSS are a national membership organisation which actively promotes independent living by supporting, working with and championing the aims of Self-Directed Support disabled peoples organisations.

SDSS website offers useful resources and information factsheets about Self-Directed Support and information pertaining to it. We have included a number of useful fact sheets which we think are particularly helpful.

**Website:** http://www.sdsscotland.org.uk/

## The Scottish Commission for Learning Disability (SCLD)

The SCLD is an independent charitable organisation which aims to be a knowledgeable hub that offers support, information and new ideas about learning disability in Scotland.

The SCLD is involved in evidence based research and policy and their website provides access to up-to date information and resources on a wide range of topics pertaining to learning disability. They also offer a good insight into The Keys to Life which is Scotland's Learning Disability Strategy, as well as access to easy read versions.

**Website:** http://www.scld.org.uk/

## Learning Disability Alliance Scotland (LDAS)

LDAS is a campaigning organisation which supports people with learning disabilities throughout Scotland. Their website offers up-to date information on current campaigns and issues for learning disabled people, as well as access to useful resources pertaining to Self-Directed Support.

**Website**: http://www.ldascotland.org/

## Scottish Personal Assistance Employers Network (SPAEN)

SPAEN aims to offer a range of supports and services to SDS users across Scotland, ranging from HR and employment related advice and guidance for PA employers to Managed Account Services and Support Planning for Option 2 recipients.

Their website is also contains helpful resource guides on SDS, as well as useful information on pensions for personal assistant employers.

**Website:** http://spaen.co.uk/

## Glasgow Centre for Inclusive Living (GCIL)

The GCIL is a disabled people's organisation which offers assistance, advice, information and training for disabled people (and their carers) who want to manage their own Self-Directed Support. They offer a range of payroll options which aims to make the process of employing PA's and paying service providers much easier.

**Website:** http://www.gcil.org.uk/

## Glasgow Disability Alliance (GDA)

The GDA is an organisation of disabled people who aim to act as a collective, representative voice for disabled people, to promote equality, rights and social justice.

The GDA's website contains useful publications and resources on Self-Directed Support.

**Website:** http://www.gdaonline.co.uk/index.html

## Patient Advice and Support Service (PASS)

The Patient Advice and Support Service is an independent service which provides free, accessible and confidential information, advice and support to patients, their carers' and their families. This service is for anyone who wants to give feedback, make comments, raise concerns or make a complaint about treatment and care provided by the NHS in Scotland.

**Website:** http://www.patientadvicescotland.org.uk/

## Scotland's Financial Health Service (SFHS)

The Scottish Government has developed a website and telephone service designed to be a one-stop-shop for those who have money problems or are seeking general financial assistance. The website is impartial and does not provide advice directly as its aim is to signpost people to the most appropriate area of support. You can contact the telephone service on: 0800 707 6696

**Website:** https://www.scotlandsfinancialhealthservice.gov.uk/home

### Citizens Advice Scotland (CAS)

CAS is the largest independent advice network offering free, impartial and confidential advice throughout Scotland. They have 61 bureaux within Scotland, as well as a telephone advisory service and a website designed to offer access to information on a wide range of topics, including: benefits, work, debt and money, consumer, housing, law and rights, discrimination, healthcare and education.

**Website:** https://www.citizensadvice.org.uk/scotland/

## Scottish Government & Regulatory Bodies

### Self-Directed Support in Scotland

This is the Scottish Government's Self-Directed Support website, which is a one-stop shop for information about SDS. On this website you will be able to access and download the Scottish Government's three guides to SDS: there is one each for those who use social care services, their carers' and health and social care practitioners. In addition, it offers access to an easy read guide to the Social Care (Self-Directed Support) (Scotland) Act 2013.

**Website:** http://www.selfdirectedsupportscotland.org.uk/

### The Scottish Government

To access general information pertaining to Health and Social Care, The Scottish Government's website offers up-to date information, as well as access to various links to other organisations which you may find useful.

**Website:** http://www.gov.scot/Topics/Health

## The Knowledge Network

The Knowledge Network is Scotland's source of knowledge for health and social care. The website offers a vast array of informative resources on Self-Directed Support and is helpful to develop a much deeper understanding of what SDS is.

**Website:** http://www.knowledge.scot.nhs.uk/home/portals-and-topics/self-directed-support.aspx

## The Care Inspectorate

The Care Inspectorate are the official body responsible for inspecting standards of care in Scotland.

Their website contains detailed information on using care services; finding care services; inspection reports; statistics and publications; and raising concerns or complaints. Additionally, you are able to access a dedicated site which allows you to share your opinion on your relative's use of social care services and also find out what others are saying about specific services.

**Website:** http://www.careinspectorate.com/index.php

## Scottish Public Services Ombudsman (SPSO)

The SPSO is the final stage for complaints about councils, the National Health Service, housing associations, colleges, The Scottish Government, and its agencies and departments and most Scottish authorities.

The SPSO website explains the process for making complaints and also provides useful information leaflets and resources. In addition to this, you can contact the Freephone advice line for assistance on: 0800 377 7330

**Website:** http://www.spso.org.uk/

# SECTION 6: GLOSSARY

# A

**Additional Support Needs** – A child or young person is said to have additional support needs if they need more – or different support – to what is normally provided in schools or preschools to children of the same age.

**Adults Support and Protection (Scotland) Act 2007** – is legislation which seeks to protect adults who are 'at risk' from being harmed and who would find it difficult to stop harm from happening to them.

**Adults with Incapacity Act 2000** -- This creates provisions for protecting the welfare of adults who are unable to make decisions for themselves because of a learning disability or an inability to communicate.

**Advocacy** - A service that helps get a person's voice heard, offers options and safeguards their rights.

**Arranged Service (Option 3)** - This means that after discussing with the service user or family carer, the local authority will arrange and manage the package of support on behalf of the person.

**Assertive** – being able to stand up for your own and others people's rights in a calm and positive way, without being either aggressive or passively accepting 'wrong'. Assertive individuals are able to get their point across without upsetting others or becoming upset themselves.

**Assessment of Need** – is an assessment which is carried out by Social Work to identify needs for services. This is different from a Carers assessment.

# B

**Body language** – the conscious and unconscious movements and postures by which attitudes and feelings are communicated.

## C

**Carer** - An adult that provides unpaid care to a relative, friend or neighbour. Care includes providing practical help, assisting with medication, providing emotional support and company to the cared for person.

**Carers Assessment** - A process where the carer's needs are assessed in their own right. A carer has a right to have a carer’s assessment if they are providing regular and substantial care. This can be carried out independently of a Care Needs Assessment/Single Shared Assessment/Integrated Care Assessment for the cared for person. Services can be identified for the carer as a result of a Carers Assessment, although it is dependent on what the local authority assess the carer as needing, in order to carry on caring.

**Carers (Recognition and Services) Act 1995** – This legislation legally recognised carers. It established carers’ right to have their own separate Carers Assessment during the assessment process for the cared-for person.

**Carers (Scotland) Act 2016** – This legislation will be implemented in April 2018 and will ensure that better and more consistent support is available to carers. The Act will introduce a range of provisions to identify, assess and support carers.

**Children (Scotland) Act 1995 -** Under Section 23 of this legislation, disabled children are entitled to a social work assessment as requested by their parent/guardian. The assessment should consider all the help that the disabled child needs, the needs of any other children in the family (including any care provided by a young carer) and the help that a parent may need to care for their disabled child.

**Child’s Plan** – is a single planning process which is coordinated by a Lead Professional to provide your child with the extra support required to meet needs and improve their overall wellbeing.

**Children and Young People (Scotland) Act 2014** - This legislation furthers the Scottish Government’s ambition of improving the wellbeing of children and young people in Scotland by taking forward key elements of the Getting It Right For Every Child approach (GIRFEC).

**Community Care and Health (Scotland) Act 2002** – This legislation gave carers who provided ‘regular and substantial care’ the right to a Carers Assessment independent of the assessment process for the person being cared for.

**Coordinated Support Plan (CSP)** - Services and interventions that are identified as being required to support a child who has additional support needs in school. CSPs have legal status and must be met. A referral to an Additional Support Needs Tribunal can be made if these needs are not being met at school.

**Co-production** - The concept where a care package is developed equally between the service user and/or carers and professionals from social services and others.

## D

**Direct Payment (Option 1)** - This is where payments are made by the local authority to the service user or Financial Guardian, allowing the person to choose, organise and buy support.

## E

**Education (Additional Support for Learning) Act 2004 (amended 2009)** - Legislation that recognised 'additional support needs' for children and laid down processes of how children could get their needs written into formal plans.

**Emergency Planning** - Process of creating a plan to keep the cared for person safe and their needs met if the carer becomes temporarily unable to care, through illness or accident.

**Equality Act 2010** - Legislation that brought together a number of anti-discrimination laws and also protects carers against discrimination by association with a disabled person.

**Equivalence Model** - is a system that relies on the professional judgement of the social worker to establish the level of budget. They decide what support they would normally provide to the person with social care needs and then monetise that service into the form of an indicative budget.

## F

**Financial Assessment** - When the income of an individual is assessed to calculate any contribution they are to pay towards the cost of their assessed service/s. Couples are usually assessed jointly, even if there is only one person who requires services.

**Financial Guardian** – The legal status of someone who has been given powers by the local Sherriff Court to decide on the financial decisions of someone who cannot make decisions for themselves.

**Flexible Working** - When an employee can work hours that enable them to take part in paid work alongside other responsibilities such caring. An employee can ask for flexible working once every year and the employer must give a specific business reason if they do not agree to flexible working.

**Future Planning** - Process of creating a plan to keep the cared for person safe and their needs met if the carer becomes unable to care in the future.

## G

**Getting It Right For Every Child (GIRFEC)** - a Scottish Government set of principles to ensure that all children and young people get the best start in life, by ensuring that the people involved in supporting the child or young person work together seamlessly to give the child the support they need and at the right time to enable them to achieve their specific outcomes.

## I

**Income Maximisation** – a service which can provide advice, guidance and assistance to ensure you receive your full entitlement to a range of welfare benefits.

**Indicative Budget** - a working budget that is estimated and used as the basis of the Outcome Based Support Plan.

**Individual Budget** - an amount of money that is agreed by the social work department as necessary to meet assessed care needs.

**Individual Service Fund (Option 2)** - An ISF is where payments are made by the local authority to a third party; this could be a specific care provider, agency or the local authority, who will manage the allocated budget and spend it on the support that the service user or family carer on behalf of the person, has instructed they would like.

## M

**Mediation** - Intervention to help resolve disputes between service users and service providers providing an impartial voice and facilitating more understanding on both sides to resolve difficulties. Also used with couple disputes over custody of children. All parties must agree to mediation.

**Mental Health (Care and Treatment) (Scotland) Act 2003** – the purpose of this legislation is to increase the rights and protection of people with mental disorders, which encompasses people with learning disabilities. It also details how someone with learning disabilities can be given care and treatment and sets up a 'named' person who helps protect the rights and interests of the person receiving treatment.

**Mindfulness -** Mindfulness is a method of meditation which aims to promote wellbeing and reduce stress. It focuses on breathing techniques and self-awareness. The practice of mindfulness falls into two categories, guided and self-directed meditations.

**Mixed Options (Option 4)** - This is where you are able to choose from the combination of Self-Directed Support Options 1, 2, and 3.

## N

**Named Person** - Part of the Mental Health (Care and Treatment Act) (Scotland) that enables a person with mental illness/learning disability to have someone to support their interests in their treatment under the Act. The named person has rights in mental health tribunals. A family member/carer can become the named person and automatically becomes the named person if no-one is given this role.

## O

**Outcomes** - A result that the service user would like to achieve as a result of the support they have received.

**Outcome Based Support Plan** - A plan that professionals, the service user and carers create to provide the person with the services that meet their specific care outcomes.

## P

**Patient Rights (Scotland) Act** 2011 - This legislation gives the service user the right to have healthcare which considers their needs and promotes active participation in discussions regarding one's health. The Act recognises that carers play a key role in supporting the person they care for to have their voice heard and that carers views, regarding their relative's care and treatment should be taken into account when planning and providing care.

**Payroll Service** – is used by some service users or their carers to manage their budget under Option 1. This type of service will typically be able to offer to register you as an employer with HMRC; register all your employees; communicate with HMRC on your behalf; calculate and pay your PA's salary; calculate and pay HMRC income tax and National Insurance contributions deducted from your PA's earnings; and calculate and pay your employer's National Insurance contributions from your designated account.

**Personalisation** - the concept of services being more personalised to the needs of individuals, rather than people fitting around service design.

**Public Bodies (Joint Working) (Scotland) Act 2014** - Legislation that compels local health boards and social work departments to work in a co-ordinated way in the delivery of services to adults in Scotland and which has created Health and Social Care Partnerships.

## R

**Resource Allocation System** – is a system which translates identified social care needs into points, which are then used to calculate an indicative budget in which to base the Outcome Based Support Plan on. A large proportion of local authorities in Scotland use this system.

**Respite** - A break from caring or being cared for. Carers and service users are entitled to respite, however how much someone gets is dependent on how much the local authority assess you as needing.

**Risk Management** - The assessment process should assess the risk that the proposed care package may imply. Carers/Welfare Guardians should have the opportunity to express their views on where risks of the care package may outweigh its benefits, and potentially, where benefits to the person may outweigh the risks. Where there are concerns around the level of risk, a formal risk assessment should be requested.

## S

**Self-Directed Support** - A mechanism to deliver social care support, which offers service users choice and control over how their care packages are delivered.

**Self-Directed Support Strategy 2010-2020** – The Scottish Government's ten year strategy, with the purpose of driving a cultural shift in the way that the provision of support is delivered in Scotland.

**Service User** - Someone who uses a publicly or privately delivered service to meet their assessed needs. This includes children with assessed additional support needs, someone using day care or residential care.

**SHANARRI** – at the heart of the GIRFEC framework is the 'wellbeing' indicators which compose the SHANARRI acronym. These are: safe, healthily, achieving, nurtured, active, respected, responsible and included.

**Short Breaks** - Holidays away from the usual routine. Available to service users and carers, based on assessed need. Also known as respite. Short breaks is a more modern term and describes more creative and individual breaks that are available.

**Social Care (Self-Directed Support) (Scotland) Act 2013** - This piece of legislation brought into statute the ambitions of the Scottish Government's ten-year vision for Self-Directed Support (SDS) to become the mainstream way in which social care is delivered. The Act places duties on local authorities to offer a range of self-directed support options to children and adults with assessed support needs, so that social care services are delivered in a way best tailored to meet their outcomes.

**Social Work Assessments**– are often termed interchangeably by different local authorities. They can be called: 'care needs assessment'; 'single shared assessment' or 'integrated assessment'. They all refer to an assessment which is carried out by Social Work to identify needs for services. This is different from a Carers assessment.

## W

**Welfare Guardian** - The legal status of someone who has been given powers by the local Sherriff Court to decide on the welfare decisions of someone who cannot make decisions for themselves.

**Work and Families Act 2006** - UK legislation that gives family members the right to ask for flexible working to fit around caring responsibilities. There is no right for the employee to be given flexible working, but the employer must give a good reason to refuse the request.

## Y

**Young Carer** - Someone under the age of 18 who provides care to a relative, friend or neighbour. Care includes providing practical help, assisting with medication, providing emotional support and company to the cared for person.

**The PAMIS Self-Directed Support Team noted below produced and published this information document.**

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**_PAMIS_ is the only organisation in Scotland that works solely with people with profound and multiple learning disabilities and their families for a better life.**