

FACTSHEET:

Self-directed Support (SDS) for Children What to Expect - Information for Parents



1. What is self-directed support?

Self-Directed Support (SDS) is the mainstream way of providing social care support in Scotland and is the mechanism which supports independent living. It means having rights to practical assistance and support that children need to reach their full potential, participate in society and live an ordinary life. In particular, it provides the opportunity for children and families to take greater control over the support provided to them.

In 2022 updated SDS guidance specifies that it is 'designed to ensure that what matters to the child is central to every decision made.'

You know your child best and so you are in the best position to make informed choices and decisions about what support is right for them.

SDS is not a benefit and does not affect any benefits that your child already receives. SDS funding is there to meet a person's assessed need for social care and support.

2. Children with neurological conditions and SDS

The likelihood that a child with a neurological condition needs additional support can be high. Sometimes children are born with a neurological condition like epilepsy or neural tube defects like spina bifida.

Others can be caused by brain injury, including birth injuries, or infections like meningitis.

These conditions, and other less common conditions, can cause a range of behavioural and learning challenges.

SDS is there to support this.

Regardless of whether a child was born with a neurological condition or whether it developed later, they will often have additional needs. Any child with additional needs is entitled to have those needs assessed by a social worker, and if this results in care or services being required, SDS provides the framework for conversations with you - and your child - about the best way to meet those needs. This assessment of need and access to how support is provided is not dependent on a diagnosis.

We want to help more people get the support they need by raising awareness of SDS.

3. How do you access SDS – which professionals can help?

In order to assess your child's requirements, the local authority will need to meet you and your child and have a conversation about your child's support needs. This is called an assessment and is usually done by a social worker.

If you think your child may benefit from an assessment of their needs, contact your local social work children's services team. If your child already has a child's plan and professionals involved in working with you, speak to them first.

Many local areas have independent self-directed support organisations, and we would encourage you to contact your local support organisation for help and advice.

<https://www.sdsscotland.org.uk/>

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4. What would you use SDS for?

Once your child's needs have been assessed, whoever did that assessment will speak to you about the best way of meeting those needs. For example:

- Develop their social skills by mixing with other children at a local club
- Develop their co-ordination and core mobility skills by attending riding for the disabled or swimming
- Pay for additional support during school holidays or outside of school
- Equipment that helps physical and developmental wellbeing

Your social work team needs to agree that these and any other activities are important for your child to thrive.

5. The assessment process

There are some useful steps you can take to prepare for an assessment. Make a note of the following before you call your local authority:

- Your child's medical history, reports and assessments
- Information about your child's condition, including from a charity or the NHS
- Any medical challenges your child has
- Highlight other organisations or professionals involved in your child's care
- Highlight if they have a carer
- Be upfront about adjustments needed

The assessment is a conversation with a social worker about what your child needs to live to their full potential, so it's important to be open about everything.

If carers are involved, they may be asked to contribute their thoughts to what your child needs.

You may like to include other people in this process, for instance, a family member, a friend, a support worker, or a professional.

6. Children - who can make decisions

If your child is aged under 16, you will be responsible for deciding how to receive the SDS budget. You need to consider your child's views on what support they might need. As your child grows up they might like to be more involved and take more responsibility for their support.

7. Transition age: 14 - 18

The move from childhood to adulthood can be difficult for all young people and their families. Young people start to take more responsibility and control for themselves. For those with additional support needs, this is a particularly important time and early planning is important.

ARC Scotland have developed useful information and supports for both children and their families called Principles in to Practice, which helps to navigate through this period.

This can be found at <https://scottishtransitions.org.uk/>

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8. Young people, 16 - 17

Young people who have capacity to make their own decisions can start to receive SDS payments themselves from the age of 16 and they can decide how to use it.

For those without capacity, parents need to apply for legal authority to receive the funding and continue to manage it on behalf of their child.

Once your child's needs have been assessed, the social worker or assessor will speak with you about the SDS options and which are best for you and your child.

There are four options:

Option 1: A direct payment where the council gives you the money you need to pay for your child's support

Option 2: You agree that someone will arrange the service of your choice on your behalf

Option 3: An arrangement, where the local authority identifies a service you would be happy to use and they arrange this for you

Option 4: A mix and match of any of the other 3 options

9. Support for family and friends who are carers

Many people who care for friends or family members do not recognise themselves as carers. It is important that unpaid carers are aware that SDS can also apply to them. This is the case even if the person they care for is already in receipt of support under SDS or they live in a different area.

Carers have to be offered an Adult Carers Support Plan (ACSP) or a Young Carers' Statement (YCS). This enables them to have a 'good conversation' about their needs as a carer and be connected to relevant local support.

If the carer meets local eligibility criteria, they could be offered an SDS budget in their own right, to give them a break from their caring role, or to support their own health and well-being.

ACSPs and YCSs are often carried out by local carers centres. You can find more details and helpful information for carers from the Coalition of Carers: <https://www.carersnet.org/>

To find your own local authority contact details, click 'find help' on: <https://www.sdsscotland.org.uk>

"We use our daughter's SDS budget to employ Personal Assistants - doing all the recruitment ourselves. This means we can employ people who are flexible enough to suit our daughter's needs".

Parent of a young person with ME

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9. Communication and capacity

For some people, their neurological condition can make them unable to speak or communicate effectively even though they may be fully cognisant and aware of what is going on around them.

It is important not to confuse difficulties with communication with difficulties in understanding.

Children and young people may need additional support to communicate their views to health and social care staff. Family members and carers might be very helpful in supporting this.

Some people also may need the support of an independent advocate, who can help people get their views across to relevant professionals. You can find details of local advocacy services from the Scottish Independent Advocacy Alliance (SIAA): <https://www.siaa.org.uk/find-an-advocate>

For updated SDS guidance see:
<https://www.gov.scot/publications/statutory-guidance-accompany-social-care-self-directed-support-scotland-act-2013-2/>

Self Directed Support Scotland
Contact us on:
info@sdsscotland.org.uk
Scottish charity no: SC039587
Company registered in Scotland:
SC371469

Neurological Alliance of Scotland
Contact us on:
info@scottishneurological.org.uk
Scottish charity no: SC048555

10. What to do when things change

We all know that things can change, sometimes very suddenly. Even if someone's circumstances change soon after an assessment, they should ask the local authority to review their needs. This includes a deterioration in the person's condition or if their carer is finding it harder to support them.

With rapidly progressive conditions, such as some forms of muscular dystrophy, and fluctuating conditions such as ME, timescales on reassessments can be difficult to manage and can require short term planning. If someone thinks their need for support is critical, they should ask for support as soon as possible.

More information about SDS:

There are now Independent SDS Information and Support services in all local authorities in Scotland. They help local people to apply for the support they need.

<https://www.sdsscotland.org.uk/>

Thanks to these NAOs member organisations for helping to produce this document



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