

The logo features the text "My support my choice" in white, with "My" and "my" in a smaller font above "support" and "choice". The text is set against a blue, cloud-like shape. This central element is surrounded by several overlapping speech bubbles in shades of orange, yellow, and pink, all set against a solid orange background.

My
support
my
choice

My Support My Choice:

People with Learning Disabilities' Experiences of Self-directed Support and Social Care

Thematic Report, December 2020



Easy Read Version



SCLD Easy Read written by SCLD

What is this Easy Read About?



This is an Easy Read Version of another report.



The full report is called “My Support My Choice: People with Learning Disabilities’ Experiences of Self-directed Support and Social Care in Scotland”



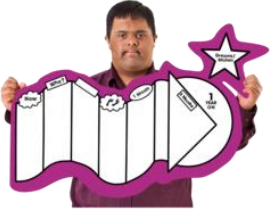
This is part of a collection of reports.



This report is about the answers that people with learning disabilities gave to some research questions.



The research was done by Self Directed Support Scotland and The Health and Social Care Alliance Scotland.



This report is about how **Self-directed Support** has been for people with learning disabilities.



Self-directed Support is a way of organising the support that people get.



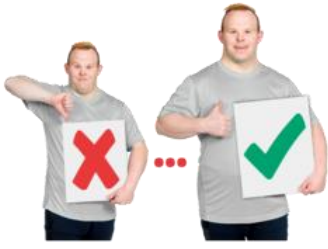
124 people with learning disabilities told the researchers about their experiences.



This was all done before the COVID 19 lockdown so does not talk about any changes that have happened because of that.



Most people with learning disabilities said Self-directed Support had made things better.



There are some things that could be made better.



There are some recommendations in this report.

Not having enough money



Quite a lot with people with learning disabilities live below the **poverty threshold**.



The **poverty threshold** is the amount of money you need to have to live a good life.



If people do not get a Self-directed Support budget or their budget is cut they might not have enough money to get support.



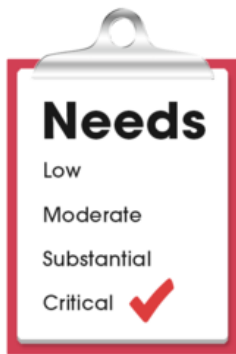
If people do not have enough support they cannot live a good life.



Family or Friends might need to give support without being paid.



The report recommends that care is taken to make sure that cuts to Self-directed Support budgets do not leave people with learning disabilities without enough money to get the support they need.



If there are changes to who can get a budget then it is important that this does not leave people missing out on care because they cannot afford it.

Collecting information and what it tells us



Not enough information is collected about Self-directed Support.



It is important that we know who has got a budget.



Information does not always tell us when a person has a learning disability.



The report says it is very important that collecting information gets better.



It is important that we know as much as possible about who is and who is not getting a budget and support.



Knowing this information helps us to make sure the system is fair.

Experiences of Self-directed Support



Some people with learning disabilities said they had a good experience with Self-directed Support.



Other people said they had a bad experience with Self-directed Support.



Most people said their experience of social care was better since getting Self-directed Support.

Getting information about Self-directed Support.



People got information about Self-directed Support from different types of places.



Lots of people said it was easy to get information.



Some people said it was difficult to get in touch with social work when you were trying to get Self-directed Support.



People with learning disabilities said their questions were not answered more often than other people.



Most people said meeting their social worker in person was really important.



People said they needed good information to be given to them before making decisions about support.



Some people were not given information that was accessible for them.

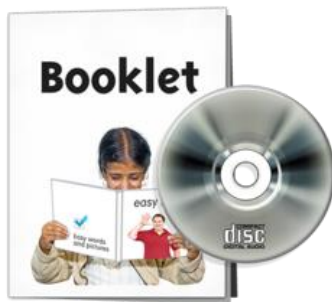


Some people had asked for accessible information and have still not got it.

These are the recommendations the report makes about information.



People need to be able to get good clear information about Self-directed Support and social care.



Information needs to be available in a range of different types for example Easy Read.



Information should be given to people when they need it.



This means that different bits of information should be given before assessments, during assessments and once support is in place.



The report recommends people with learning disabilities should be told about all 4 options available for the budget.



The report recommends that people with learning disabilities should be supported to think about all 4 options before making a decision.



People who work in Health, Education, Housing, Addictions and communities need to be trained so that they can tell people about Self-directed Support and how to apply.



People with learning disabilities need to have information that they can understand.



There needs to be some work done to make sure information gets to people with learning disabilities.



There needs to be information for people with learning disabilities that tells them what to expect from their social worker.



There needs to be information for people with learning disabilities that tells them about their rights.



People should be given information that tells them when they can expect to get decisions about their budget and support.



People should get clear information telling them who makes decisions about their budget.



There needs to be enough time for meetings so that people have time to ask questions and get answers.



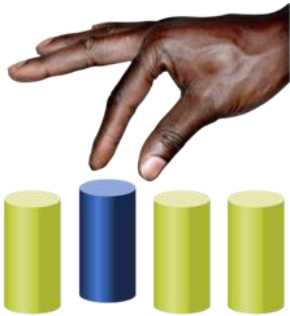
People need to be given enough time to understand and think about the 4 options.



Some professionals need more information and training to help to support people to make decisions.



Some professionals need more information and training to help them to talk to people about all of the options available.



People should be supported to understand what is good and bad about each of the options before they make their decisions.



Parents and other unpaid carers should be encouraged to do carers assessments and get the support they need.



Social workers should have time to read people's files and get to know them before starting the assessment.



Social work staff should make sure to check with people that everything is going well after their support has started.



There needs to be different ways to contact social work that suit different communication needs.



These ways to get in touch should include phone, email and online chat.



People with learning disabilities should have the support of **an advocate** if they want and interpreters if they need them.



An advocate is someone who can help you to understand your rights and to speak up for yourself.



People should be given copies of all of the paperwork about their assessments in a way that they can understand.



People with learning disabilities should be offered support to understand and make good decisions about their money and the charges they have to pay for care.

Making choices and having control



Most people with learning disabilities felt fully involved in decisions about their care and support.



Most people with learning disabilities said they had chosen their favourite option.



Most people said they were given enough time to make their choices.



Most people said they had been given information about their personal budget.



Most people said they were given a choice about who manages their budget.



Some people had to wait a long time for their assessment.



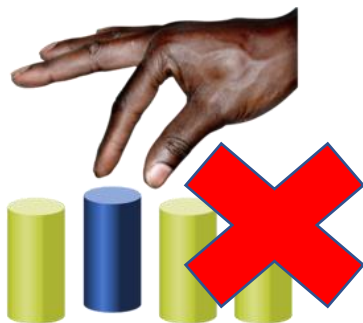
When people had to wait a long time this made them stressed.



People who spoke to the researchers said they wanted more information about how long you should be expected to wait.



People with learning disabilities often said that waiting for answers made their Self-directed Support process more difficult.



People with learning disabilities were less likely than other people to have been able to make their own choices about their support.

These are the recommendations in the report about Choice and Control



The report recommends that social workers are given training in **supported decision making**.



Supported decision making is when the person is given the information and support they need to make their own decisions.



Sometimes social workers make decisions for the person.



The report says people with learning disabilities need to be treated with dignity and respect.



People should be given longer than a week to think about their options and make decisions.



It is important that people do not have to wait a long time for each part of the process.



Waiting makes people more stressed.



Waiting to get support put in place can make people's health get worse.



People with learning disabilities should be given enough notice before they have a review or assessment.



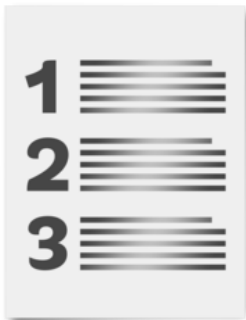
People with learning disabilities must be offered all **4 options**.



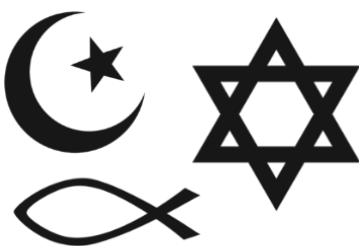
The **4 options** are the different ways you can manage your budget.



Support must be based on their needs and wishes.



Social workers should give people an easy to understand list of all the different support providers and services available to them.



Assessments need to make sure they are right for the person and their needs and wishes.

This includes understanding their religion, culture, sexuality or health needs.



If a person's package is changed this can be bad for the person's mental health.



Staff need to help the person through this and help them to get support somewhere else if they need it.



People should not be made to feel pressured to move into a residential care home if they do not want to.



People should have support to help them to stay at home if it is possible.



People need to be able to change their support if their life changes.



Respite is an important part of a package for a lot of people.

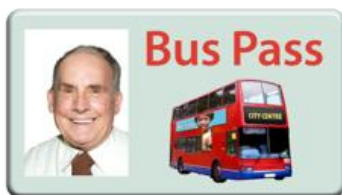
Social workers should be encouraging people to use their budget to get respite.



People with learning disabilities need to have travel costs included in their budgets.



Travel costs can be especially high if you live in the countryside.



People should be given help if they need it to get funding for mobility cars or travel passes.



Social workers need to make sure they are treating everyone fairly.



They should do a type of assessment called an **equality assessment** to make sure they are being fair to everyone.

Communication and relationships with social work



People said that it is important to have good relationships with social workers where there is trust.



People said it is important to have the same social worker throughout the process.



People said good and clear communication was very important.



Most people said they found their assessments and reviews to be fine.



Some people said they did not always get answers to the questions they asked.



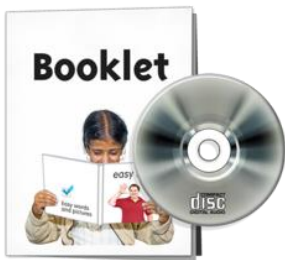
Some people said that they were not treated well by social work or social care staff.



People with learning disabilities need to have clear answers about how decisions are made and who made them.



Information needs to be easy to get hold of.



Different communication methods need to be available.



Some people say it is hard to get copies of their paperwork.



People said it was hard to get information about how to make complaints.



Some people said they were ignored when they made choices particularly about where they wanted to live.

These are the things the report recommends about communication and relationships with social work



The report recommends social workers get time and skills to build relationships and trust with people.



People with learning disabilities should be informed if their social worker changes.



People should be told they have the right to change social worker if they do not feel they have a good trusting relationship.



There should be good records kept of what people say in assessments and reviews so that it can be shown that they have made choices themselves.



Social workers need to get training to help them to understand that they might not always be treating everyone the same.



Social work staff need to ask people for their feedback so that they can make things better.



Social work staff should tell people how to complain and how to say if they are unhappy with decisions.



Social work staff should tell people how to get support from advocacy and advice places.



It is important that the whole process of Self - directed Support is clear so that people know how to get a budget, what they can spend it on, how decisions are made and how to complain if they are unhappy.

Families, relationships, and Self-directed Support



Some people said they have better relationships since getting a budget.



The report says social workers should respect people's wishes if they do not want their family to be their main carer

These are the report's recommendations about Self-directed Support and families.



The report recommends that carers are offered assessments and their rights explained to them.



People said that it is important social workers do not expect families to give care for free.



They should also not always think that a person wants to be given care by their family.



When family members say they want to give less unpaid care they should get support from social work to make this happen.

Getting good support staff



Some people find it difficult to recruit support workers.



Some people had difficulty with finding good training for support workers.



People said good support workers made a positive difference to their lives.



Some people with learning disabilities said they would like some help to arrange staff training.

These are the report's recommendations about getting good support staff



Some people need more help from local councils to recruit and train care staff.



Local councils need to work with people who get Self-directed Support and their families to make it easier to get good staff.



Self-directed Support budgets should include enough money for any training that support-staff need.



There needs to be training for staff in social work and social care to help them to work with people who have had bad experiences with social care staff in the past.

Independent advocacy and support



People with learning disabilities said that having an **advocacy worker** is really helpful.



An **advocacy worker** is someone who can help you to speak up for yourself.



An **advocacy worker** can make sure you understand your rights.



Independent advice is very useful for people too.



Peer support is also useful so that people who have already been through the process of getting a budget and support can tell others about it.

These are the report's recommendations about independent advocacy and support.



The report recommends that there is enough money given to make sure that advocacy and advice is available to everyone who wants it.



The report recommends that people who work for the local councils are given training and information about advice, support and advocacy.



This will help to make sure they tell people with learning disabilities that it is available.



People who work for local councils should help people to get in touch with advocacy and advice services.



Social workers should give people easy to understand information about advocacy and support.



A free independent helpline should be set up to answer questions about Self-directed Support.



Local networks of people who have already been through the process should be set up.



You can read more about this research by following this link

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

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