







**Easy Read Version** 



Easy Read written by SCLD

## My Support My Choice



This is an easy read version of an **Executive Summary.** 



An **executive summar**y is the most important parts of a bigger report.



The full report is called My Support My Choice: People's Experiences of Self-directed Support and Social Care in Scotland.





This report is about research done by Self Directed Support Scotland and The Health and Social Care Alliance



This report tells you what was found out from doing the research.



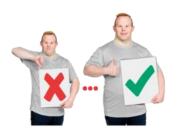
The research was about **Self-directed Support** in Scotland.



**Self-directed Support** is the name given to a way of organising the support you get.



It is supposed to make sure you get a choice about what you do with your support, where you get support and who gives you support.



The research wanted to find out what was going well and what needs to be better.



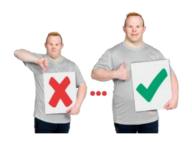
We did the research before coronavirus and before lockdown.



The researchers heard from 637 people who had been assessed for or been given a budget.



People said that Self-directed Support is very important to help them live independently.



People said some things need to improve.

## Poverty and Self-directed Support



The report says that if there are changes to a person's Self-directed Support budget it can mean they are left without enough money.



People sometimes have to go without any support because they do not have enough money to pay for it.



When people do not get the support they need it can affect their health.



When people do not get the support they need sometimes family or friends have to become unpaid carers.



This is harder for people who are already struggling with money.



Organisations must make sure that people do not have to go without support because they cannot afford it.

# Collecting and understanding information



It is important that enough information about who gets a budget is collected.



The information we collect just now is not good enough.



It does not tell us about some groups of people.

# Getting information about Self-directed Support



Many people said that the information they got about Self-directed Support was good.



These are some things that people said should be better.



It should be easier to contact a social worker when you are asking for support for the first time.



People need better information at the start.



People need more information about the 4 Self-directed Support options.



Lots of people said they were not told about all the options.



There are four different ways you can have more control over your own support.



You can choose which one you want.



These are called the 4 options.



The information needs to say what is good and bad about each option.



Information needs to be more accessible and in different formats.



People need better information at the start and when they are being assessed.



Women got less information given to them than men did.



These are some groups that need better information about Self-directed Support.



Older people.



Black and minority ethnic people.



Women.

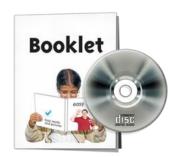


People that have been homeless.

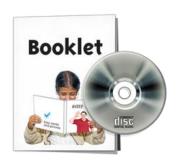


Young people.

# What the report says would make things better



Everyone should be given good quality information about Self-directed Support.



The information should be given in a way the person can understand.



The report says more work needs to be done to get good information to some people.

## Being in control of your choices



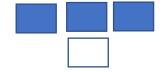
Most people had time to choose the option that they wanted.



Some people had to wait too long to be assessed.



These people found it stressful to get their Selfdirected Support sorted out.



3 people out of 4 are on the Self-directed Support option that they wanted. This is good.



But 1 person out of 4 is not on the Self-directed Support option that they wanted. This is not good.



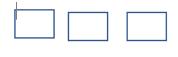
It means that someone else made that choice for them.



Social workers are supposed to help the person make a choice but sometimes they chose for them.



Most people were able to choose who managed their budget for them.



1 out of every 4 people said they were given no choice.



Lots of people said that having flexible support was really good.



There were differences about what people could do with their budget depending on where they live.



Some people said they have had cuts to their budget and now get less support.



They said this has made their physical and mental health worse.



These are some people that do not get the same chance to make their own decisions.



People with learning disabilities.



Women.



People who are homeless.



People who live in areas where people often have less money.

## What the report says would make things better



Social workers should be trained how to help people make their own decisions.



People should work hard to make sure that everyone gets the support they need to make good decisions.



It is important that the assessment and support works for everyone.



This means there needs to be different ways of doing things that suit different people.



No one should be pressured to move into a care home if they do not want to.



It is important to help people to stay in their own home with the right support.

## Communication and relationships with social work



People said good relationships with social work are important.



There needs to be trust between social workers and the person.



Communication needs to be clear and they need to be easy to contact.



Some people said they had good experiences.



Other people said they did not get answers to all of their questions.



Some people said they were not always treated with respect by social work or social care staff.



A small group of people said they felt bullied harassed or treated unfairly.



Lots of people said it needed to be clear how the decisions were made.



Lots of people were not sure who made their budget decisions.



Information needed to be easier to get.



There needs to be better use of different ways to communicate.



Some people found it was difficult to get copies of their own paperwork.



Some people said it was hard to find out how to make a complaint.



People with mental health problems often said they felt they were not treated fairly and were not listened to about their choices.

## What the report says would make things better



Social workers need the time and skills to build good trusting relationships.



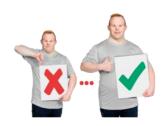
People should be told quicker if there is a change of social worker.



People should be able to change their social worker if they do not have a good relationship.



Social work should ask for people's views and experiences regularly.



This will help them to get better.



Information should be given to people and their families so they know how to complain or ask questions.



People should be told how to get support from an advocacy worker.



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



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



People should be told how to make a complaint.

## Families, relationships and Self-directed Support



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



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.



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

## Mental health and Self-directed Support



People said that if they get good support it helps their mental health.



But mental health is made worse by not getting good support or by the assessments being bad.



It is important that any effect on people's mental health is thought about when doing the budget.

## Support staff recruitment and training



People said it can be hard to find good care staff or personal assistants.



Support is needed to help with recruitment and training of staff.



Local councils need to work with people who have Self-directed Support to try to make this work better.

# Advocacy and advice



People said advocacy and advice is really helpful.



There needs to be promotion of advocacy so that all groups of people know it is available.



Peer support networks are also useful.

# The recommendations that are in the report.



This is an easy read version of the report's **recommendations**.



The **recommendations** say what people should do.



There are 66 recommendations.

## Self-directed Support and not having enough money



Some people who get Self-directed Support do not get much money.



If changes are made to their support or the amount of money in their budget this can make them unwell and stressed.



### Recommendation 1.

National and local organisations should make sure that these people do not get physically or emotionally unwell.

### Information about Self-Directed Support



#### Recommendation 2.

**Public bodies** need to get better at collecting information about people who are applying for Self-directed Support.

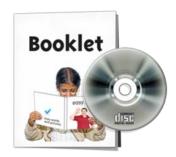


**Public bodies** are organisations like local councils, the Scottish Government, The NHS and the Health and Social Care partnerships in each local area.



### Recommendation 3.

People need the right information about Selfdirected Support at the right time.



Different people need this information in different formats.



### Recommendation 4.

More professional people need to know about Self-directed Support.



They need to know who can help people apply for Self-directed Support .



### Recommendation 5.

There needs to be better communication for older people and people from Black and ethnic minority communities.



### Recommendation 6.

Some people need information that is especially for them.



Women, homeless people and younger people need special information.



### Recommendation 7.

Some people might need special information depending on how well off they are and where they live.



### **Recommendation 8.**

Information for people should include information about their rights and information about what social work can do for them.





People should be told how long they need to wait for decisions to be made.



They should be told who will make each decision and when.



#### Recommendation 10.

Social work must give people enough time to think about the 4 Self-directed Support options and which one they want to choose.



### **Recommendation 11.**

Social Workers might need training about Selfdirected Support.



### Recommendation 12.

People should be given information about all 4 Self-directed Support options so that they can choose for themselves.



Some people only get told about some of the options.



### Recommendation 13.

There should be support for people to think about what is good and bad about all 4 Self-directed Support options.

## Making support plans.



### Recommendation 14.

Unpaid carers should be given support to understand Self-directed Support and to complete assessments to see what help they need.



#### Recommendation 15.

When people go into hospital they should have a plan for their care. This is called an **emergency** support plan.



After people come out of hospital they should think about how well the **emergency support plan** worked.



They should decide if the plan needs to be changed.

## Getting the right help to apply for a budget.



Recommendation 16.

Social workers should have time to get to know the people they support and time to prepare properly for meetings.



Recommendation 17.

Social workers should talk to people after their assessment and make sure they are happy with everything.



Recommendation 18.

Social workers should make sure that people can communicate with them in a way that suits them.



Recommendation 19.

People should always be able to have an advocate to help them apply for Self-directed Support.



### Recommendation 20.

People should always be given all the information about their Self-directed Support.



This information should be in a format that suits the person.



### Recommendation 21.

Everyone should be told how much money they are being given to pay for their support.



### Recommendation 22.

People should be able to make their own decisions about money.



They should be given all the support they need to understand the money situation.



### Recommendation 23.

If there is going to be a change to the **social care charge**, people must be told in plenty of time.



The **social care charge** is money that people have to pay for their support.

### Making choices and having control



### Recommendation 24.

People should have more than 1 week to decide which Self-directed Support option they want.



### Recommendation 25.

There needs to be improvements made to make sure that every gets through the process quickly.



Waiting a long time for a budget and support to be sorted causes stress and can make people ill.



### Recommendation 26.

Social work should make sure that people have enough time to prepare for their assessments and other meetings.



#### Recommendation 27.

Social workers should make sure that people have the support they need to decide which of the 4 Selfdirected Support options they want.



#### Recommendation 28.

Social workers should get training in how to give people the right information and support to make their own decisions about Self-directed Support.



Sometimes they make decisions for people instead of helping them to make their own decisions.



### Recommendation 29.

Social work needs to make a special effort to make sure that some groups of people get the information and support they need.



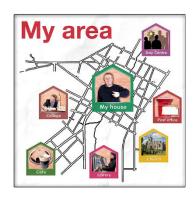


The report says that women, people who are homeless and people living in the poorest areas do not always get the information and support they need to make their own decisions.



## Recommendation 30.

Social work should make sure that people with learning disabilities and people from Black and ethnic minorities are treated equally and fairly.



### Recommendation 31.

Social work should make sure that people who live in villages and in the countryside are able to choose any of the Self-directed Support options.



All the different kinds of support should be available to them.

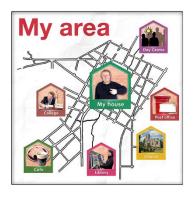


They should not have to pay more or move house to get the same support as other people.



#### Recommendation 32.

Support for disabled parents must be fair and equal.



### Recommendation 33.

Social workers should tell people what services are available in their area.



## Recommendation 34.

Assessments need to be right for the person and their needs and wishes.

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



## Recommendation 35.

If a person's budget or support is changed this can be bad for their mental health.



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



## Recommendation 36.

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 should not feel pressured to share support with others if they do not want to.



### Recommendation 37.

The support people get should be flexible so that it can change as people's needs change.



## Recommendation 38.

People should be able to get respite when they need it.

This should be flexible so that it can change as people's needs change.



## Recommendation 39.

People should get the money that it really costs to pay for their travel in their budget.



### Recommendation 40.

People should get the support they need to get travel passes and apply for Motability cars.



## Recommendation 41.

Social workers should do **equality impact** assessments.



**Equality Impact Assessments** are checks that people do to make sure they way they work is fair for everyone.

## Communication and relationships with social work



### Recommendation 42.

Relationships and communication between social workers and the people they work with are important.

Everyone should work at relationships and communication.



## Recommendation 43.

Social workers need time to build up trust and good relationships with the people they are working with.



### Recommendation 44.

People should be told if their social worker changes.

People should be able to change their social worker if they cannot trust them.



## Recommendation 45.

In meetings what people say should be written down. This will show how much say they had over the support they get.



### Recommendation 46.

Social workers should get regular training on LGBT+ issues.



Local support groups for LGBT+ people should get the funding they need.



### Recommendation 47.

Social workers should get all the training they need to make sure that they treat people equally and fairly and kindly.

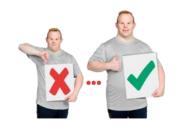


Social Workers should understand it is their job to make sure that people get all their rights.



#### Recommendation 48.

Social Workers should be asking people how well they are doing their job.



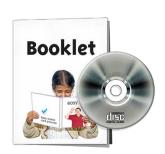
This is so they can get better at supporting people.



### Recommendation 49.

Social workers should give people information about the different ways of asking for a change if they are not happy with a decision.

They should not wait to be asked for this information.



### Recommendation 50.

It should be easy for people to get the information they need about their own Self-directed Support and all the decisions that have been made about them.

# Families and Relationships and Self-directed Support



### Recommendation 51.

Social workers should offer to assess the support needs of all unpaid carers.

They should explain what rights they have to get Selfdirected Support.



#### Recommendation 52.

Social workers should not decide that families have to help to care for someone without asking.

Social workers should help to plan for other people to give care if family cannot.



### Recommendation 53.

Social work should assess someone for paid support if they do not want their family to provide unpaid support.



#### Recommendation 54.

People need to make young people's **transition** easier and better.

**Transition** is the change from being a child to being an adult and from children's services to adult's services.

# Self-directed Support and mental health





### Recommendation 55.

Social work should understand how changes to support or making cuts to support can badly affect people's mental health.



## Recommendation 56.

People should get any support they need to access mental health services.

Mental health services should get the funding they need.

# Getting and training staff.



### Recommendation 57.

Local councils should help with recruiting and training good quality workers for people.



## Recommendation 58.

There should be money for staff training included in people's Self-directed Support budgets.



Some people do not trust workers or social workers because of things that happened in the past.



#### Recommendation 59.

Workers and social workers should be trained to understand this and work to build trust back up.



### Recommendation 60.

Social work and support workers must make sure that they treat everyone equally and fairly with no discrimination.

# Advocacy and advice services



Recommendation 61.

Advocacy and advice services should get the funding they need.



### Recommendation 62.

Advocacy and advice services should be equally available to people from all backgrounds.



### Recommendation 63.

Local council staff should know all about advocacy and advice services so that they can tell people about them.



## Recommendation 64.

Social workers should give people information about advocacy and advice services in the format they prefer.



### Recommendation 65.

There should be a national helpline for people who have questions about Self-directed Support.



### Recommendation 66.

There should be ways for people who use Selfdirected Support to stay in touch with each other and share information.



You can read more about this research by clicking this link

https://www.sdsscotland.org.uk/mysupportmychoice/





