



No Research
About Us
Without Us



Including people with learning disabilities in research projects





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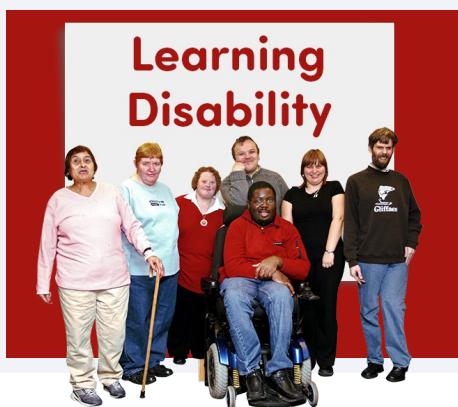
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Introduction



It is important to involve people with learning disabilities in research projects.



Research will benefit from involving people with learning disabilities.



We have written some practical ways people with learning disabilities can have good experiences as researchers in research projects.



Being involved in research projects can help people's confidence and self-esteem (feeling good about yourself).



No Research
About Us
Without Us

We have written this booklet as part of the No Research About Us, Without Us research project.



We have learned lots through this project, and want to share what we learned.

We have split the booklet into sections to make it easier to read.



You can read more about the project on the [Learning Disability England](#) website.

Money



People with learning disabilities should be paid for their time working on projects.



People should be paid fairly.



There should also be money available to pay for support if it is needed.



"I just want people to paid equally for their time and not being taking advantage of."

Gary Bourlet, Learning Disability England



Funding should be available so that people can access meetings fairly.



Funding should be available so that people can have the right transport to meetings.

For example, taxi fare or train tickets.



Vicky Farnsworth, self advocate:

"Having my colleague to talk through things one to one a week before meetings was really important to me."



Vicky Farnsworth, self advocate:

"Asking for my ideas on the spot is difficult. I need more time to prepare."

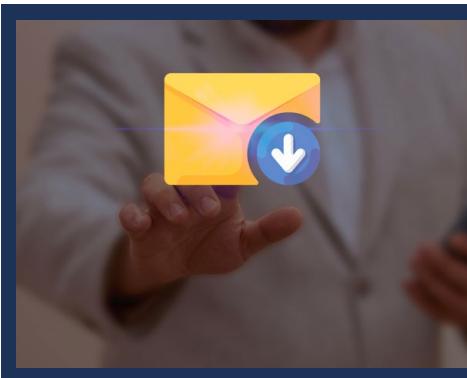


Gary Bourlet, Learning Disability England:

"Sometimes I struggle with the amount that is said through emails and what actions were mine!"



"I am involved in about 6 research projects at a time. I was getting confused about which research was being talked about."



"As a result we all agreed we could try and keep emails to a minimum. We also added a subject line in emails to help me keep on track."



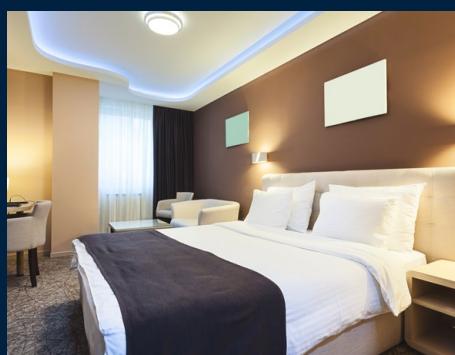
You can ask for reasonable adjustments.

For example:



You can get help with travel and accommodation if you need it.

If meetings are far away, you could ask to travel the night before when it is less busy.



If you are staying in a hotel, you can ask for an accessible room.



Getting paid in a way that works for you (sometimes payments can affect benefits).



Research teams need to be aware that receiving money for research work can sometimes affect people's benefits.



It is important to speak to research team early on in the project to let people know what you need.



If you are travelling far away on public transport, you can ask about passenger assistance.



Click here to find out about passenger assistance

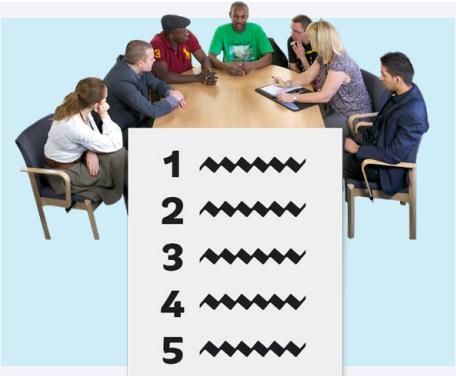
Communication



Good communication between you and other people in the research team is really important.



It might be a good idea to have one point of contact between you and the rest of the team.



Most research projects will have lots of meetings.

We have listed some ways to make meetings are more accessible.

Pre-meeting



You might want to think about doing pre-meetings ahead of the main meeting.



People should start meetings with friendly introductions.

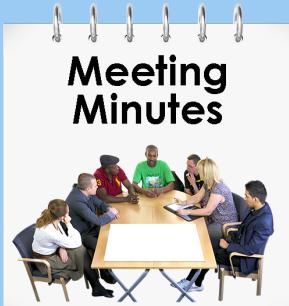


Make meetings creative.

For example, use photo check ins as meeting icebreakers.



Create a map or take a picture of the room or venue. This will help people to be familiar with the space.



Go over what happened in the last meeting.

This will help people remember.



Theme meetings or agenda items to make them more memorable.



Self-advocates Vicky and Jodie went on holiday to Egypt just before one of our face to face meetings.



We decided to have an Egypt theme for this meeting.



Vicky's words about the Egypt them:

"It was fun, and made me more interested to be involved and we didn't lose focus. It got us talking."

Simple Language

Use simple language whenever possible.

Try not to use acronyms.



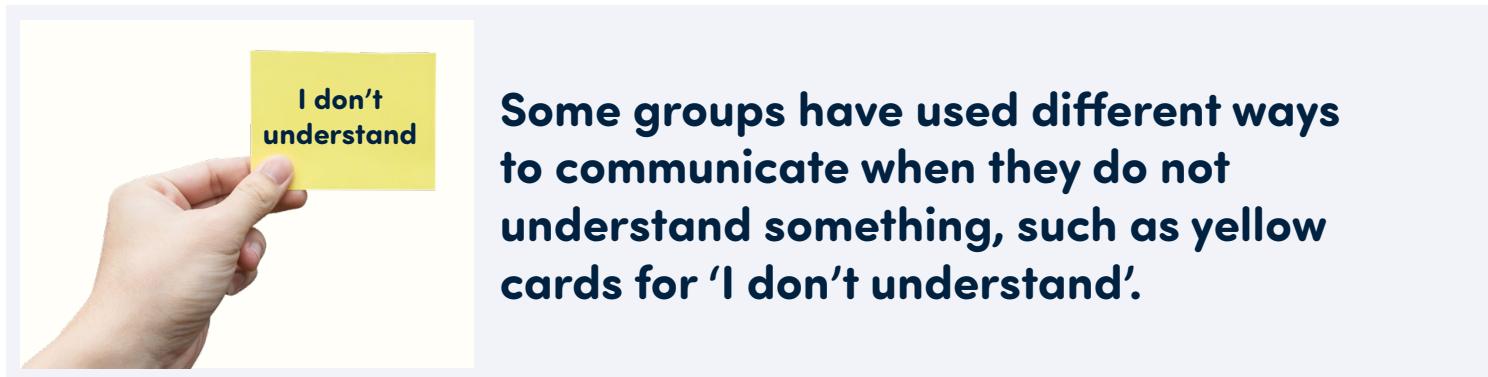
Use different ways of communicating with each other, such as sign language or easy-read.



Make sure that everyone gets a chance to speak.



Regularly check in with everyone to see if they understand what is being talked about.



Some groups have used different ways to communicate when they do not understand something, such as yellow cards for 'I don't understand'.



Think carefully about how people with high or complex support needs can be fully included in meetings.



Think carefully about how to involve people who don't use words to communicate.



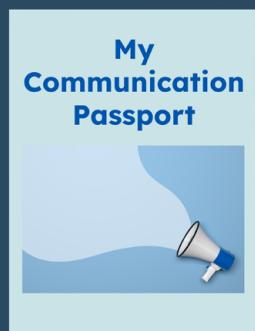
Ask people what they need to be fully involved. Make sure the whole team are aware.



There are lots of tools to help you with communication. But you need to find out what the person needs first.



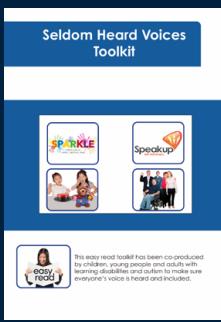
If you cannot ask them, ask the people who know them best; their family, carers, or friends.



They might have a Communication Passport too, which tells people how to communicate with them



**Speakup have made a toolkit called
Listening to Seldom Heard Voices.**



[**Click here to download the toolkit.**](#)

Making information accessible



Making written materials accessible is really important for everyone.



It is important that people with learning disabilities are involved from the very start of making any accessible materials.



It is important to develop a **terms of reference for the project.**



A **terms of reference** helps to describe the purpose of a group or project.



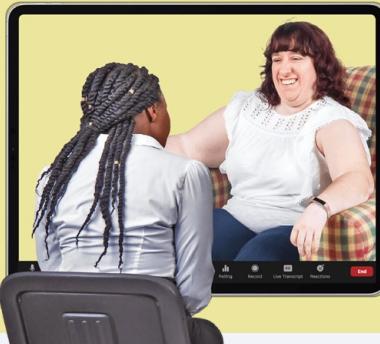
It helps teams focus on what needs to be done and who is doing what task.



We realised that some people with learning disabilities might not understand 'Terms of Reference'. We called ours 'How we will work together' instead.



Documents such as agendas and meetings minutes should be made into easy-read or plain English.



Have smaller, one to one meetings if they work better for people.



Venues for meetings and project work should be accessible by transport and easy for people with less mobility to access.

Building good relationships



Building good relationships is really important for everyone to work well together.



It is important to listen to peoples stories.

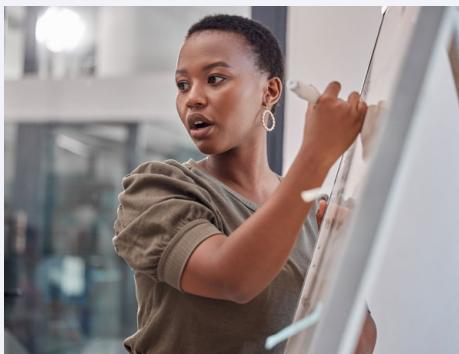


Information packs and photos of the research team can help people to prepare before meeting the whole team.

Trust



Building trust is really important for people to work well together.



It is important to provide people with training so that people can fully get involved and having their own opinion.



This might include training about understanding research or training about different methods of communication.



Good relationships and trust helps people to open up.

Gary said:



"There were 3 of us in the project who were a bit more quiet at the beginning, but building good relationships helped us to open up with the group."



"The fun activities also helped me to develop better relationships with people and break the ice."



Vicky said:

"We had the project aims into circles on a big piece of paper. We were asked to put stickers on the circle to show how included we felt. The closer to the centre, the more we felt included. It was really easy to do!"

Power



Sharing power is very important in any research project.



We shared power, wherever possible.



We made sure everyone could make important decisions in the project, not just leaving decision-making to one or two people.

Person-Centred working



It is important to ask everyone what they need. Sometimes it is just the little things make a big difference.



Working in a person-centred way was very important in our project.



We made sure everyone was involved right from the start of any piece of work.

For each piece of work, we wanted a good mix of people with different skills.



It is important to check everyone understands things brought up in meetings.



Geoff Doncaster from Speakup said:



"Ask people if they understand. Sometimes people might say they understand, but don't really. This might be because they feel they have to say they understand or they might not feel they can have an opinion."

Ask people in different ways to check their understanding. Make it fun and use pictures!





Regularly ask for people's opinions.



Use existing support. If someone has a supporter who comes with them, they can help with communication.



It is important to have the right environment to work in.



This might include looking at the size of the room, lighting, noise levels and access.



This easy-read document has been co-produced by:

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To find out more visit our website:

www.learningdisabilityengland.org.uk/no-research-about-us-without-us

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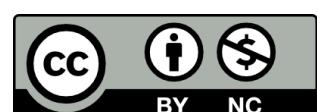
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