



Listen



Believe



Do

Looking into Abuse Research project

EasyRead Report 2

What we found out about researching together



Looking into abuse: research by people with learning disabilities. Part 2 What we found out about researching together



This research project was done with researchers at a university and people with learning disabilities.



3 people with learning disabilities were employed as co researchers. These are the things we learnt about researching together.



Teamwork

'I am finding more and more that this project is about teamwork and that is what makes it all work'



We had 3 different places working together.



We had to understand how things worked in each place, things like:



- How everyone looked after the money.



- What computers everyone used.



- Big places take longer to do things than small places.



The people working on the project had to be a team. To help this we had 2 workshops on team building - these helped us to:



- Get to know each other.



- Think about what we hoped the project will do.



- Understand that we all wanted abuse to stop.



In this team everyone had a go at every part of the research.



It might be better to let people work on just the bits that they are good at. They should still have a chance to try other research jobs if they want to.



Money



When you work in different places there are different rules for looking after money. It is important to find the best ways to work together. This takes a lot of time.



People with learning disabilities need to make decisions about spending research money. Researchers need to find ways to make this happen.



Having a job

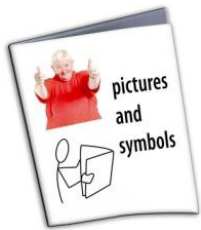


The co researchers had a personal assistant each. They said what they wanted a Pa to do. They interviewed the people for the jobs.

Access for everyone



When choosing places for meetings it is important to think about things like: staff attitudes, transport, and people who use wheelchairs.



There is a lot of writing and planning when you do research. As much as possible should be easy read - like this report.



Easy read:

- costs a lot of money.



- takes a lot of time.



- needs a lot of memory on computers.



Time

Doing research together takes more time. Time is needed:



- for everyone to understand what is being done.



- to learn new things.



- to involve people with learning disabilities in decisions. This means more money is needed to pay for this time.



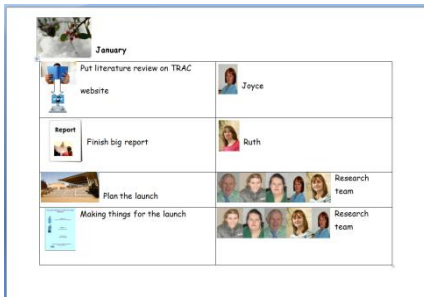
Plan carefully what everyone has to do. Make sure you ask for enough money for all this.



Advice from experts about how much people on benefits can earn is important. Do this when you are planning the research.



The co researchers said that working 4 hours a week is not enough. They think that working 2 or 3 half days a week is better.



There were a lot of things to be done every year. Making an EasyRead planner helped. Each month showed what needed to be done.

New Ways of Researching Together



We invited 50 people with learning disabilities to a hotel for 3 days. This was to do the interviews and focus groups.



Some things can be difficult to talk about in research. It is important that people feel supported.



It is also important that they have some nice things to do.



There is a lot to do when you go to a hotel for research. More researchers are needed so everyone gets a rest.

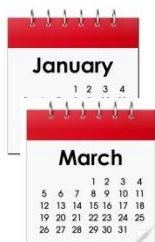


When you are finding out about things that can upset people- like abuse - having counsellors there can really help.

Research Advisory Group (RAG)



At least 20 people come to the RAG meetings. Over half are people with learning disabilities. The group is chaired by Lynne Evans who is a woman with learning disabilities.



RAG has met every 2 months.

RAG have:



- Made sure we have done all the jobs we needed to do.



- Checked all the EasyRead information.



- Advised us when we were not sure how to do something.



- Made decisions, like which hotel to use for the residential.

'...if we did not have the RAG, we would not have been able to get all the work done'



In big meetings it helps everyone take part when we work in small groups.



Some people may not have a lot of money. Do not make decisions in a group that means they have to spend money. Decisions like what to wear for conferences.

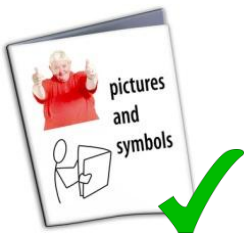
Research Ethics



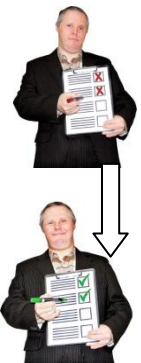
Ethics is about showing that you are planning to look after everyone properly. In research about abuse this is very important. We asked an 'ethics committee' to say our plan to look after everyone was good.



We talked with the ethics committee a lot before we asked if our plan was good. This was to make sure they understood how we worked. And to make sure we did everything they wanted.



We put all the ethics committee forms in EasyRead. We had ideas about how we could work with the ethics committee. They liked our ideas.



It is important to try and think of everything that can go wrong and have a plan for what you would do about it.



Talking about things like abuse can upset people. It is important to have the right helpers around.



It is very important to listened to and believe what people with learning disabilitites say. Specially when it is about difficult and painful things.



Research is a way to do this.

Doing research together



Everyone gets something different from doing research together. Things like



- Writing articles for magazines.



- Getting more confident. We learnt to speak in front of 80 people or more.



- Learning to use buses. For one of us it meant she could travel where she wanted.

Who is in charge



We worked hard to share power when we made decisions.



To share power better we must make sure that all researchers in a team have fair pay and work for about the same hours.

Changing things



There has been a lot written about abuse and people with learning disabilities. It is written in books and magazines, in big words and jargon.



We think that people with learning disabilities have a right to read what is written about them.



We have made a 'literature review' (what has been written and what we think about it). It is in EasyRead with some of it recorded. We hope that people with learning disabilities will be able to use this and know more about abuse. It is at



<http://udid.research.glam.ac.uk/trac/research/trac/li>
[a/](#)

The last thing we want to say is:

People with learning disabilities want to do research.



If we all take time, think about it and work together most things are possible.

Thanks to our RAG:

