

Carlisle People First Research Team Ltd.

Who we are and what we do

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Inklusive Forschung

Gemeinsam mit Menschen mit Lernschwierigkeiten
forschen

Buchner / Koenig / Schuppener
Inklusive Forschung

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Inklusive Forschung

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Carlisle People First Research Team Ltd.

Who we are and what we do



Abb. 1: From left to right: Lou, Pamela, Sara, Chloe, Rohhss, Clarence and Elizabeth
(Val and John out of picture)

This chapter is about the work of the Carlisle People First Research Team. We will tell you who we are, what we do and how we do it. We also have some ‘top tips’ for other people want to research together.

Summary

We are very serious about our research but we like to have fun and travel as well. Over the years we have worked on lots of projects together.

We have been to many conferences at home and abroad to talk about our work. Travelling together helps the team to gel. People have ups and downs in life and we try to help each other out.

Some of the places we have visited are Iceland, Belgium, Canada, Bali, Australia, America, Ireland and Alaska.

It's good to start out working on people's own life histories. We have taped each other and set about getting things written down. It helps people to get to know each other and build trust. When new members join a group this is a very good thing to do.

Lou and Clarence have written books about their lives and other peoples' lives.

Elizabeth and Andy have also made presentations at conferences about their lives. We hope you are able to start your own research team and wish you all the best of luck. Keep in touch with us and let us know how it goes!

Who we are

We are based in the North of England in Cumbria, UK. It is a very beautiful county with lakes and fells (small mountains). We all have a background in the UK self-advocacy movement.

We started the team in 1997. We are registered as a company now, where we are all Directors. We all have a share in the company. We have a very kind accountant called Steve Farber, who works for us free of charge.

Some people in the team are labeled as having learning difficulties and some are not. Our team prefers not to use labels at all if possible. One of the important things about our group is that we are friends. We have been working together a long time and know a lot about each other's lives.

Mark and Fred who were in our team have both sadly died. Andy and Niall have moved on and we miss them very much. Pamela, Sara and Val are the newest members of the team.

Sometimes Nathan joins us at research meetings or on our visits away. He is Chloe's baby.

What we do

Carlisle People First Research Team Ltd does 'inclusive' or 'collaborative' research. These are names for researching together.

We work as a team using each other's best strengths. We talk about this in the section 'How we do it'.

When we first set up the research team, some of us were working together in a Self Advocacy group called Carlisle People First¹.

We started out by talking about life histories. As time went on we began discussing research skills to help with this. Rohhss already knew a bit about research and passed on what she knew. It linked to speaking out, to what self advocacy was all about. Everyone in the new team was very keen.

We were asked to do a piece of research for a day centre that was closing down. The service wanted the views of people with learning difficulties about the closure. We planned this out and then went to the centre and started the interviews in pairs.

¹ Carlisle People First later merged into People First Independent Advocacy which is now a generic advocacy organisation across the county of Cumbria, UK.

We quickly found out that people had not been told their centre was closing! They were really very upset about it. Because we were asking people about it, they thought it was to do with us.

We were angry that people had not already been told what was happening. We just assumed that would have happened. Lou and Rohhss wrote an article about it (Chapman & Townson 2002).

Everything had happened the wrong way around. We felt we had just been used to break bad news. This work taught us an important lesson. The lesson was to make sure you know exactly what is going on. We stopped doing the interviews until the service told everyone. Then we went back in because we wanted to help people have their say.

In 2000, our supporter Rohhss went to study for a PhD about inclusive research (Chapman 2006). This was talked about in the research team and we gave her a reference. Everyone wanted to get involved in working on the project about People First groups in the UK and the views of support workers.

We all went to meet her supervisors at the Open University and from this we began to form links.

It started us off getting to know lots of other researchers from different countries. We became part of a 'Grundtvig' project (Schoeters, Schelfhout, Roets., Van Hove, Townson, Chapman & Buchanan 2005). This was about working in partnership with people with learning difficulties in the four different countries of Ireland, UK, Belgium and Iceland.

We went to visit each of these countries and made new friends. We found out lots of different ways of people working together. We still work with some of these people. Some of them have written chapters in a new book edited by Rohhss and Lou about sexuality and relationships (Chapman, Ledger, Townson & Docherty 2015).

We also went around the UK researching different self advocacy groups (Townson, Macauley, Harkness, Chapman, Docherty, Dias, Eardley & McNulty 2004). We ran another project alongside the PhD, to be owned by the team. This was about the History of People First Groups in the UK (Townson, Harkness, Docherty, Eardley, Chapman. & McNulty 2001).

We worked with members of self advocacy groups and held a national workshop. We did this on our own to help other groups develop.

Later on, we worked to get funding for other projects we wanted to do.

Some of the bigger projects we have had funding for are:

- The History of Self Advocacy Groups in the UK
- Self Advocacy and Autism
- Peoples Experiences of Direct Payments
- The War Memories of People with Learning Difficulties in Cumbria

At the moment we are working on a project with the Open University about how to archive our research by using the internet². We are also working on a bid for another history project.

How we do our work

Over the years we have developed some guidelines about how to do inclusive research. Here are some of the main ideas:

No-one is rejected

Elizabeth says it is important that no-one is rejected when we carry out research. She said that if people are not included it means they are being actively rejected (Chapman & McNulty 2004). This is a very important basis for our work.

Ideas come straight from people themselves

The ideas for the research have come from people with learning difficulties about what is important in their own lives. For example, Andy wanted to do the project about war memories because of his interest in history and also Clarence's interest in the holocaust (Dias, Eardley, Harkness, Townson, Brownlee-Chapman & Chapman 2007).

Elizabeth wanted to research autism and self advocacy because she has the label of autism (Chapman, Townson, Macauley, Harkness, Docherty, Dias & Eardley 2007). Lou and John were interested in relationships and sexuality. Lou had worked in a post as a woman's worker before.

Clarence had lived in an institution called Dovenby in Cumbria. He wanted the team to develop a project about what it was like to live there in order to provide some lessons for supported living today. This is the project we are currently trying to get funding for.

Working to people's strengths

We work to people's strengths to make sure everyone is included. In our team only some people can read, whereas others are great at finding things out in other ways. We all have different skills and things we are good at.

Listening well, asking questions, interviewing and working in groups are some of the key skills we use.

We find it best to learn new research skills as it comes up in our work. When John was working on the war memories project, he took a course on oral history with

2 Online unter: <https://www.klikin.eu/page/view/cat/3407>

his co-researcher. The university made it more accessible for the whole group so that John could be included well. This helped everyone on the course!

When we are on fieldwork we discuss what will happen and how we might go about it each day. That way it keeps things fresh in peoples' minds so we all know what we need to do.

Planning projects together

When we plan a project we use a PATH.

This is a graphic way of getting everyone's thoughts and ideas down. We sit in a big room with a long wall where we draw our ideas out onto paper. We work out where we want to get to and what needs to happen along the way. For example, we used a 'River Of History' to help us work out our 'History of People First Groups' project (Chapman & Townson 2013). We came up with the idea of using a 'time machine' for going back to the past (see 7 on the diagram) to help people recover their history.

We have also designed a 'research cycle' which gets worked through for each project (Carlisle People First Research Team (Townson, Harkness, Chapman, Docherty, Eardley, & McNulty) 2001).

By using the research cycle we developed we can check that we have thought about every stage of the project.

Doing the research

When we do research we think about which tasks each person will do. Usually each person will say what they want to do. Everyone then has a set of jobs to carry out that they are responsible for. We talk about the support needed to get the task done.

The main thing is that working together takes a lot of time to do it well. Sometimes funders and other people do not realise this is so important.

Keeping work accessible is very important to us. This is why we like to tell people about our work at conferences, face to face.

We do also write articles and book chapters together but that is quite hard for us and takes a long time! Mostly, we discuss what is important to say and then it gets typed up from a tape which gets transcribed. We go through it again until it is agreed. Sometimes a couple of people will go off together to work on a section and bring it back to join onto the others.

Equality

We also think people should be paid at the same rate as each other. When we get funding for a project that is what we do. Each researcher gets the same pay. This

tells the world that we all have something important to give and that we are a team.

Over the years we have learned some lessons the hard way.

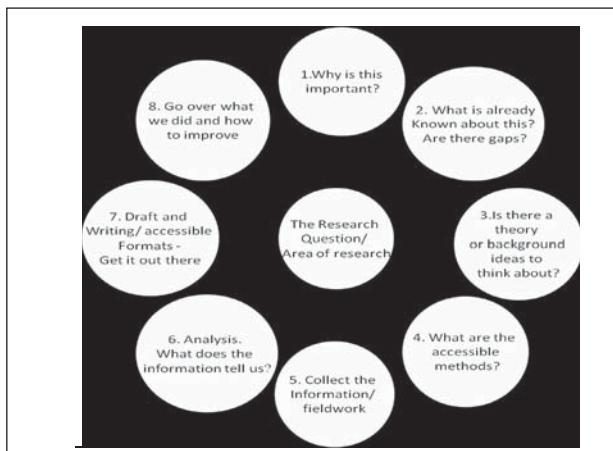


Abb. 2

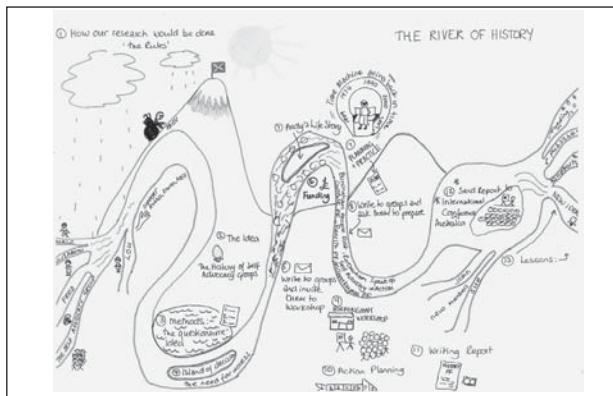


Abb. 3

Top tips for inclusive research

We like to help new groups set up. We offer to do training in researching together for them. We have been lucky to have found good friends who give us a lot of support. Becoming part of a research community can really help.

We do sometimes work with other people, who have asked us to join in on their research. This can be tricky. We have found it's important to work out ways of making sure we are happy with our role. We all have to agree it's a good project to be involved in. Sometimes we have said 'no', because we were not properly included. We have worked out some tips that may help you!

CARLISLE PEOPLE FIRST RESEARCH TEAM

TOP TIPS FOR RESEARCH!

1. Everyone has skills they are good at. Find out in your group who is good at what. Also find out who wants to learn new skills.
2. Research training is important but needs to feel useful at the time. Doing a mini project will help you practice the skills you need. Get the help you need from outside as you need it.
3. Use our research cycle to help you plan a project!
4. On a research project, think about the main research questions. They need to be interesting and useful to people with learning difficulties.
5. Having a steering group for a project is a great idea. It's a good way to get expert help without other people taking over. It works best when chaired by a researcher with learning difficulties.
6. People from universities and other organisations may want your help. Ask these people to visit the team or write to all of you. If they just contact one person it is hard to share everything.
7. When you reply to people from outside the team, make sure you do it together as a team. This will help your working together. We do group e mails at the end of our research meetings.
8. Networking with universities and others is very good for making links. It helps you get to do more things such as new projects or travelling.
9. Some people will want you to work with them when they have already decided what to do. If the project is already worked out, think about if you agree with it and what it will mean for the team. Make sure you have a proper contract.
10. Make sure you tell other people about what you have been doing. There is no point in research sitting on a dusty shelf.
11. Go back over your projects soon after they have finished to work out what could have been done to make it better. Think about what worked really well so you can use it again.
12. *Always* celebrate what you have done!

Abb. 4

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Inklusive Forschung stellt einen Ansatz dar, in dem Menschen mit Lernschwierigkeiten über den gesamten Forschungsprozess hinweg eine aktiv gestaltende Rolle einnehmen. Sie verkörpert somit eine *gemeinsame Forschung von Menschen mit und ohne akademischen Bildungshintergrund*. Während sich dieser Forschungsansatz in den letzten drei Jahrzehnten in vielen englischsprachigen Ländern zunehmend etabliert hat, begann ein vergleichbarer Prozess im deutschsprachigen Raum erst ab den frühen 2000er Jahren – hat aber seitdem eine interessante Entwicklung erfahren, die bislang kaum dokumentiert wurde. Dieses Buch hat daher das Ziel, einen Überblick zu aktuellen und bisherigen Bemühungen im Kontext von Inklusiver Forschung in Deutschland, Österreich und der Schweiz zu geben. Zudem werden hier die gesammelten (Forschungs-)Erfahrungen sowie die damit verbundenen Diskussionen und Herausforderungen kritisch reflektiert.

Zudem finden sich in dieser zweisprachigen HerausgeberInnenchaft Beiträge von VordenkerInnen aus der internationalen Forschungscommunity.

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