

Behind the scenes: Action Research with people with learning disabilities



This is one of a set of information produced from The Bridge, a two year action research project asking "How can people with learning disabilities start businesses to earn real money for real work?". It was funded by the National Lottery Community Fund as part of the DRILL programme.

For more information about this research, visit www.barod.org.

For more information about DRILL, visit www.drilluk.org.uk.

About The Bridge

Many potential entrepreneurs with learning disabilities are part of self-advocacy organisations. These are organisations set up and run by and for people with learning disabilities. Most are charities and/or companies limited by guarantee with paid facilitators, staff and offices.

The research partnership was made up of three self-advocacy organisations:

- Carmarthenshire People First,
- My Life My Choice in Oxford and
- People First Dorset

together with **Social Firms Wales**, a business support organisation, and the lead partner, **Barod Community Interest Company**, a cooperative business of people with and without learning disabilities.

Two of the self-advocacy organisations investigated how to turn projects into businesses that were led by and employed people with learning disabilities. One self-advocacy organisations supported members to investigate setting up individual self-employed businesses.

As part of the action research we developed two resources:

- An online glossary of business words that people found hard to understand
- A business blocks pack that helped people to work on their business idea and monitor how far they had got.

The research has highlighted political, economic and social barriers which we will continue to address after the lifetime of The Bridge.



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People with learning disabilities have many roles in research. In this research, some were co-researchers and some were participants. The boundary between these roles blurs in Participatory Action Research, perhaps more than in some other research approaches.

Research involves power at every stage of the research process, from deciding what needs researching to deciding whether and how to use the research findings to change practice.

The lead co-researchers needed to be as aware as possible of this throughout The Bridge.

Research also involves culture. There can be a mismatch of culture when people inside and outside the academic world want to research together. For us, this showed itself in a mismatch between how text books said action research *should* be done, and how participants worked.



What We Did

We used a method called Participatory Action Research. This means that we involved people who were starting a business to find out what happens when they did things. Groups go through a Plan-Action-Review cycle to try out ideas and see what works best for them. They record what happens and researchers also collect information about how they feel and react to what is happening.

Each pilot partner had a team of four people, all paid to carry out the Bridge work. Two of these were self advocates.

We started by having a meeting of everyone to get to know each other and to find out about doing research and how to do Action Research. We called these meetings Big Thinks.

The self-advocacy groups decided on a business idea to develop. Barod and Social Firms Wales (SFW) met each group and talked about how to start it off. Then the groups and individuals worked on their idea using the Plan-Action-Review cycle. The aim was to go through 10 cycles in the 18 months of data collection

Barod and Social Firms Wales developed, adapted and piloted business support tools with the groups in response to information needs not met by existing business support tools.

After about a year, the action researchers from Barod visited the developing businesses and did interviews and made observations.

As the business ideas progressed, we have had three more Big Think meetings to discuss important ideas and to collect research information. These used participative methods, had breaks every hour and all information was accessible.

What we Found

The reality of the research project didn't match our plans:

- The groups co-worked, usually about a day a week, to develop their business idea, plan what needed to be done and carry out the plan. This meant that things took longer than we anticipated. Only 5 or 6 Plan-Action-Review cycles are discernible in the 18 months of data collection.
- Some of the actions involved the trustees or directors of the organisations involved. These actions took 6 months to reach a conclusion.
- There were few formal meetings with notes. This reflected the continuous 'working together' nature of the groups. There wasn't the usual Bob does this and reports back, Martha checks with the manager and reports back.
- Participants saw their work as being part of the Bridge Project, and sometimes didn't differentiate between developing 'their' business and the action research project.
- Some people didn't get the purpose of reflective diaries and particularly people with learning disabilities had difficulty communicating their reflections in any depth.
- There were issues with getting everyone together for the Big Thinks. The first meeting was cancelled due to snow, and rearranged as an induction visit from the Barod/Social Firms Wales team and a later one day meeting. One group was not able to attend the third Big Think, so we arranged to re-run the most important parts on an alternative date.
- We originally planned 'partnership meetings' of the coordinators from each partner to meet during the Big Thinks

or by teleconference. These proved impossible to arrange, largely because of almost everybody being part-time.

- Transport and support were complicating factors in the Big Thinks. Having the accommodation and meeting in the same place was best.

We adjusted our approach in a number of ways:

- We introduced three liaison roles in the Barod/SFW team. These people had a monthly catch up with the coordinator from the pilot project. These conversations were recorded and took the place of local review meeting notes. They also helped the central team to coordinate support and keep the project working as one.
- We held four 'Merthyr meetings' where the nine people in Barod and Social Firms Wales met to discuss progress and problems, and plan work for the desired outcomes. These were audio recorded and formed part of the data for the project.
- We tried several ways of doing the Big Thinks: a 9:30-4:30 day meeting, a midday to midday meeting with overnight stay and a 5pm to 3pm the following day with overnight stay. The latter was the most successful.
- We had planned to do site visits and interviews anyway, but they became essential as we needed to record conversations with people to more fully understand their views and experiences.

Doing research as a team of co-researchers takes more time than you allow for. This can be because people need regular breaks to refocus or tire during the day. Almost everyone on the project worked part-time, which meant that meeting together disrupted other parts of people's lives. One potential team member had to withdraw because his supported employment day could not be changed to accommodate the day chosen to work on the business proposal. One team had a change of coordinator, with a gap of six weeks, and several people had serious disruptions in their personal lives. Co-working needs time to get back into the rhythm, so these interruptions delayed the development of the businesses.

Co-working in the Barod/SFW team meant that we had people with lived experience planning support workshops, co-leading Big Thinks, doing site visits and interviews and when we analysed data and discussed conclusions. This way of co-working also rewrote the impact plan at one Big Think and the whole team is involved in dissemination. Two co-researchers with learning disabilities presented findings at an academic conference.

Doing research with participants with learning disabilities leads to significant insights if you let them explain the world from their perspective, rather than ask them things from your perspective. A Barod team member and a pilot team member were able to describe the change in how they see themselves because of working in ways that would not have happened had the conversation been dominated by other people's view of the world of work.

During the research it emerged that taking risks was one of the areas of developing business like thinking that groups and individuals had to work on. Reflecting on this, it seems that as a research method, Action Research is fitted to this research topic as it involves trying something to change the situation, with the possibility of failure. The Action Research response to failure is very similar to the entrepreneur's response: pick yourself up, learn from your experience and try something different.

There were some ethical challenges when working with people on benefits during the introduction of Universal Credit. The very real possibility of those you work with losing money through being transferred to Universal Credit early because of a change in circumstances meant that a number of potential actions were not deemed ethical. This meant that all self advocates worked less than 16 hours a week for the duration of the project.

The impact plan had initially involved developing some business tools, writing a report with an easy read edition and a launch event. Co-working with everyone involved we decided that several the launch event should be replaced by several short videos, factsheets aimed at different audiences, including people with learning disabilities and virtual webinars.

Co-producing short films with participants has helped to relive the findings from the research. This has allowed further links to emerge through the deliberations and conversations within the team and with the film maker.

Try this

Researchers and universities

Academics need to think what their decisions and practices say about how they value different knowledges.

Research teams of co-researchers need to be forgiving, value each other and be unafraid to use each others' knowledges and perspectives to forge new ground.

Respecting each other's limitations, either in stamina, around practical support and the way we see the world because of our different lived experiences makes Participative Action Research an effective way of providing evidence for ways things can change.

When using action research with activists, you need to be clear how the reflecting and talking will make the action more effective. If their reflections are difficult to communicate, then alternative methods are needed.

When doing research with people on benefits, the potential for DWP investigation and/or changes in eligibility for benefits must be considered.

When planning research, allowing time for the actions to have an effect is critical.

Doing Action Research successfully in one context does not mean the same approach will be successful in a different context.

Research ethics committees need to understand action research and what researching ethically means for this type of research.

Funders

Be aware that action research is more costly, and is less predictable than some other forms of research. However, this is more than offset by the value of the new knowledge and understandings that this approach makes possible. If you are new to funding this type of research, it is worth taking advice from experienced action researchers.

Policy makers

Participative Action Research is an effective method for involving the people affected by research in the research that is carried out. It leads to high quality evidence that is likely to translate into effective policy. This is because it is rooted in the participants' everyday lives.

People in Self Advocacy groups

You can get involved in research that works at your pace and you have control over the questions it asks and how they are answered.

Academic researchers don't see the world the same way that you do. If you can explain how you see the world, their research will be better at helping to change things in your world.

Make sure you understand the risks to your benefits before you get paid to be involved in research.



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