

Case study four

A study of postural care for children with disability in mainstream schools

Aims of the project

To help teachers and teaching assistants support children with complex disabilities in mainstream schools.

How you found people to involve

We realised there were some problems with how well children with disabilities were being supported in mainstream schools. That was our starting point. But first off we wanted to explore what the issues were. So we decided to talk to some parents. We convened a meeting, a small coffee morning really, and invited parents of disabled children from the local community. It was very informal. We talked about the ideas we had and the research we were thinking of doing. It was a very interesting experience. What it revealed to us was that there were a lot of emotions and concerns amongst parents that we hadn't anticipated and it raised a lot of other issues affecting these families that weren't being addressed.

After the first meeting, we needed to identify parents who would be willing to commit to working on a steering group, who could give more time and contribute more. We wanted them to be involved in directing the whole project. Two of the parents from the meeting agreed to take on this role. Their involvement kept us focused. It was a constant coming back to: What is important? How is this going to make a difference? It's hard to say where the project started and ends and the involvement has been continuous – parents have been involved at every stage and influenced every aspect.

How you involved people

I worked with Sharon [Godden, a mother of three children, one of whom is severely affected by cerebral palsy] and Judi [Mortimore, a mother of two children, one of whom is affected by cerebral palsy and attends a mainstream school]. Sharon was involved from the beginning of the project and helped with the design of the study. Judi joined the project after the fieldwork had been completed and both helped with the analysis and interpretation of the data. Sharon and Judi also worked with the team on the production of a booklet 'The A-Z of postural care'. This has been made available to all the schools in Kent and has been very well received. The team are continuing to work together on a second phase of the project. This is based on the findings from the first stage and will lead to the development of training to support the implementation of good practice.

What training and support did you offer?

We were a very well-behaved steering committee. That was an important factor in terms of 'keeping the kettle hot' and not getting too academic about it. We discussed things and managed things well. Having a parent there makes sure you explain things properly – which benefits the whole group. We always had meetings locally and at the same place. We always tried to make a date so that the parents could get there and if they couldn't, we'd meet them for a coffee in the evening to catch up. We always made sure there were sandwiches and refreshments – that was important as well. The parents weren't paid for their time. But all their costs were paid for and they came to the INVOLVE conference and all their travel and accommodation was paid for them to attend.

What difference did public involvement make?

The first meeting made a big difference right from the beginning. With research you might set off with a particular idea in mind about what needs to be done – then talking to other people you realise that actually, there are other issues

that need to be explored that are equally important. We came away from that first coffee morning realising two things, one we were addressing an important issue and two there were other related issues to do with the inclusion of children with physical disabilities more generally. And the thing that stuck in my mind was one parent saying 'We want to keep the kettle hot' which was about them wanting something positive to come out of this. They didn't want to be involved in something that was just going to be a talking shop and didn't lead to any changes or improvements for their children. It was actually a really useful experience which helped us to go away and reformulate our ideas. It also strengthened our commitment to having a positive outcome to the research. We felt a responsibility in a way that perhaps you might not feel if you haven't got that involvement. The parents were very much driving the project.

At the end of the project we got some money from Kent County Council to follow through on one of the key recommendations – to provide more information for teachers and teaching assistants working with children with complex disabilities. So we decided to produce a small booklet – 'The A-Z of postural care'. So the steering group met again and the parents gave a lot of time and got very involved in designing and writing the booklet. It was very much a team effort. Professionals tend to use jargon, but the parents made a real emphasis on making sure things were understandable. Producing the booklet was a real sense of achievement for all of us, especially for the parents. I would hope that we would have done that anyway – but the fact that we had parents who had been heavily involved and given a lot of their time really gave us that drive to get things done.

What would you advise other researchers about involvement?

If you involve people the work that you do becomes very meaningful and very applied – without involvement you might not always be focused on feeding back into practice. But you

have to tread carefully. You've to think about how to draw people into discussion and give them time to express their feelings as well. I suspect that the people that do get involved are people who feel very passionately about the work and therefore there will be a lot of charged emotions. Researchers need to be aware of that and respond sensitively to any emotional issues. It's a lot more straightforward not to involve people – certainly in terms of the time involved. We had our original idea but then we had to go back to the drawing board. We were going to put together a funding bid, but we realised we had to do more work first. So it held us up a little bit – but in a very positive way. It's definitely a stronger proposal as a result. It has taken us longer to get there – but it was time well spent.

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