Carrying out a needs assessment for training and support

What does a needs assessment involve?

A needs assessment for training and support may be relevant for members of the public and researchers.

There are different ways to carry out a needs assessment for an individual or for a group. It can be as simple as having a one-to-one conversation with someone, or it may involve organising a group meeting (see **case study nine**) or conducting a more formal survey of a large group (see **case study ten** and **case study 11**).

The examples we found for the case studies describe the formal processes used for assessing training needs. Identifying support needs is likely to happen in a more informal way, through conversations, as people experience their role. Trying to develop an integrated training and support package is likely to be more effective.

You will need to:

1. Identify what skills, knowledge, experience and support are needed for a particular involvement role – look at the job description where relevant and / or talk to people who have been in that role for some time.

2. Ask people to reflect on the skills, knowledge, experience and support they have that help them to fulfil this role, and aspects of the role they may find challenging – this includes asking people about the activities they carry out, how important they feel these are and how confident they feel in this role.

3. Identify training and support needs – ask people to identify specific areas where they would like to increase their confidence and/or build on their skills or knowledge to help them become more effective.

It can also be helpful to ask about people's learning styles, for example whether they would prefer in-house training, attending external courses, e-learning, books, or shadowing as a method of learning.

It is likely that a needs assessment will identify more than one training and support need and different preferences as to how this is provided. Making a decision about what training and support to provide and in what format will then require a dialogue between all the stakeholders involved – training managers, budget holders and potential trainees. This can help to prioritise training and support based on the:

- urgency / timeliness of the need
- extent of the need – how many people need training and support
- the resources available and potential sources of training and support.

When is the best time to carry out a needs assessment?

Although it is helpful to provide some kind of training and support before people take on a new role, for example via an **introduction/induction event**, until they have spent some time on the job, they may not know what further training or support would be useful. In addition, people's involvement roles may develop over time extending into new areas of responsibility. Therefore carrying out a needs assessment is not a one-off event. It is best carried out after people have had time to learn about their role, and then repeated regularly in parallel with the individual's (or group's) personal development.

It is important to be realistic about training and support opportunities and not to raise expectations too high. If you ask about people’s needs, then you need to be prepared to respond relatively quickly. For example, if people are asked about training and then don’t receive any, they can get disenchanted. Think about the availability of funding and possible sources of suitable training and support when carrying out an assessment – you may need to limit what you ask about/offer.

Introduction to this resource

Introduction

This resource offers advice and guidance to help you develop your own training and support packages suited to different situations and contexts. The information in the resource is drawn from the direct experience of members of the public, researchers, trainers and public involvement specialists (see **About this resource** for further information).

There are a number of different situations in which people will need training and support for public involvement in research. These range from large research organisations aiming to train a large number of researchers working across a network, where a formally run training course might be appropriate, through to individual researchers developing informal ‘on-the-job’ approaches to train and support one or two members of the public on a small, low-budget project.

Tailoring training and support for public involvement to each individual situation, if possible, is helpful and constructive.

Using this resource

Start by looking at **What do we mean by ‘training’ and ‘support’?** for an explanation of these terms and guiding principles for any training or support packages.

The resource provides an overview of training and support for both researchers and members of the public and information on how to carry out a **needs assessment**.

We provide more detailed advice and guidance about training and supporting members of the public focusing on five common ways people are getting involved:

Research panel member

Project advisory group member

Project steering group member

Public reviewer

Peer interviewer

In these sections, where relevant and where we are able to draw on people’s direct experience, we also consider the training and support that researchers might want to manage these different types of involvement.

In all sections, a wide range of **case studies** are included to illustrate how this guidance has been put into practice in different contexts. You can view these from the list of case studies at the bottom of the web pages or **browse them all**.

What this resource does not do

This resource does not offer ‘off-the-shelf’ training programmes or a directory of training courses. We explain why we have not taken that approach in the About this resource section.

Let us know what you think

We welcome your comments and feedback on this resource. Please also send us ideas for more case studies and links to other useful resources.

Send your comments, information and ideas to: **training@invo.org.uk**

What do we mean by 'training' and 'support'?

What do we mean by 'training'?

We use the term **'training'** to describe the wide range of activity that aims to help members of the public and researchers develop their knowledge, skills and experience to prepare them for public involvement in research.

The term training tends to suggest a one-off, one-day event to introduce a new skill but it is not always helpful to view training for public involvement in this narrow way. 'Training' in this context describes a multitude of different kinds of learning opportunities including:

- group sessions with a trainer
- providing high quality written materials and guidance
- learning on-the-job
- attending conferences
- networking and shared learning with peers
- online activities
- university or college courses.

Think creatively and be open-minded when planning training for public involvement and try not to be constrained by a limited concept of what training involves. Recognise that those getting involved, whether researchers or members of the public, will come with a wide range of skills and experience. They will also have different learning styles – so individuals may have different preferences as to how they want to be trained and what may help them to learn the most.

What do we mean by ‘support’?

We have used the term ‘**support**’ to describe a wide range of activity that enables researchers and service users to work together in research. This includes support to address:

- practical and financial issues
- emotional and psychological support
- project supervision to promote professional and personal development.

Support can be offered in a range of different ways including via:

- a user support worker
- a member of the research team
- a mentor with similar experience
- team meetings
- one-to-one meetings with line managers
- informal or formal mechanisms of peer support.

Think about offering support through a variety of mechanisms for both researchers and members of the public when planning public involvement in research.

Essential principles for training and support

Any form of training and support for members of the public, researchers or staff in research organisations should, ideally, be based on the following principles.

Training and support needs to be tailored to the situation. There is no ‘one size fits all’ approach. Training and support need to reflect the nature of the research project, the remit of the group, the specific needs of the individuals involved, and the resources available.

If you’re offering training or support, it is best to be responsive to individual needs – so make sure any ‘off the shelf’, ready-made training courses offer what people have said they want to learn. Training and support also need to be in a style that suits them – for example training for young people may need to be delivered in a different way to training for adults.

Anyone in a research team may need training and / or support to develop their skills. Don’t assume researchers have all the necessary skills and knowledge for public involvement in research. Don’t assume that all members of the public lack the necessary skills and knowledge – they may only need help with adapting their existing skills to the research context. Build on the knowledge, skills and experience that people have already. Training members of the public and researchers together can often be very powerful.

Training and support should not be seen as one-off events. Both may need to continue throughout the life of a project or the life of a group. Learning opportunities should be built into all stages and linked directly to the task in hand.

The success of training and support is often due to the skills and competencies of the person delivering it. Offering training or support requires specific skills and experience. For example, you may be good at something, but that doesn’t mean you’ll be good at training others to understand it or how to do it. If you don’t have the necessary skills or experience, draw on people who do.

Don’t assume that members of the public are only bringing their direct, personal experience of the topic. They bring a much wider variety of skills and knowledge to the research process. They often have as much to teach researchers as researchers have to teach them. The process of working together should be seen as an ongoing, two-way process of mutual learning and personal development.

Template two

Role description template

This template is designed to help you develop a role description for a public member of a group such as a project advisory group or panel. The suggested headings and questions are not intended to be prescriptive but will give you some ideas based on what other people have included in their role descriptions. The ‘See also’ boxes on this page contain a Word version of this template which can be edited or adapted to suit your needs (for non-commercial purposes), together with some real-life examples of role descriptions.

Title: Role description for [insert role and name of group]

Background: for example

- what is the broad purpose / role of the group?
- what are the aims / responsibilities of the group?
- who else is in the group?
- what will the public member be expected to contribute to the group in broad terms?

Your responsibilities: for example

- what are the expectations of the group member in relation to attending meetings, for example how many

meetings is the member expected to attend and what perspective will they be expected to bring?
- what preparatory work will the group member be required to carry out in advance of meetings, for example reading paperwork?
- will there be any additional responsibilities apart from preparing for and attending meetings, and how much time will the member be expected to spend on these activities?
- what are the expectations in relation to maintaining confidentiality and declaring any conflicts of interest?

Our responsibilities: for example

- what support will you offer to the group member, for example will they be offered an initial meeting or will they be allocated a named contact?

Duration of role: for example

- how long is the term of office and can it be extended?

Payment and expenses: for example

- will people be paid for their time and if so, how much are they entitled to receive and are there any restrictions on who is eligible to claim such payments?
- what travel and other expenses will be covered and what is the procedure for claiming them, for example will you provide a claim form?

Person specification: for example use the following grid to list the essential and desirable attributes of the role:

Criteria	**Essential attributes**	**Desirable attributes**
Experience		
Knowledge		
Skills		
Personal qualities		

Contact details: for example

- what is the name, address and contact details (email and telephone number) of the person to contact with any queries in relation to this role?
- is there a web page where prospective members can find further relevant information?

Closing date for applications: [insert closing date if applicable]

Template one

Terms of reference template

This template is designed to help you develop terms of reference for a group such as a project advisory group or panel. The suggested headings and questions are not intended to be prescriptive but will give you some ideas based on what other people have included in their terms of reference. The ‘See also’ boxes on this page contain a Word version of this template which can be edited or adapted to suit your needs (for non-commercial purposes), together with some real-life examples of terms of reference.

Name of group:

Title: Terms of reference (followed by date terms of reference written / revised)

Purpose / role of the group: for example

- what is the broad purpose / role of the group?
- when was the group established and by whom?
- what are the aims / responsibilities of the group?

Membership: for example

- who is membership of the group open to?
- are there any restrictions on numbers?
- are patient / public members involved?
- are any representatives from other organisations included?
- how long is the period of membership and can it be extended?

Accountability: for example

- are individual group members responsible for reporting back on activities of the group and if so to whom?

Review: for example

- how often will the group review the relevance and value of its work and the terms of reference?

Working methods / ways of working: for example

- what method / approach to working will you adopt (for example a shared learning approach)?
- will any sub groups be convened?
- what will your chosen working method involve in practical terms, for example with reference to:

meetings for example

- how many meetings will be held each year and where will they be held?
- who will organise and chair the meetings?
- how will topics for the agenda be generated?
- how and when will meeting papers be circulated?
- what will the format of meetings be, for example will they include small group discussions?
- will non-members be invited to group meetings and if so, under what circumstances?
- who will provide secretariat for the group?

sharing of information and resources (including confidential materials) for example

- how will group members share information and resources?
- how will confidential materials and copyright issues be identified and dealt with?
- will there be a web space for the group and if so, will it be password protected and who will be responsible for facilitating it?

Definition of terms

- provide definitions of any key terms.

Case study seven

Connect Works – Connect in the North

Aims of the project

This project was carried out by Connect in the North (www.citn.org.uk), an organisation led by people with learning difficulties. Connect in the North works to improve services and opportunities for people with learning difficulties. The project used research as the basis for developing a training course to train people to become personal assistants for people with learning difficulties. The aim was to enable people with learning difficulties to be able to choose a personal assistant from a list of people who have already been chosen and trained by people with learning difficulties (the Connect Works team).

How you found people to involve

The original idea for the project came from a Connect in the North members meeting. Connect in the North believes that people with learning difficulties should have control over their lives. Training people to be personal assistants is one way of doing this. The personalisation agenda, which has become prominent in recent times, meant that the idea could be realised, as it helped them get the funding to carry it out.

Personalisation means starting with the person as an individual with strengths, preferences and aspirations and putting them at the centre of the process of identifying their needs and making choices about how and when they are supported to live their lives (Social Care Institute for Excellence, 2010). Funding for the research part of the project came from Leeds City Council. Funding for the training came from Skills for Care: New types of worker money. The people involved were: Claire Massa, Jocelyn Richards, Philip Hawley, David Boyes, Bhupesh Limbachia, Alan Hicks, Manjinder Singh and Susan Hanley (who used to work at Connect in the North) with Sarah Wheatley supporting them.

How you involved people

The team formed two groups: one to work on the research and one to work on the training. The group looked at their own lives as a starting point: they came up with a list of what they would want from a personal assistant and put it up on the wall for people to identify what is good and what is bad. In this way they designed the questions to ask of other people. In the research, they spoke to 89 people, often in groups face to face, some through questionnaires. They would start a group with an icebreaker and then ask people the questions. They would put up the answers on the wall and ask people to put stickers or ticks against the things that were important to them. The team would gather up the information at the end. Claire put the information on computer. They also sent out questionnaires to involve other members of the family, but this was not very successful.

What training and support did you offer?

The research helped the team to design the training for personal assistants: what training do personal assistants need to make them understand what they have to do? It helped to decide what types of people should come on the training and what was in the training. One thing they found was that values (for example treating people with respect) were more important than experience. People also thought that being on time and record keeping were important features. The team ran the Connect Works training twice. They selected people for the course, ran the training and evaluated the trainers on the basis of their coursework. They then evaluated the course and decided that it needed to be longer. Nine people from the training were chosen to be on a list of personal assistants. This is available to anyone with a learning difficulty who uses direct payments or has an individual budget. The plan for the future is to get the course accredited.

Sarah’s role was to facilitate the sessions, to give them a focus. She helped Susan and Claire to decide how to run the sessions. She also wrote up the ideas, writing it up in different ways for the group to decide which was best. They described the control of the project as ‘equal but in different ways’. Claire or Susan would come up with the ideas and Sarah would fit it together. It was important to them that people with learning difficulties were in control of the project. People with learning disabilities selected people for the training course, trained people and evaluated both the trainees and the course itself, with Sarah’s support.

What difference did public involvement make?

- One of the team, David, now works as an associate trainer, after volunteering for Connect Works. It is his first ever paid employment.
- People have employed personal assistants from the course.
- They have a list of trained personal assistants working in the community.
- People have really changed what they were doing and are happy.

- The four-week course changed to a ten-week one: it is half a day a week for ten weeks. It has been run twice.
- It was a diverse group of people, which was good. Everyone felt able to share their views.

What would you advise other researchers about involvement?

Things that helped the research

The team listed many things that helped:

- Friendship was the main big thing – it had to be there to communicate with each other: ‘I miss you all.’
- Working together; being patient, tolerant, understanding, thoughtful; having fun!
- No jargon
- Could slow down so people could keep up; we had breaks
- Being organised – the information was counted up and put on computer (Claire did this)

Things that made the research difficult

- There were differences of opinion amongst the group, but they reached agreement: ‘[we] would put opinions together to get your say into one.’
- Claire said she would get upset sometimes: ‘I would give a bit of my past to show what I meant by something, explaining something.’ They all agreed that there was a lot of support within the group which helped if someone got upset.
- Some participants did not turn up for the training course.

Future plans

Some barriers for the development of the project were identified in the project’s final report. Connect in the North found that there are barriers to trainers with learning difficulties running accredited training. This is because many organisations funding courses leading to qualifications require the trainers to have a qualification. It is difficult for people with learning difficulties to obtain a qualification in training, although Connect in the North is continuing to explore this. The Open College Network will accredit training led by people with learning difficulties but it is expensive for a small organisation.

Connect in the North are also exploring different ways of funding the training course for the future. These include:

- Contributions from people who have an individual budget
- Core funding from the local authority
- Learning and Skills Council in partnership with a local college.

Links to any relevant reports or articles

The project is reported on the Skills for Care New Types of Worker website and a copy of the report may be found there: **www.newtypesofworker.co.uk/pages/projects/connect-works/useful documents**

Contact details

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Acknowledgement

This case study first appeared in Faulkner, A. (2010) **Changing our Worlds: Examples of user-controlled research in action**, INVOLVE, Eastleigh.

Case study six

A study of adoption support services

Aims of the project

We responded to a call for proposals from the Department of Children, Schools and Families. They said they wanted user involvement. So in our original draft we said we would involve people in planning the research and as part of our advisory group. But we were pushed by the funders to consider taking it quite a bit further. They indicated that they would be willing to support us financially to do something more ambitious. So our motivations were partly about satisfying the funders and partly about satisfying ourselves. When we were pushed to think about it, we thought it could be very interesting and useful. We were willing to give it a go.

How you found people to involve

We wanted to recruit people who had similar experiences to the service users who were going to be participants in the research. We knew birth relatives of adopted children typically have a number of problems – such as mental health problems or learning difficulties. We knew we would be interviewing people like this. So we tried to recruit birth parents with similar life experiences.We made use of the relationships we had already established with adoption agencies and support agencies as well as individuals. We asked the agencies to find people who matched our criteria – experience of having a child adopted and an interest and willingness to take on the role. I also contacted some adoptive parents who had been participants in a previous project of mine – so they also had some experience of taking part in research. We also wanted to involve some parents from ethnic minorities, so we went to a black adoptive parents group. The group leader circulated our publicity material to their members. We decided to try to recruit quite a lot of people because we knew we would be working with people who had a lot of other challenges in their lives – and that the project was going to run for several years and we weren't sure if people would be able to make a commitment for that whole time. So we thought if we lose a few people along the way, we'll still have enough at the end.

How you involved people

This was a major study of adoption support that took place over a number of years. There were different parts to the study. Imogen [Cooper, a birth mother] was involved in the part that evaluated the support services provided to birth relatives, particularly the parents and grandparents of children in compulsory adoptions. Two groups of birth parents were involved. They helped at all stages of the research, except the data collection phase. They helped to plan the overall design, analyse the data and interpret the findings.

They will also be taking part in the final launch conference. The birth parents have been involved in planning the conference. They said we needed to get the voice of service users across to make it more powerful. So we've been talking about people participating in the conference. A lot of them said they were willing to take part, but it's going to be a high profile event with 150 people. It's a lot to ask people to speak live and so we have decided we will prerecord it.

We’re going to take people to Norwich where the University has a TV recording studio. We’ll ask them to reflect on their own experience and use edited highlights. Then I don’t have to worry about people getting stage fright or not turning up. They are all invited so they will then have an opportunity to talk to people on a one-to-one basis. So that will raise their profile and the professionals won’t be able to ignore them. We’ll put them up and pay for their expenses and take them out to dinner – it will be a last hurrah!

What training and support did you offer?

One of the major challenges was to ensure that service users were clear about what was expected of them. At one of the first meetings, the service users started to tell us about their experiences of losing their children to adoption. Obviously this became a very emotional meeting with people telling their stories and people getting upset. It was very difficult for people to take in what we were wanting from them – and we were just learning ourselves. It brought it home to us how difficult it is for people to understand what we were after and how complex the tasks are. We didn’t want to say we weren’t interested in people’s experiences as this is exactly the perspective we needed. But we needed people to be able to focus on the study. We felt stuck.

So we decided to get our heads together with people who were working in practice. We found a woman who was a birth mother and a counsellor working with birth parents and also a person working in citizen advocacy with people with learning difficulties. They had a lot of relevant experience and helped us with the way forward.

Before we met with the second group, we did a lot more preparation. We rang up everyone who expressed an interest and went to visit people in person if we felt this was necessary – so that then people were happy to meet in a group. We also gave them an option to be involved individually. On the day we knew we had to manage people’s personal experiences. So we began with that – because that’s where everyone was coming from and what they had in common. So we allowed people some space to say that to begin with, in a managed and controlled way then closed it down and moved it on. The two practitioners facilitated the day and helped with that. We also had to be clearer about the role of a user consultant. I remember saying to them very clearly: “It’s really important that you understand that why we’ve asked you to be here – it’s about what we’re hoping you’re going to do for us – it’s about you helping us, not us helping you.” That was a key moment. People seemed to find it empowering. They’re so used to engaging with people in terms of trying to get help. It was a new idea that they were being asked as an expert to give their help and advice.

To some extent we were learning as we went along throughout the whole thing. But I think what helped was that at every stage, we thought it all through and wrote it all out before we began anything. And getting the advice from people with experience of working with birth parents made an enormous difference. What has been absolutely vital is that we’ve had the support of our funders to do it. It was quite expensive – our budget was £12k. So we’ve been able to treat people with respect, to pay them for their time and their travel expenses. We could meet in nice venues, that had a nice canteen and everyone could have what they wanted for lunch, lots of drinks and cakes and biscuits. We looked after people. It backed up this message – you’re helping us and we’re going to reward you for that. That really helped people to understand the role. And we’ve kept in touch with people – like sending them Christmas cards – throughout the whole research phase which took two years. That was a long gap – people came back three years later to help with the analysis of the data. Every one of the birth parents who started with us at the beginning of the project, has stayed with us right till the end. We didn’t lose any one of them in all that time.

What difference did public involvement make?

The birth parents made a big difference to all aspects of the recruitment. First we mocked up a leaflet. Everybody savaged it. They said it had way too much writing in it and it looked cheap. They advised us to have it professionally designed so that people would know we were kosher and that the study was respectable. They told us to put on the minimal information – just to get people to call up – then we could give all the chapter and verse on the phone. Too much detail would put people off. They also helped us to understand what would motivate people to take part. They really emphasised the importance of saying – you'll be able to help other people like you. They advised us to have a website, to have a freephone number and to allow people to text us. Texts are cheaper and a lot of people only have mobiles. We had to find some people via agencies. The birth parents told us that it's really important that the research team was seen as completely independent of the statutory agencies. When we sent out the invitation letters, they told us to make sure there was a stamp on the envelope and that it hadn't gone through the social service franking machine – or it would have just gone in the bin. They helped us to understand how hostile people feel to statutory agencies and social work. After all this, we didn't have any problems recruiting to the study. In my experience recruiting birth family members is very difficult. We knew of other studies having real problems getting started because they weren't getting any response. But we met our target and within our time-scale. I think that's because our birth parents helped us get our approach right.

The birth parents also infleunced the design of our study. We had planned to do the majority of interviews by phone and the birth parents said you need to offer face-to-face interviews. So we had to go to our funders and say this might take longer and cost us more. Thankfully, they said fine, if your service users are telling you that, we will support you. Our birth parents were also very against written consent forms, because birth relatives may be suspicious of signing anything, or may not be able to read it well or understand what they are signing. And when they looked at a draft form they said it sounded like a police caution! They said it’s better if you just explain it to people and get a record of their consent on tape. We had to persuade two local authorities that we were still meeting their requirements for research governance, but they listened to us because we had the weight of the service users behind us.

We didn’t have a clue how to involve people at the data analysis stage. We looked at what other researchers had done and it seemed they just did the analysis and showed it to service users. This seemed a bit tokenistic and I felt we should involve people before we did the analysis, not after. We had massive amounts of data and we thought it would be impossible to ask them to advise us on all of it. So we thought about where their input would be most helpful and focused on that. We didn’t want them to become like us – we wanted to them to keep their unique perspective. We felt we needed to introduce them to the data in some way but also keep the confidentially. We thought about doing a presentation or handout or slides, but then remembered what everyone had said about literacy. So we decided to present the material by audio on a cd. We selected ten-minute excerpts from some of the key interviews, and made sure these reflected the issues we were trying to tackle in the analysis. Then we hired actors to read them out and recorded it all with our digital recorder. We only paid the actors about £50 as it was an hour’s work. They did it really well and read the words with feeling and meaning.

It worked incredibly well. The birth parents could relate to them immediately. People said this is the best meeting we’d had – because the interview material was so powerful. The birth parents gave us their views on what they thought about the interviews. A lot of what they said agreed with what we thought, but some of it was really different and that was particularly valuable. For example, they rejected the idea of recovery or getting over your child being adopted – saying that you never get over it and that you only learn to cope with it better. So our analysis was then focused on the concept of coping and how well or badly people were coping with the loss of their child. What they also brought to our attention was that what people tell us is only part of their experience and people can present themselves in a different way to the way they actually feel. We wouldn’t have got that without the birth parents’ insights. That really was a phase of the project that we understood how our service user can bring a different perspective – and how we can’t see the world through their eyes.

When we had a sense of the main findings, we had another meeting with the birth parents. We made posters without much writing and lots of drawings to illustrate the main things we were going to be saying. We asked the birth parents to focus on the issue of support needs. We asked them to tell us their views of the ideal service that would meet these needs. That helped people to think out of the box and they were very creative. But these were very concrete ideas. They made very practical suggestions. They emphasised the role of peer support much more than we would have done. I’ve just put these ideas word-for-word into one of the final reports. I can’t really improve on them.

Involvement has been important all the way along and we’ve got something out of it at every stage. Maybe it was less useful asking them to comment on the data collection – because that’s where the gap between us and them was smallest. Because actually I’ve got a lot more experience than them in terms of interviewing people, but in other areas they clearly have the expertise and I haven’t. Maybe it’s most useful where there’s really added value from gaining the user perspective.

What would you advise other researchers about involvement?

Be ambitious. Don’t play it too safe. We were learning as we went along. We felt out of our depth some of the time. But we got a lot out of it.

Don’t just involve people who are used to being involved, or who are less troubled in life. We got a lot out of the birth parents who worked with us who had more problems.

Get people involved at the proposal writing stage to check out you’re actually asking the right research questions. To give people a real say you have to get them in earlier. Our birth parents felt we hadn’t invited them in soon enough. If they had been given a blank sheet they would have asked different questions to us. It made me realise the importance of involving users right from the beginning – right from when funders are developing the brief.

It takes time and resources – you’ve got to be committed to it. At times that’s all we had – commitment. We didn’t know how we were going to do it. But we were going to give it a damned good go!

It is very challenging work. One of the biggest challenges was helping people to move on from talking about their own experiences to thinking about the experiences of the birth relatives taking part in the study. We had to be quite directive about that at times. We had to be kind but firm.

Pay people in cash on the day. If they are on a low income they need their train fare back that day otherwise they will be out of pocket. We had to fight that corner with the university. We had to be clear we weren’t making salary payments. But in the end they did agree to give us loads of petty cash.

Keep an open mind about what people can do and what they contribute. People will be very, very hard working and dedicated.

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Acknowledgement

This case study first appeared in Blackburn H., Hanley B. and Staley K. (2010) Turning the pyramid upside down: examples of public involvement in social care research, INVOLVE, Eastleigh.

Case study one

Understanding and improving

transitions of older people: a user and cared centred approach (Nov 2008 – Oct 2011)

Aims of the project

The project explored older people's experiences of transitions in care, what needs older people have during times of transition, and whether those needs are being met by local services. The project focused on four groups of older people whose needs are not well understood and/or whose needs might be expected to be more complex. One of those groups was older people from black and minority ethnic (BME) communities, and the research that explored the experiences of this group took place in Leicester. The project used a participatory research approach, involving developing and maintaining partnerships with older people as 'co-researchers' throughout the research process. In Leicester, eight people from Leicester's BME communities contributed to the project as co-researchers.

How you found people to involve

In each of the areas taking part in the project, the research lead formed a partnership with a local voluntary sector organisation that was working closely with the group that it wanted to involve. In Leicester, the partner organisation was the local branch of Age UK, with the organisation's BME community development worker team playing a particularly important role in the partnership. Working through Age UK's networks, information about the project and the opportunity to become a co-researcher was distributed to many local BME groups across the area. Given the responsibilities associated with the role, it was decided that people would have to submit an application and a short (informal) telephone interview was carried out. All co-researchers were CRB checked.

How you involved people

The research team had reviewed the literature on involving older people in research before getting underway with the project. From this they were aware that previous efforts of involve older people as co-researchers had often been limited to participation in data collection, but had not extended to other aspects of the research project (such as research design or data analysis). With this in mind, they tried to design a project that could be co-produced at all stages. In Leicester, co-researchers were involved in:

- Identifying key issues to explore in the in-depth interviews, helping to ensure that the researched focused on the issues that mattered most to older people
- Developing interview tools, including a visual representation of the transition and interview prompt cards
- Reviewing data to identify the main themes and make sense of any complex issues emerging from the interviews
- Presenting the findings at feedback events
- Participating in ‘All Sites Days’ which brought together people from the different areas taking part in the project

What training and support did you offer?

A training programme was designed for co-researchers, which was delivered at various stages of the project. As well as the training days, the research lead met with the co-researchers as a group on other occasions as and when needed. The training programme was designed to fulfil three aims:

- Supporting co-researchers to develop the knowledge and skills needed to fulfil their role.
- Enabling relationships and trust (between co-

researchers, and between co-researchers and the research lead) to develop.
- Creating opportunities for co-researchers to shape the research process – see above for more details.

Early training sessions included role play activities to practice interview skills and the research team developed a DVD (with members of a service user and carer network at the University of Birmingham) with good and bad interview scenarios to encourage discussion. Support was offered to co-researchers on an ongoing basis in many ways, including debriefs at the end of each interview. The involvement of the voluntary sector partner was also vital in this respect, as it gave co-researchers a source of support from somebody who was independent of the research team.

What difference did public involvement make?

The project's participatory approach was evaluated to explore what difference it made in terms of the research process and outcomes. The evaluation clearly demonstrated that both the academic researchers and co-researchers really enjoyed working together and learning from one another. The involvement of co-researchers in Leicester benefitted the project in many ways:

- They helped to ensure that the research focused on issues that matter to older people
- Their involvement in interviews often put people at ease and helped to elicit richer insights
- They played a vital role in approaching and recruiting people to take part in the research
- They carried out a number of interviews in their own community languages
- Their involvement in feedback activities was particularly beneficial: they 'gave voice' to the people who had shared their experiences by selecting and

reading out quotes from interviews at feedback events.

What would you advise other researchers about involvement?

Learning from the project suggests that the following factors contribute to the success of co-research approaches:

- Recognise the value of peer support and take opportunities to develop this as part of the research process
- Always be open to the unexpected and to new ways of doing things
- Be open and flexible in your own boundaries, for example regarding self-disclosure
- Make sure that practical matters – like payment, transport, CRB checks – are properly thought out
- Allow enough time for regular communication and effective support
- Constantly work at building and maintaining relationships and trust
- Treat co-research as a learning process, and work together to try and solve problems and overcome challenges
- Keep co-researchers informed about what’s happening, even if nothing’s happening!

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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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Acknowledgement

This case study first appeared in Blackburn H., Hanley B. and Staley K. (2010) **Turning the pyramid upside down: examples of public involvement in social care research**, INVOLVE, Eastleigh.

Case study two

An assessment of the accommodation and health and social care needs of Gypsies and Travellers

Aims of the project

To assess the accommodation and health and social care needs of Gypsies and Travellers in Cambridgeshire.

How you found people to involve

When you’re working with a community that has experienced a huge amount of discrimination and oppression – you can’t just walk in and expect they’ll tell you everything you want to know. We had to earn their trust – by demonstrating that we were working in partnership and that all parts of that partnership were working well. And it worked. The local community were able to trust us because we were vouched for by the people involved. Having those people on the spot meant that they could put the word out – that this survey was taking place and that we were people who could be trusted.

We wanted to have equal engagement of English Gypsies and Irish Travellers because we knew we needed to interview both those groups and there wasn’t a huge amount of communication between the two. So we spoke to a nationally-based group that had credibility and respect in this area. They had already been successful in bringing those two groups together. We asked some of their members if they’d be willing to join the project steering group – because it was very important to have that buy-in from people who could speak to the different communities. By bringing in national figures, we then got buy-in from the local community. It avoided suspicion amongst the local Gypsies and Travellers who didn’t know us or our work. We recruited local people to be peer-interviewers largely through word-of-mouth. The people we had recruited nationally were able to tell us if they knew people in the area who had good potential for this type of role and were ‘sound’ (trustworthy and discreet). Via the local council, we also contacted the local Traveller Education Service. They were able to identify several Gypsy/Traveller women who were working as educational assistants. We invited these women to a meeting about the project and got some excellent interviewers that way.

How you involved people

Members of the Gypsy and Traveller communities were involved in the steering group overseeing all parts of the project. They also developed and helped to run focus groups with younger and older people. Local Gypsies and Travellers were recruited as peer interviewers. After training, the peer interviewers carried out face-to-face interviews with their local community. They were also involved in the analysis and write-up of the results and the launch of the final report. This model of involvement has been recognised internationally as a model of best practice. It has since been used to carry out similar assessments of Gypsy/Traveller needs in other parts of the UK and Europe.

What training and support did you offer?

With the people on the steering group, we agreed to have some closed sessions in the group meetings, just for the Gypsy and Traveller members. So they were able to do some work without us, to review our questionnaire and to discuss whether or not they trusted us and what we were doing. For the interviewers, it proved crucial that we provided lots of training and support. Most importantly we provided the training that the peer interviewers said they wanted. We knew we had to include training on issues such as confidentiality and child protection for ethical reasons – but there were other things they asked for that I wouldn’t have thought of, such as dealing with awkward people and how to probe for more information.We also had to do masses of work to build up trust and to show that the interview data would be anonymised and all be kept confidentially and that our interviewers would be highly professional. Some of the local community members were concerned that the peer interviewers might gossip about them. So we had to make sure people felt they could trust the interviewers, otherwise they wouldn’t have taken part. We also had to address the concerns about the quality of the interviews that came from other stakeholders initially. Some were suspicious that peer interviewers would not be objective or would deliver poor quality data. So we built in ongoing monitoring of the peer interviewers. Academic members of the team went out with each peer interviewer at different points to watch their technique and give feedback. In fact the completed questionnaires were generally of as high quality as those administered by PhD students or ‘professional’ interviewers. We found that the peer interviewers needed vast amounts of support especially at the beginning of the project – this did decrease over time. I gave them my mobile phone number so they could get hold of me anytime there was a problem. I had their mobile numbers and home numbers, so it was only fair that it worked the other way round. It created respect and trust. Not a single person abused it. People only phoned in when they were concerned. And they knew we would come out to help them.

What difference did public involvement make?

The steering group helped us to devise publicity material for the study. They helped us sell the project. They made sure we explained that we would be asking quite personal questions at times – and the reasons for it and importantly that all the data would be held confidentially. They helped us get that right and that was very, very important. They also made significant changes to the questionnaire. They included new questions on areas that we hadn’t thought of – like health and safety factors on Gypsy/Traveller sites, which gave us some really dramatic results – for example we found out about the lack of fire hoses and other safety issues on some publically owned sites – which we wouldn’t have heard about otherwise. With other questions the steering group members were able to say – don’t be silly if you ask that, you won’t get any answers and people will walk away. If those questions had to be included to fulfil our contract, then we had to say we can’t completely remove that question, so how do you suggest we rephrase it to get it answered?

Involving Gypsies and Travellers as researchers meant we could get out and talk to people who had never been interviewed before. So we learnt much more about the depths of exclusion experienced by some community members. For example, we found out about some disabled people who were living in trailers that weren’t adapted in any way and who simply didn’t know about relevant services or their rights to access services.

At the final launch we jointly presented the findings from the project and the Gypsy/Traveller members received their certificates of training as a community interviewer or steering group member – like a graduation ceremony. This meant that the people we involved felt incredibly valued and it went down amazingly well. It also meant that the staff from health authorities and social services as well as local councillors, who had never met Gypsies/Travellers before, had a chance to set aside their prejudices, communicate and listen for the first time. That was incredibly valuable.

I think in the end everyone was happy with the results – the council felt that they got an accurate picture of what was going on in the community and the community members felt that they had been involved, so they were happy with the outcome. So then at the start of any subsequent political or legal process, we were going to be in a win-win situation. It’s not that the council put down some figures and the community said this is completely wrong – you haven’t consulted us. There’s more cohesion from the beginning, because everyone has been in dialogue. We’re not immediately at loggerheads.

As had been planned from the beginning, the project helped to establish local Gypsy/Traveller forums. These have continued to provide a means of communication between the council and the local community long after the research project finished.

What would you advise other researchers about involvement?

Trust made the involvement work well. I can’t say that often enough – trust, trust, trust and trust. We were very open. Because of the history of Gypsies/Travellers being exploited, there were concerns that we would come in, write up a report, get paid vast amounts of money, go away and there would be no change. So we were open – we talked to the people involved throughout the project saying we cannot guarantee what will be delivered at the end of this, but we will do the absolute best we can. We work in partnership. We are with you every step of the way. We were also open about the budget. We said this is how it divides up – this is what’s spent on administration or petrol costs – so people could see precisely what was going on. We paid people to attend steering group meetings. And we paid the interviewers. We were clear they were paid exactly the same as a postgraduate student – given the same training, same rate of pay, and that the same degree of professionalism was expected.

I would advise other social care researchers to use this type of approach. It is morally and ethically sound. It does deliver results. It is the right way to work as far as I’m concerned and I’m unshakeable on that. It’s not the cheapest way – it would be easier to bring in experienced researchers who don’t know the community. But it’s better to work with local knowledge – with someone who speaks to the community, who knows the people. And it’s very time consuming. You need to have a huge commitment in terms of training and working with community members, very regular meetings and lots of phone calls with people.

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Acknowledgement

This case study first appeared in Blackburn H., Hanley B. and Staley K. (2010) Turning the pyramid upside down: examples of public involvement in social care research, INVOLVE, Eastleigh.

Briefing note ten: Where to go for further information

Where to go for further information

INVOLVE resources

All of our publications and resources are freely available to view or download from the INVOLVE website.

INVOLVE online resource for researchers: ten briefing notes on how to involve members of the public in research.

Supplements on:

- Strategies for diversity and inclusion in public

involvement
- Public involvement in clinical trials
- Public involvement in systematic reviews

Case studies highlighting examples of public involvement in research.

Templates with examples of useful documents such as job descriptions and terms of reference.

INVOLVE **Putting it into practice database**: a database of references for reports and publications on:

- guidance on good practice
- reports of the lessons learnt from direct experience of involvement
- descriptions of involvement in research projects.

INVOLVE **Evidence library**: a database of references on the impact, nature and extent of and reflections on public involvement in research.

INVOLVE **online resource on training and development**

invoDIRECT: an online directory of networks, groups and organisations that support active public involvement in NHS, public health and social care research

Budgeting for public involvement: practical advice on how to budget for public involvement and an online cost calculator

People in Research: a resource to help members of the public find opportunities to get involved in research and for research organisations / researchers to advertise involvement opportunities

Other resources and information

National Institute for Health Research (NIHR) Research Design Service (RDS) supports researchers to develop research proposals for submission to the NIHR and other national, peer-reviewed funding competitions for applied health or social care research. This includes giving advice on patient and public involvement in the development of proposals.

There are ten NIHR Research Design Services:

- **East of England**
- **East Midlands**
- **London**
- **North East**
- **North West**
- **South Central**
- **South East**
- **South West**
- **West Midlands**
- **Yorkshire and the Humber**

National Institute for Health Research (NIHR) Clinical Research Network website provides an overview of their work and information on the research networks and public involvement and engagement.

National Institute for Health Research (NIHR) – information for researchers on public involvement in NIHR funded research and how members of the public are involved in the NIHR.

Involving London – a website providing a range of information and opportunities for patient and public involvement in London

Involving users in the research process – leaflet produced by Guy's and St. Thomas' and King's College London Biomedical Research Centre

North West People in Research Forum – an organisation supporting patient and public involvement and engagement in the North West

Handbook of user involvement in nursing and healthcare

research – Elizabeth Morrow, Annette Boaz, Sally Brearley and Fiona Ross – a book published 2012

User involvement in research: A route map. TwoCan Associates – for organisations who commission or fund research and want to involve service users in their work

References in the Briefing notes

Case study five

An evaluation of a teenage pregnancy prevention strategy

Aims of the project

This project, funded by Leicester City Council, aimed to evaluate the local teenage pregnancy prevention strategy.

How you found people to involve

We made flyers and advertisements and sent them out through the agencies which were part of the teenage pregnancy prevention strategy board and through the youth clubs. Connexions was part of the board and they offered to employ the young people for us. They were part of the recruitment process and the young people's contracts were with them.

We got a big response. So we invited them all in for an 'information and selection' day where they could find out about the project. Young people often don't know what research is. So we talked through different news articles for them to think about evidence and how much credibility you give to different information. So they got a better idea about what we were going to do. We also got them to do tasks that helped us to make an assessment of their skills and abilities to do the job. We thought all the young people who were prepared to make the commitment were up to doing the job – so we offered a post to all that wanted it in the end. We took on more people than we had expected – because a lot of them turned out to be young parents (although that wasn't our intention) – so we knew there would be availability issues. We had a team of eight young people – seven young women and one young man and all but two were parents.

How you involved people

Young people were involved in the project as peer researchers. They designed the information collection methods, carried out interviews with other young people in local youth clubs and schools and helped with the analysis and presentation of the findings. They also contributed to the development of the interview schedules for other interviews with parents and teachers.

I involved young people in my research because it's just the way I have always done things. I have a background in youth work and I’ve involved young people in all the research I’ve done. You get a double benefit. You benefit from the knowledge, experience and advice of the young people you work with – but the fact that you involve young people also gives you credibility with the group of people you want to take part in your research. It puts you in a better place to know how to work with young people as well as a deeper understanding of the work you do. Since we did this project, we have been able to work with the University to employ young people on bank contracts – as Associate Research Assistants (ARAs) – so we’re able to work with them on a sessional basis for a year. Over the past 12 months the ARAs have been actively involved in one big project and have been involved in an advisory capacity on other projects. They are also thinking about how they might take forward their own piece of research. In the past our formal contact with young researchers finished when their specific project came to an end. So employing ARAs is a good way of keeping people on board after a project has finished and making the most of their new skills and experience. Young people tend to move on very quickly in their lives – so being able to keep them involved in this way helps us to get the most out of our investment of time and resources. It also means we can involve them at much earlier stages of a project (for example writing bids). It’s a more satisfying experience for them too.

What training and support did you offer?

We provided a lot of training and made sure that it met their needs. We did it over a number of short days. The young people were paid to attend the training, as it was an essential part of their work. We held it at Connexions and organised a lunch but importantly we also had to organise a crèche. Some of the young parents had never left their children in a nursery before. So we had a day before they started, where they could take the children to the nursery for a while and stay with them, as a way for them to feel comfortable leaving their children. We covered a lot of material around methods – what is research and evaluation, different information collection methods and they considered each method’s advantages and disadvantages – and in so doing built up decisions for what we were going to do in the project. So the young people decided how we would collect the information. And we did a lot around ethics and informed consent and confidentiality. They were very anxious about two things – child protection issues, in particular what would happen if someone told them something they were concerned about. And secondly what they would do if the young people they were interviewing weren’t interested or behaved badly or were rude. So we did a lot of role-playing and rehearsed exactly what to say in the interviews, so they could also develop all the wording about introducing the project and explaining the ethical and confidentiality issues in a way they were comfortable with.

The young people never went out to do interviews on their own. They were always accompanied by somebody from the University. We would arrange to meet up in town and then go to the site together in a taxi but at the schools and youth clubs they did all the interviews and facilitated the group sessions themselves. Some of the young people also came with personal issues that we were not able to respond to and maybe it was not our responsibility, but we did know where they could go to get the appropriate help. So we didn’t counsel people. We suggested people and places that could help them, and then we checked they had been and were getting support.

What difference did public involvement make?

The young people made a big difference to the part of the project that involved interviewing other young people. They decided what methods to use, helped us decide what questions to ask and which local schools and youth clubs to work with. They were really reflective about collecting this information

– along the lines of – ‘If I was in school and people were coming to ask me about this – who would I rather talk to?’, ‘What would I think if someone asked me that?’. They did all the information collection with young people – both through one-to-one interviews and facilitating group sessions.They also influenced other parts of the project through raising questions and making us look at things in ways we wouldn’t have thought of. For example one of the things they talked about beforehand (that was confirmed by our research) was that the people they really wanted to talk to about sex and relationships were their parents. But their parents couldn’t do this. They pointed out that it was the parents who needed most help. So that prompted us to ask parents more about this in our interviews than we might otherwise have done.

I don’t think there’s any way, that without their involvement, we could have got the sort of data that they got – even if we had had an advisory group and used their questions and advice. Without a doubt they had it. There were times when we thought they were brusque in the questioning but the other young people didn’t mind. As adults we use politeness to show we are respectful of young people – but the young people didn’t feel the need to do that amongst themselves.And there’s also no doubt that young people were really impressed to see other young people in this kind of a role. At some of the youth clubs, the workers said how good it was to see how young people can be involved in research.

The young people helped us to analyse the findings and draw out the recommendations. This had an enormous impact. Because we gave the commissioners action points which had quite clearly come from the young people’s analysis of the findings – nearly all of them have been implemented. One of my colleagues bumped into one of the staff on the strategy board, and they said it was the best piece of research they’d had, that they’d followed through on all the actions and that the teenage pregnancy rate is now dropping. We can’t prove any connection between all these things – but there could be a link. It also helped that one of the young people co-presented the findings and that they had all written the presentation. The fact that young people were involved gave the research added credibility as well. Not everyone would have been more impressed with a piece of research that young people had been involved in – but that particular audience was. That made a big difference to the impact of the results.

What would you advise other researchers about involvement?

I do think it improves research. There are different types of knowledge and understanding. It’s about recognising that young people or service users not only have something to contribute in terms of answering your questions – but can actually help to frame those questions and the whole process. You have to work with people on their terms. With young people, they don’t turn up sometimes, they don’t always communicate – but that’s young people – that’s just what happens. If you engage with young people, you just have to accept that that’s the case. It makes the research more interesting for other people. We ask quite a lot of people in terms of giving their time to our projects and our interests. The least that we can do is to make it as interesting and pleasant as it can be and I think involvement helps to do that. You do have to believe in it and believe in the underpinning values of it to be able to do it – there’s nothing worse than tokenistic involvement. It takes an awful lot of time, but I am 100% convinced that it’s worth it.

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Acknowledgement

This case study first appeared in Blackburn H., Hanley B. and Staley K. (2010) **Turning the pyramid upside down: examples of public involvement in social care research**, INVOLVE, Eastleigh.