Involving children and young people in research: not the usual suspects

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Involving young people in the Youth Social Behaviour and Network Therapy Study (YSBNT) project

YSBNT is a 30-month project which is adapting and testing an intervention (way of delivering services) originally developed for adults, so that it can be used with young people using drug and alcohol services and their families and social networks.

The study is also looking at how best to involve young people with experience of using drug and alcohol services in the research process. So far 10 young people have been involved at different points through one-to-one and group meetings, as well as by phone and email. The young advisors have been involved throughout the project in a range of ways, including contributing to the development of research and training materials and the YSBNT intervention currently being piloted. We are now planning how they will be involved in the next stages of the research, including analysis and writing up.

Developing flexible and young person-centred methods of involvement

The study is also looking at how best to involve a group of young people who don’t often get involved in research. Our

original plan was to go for a traditional model of public involvement, and have an advisory group of 10-12 young people who would be actively engaged throughout the project. We found out very quickly that this was not going to work! There were a number of reasons for this, including more problems than we anticipated with services being able to identify and support young people who could potentially be involved. The young people who did express an interest were also often at points in their lives or living in circumstances in which it was difficult for them to commit to ongoing involvement. This could be because of work or education commitments, because they were living in hostels or other temporary accommodation and/or because they had a lot of other things going on in their lives. As well as changing circumstances it was difficult to keep in contact with many of the young people involved because of changes to addresses or phone numbers and often limited internet access or phone credit. Issues of consent and safeguarding for young people under 18 are also inevitably more complicated if those young people are not living with their birth families.

Despite these challenges we have managed to work with a number of young advisors throughout the project; their input has been extremely helpful and has informed key elements of the intervention/project. Although a traditional model of an advisory group which gets together regularly in one place has not really worked, we have been able to work with the young advisors to develop a much more flexible and young people-centred way of working. We start by going to where the young people are and meet them in places they feel comfortable (e.g. fast food restaurants or coffee shops) rather than expect them to come to us. For the analysis and writing up stages we are looking at how we can get young advisors' input by phone, post and online in ways that work for them. The young people involved are helping us to develop a better model of involvement should this pilot project develop into a bigger trial study. We hope that learning from the study will

contribute to the wider emerging evidence base on young people's involvement in research, and inform other studies and involvement activity with young people whose voices are less frequently heard in traditional models.

What difference has this involvement made?

So far the young advisors' involvement has informed key elements of the YSBNT intervention and their input into recruitment materials and plans on how to approach young people has been invaluable in helping recruitment. But the final word should go to two of the young advisors who have been involved in the project:

"I think it's important to involve young people who have used [drug and alcohol] services as they can understand what it's like for others who are in the shoes that they've been in. I personally needed someone that has been through what I was going through as they understood me better and knew what I was feeling and thinking – no offence to people that have got degrees! I wanted to get involved with this project because I've always wanted to do something like this to show others that it is possible and there is light at the end of the tunnel – and that no matter what circumstances they're in they've always got a voice." (SB, 18)

"I got involved in the project because I think that it's important that young people can get the help that they need in the most helpful and supportive way so it doesn't damage them. I think I've gained an insight into research with young people and the opinions of young people held by social agencies and professional networks….I didn't realise just how useful I'd find it, hearing everyone's experiences is wonderful, everyone's unique and that's very comforting." (BB, 18)

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