



Information for family/friends

Project: The Role of Social Capital in the Personalisation of Care

Investigator: Nick Willmore

Sponsor: University of Birmingham

Course: Doctorate in Business Administration

You are being invited to be involved in a research study as a friend or family member of someone who is receiving care and support from a local authority through a personal budget. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. At no time will participation in the study, or choosing not to do so, have any impact on the care and support being received by the participant from the local authority.

We refer to the individual who has been allocated the personal budget as 'the participant' in the study. This information sheet has been prepared for those family or friends that are interested in knowing more about what we are doing or who have been invited by the participant to join them in the interview. Where the participant asks you to join them in the interview and to contribute to the discussion you will be considered to have become a participant in your own right.

What is the study about?

The study is looking at two things with a common link. Firstly it is trying to establish if the support required by people is influenced by their existing networks and if so is it different for different groups of people? Secondly does the support provided to people with a learning disability have to be more expensive because they receive less natural support and so carers have to be more pro-active when supporting them?

In 2009 the Government announced that there was to be a transformation of social care in which individuals and their families would be able to take control of their care resources and arrange their own support. The early pilots showed that this was a way for the cost of state funded care to be reduced without cutting care. Indeed for many it resulted in an improved quality of life. Since then the resulting arrangements have not been as promising, so the question is why not. The study is taking one aspect behind the way that people organise their support (their normal relationships, friendships and community links) and investigating what the real impact this has on individuals.

Risks and benefits

The study does not involve any changes in care arrangements and is not linked to the assessment that the local authority undertakes. Therefore there are few risks to participating in the study. The main risk is that we will be talking about what happened when their care was arranged and sometimes this can be upsetting. If you think there will be strong feeling about this for you, you might want to think about whether, or how, you wish to participate.

The benefits are similar to many other studies in that participants report that it is helpful talking about how things that become important to them happen as they can gain an insight into how to better organise things in the future. An interview that is set out to discuss the different aspects of a decision or event can also help the participant better accept what has happened to them. Each person gets something different from this sort of experience, but it is unusual for someone to get nothing back.

How will the study work?

The study will involve interviews with 40 people who receive funding from local authorities. Half will have a learning disability, the other half will be older adults. They will be selected at random by the host local authorities and their agreement sought to participate in the study. Only once this agreement is obtained can the local authority share details such as addresses with the researcher.

Once they have agreed to be involved as a participant the researcher will make contact and arrange the interview. Each interview will take about two hours to complete. This can be split over two sessions if the participant prefers, and we will certainly want to take breaks during the interview if we do it in one session.

The interview will take place in a venue of the participant's choice whether that is their home, a community venue or wherever they feel comfortable. At the start of the interview the researcher will ensure that you understand what is involved and together we sign the consent form. The interview will loosely follow a prepared list of subjects, but will be guided by the participant To ensure that

the interview is accurately captured it is proposed that it is recorded on tape and then transcribed into writing. The participant will be offered a copy of the written record or the audio recording. They will be asked to check that it is accurate as far as they can recollect.

As the study is looking at the way that families and friends contribute to the participant's life you are more than welcome to join us in the interview. We do ask that you allow the participant to lead the discussion and, whilst we are interested in your contribution, its interest is greater where we can hear both the participant's perspective as well as your own.

Occasionally interviews bring up difficult experiences and emotions. Sometimes we can work through this together, sometimes we might have to ask for someone else to offer longer term support. We can sort this out together if it seems appropriate. However we rarely come across issues that need to be addressed as a safeguarding concern (such as neglect or inappropriate financial dealings). If the researcher were to hear of significant concerns for the welfare of a vulnerable person there would be a requirement that the appropriate local authority team is notified.

What happens next?

After the interview the researcher will be bringing together all the interview results and looking for common themes. This is expected to be finished at the end of October and will then be set out in a report that forms part of the final thesis. This draft report will be sent to the participant to comment on. It is possible that in the report there will be quotes taken from individual interviews to be used in the final thesis; this will be highlighted to the individual(s) concerned..

What will the researcher be told by the host site?

The only information we are asking from the local authorities in the study is for contact details for individuals, whether they have a personal budget or direct payment as part of their care provision and whether there are active family or friends (but not their contact details). As to the reason for support this only needs to be whether they are an older adult or have a learning disability. The final information will be whether the participant has any specific communication needs. We do not want details about care, or the history of care arrangements. It is up to the participant or their family or friends to tell us about care needs and why care has been allocated to them.

What consent am I asked for?

In giving their consent to be interviewed participants will also be giving their agreement that what they say can be used anonymously in the final report and thesis. This means that if, after the interview has taken place, the participant loses mental capacity to give consent, what is said at the interview would still be

used. If you also participate in the discussion you will also be asked to give your consent to being involved and for your contributions to be included in the final report and thesis.

What personal information is held?

The final thesis will be available to the public so, in the reports it is based on, no information that could identify an individual will be included. The records of interviews and other documents used in the study will refer to individuals by their initials. In order to manage the study there will be a master key, which will include all the contact details relating to participants and the initials used to identify each interview elsewhere in the study. This makes it very difficult for someone other than the researcher to link individuals and the comments they might make. The master key will be kept in a secure electronic file separately from the interview records.

The study is being undertaken by a part-time student who also runs a social work business, IAC. The study records will be held on a secure server owned by IAC. Only the researcher will have access to the records and the master key referred to above. This is a practical response to living in Sussex with the university being in Birmingham.

A year after the study is completed the master key will be destroyed so no-one will be able to identify the participants. The records of interviews will be kept for ten years in case anyone wishes to review the conclusions of the study.

Contact details

For further information on the study, what is involved and the arrangements relating to participants the researcher can be contacted as below.

Telephone	01444 226468	email	Npw744@bham.ac.uk
Address	22 Royal George Road, Burgess Hill, West Sussex, RH15 9SD		

To verify the authenticity of the researcher or the study please contact the Health Services Management Centre at the University of Birmingham.

Telephone	0121 414 7068	email	j.glasby@bham.ac.uk
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Thank you for considering participating in this study and I hope to meet you in the near future to take it forward.

Nick Willmore

29 February 2012