

## **Carer Information sheet- Focus group**

### **Title: Pilot randomised controlled trial of one to one befriending by volunteers for people with intellectual disability (ID)**

#### **Introduction**

You are being invited to participate in a research project. Before you decide, it is important for you to understand why the research is being conducted and what it will involve.

Please take time to read the following information carefully. If anything is not clear, feel free to ask any questions and to discuss it with your friends, relatives or others.

#### **What is the purpose of the study?**

Befriending is a one to one relationship that is based on providing friendship and emotional support. We are carrying out a study to find out if befriending can help to improve wellbeing and social participation in people who have learning disability (also known as intellectual disability). In this study we will be evaluating befriending schemes that are provided by community organizations.

Learning disability is defined as having low intellectual functioning (IQ below 70) and difficulties with activities of daily living that arise in childhood. People with learning disability often experience loneliness and isolation because they have smaller social networks and lower levels of social support. They may be unable to access the community by themselves and may rely on carers (family or paid) for support, resulting in lower levels of social participation. All this may decrease self esteem and increase their vulnerability to depression. Befriending may be helpful for people with learning disability as it may provide social support and help them to access activities in the community, thereby reducing feelings of loneliness and depression.

Studies of trials in the general population suggest that befriending may reduce symptoms of depression. However, there have not been any published trials of befriending in people with

learning disability. This study is a pilot study and will help to determine whether a larger trial can and should be carried out in this group.

We would like to obtain the views of volunteer coordinators and members of staff at the befriending service about their views on the befriending intervention and the study processes.

### **Why have I been invited?**

You have been invited because you are a carer for a person with learning disability who has taken part in the befriending study. We would like to find out what your views are about the intervention and the study processes.

### **Do I have to take part?**

No, it is up to you whether you would like to take part and there will be no penalty for choosing not to take part. If you decide to participate, you will be required to sign a consent form. You can withdraw your consent at any time without having to give a reason.

### **What will happen to me if I take part?**

If you agree to take part, you will be invited to attend a focus group with other carers. There will be between five to eight people in the group and the group will last about 90 minutes. The group will be facilitated by two members of the research team. We will ask questions about your thoughts on the befriending intervention and the study processes. This will include questions about what impact you think the befriending has had on the person you care for, what aspects of the intervention worked well and what could be improved.

We will audio-tape the focus group discussion using an encrypted digital recorder. We will transfer the recording onto an encrypted computer immediately after the group and the recording will be deleted from the recorder. The recording will be transferred but any personal information that could identify you will be removed.

### **What are the possible disadvantages and risks of taking part?**

We do not anticipate that there will be any risks to taking part in the study. If for any reason, you are upset by the content of the discussions, you are free to leave the group and one of the facilitators of the group will speak to you to make sure you are OK.

### **What are the potential advantages of taking part?**

There are no direct advantages of taking part in the study. However, we hope that the information you provide will help us to make improvements to the study and intervention, which will help to inform the design of a future large scale study on befriending.

### **Will there be any payment or reimbursement of expenses?**

As a thank you for taking part in the focus group, we will give you a £15 gift voucher.

### **Will my participation be kept confidential?**

Yes. All information about you will be kept confidential. A code number, instead of your name will be used to identify data about you, and the list that links the codes to your identity will be kept separately from the data. It might be important to look at the data in years to come, so we will keep it for 20 years and then it will be destroyed. All data use is strictly within the terms of the Data Protection Act (DPA 1998).

The audio recording will be transferred immediately to an encrypted computer and the file will be erased from the digital recorder. We will transcribe the recording but any information that could identify you will be removed.

### **Data Protection Privacy notice**

#### **Notice:**

UCL is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and looking after it properly. UCL will keep identifiable information about you for 6-12 months after the study has finished.

In this study, participants may access, change or move information at their request. If you withdraw from the study, we will keep information about you that we have already obtained. To safeguard your rights we will use the minimum identifiable information possible.

You can find out more about how we use your information at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk).

The befriending organisation will collect information from you for this research study in accordance with our instructions.

The befriending organisation and research team will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from UCL and regulatory organisations may look at your research records to check the accuracy of the research study. The befriending organisation will pass these details to UCL along with the information collected from you. The only people in UCL who will have access to information that identifies you will be people who need to audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name, or contact details.

The befriending organization and research team will keep information about you from this study for 6-12 months after the study has ended.

### **What will happen if I don't want to carry on with this study?**

You are free to withdraw from the study at any time without giving a reason and will not be penalised in any way. If you have taken part in the focus group discussion we will use the data unless you tell us specifically not to.

### **Who is organising and funding this research?**

The study is being organised by Dr Afia Ali, University College London, who is the Chief Investigator of the research project, and is responsible for overseeing the research, and for the secure storage of data.

The study is being funded by the Public Health Research funding stream of the National Institute of Health Research. They will have no involvement in the conduct of the study. The study is being sponsored by University College London.

### **Has the research been reviewed by an appropriate research ethics committee?**

We have had this study reviewed by an appropriate NHS research ethics committee (REC ID: 240552) who have given us advice about the study documents and conduct of the study.

### **What will happen to the results of the research?**

The focus group is part of a study on befriending and the study findings will be reported to the National Institute of Health Research and will be presented at conferences. We would also like to publish the results in a scientific journal and we plan to hold a public engagement seminar where we will discuss the results with stakeholders (e.g. befriending services, commissioners, individuals and carers with learning disability). Your name will not be used in any report or publication. We will provide a summary of the results in a newsletter, and can send this to you if you wish.

### **What happens if there is a problem?**

If you have any concerns or wish to discuss the project with someone then you can speak to the research assistant who will do their best to answer your questions or resolve any difficulties that you have. If you are not satisfied with the response then you can contact the Chief Investigator (see details below) who will do her best to address the issues.

In the event that something goes wrong and you are harmed during the research and this is due to someone's negligence, then you may have grounds for legal action in order to obtain compensation from University College London. However, you may have to pay your legal costs.

### **What happens if you would like more information about the study?**

If you would like more information about the study, please contact the study research assistant or Dr Afia Ali. Their details are below

Name:

Research Assistant  
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University College London  
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Dr Afia Ali  
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Consultant Psychiatrist and Senior Clinical Lecturer  
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**Thank you for reading this information sheet.**