

Volunteer Information sheet

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.

Why have I been invited?

You have been invited because you have expressed an interest in being a volunteer befriender to someone with learning disability.

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 first be invited to an interview by the befriending service to see if you are suitable for the volunteer role. Then you will be asked to attend training sessions that will be delivered by the befriending service as face to face and as e-learning (about 2 days in total), which will provide you with information on becoming a volunteer befriender. The training will also help you to gain knowledge and understanding about people with learning disability. There will be discussions on communication and listening skills as well as how to cope with challenging behaviour. Advice on establishing boundaries and ending the relationship will be provided. Procedures on arranging and cancelling visits as well as types of activities will also be discussed. You will also be asked to complete a Disclosure & Barring Service (DBS) check and a references check before you begin your volunteering role. We request that you disclose any pending convictions, including any convictions that may arise during the period of your befriending relationship. Unfortunately we are not able to accept volunteers who have previous, current or pending convictions in order to ensure the safety of vulnerable individuals.

Following training, the volunteer coordinator at the befriending service will match you to an individual with learning disability based on common interests and your availability. An introductory meeting will be carried out where you will be introduced to the individual to determine suitability. The volunteer coordinator will be present at this meeting to discuss ground rules and to resolve any potential issues. If you both agree on the match, the relationship will begin and you will be expected to meet up with the person once a week for six months. There will be a review meeting at six weeks with the volunteer coordinator to monitor the progress of the relationship and at the end of the six months to discuss the ending of the relationship. If the person you are matched with decides to leave the study, you may be matched with someone else. We may also talk to you about whether you would like to befriend more than one person but you can choose to befriend only one person if you wish.

What will I do as a volunteer befriender?

As a volunteer, you would be required to meet up with a person with learning disability once a week for at least one hour, over a period of six months. As a volunteer you will not be paid for the time you spend in weekly meetings, but you may be able to claim reasonable expenses. You will be given a booklet with information about local activities that you could access together. You will be asked to keep a diary of activities that you do together and the amount of time you spend doing the activities.

As part of your role, you will be expected to keep information relating to your match confidential and you should not share this information with anyone else.

We will ask you to complete some questionnaires before the matching process and then at six and 12 months after the matching process. The questionnaires will cover questions about your wellbeing, loneliness and attitudes towards people with learning disability.

At the end of the study, we may invite you to attend a focus group to discuss your experiences of the befriending intervention and your experience of participating in the study. We will ask you about your views of what worked well and what could be improved. There will be between 5-8 volunteers taking part in the focus group and we will audio-tape the discussion. Attending this group is optional. You do not have to take part in this if you do not wish to.

What support will I receive throughout the study?

You will receive ongoing support and supervision from the volunteer coordinator. This will involve either a monthly face to face meeting or telephone/ skype contact or group supervision with the volunteer coordinator. This will provide a forum to discuss any issues that may arise from the befriending relationship including managing boundaries and the termination of the relationship. You and the individual you support will also meet with the volunteer coordinator six weeks after the initial introductory meeting and again just before the end of the relationship at six months. You can contact the volunteer coordinator at other times if you have any concerns that you would like to discuss.

What happens at the end of the study?

You may continue the relationship beyond six months if you both wish to do so. If you decide to do this, this will be outside the trial and you will need to follow local procedures and arrangements with the befriending service. The volunteer coordinator will discuss this with you.

What are the possible disadvantages and risks of taking part?

The intervention is potentially burdensome as it requires commitment from you to meet with the befriender once a week for six months. However, we understand that sometimes it will not be possible for you to meet the person every week. There is a possibility that the person you befriend may become attached to you but we will discuss how to manage situations like this in supervision sessions. We will take measures to ensure both your safety and the safety of the person you befriend such as ensuring that lone working arrangements are followed.

What are the potential advantages of taking part?

There are no direct advantages of taking part in the study. However, we hope that the experience is rewarding as you could make a valuable contribution to the person's quality of life. You may also gain some skills and knowledge of working with people with learning disabilities.

Will there be any payment or reimbursement of expenses?

This is a voluntary role, which means that you will not be paid. You will be able to claim back travel expenses and other expenses that have been pre-agreed with the befriending service.

As a thank you for taking part in the study, we will give you a £30 gift voucher (£15 for completing questionnaires at each follow up assessment)

Will my participation be kept confidential?

Yes. All information about you will be kept confidential. Personal data will be stored securely using encryption. 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.

If you take part in the focus group, we will use an encrypted digital recorder to record the session and then 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.

The only situation where we may need to break confidentiality is if we have any concerns about your safety or the safety of the person you will be befriending. If this occurs, we would follow local safeguarding procedures. This is standard practice.

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.

The befriending organization and research team 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 happens if I wish to leave the study early?

You are free to leave the study at any point you want to. If you choose to leave before the official end of the study we will keep all of the information we have collected about you up to that point and use it in our analysis. If you do not wish for us to keep this data you can ask us to destroy your data.

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 results of this research 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

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Thank you for reading this information sheet.