

UCL Research Ethics Committee Approval ID Number: 0241/005

**We are working on a study which aims to advance our understanding of how people with learning disabilities respond to prejudice and discrimination they may experience, and whether a new group programme can support them in this process. This research is funded by the National Institute of Health Research (NIHR).**

### **Our research team**

- We are a team of researchers from University College London (UCL), we are part of the UCL Unit for Stigma Research (UCLUS).
- We are working with other researchers from Cardiff University and the London School of Economics (LSE).
- Our research team also includes researchers, clinicians and self-advocates with learning disabilities from other parts of the UK.

### **Contact details for the research team:**

Should you have any queries or require any further information, please do not hesitate to contact the research team.

Please contact Michaela Osborne (Research Assistant) if your group may be interested in taking part -

Email: [m.osborne@ucl.ac.uk](mailto:m.osborne@ucl.ac.uk)

Please contact Lisa Richardson (Study Manager) in case of any complaints-

Email: [lisa.richardson@ucl.ac.uk](mailto:lisa.richardson@ucl.ac.uk) (Working days- Monday, Tuesday and Wednesday)

## **Background to this research study**

- Research shows that people with learning disabilities often face negative consequences because of negative stereotypes, prejudice, bullying and discrimination associated with having a learning disability (what we collectively refer to as 'stigma' hereafter).
- Despite positive changes in policies, service provision and societal views, negative attitudes and discrimination remain everyday realities for many people with learning disabilities.
- Despite a clear need to do more to empower people with learning disabilities to manage and resist stigma, to date few interventions have targeted this and none have been shown to be effective.
- Developing effective ways of promoting skills and confidence in standing up to stigma is likely to have positive effects on their mental well-being and social interactions.

## **About the research study**

- We have developed a new psychosocial group programme called Standing Up for Myself (STORM), to help people with learning disabilities cope with and stand up to the stigma they often have to face on account of having a learning disability. More information about STORM is provided further down.
- We would now like to test the feasibility of running this programme and evaluating its impact with people with learning disabilities.
- In order to do this, we aim to recruit 16 groups for people with learning disabilities. Eight of these groups will continue to do their usual activities, the other eight groups will do the STORM programme. This is so that we can assess the impact of STORM compared to groups who carry out their usual activities and not STORM.
- Whether the group that you facilitate does or does not do STORM will be decided at random, like flipping a coin. Therefore, every group has an equal chance of doing the STORM group programme or continuing with their usual activities.
- If STORM is found to be acceptable and to have potential benefits for participants' wellbeing and ability to respond to stigma, then all participating groups will have access to the STORM programme materials and guidance after the research has finished and will be able to choose whether to use them.
- In the future we hope that this programme will be a freely available resource that group facilitators can use with groups of people with learning disabilities when they feel that this may be useful.
- All group facilitators and group members that take part will receive a certificate of contribution to research on completion of the study.

## Who can participate in the study?

- We are looking to include existing groups of people with learning disabilities in this study (regardless of whether their usual focus is educational, social, activity-based or self-advocacy).
- As part of this, it is important that the group members:
  - Have a mild-moderate learning disability  
This is because the study has ethical approval only for people who have capacity to consent. Also the activities in this programme involve watching films and discussing these – we are in no way looking to exclude people with severe and profound learning disabilities but feel an intervention that meaningfully involves them would need to be designed in line with their needs.
  - Are aged 16 or over
  - Know one another
  - Ideally have someone that they can talk to for supportIf you are unsure about someone's suitability to take part in the programme, we are happy to discuss your concerns.
- It is also important that the group:
  - Has at least 4 group members who would like to take part – we suggest around 10 members as an upper limit, although this is not set – in any case the group size must allow for meaningful discussions
  - Is able to meet regularly for 1.5 hours (this could be weekly or fortnightly)
  - Is able to meet on 4 separate occasions, and again around one month after the fourth meeting
  - Is run by a group facilitator who is familiar with group members
  - Has access to a comfortable venue which people can easily travel to and that has access to a laptop or computer or wifi.

## What will I need to do as a group facilitator?

- Clarify in discussion with the research team whether the group as a whole and individual group members are suitable to take part in the study.
- If yes, we would like your assistance in collecting some information from group members:
  - Once group members have had the study presented to them and expressed interest in taking part, a member of the research team will meet with each group member individually to obtain their informed consent and complete a questionnaire. These meetings will be organised through you as the group facilitator.
  - We will meet with every group member three times throughout the study to complete the questionnaire. The first occasion will be soon after they have expressed interest in taking part in the study, then around 3 months after the first meeting, and then about 10-12 months after the first occasion. This is so that all participants complete the questionnaire at the same time points, regardless whether they are in the usual activities or STORM arm of the study
  - The questionnaire contains questions about how individuals feel about themselves, their wellbeing, how empowered they feel, how they feel having a learning disability affects them, and about services they access for support
  - Setting up an interview with some of the group members who have taken part in the STORM groups and would like to do this.
- You will be asked to take part in an interview:
  - The interview will be with a member of the research team 4- 6 months after group members complete the questionnaires for the first time.
  - If you facilitate a group that takes part in STORM, we would also like to find out your views on the

STORM programme.

- If you facilitate a group that continues with usual activities, we would like to know more about the activities that your group did and your thoughts about the group taking part in the study.
  - The interview will be audio recorded, transcribed and analysed. Transcripts will be anonymised and you will therefore not be identifiable.
  - As a thank you for your time, you will receive payment of £10 or will be able to nominate a charity to have £10 donated to.
- If the group you facilitate is allocated to do the STORM programme (more information about the programme below), this will involve:
    - Facilitating the delivery of sessions 1-4, and a follow-up session approximately one month later.
    - You will be provided with a facilitators' manual which provides clear details on how to deliver each session and all resources and materials. This will be provided in a web based version to assist with the delivery of sessions, alongside an electronic or hard copy of the manual.
    - You will be supported by Mencap, our partner in this research, to deliver the programme, including:
      - Receiving 2 to 3 hours of training, wherever possible at a time and in a manner that is convenient for you
      - 'Supervision' to support you in delivering the programme to your group – in addition to planned meetings or telephone calls you will be able to contact the Mencap lead for the STORM programme if any queries or concerns arise at any other times
    - We will ask you to audio record the group sessions (with group members' consent), this is so that we can assess consistency of delivery across groups and learn more about how the STORM programme can be run in different settings and with different groups.
    - If you have any queries or concerns about the study itself you will be able to contact the Study Manager at any time.
    - You will be required to explain the confidentiality limits within the group. This includes ensuring that group members understand that what they say in the group will be kept confidential unless group members share information that may cause harm to the person or someone else. The safeguarding procedures at the site that the groups are held should be followed as per usual.

### **The Standing Up for Myself (STORM) programme**

- STORM is a 4-session group programme (plus 1 follow-up session) which consists of sessions that lasts 1 hour and 30 minutes.
- The group will watch filmed first-hand testimonials by people with learning disabilities, engage in discussions and practical exercises.
- It is designed to be interactive, thought-provoking and fun, despite the serious topic.
- The STORM programme draws on psychological theories and evidence.

The STORM group sessions will be audio recorded with participants' consent in order to help the

The themes of the four sessions are:

- 1) What does 'learning disability' mean to people with learning disabilities? What does it mean to me?
- 2) How are people with learning disabilities treated by others?
- 3) How do people with learning disabilities respond to negative treatment from others?  
What strategies can I use?
- 4) What do I want to try and do more of to respond to negative treatment from others?

research team to understand how the STORM programme is delivered by facilitators in different settings and to different groups.

### **What will happen to the questionnaires, group recordings and interview recordings?**

The research team will share anonymised responses to the questionnaires with the research team at Cardiff University and at LSE, who will analyse the results of this study. No one outside of the research team will have access to any information about participants. The information will be stored safely on a computer. The audio recordings will be transcribed and once any information that might identify participants or others has been removed, the transcripts will be uploaded onto a secure database and the original recordings will be destroyed. The UK Data Protection Act 2018 will be adhered to at all times.

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

The research findings will be written into reports which will be published. It will not be possible to identify any of the individuals who take part in the study from the reports, as all the information will be anonymised, with information from many individuals grouped together.

### **Local Data Protection Privacy Notice**

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' [privacy notice for participants in health and care research studies](#).

The categories of personal data used will be the name of the organisation through which the person participates in this research, age and gender. The lawful basis that will be used to process this personal data are: 'Public task' for personal data and 'Research purposes' for special category data. The data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data provided we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how personal data is being processed, or if you would like to contact us about your and/or the rights of the participants you are supporting, please contact UCL in the first instance at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk).

### **Complaints**

If you have any concerns or complaints about the way the research is being managed you can contact Lisa Richardson or Katrina Scior in the first instance, our contact details are on page 1.

**Thank you for reading this information sheet**

## UCL Research Project- Timeline

The timeline below is a visual representation of the approximate timeline for all participating groups, whether allocated to do the STORM programme or to continuing with their usual activities. All groups will be involved in the research for a period of 12 months.

| 1 <sup>st</sup><br>Researcher<br>Visit  | 2 <sup>nd</sup><br>Researcher<br>Visit  | Allocated<br>to STORM<br>Programme  | Allocated to<br>Usual<br>Activities   | 3 <sup>rd</sup><br>Researcher<br>Visit   | 4 <sup>th</sup><br>Researcher<br>Visit  | End of<br>STORM<br>Project   |
|---|---|---|---|--|---|--|
| <p>1. A member of the research team will visit to introduce themselves and go through easy read information sheets with group members.</p> <p>2. Group members can ask questions.</p> <p><b>After 1<sup>st</sup> visit:</b><br/>Facilitators to confirm with the research team that group would like to take part.</p> <p>The researcher will be in touch to schedule a 2<sup>nd</sup> visit.</p> | <p>1. Complete consent forms</p> <p>2. Every consenting group member will complete a questionnaire individually with research team support</p> <p><b>After 2<sup>nd</sup> visit:</b><br/>Your group will be randomly allocated to either the STORM Programme or to continue their usual activities.</p> <p>Study Manager, Lisa Richardson will contact you to let you know your allocation.</p> <p>There is likely to be at least 4 weeks between visit 1 and being able to start STORM with your group. If allocated to do STORM, facilitators receive 2-3 hour training in this time.</p> | <p>Week 1: Session 1<br/>Week 2: Session 2<br/>Week 3: Session 3<br/>Week 4: Session 4</p> <p style="text-align: center;"></p> <p>4 weeks later:<br/>Follow-up session</p> | <p>Usual group activities continue</p> <p>Researchers will ask for information about what you have been doing in your groups.</p> | <p>1. Every group member will complete a questionnaire again, individually with research team support.</p> <p>2. Researcher may be in contact to invite facilitators, group members and carers to participate in an interview about the STORM programme or their usual activities.</p> | <p>1. Every group member will complete a questionnaire again, individually with research team support</p> <p>2. All group members, facilitators and carers whom participated receive certificates for their contribution to research.</p> | <p>All who participated will be informed of the research findings.</p> <p>If the STORM Programme is found acceptable, all groups who were allocated to continue their usual activities will receive access to the STORM resources and materials.</p> |
| <b>Month 1</b>  | <b>Month 1/2</b>  | <b>Months 2 &amp; 3</b>   |   | <b>Month 4/5</b>   | <b>Months 10- 12</b>  |  |

N.B. If allocated to do the STORM Programme, the number of weeks will differ if the group runs on a fortnightly basis instead of a weekly basis.