



# The Parent Carer Empowerment Project

## Easy Read Participant Information Sheet

You are invited to consider if you would like to take part in a research project. Before you decide, it is important that you understand why the research is being done and what it will involve. Please take the time to read this information and discuss it with others. You can also ask questions to the research team.

### What is the purpose of the project?

To develop a new programme to improve empowerment of parent carers of children with neurodisability.

#### What is Empowerment ?

Empowerment is described as the strengthening of a parent carer's influence and control over the decisions and actions affecting their child's care.

#### What is Neurodisability?

Neurodisability involves an impairment of the brain and its connections that limits an individual's ability to do everyday activities. This includes conditions such as cerebral palsy, muscular dystrophy, genetic or chromosomal disorders and autism.

### How are we planning to do it?

Throughout this project we will work in partnership with parent carers, health professionals and NHS managers. This phase of the project involves developing the new programme and has 2 parts.

**Part A:** We will talk with these stakeholders. This will help us find out what parent carer empowerment means to those it involves and, importantly, what they see as barriers to successful empowerment. This will be achieved using focus groups, interviews and questionnaires.

**Part B:** We will use the information collected in Part A to help us develop our programme. The intervention will be developed during two half-day workshops.

### What would taking part involve?

First you will talk to a member of the research team, to make sure you fully understand what participating in the project will involve. Once you are happy, you will be asked to sign a consent form agreeing to be a participant in the project. At this point we will gather some extra information about you, to help us make sure the group of people we talk to is as diverse as possible. We will also find out if you are interested to be involved in Part A, Part B or both Parts.

## What happens in Part A?

- You will either join a focus group or attend an interview.
- The focus group will be made up of both parent carers and health professionals.
- The focus group or interview will be conducted either face to face or online, depending on your preference.
- The focus group or interview will be facilitated by two members of the research team and will last a maximum of 90 minutes.
- The focus group or interview will be recorded on a secure audio recording device.
- If you would prefer not to join a focus group or attend an interview, you can still participate by completing a questionnaire.

## What happens in Part B?

- You will attend two half day workshops.
- Each workshop will last 3 hours.
- Workshops will be attended by parent carers, health professionals and researchers.
- Workshops will be facilitated by two members of the research team.
- We will use this time to develop the new intervention.

## Are there any risks for me?

It is not expected that there will be any significant risks or disadvantages to you taking part in the project. You will be compensated for any travel or child care costs and will also receive a £15 voucher as a 'thank you' for your help.

## What information will be collected about me?

In this research study we will use information from you. This information will be collected when you join the project and also from your focus group, interview, questionnaire or workshop. We will only use information that we need for the research project. We will let very few people know your name or contact details, and only if they really need it for this project. Any personal information collected will be deleted six months after the end of the study.

Everyone involved in this project will keep your data safe and secure. We will also follow all privacy rules. At the end of the project we will save the data from your focus group, interview, questionnaire or workshop in case we need to check it. We will make sure no-one can work out who you are from the reports we write.

If you are interested in taking part and would like some more detailed information about the project, please contact Jim Reeder (lead researcher).

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You can also scan the QR code to access the full participant information sheet.

