

Research project

Who is the researcher?

My name is Angharad and I am a PhD student at Swansea University.

What is the purpose of the study?

My research is about two people who care for each other. This is called 'mutual caring'. I am researching mutual caring relationships where at least one person has a learning disability and at least one person is above the age of 50.

I want to know what it feels like to be a carer with a learning disability, what it feels like to care for someone with a learning disability, and what it feels like to be cared for by someone else.

Can you tell me a bit more about mutual care?

Mutual care may take many forms. Some examples of mutual care may include individuals with learning disabilities who end up caring for their carer (a parent, friend, sibling, partner) due to older age of the carer, or the carer may have developed health problems of their own, etc. Also, a married couple with learning disabilities may provide regular care to each other. An example of mutual care:

Jill has a learning disability. Jill and her mum care for each other. Jill is 51 years old and her mother is 75. Jill's mother has health problems following a stroke: she has fallen in the house and Jill has had to call the emergency services. Jill does the shopping and cleaning whilst her mum does most of the cooking.

What will the research involve?

I wish to conduct a one-to-one 'interview' (an informal conversation) with professionals who support or have knowledge of either individual within a mutual caring relationship. Interview content will surround professional's experiences and perceptions regarding caring roles, carers needs and service provision.

I also wish to provide a questionnaire to, and conduct a one-to-one 'interview' (an information conversation) with those who are in a mutual caring relationship or have experienced being in a mutual caring relationship. Questionnaire and interview content will also surround their experiences, roles, needs and perceptions of service provision.

Before the research commences, I will provide potential participants with an information sheet and informed consent will be obtained. All materials for individuals with learning disabilities will be in 'easy-read' format. Individual support needs will be accounted for before participation, including the request to have another individual present during the research process. All interviews and questionnaires will be undertaken in person. Research will be carried out at a time and place which is convenient for both the participant and the researcher.

What is the researcher hoping to achieve?

As people are living longer, and an increasing number of people with learning disabilities are living with family carers over the age of 70, the incidence of mutual caring between someone with a learning disability and another is increasing.

Adults with learning disabilities who undertake caring roles are an unrecognised and under-represented group within research. I want to represent this group within research.

My research aims to raise awareness that people with learning disabilities can be carers, to provide findings that can make a positive impact to the lives of carers with learning

disabilities, and aims to help shape policies and future practice with carers and adults with learning disabilities. I want to make things better for mutual carers!

Why take part in this research?

It is entirely up to you whether you choose to take part in my research. Participation is an opportunity for professionals and the service to which they belong to show that service user's experiences and outcomes are respected. Participation is an opportunity for mutual carers to express feelings and experiences in a safe environment. You will help contribute in raising awareness that people with learning disabilities can be carers. Further, the research findings could also help improve outcomes for carers and carers with learning disabilities.

Will the study be published and if so where?

Findings will be written up as part of a PhD thesis. All findings will be anonymous therefore it will not be possible to identify individual's data. Findings may be used in presentations, publications, and within future research documents.

Is the research being funded and by whom?

My research is funded by both the College of Human and Health Sciences at Swansea University, and also by the Economic and Social Research Council.

What about my confidentiality?

Confidentiality will be kept, except in circumstances where the information that is given is thought to put an individual at risk of harm.

What are the attachments of this email?

I have attached 3 advertisements of my study.

The first attachment is for the attention of professionals, the second attachment is easy-read for the attention of carers with learning disabilities, and the third attachment is an advertisement for carers.

No further information regarding my research is included within these advertisements, but it is important that individuals with learning disabilities have access to this second attachment.

How can I contact the researcher?

Please contact me using the following details with any questions you may have.

Please contact me if you would like to take part in my research, and I will provide you with further information.

Name: Angharad Parr
Email: 522016@swansea.ac.uk
Address: Room 114 Vivian Tower
College of Human and Health Sciences
Swansea University
Singleton Park
Swansea
SA2 8PP
Tel: 01792 205678 x8699