

## **Older Family Carers Research Project: 'Future living and support options for people with learning disabilities living with older family carers in Oxfordshire'**

### **About this research**

The aim of this research project is to find out about the experiences, issues and concerns of family carers aged 60 plus, regarding future living and support options for their family member who has a learning disability and who is currently living with them. The research will take place over a four-month period from January to April 2010.

### **Background to the study**

Oxfordshire Family Support Network (OxFSN) is an organisation run **by** family carers of people with learning disabilities **for** family carers of people with learning disabilities. We believe that access to high quality, timely information is essential at all times across the lifecycle of supporting a family member who has a learning disability.

Some older family carers living in Oxfordshire have expressed their concern to us about the lack of information and support relating to future living and support options and planning for their family members who have learning disabilities. It is as a direct result of their concerns that we have decided to undertake this research.

This study also takes place against the background of key Government policy objectives for 2009-12 which states that *'all disabled people and their carers are entitled to the same aspirations and life chances as other citizens and as such they will benefit from Valuing People Now'* (DoH 2009) by:

- Having greater choice and control over their lives and have support to develop person centred plans
- Get the healthcare they need and the support they need to live healthy lives
- Have an informed choice about where they live and with whom they live with
- Arrange the support they want and choose their own support staff

In keeping with the nature of scoping studies, our aim is not to obtain a comprehensive picture of the situation, something which would be impossible to do within the timescale and parameters, but rather to provide a snapshot of the current situation from an older family carers perspective in order to inform further investigation and activity relating to the research findings.

### **The research aims:**

- Gain an insight into the experiences, issues and concerns of older family carers relating to future living and support options for people with learning disabilities who are currently living with them.
- Write up our research findings and present this to older family carers, the Partnership Board, Health and Social Care Services and elected representatives.
- Action Plan with the above and other identified parties to develop appropriate information and support for older family carers in order that they can make informed choices about future living and support options **with** and **for** their family member who has a learning disability.

### **The researchers will do this by:**

- Setting up a small steering group to assist in promoting awareness of this research project and identifying participants. This group will also be involved at the action planning stage outlined above.
- Holding face-to-face meetings or conduct telephone interviews (based on the attached questionnaire) with as many older family carers as they can reach from across the geographical locations within the county
- Holding three (possibly four) focus groups meetings for older family carers from across the geographical locations within the county
- Sending out a postal questionnaire to be completed by older family carers who cannot/do not wish to attend a focus group meeting
- Holding a focus group meeting for commissioners/care managers/housing and support providers who have a key role in supporting older family carers within the context of this study

## **Analysing the research findings:**

The data will be analysed systematically to identify key factors and key relationships in a cautious and controlled manner that is carefully documented. In order to validate this study our findings and observations will be shared with those older family carers who participated in this study. They will then be given an opportunity to talk these through with us as a way of 'grounding the knowledge' in order to confirm/improve the clarity and precision of the study. This action will go a long way to ensure that it is judged as being: robust, rigorous and of good quality by older family carers, local policy makers and significant others within the county.

## **Ethical considerations**

In keeping with the principles of research ethics we will work to avoid harming participants involved in this study by respecting and taking into account their needs and interests, including not invading their privacy and not deceiving them about the aims of this study. Our research will also be based on informed consent (i.e. the study's participants having agreed to partake on the basis of information given to them by us). We will comply with the Data Protection Act by safely and securely storing personal details.

## **If you want to know more about this research please contact:**

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