

Medication Matters

Research Findings

Medication Matters is a research project carried out by the Norah Fry Research Centre in partnership with Aspects and Milestones Trust¹ and HFT² between July 2002 and November 2004. It was funded by the Community Fund.

The project was rooted in the legal right of people to be informed about their treatment and to make decisions for themselves wherever possible. The focus of the project was to find out what people understood about:

- The reasons why psychotropic medication was prescribed for a person with learning difficulties
- The implications of taking psychotropic medication.

Psychotropic medications are tablets, medicines or injections that are prescribed to improve a person's mood, mental status or behaviour. These medications were the focus of this study for two main reasons:

- Evidence suggests that the rate of prescription for psychotropic drugs has been far in excess of the rate of psychiatric disorders for the population of people with learning difficulties (Robertson et al, 2000).
- An international group of experts concluded that '*more research is needed on the safety and efficacy of psychotropic drugs when used with this (people with learning disabilities) population*' (Reiss and Aman, 1998 p.1).

Methods

Ensuring that people with learning difficulties are meaningfully involved in the research process was an essential part of the Medication Matters project. The project team included a service user advisory group – a group of 5 co-researchers who have learning difficulties. These co-researchers were involved in all aspects of the project. As a group they worked together to produce accessible information about the project. Individual group members were also involved in interviewing service users, analysing the data from these interviews and disseminating research findings.

The researchers visited 4 different regions in England and conducted in depth interviews with:

- 21 people with learning difficulties who are being prescribed psychotropic medication
- The carers supporting those individuals
- The professionals prescribing psychotropic medication to those individuals

The topics which were explored included:

- people's knowledge and understanding about their medication
- what information people had been given about their medication and by whom
- what support people received to take their medication
- areas where people would like to receive more information and support

Findings

- ◆ There was a general lack of knowledge by people with learning difficulties about why they were taking their medication, what it was for and what the potential adverse effects might be. Most people perceived they had had little or no choice about whether they took their medication or not.
- ◆ What information they did receive about their medication was generally given to the person by their carer. However, the carers' interviews revealed large gaps in their knowledge about psychotropic medications.
- ◆ People with learning difficulties assumed their carers would know all about their medication. However, carers were generally only trained in the practical administration of medications, not in the broader issues about why it was prescribed or what the possible adverse effects of it might be.
- ◆ Some carers did not believe it to be their role to be involved in anything other than the practical administration of medication – leaving a large gap in the care and support of people with learning difficulties
- ◆ Accessible information about psychotropic medications was not commonly available.

Outcomes

As a result of our research findings we have produced a number of resources for people with learning difficulties, their carers and prescribers. These include:

- A checklist of things to ask the doctor about medication which can be used by people with learning difficulties, their families and carers.
- A booklet for people with learning difficulties, their families or carers where they can record information about their medications.
- A decision making tool for people with learning difficulties to help them make informed choices about taking the medications they are prescribed.
- A guide for prescribers of psychotropic medications of things to they should consider when issuing a prescription.
- A list of useful sources of information about medications.

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References:

Reiss, S. & Aman, M.G. (1998) The international consensus process on psychopharmacology and intellectual disability. *Journal of Intellectual Disability Research* **41** (6) 448-455.

Robertson, J., Emerson, E., Gregory, N., Hatton, C., Kessissoglou, S. & Hallam, A. (2000) Receipt of psychotropic medication by people with learning disability in residential settings. *Journal of Intellectual Disability Research* **44** (6) 666-676.

Footnotes:

- ¹ Aspects is a specialist learning disabilities service providing supported housing and residential care in the Bristol and surrounding areas.
- ² HFT is an organisation for people with learning disabilities, providing a range of services throughout England.