

Medication Matters – final report

The Medication Matters project is rooted in the legal right of people to be informed about their treatment and to make decisions for themselves wherever possible. The aim of the project has been to find out what people with learning difficulties, their carers and the prescribers of their medication understand about why psychotropic medication has been prescribed and what the implications of taking it are.

Background

Psychotropic medication is commonly used for people with learning difficulties and there has been a recent major expansion of psychotropic drug types and usage in this population (Reiss & Aman 1998, Bramble 2003).

By the term psychotropic medication we mean those drugs prescribed to stabilise or improve mood, mental status or behaviour. This includes medications typically classified as antipsychotic, antianxiety, sedative-hypnotics, stimulants or antidepressants¹.

There are two main reasons given for the use of these drugs for people with learning difficulties: firstly, they may be used to treat co-existing psychiatric disorders, such as depression or psychosis; secondly, and more controversially, the drugs are sometimes used in a more non-specific way to control difficult or challenging behaviours (Baumeister et al, 1998; Molyneux et al, 1999;).

There is a general consensus that the prevalence of psychiatric illness in people with learning difficulties is greater than in the general population (Manchester, 1993). However, it is also possible that there are many people with learning difficulties and challenging behaviour who have unrecognised psychiatric problems (Santosh, 1999; Moss, 2000), and that misdiagnosis of mental health disorders in people with learning difficulties is common (Bouras et al. 1993). This is largely due to:

- the frequent assumption that psychiatric symptoms are an inherent part of the underlying learning difficulties (Santosh, 1999)
- people with learning difficulties often expressing mental distress in a different way from the general population, particularly if they have severe cognitive or verbal limitations which mean that their symptoms may be distorted, masked or otherwise expressed differently
- they may not be able to verbally report emotional complaints or subjective experiences in a clinical interview (Pyles et al. 1997).

¹ In line with the International Consensus Handbook, Reiss and Aman (1998) we also include those medications not typically described as psychotropic when they are prescribed to improve or stabilise mood, mental status or behaviour (e.g. some antiepileptic medications are prescribed for the effect they have on a persons mental status or behaviour, not for epilepsy).

Depending on the population being studied, rates of serious psychiatric illness in people with learning difficulties vary from 8% - 15%, with psychotic illness estimated to be around 4% - 6% (Smith et al, 2002). However, the rate of prescription for psychotropic drugs is far in excess of this. Recent studies in the UK suggest prevalence rates of 20% - 50% in hospital and community-based residential services, and about 10% of people living with their natural or substitute families (Smith et al 2002).

Ashcroft et al (2001) estimates that between 7 – 30% of all adults taking antipsychotic medications in residential settings, and 5-12% in a community setting will be taking the medication to manage their challenging behaviour alone. Analyses of predictors of psychotropic medications suggest that whilst the receipt of antidepressants is predicted by symptoms of mental ill health, the receipt of both antipsychotics and hypnotics/anxiolytics is predicted by variables related to challenging behaviour (Robertson et al 2000). Aggression has been shown to be the greatest predictor of the use of antipsychotic medication in people with learning difficulties and challenging behaviour (Fraser et al. 1986); other predictive factors are: a high level of physical and motor skills and self-direction, carer perception of the behaviour, environmental factors, staffing levels, and the treatment philosophy of the care setting (Harper & Wandsworth 1993).

Concerns about the use of these medications are centred on three main issues:

- Firstly that the use of the drugs is often based on extrapolation of knowledge regarding their effects in populations without learning difficulties. Because of liability issues in studying the effects of new drugs in ‘vulnerable’ populations, the pharmaceutical industry does not test new medicines on people with learning difficulties. However, evidence suggests that mental distress is often expressed differently in people with learning difficulties (Reiss, 1994; Havercamp, 1996 quoted in Reiss and Aman 1997 article) than from those without.
- Secondly, evidence from studies on children and adolescents suggests that psychotropic medications interact with the developing brain in ways not seen in adults (Vitiello and Jensen 1995 quoted in Aman and Weiss article). It is therefore possible that as learning difficulty affects brain development, psychotropic medications have different effects in people with learning difficulties than in the general population.
- Thirdly, there is a well-documented history of the adverse effects² of psychotropic drugs (Christian et al, 1999) and the adverse effects that occur in people with learning difficulties (Hubert, 1992; Wilson et al. 1998, Baumeister et al 1998). Individual variation in medication response is probably greater in people with learning difficulties, as they are at an

² Adverse drug reactions are unwanted or unintended effects of the medication which occur during its proper use.

increased risk of developing side effects (Deb and Fraser 1994; Kalachnik, 1999), and the side effects may be less predictable and less well-recognised. Reasons why side effects may be unrecognised or ignored in people with learning difficulties include: they may have difficulty in communicating about the side effects of their medication; they may find it hard to describe such effects as blurred vision or feeling dizzy; and they may not have been informed of the potential for side-effects (Read and Wallcraft 1992; Holmes and Newnes 1996). Further, carers may not have sufficient knowledge and experience of psychiatric disorders to be able to distinguish between symptoms of psychiatric disorder, the person's natural state, and side-effects of medication (Jenkins, 2000).

The International Consensus Panel looking at the use of psychotropic medication in people with learning difficulties concluded, in 1998, that '*more research is needed on the safety and efficacy of psychotropic drugs when used with this population*' (Reiss and Aman, 1998 p. 1). They produced a basic set of guidelines for the use of psychotropic medication in people with learning difficulties. These are summarised in Table 1. However, four years later, Young and Hawkins (2002) reported that '*prescribing practices for people with mental retardation may not always be legitimate and may not follow standard prescribing practices*' (p.139).

**Table 1: Psychotropic medication guideline summary.
The 10-4 principle (from Reiss and Aman eds. 1998. p.67)**

The 10-4 Principle	
Do's	Don'ts
<ol style="list-style-type: none"> 1. Treat any substance prescribed to improve or stabilize mood, mental status, or behavior as a psychotropic medication (Guideline 1). 2. Use psychotropic medication within a coordinated multidisciplinary care plan (Guideline 3). 3. Use psychotropic medication based on a psychiatric diagnosis or a specific behavioral-pharmacologic hypothesis and only after conducting complete diagnostic and functional assessments (Guideline 4). 4. Obtain written informed consent from the individual or guardian and establish a therapeutic alliance involving all decision-makers (Guideline 5). 5. Track treatment efficacy by defining objective index behaviors and quality of life outcomes and measure them using empirical methods (Guideline 6). 6. Monitor for side effects using standardized assessment instruments (Guideline 7). 7. Monitor for tardive dyskinesia using standardized assessment instruments if antipsychotic or other dopamine blocking medications are prescribed (Guideline 8). 8. Conduct clinical and data reviews on a regular and systematic basis (Guideline 9). 9. Strive to use the lowest optimal effective dose (Guideline 10). 10. Evaluate drug and monitoring practices through a peer or team quality review or improvement group (Guideline 14). 	<p>Long-term PRN orders Use of long-acting sedative-hypnotics (e.g., chloral hydrate)</p> <p>Long-term use of short-acting sedative hypnotics (e.g. temazepam)</p> <p>Long-term use of benzodiazepine antianxiety medications (e.g. diazepam)</p> <p>High antipsychotic medication doses</p> <p>Long-term use of anticholinergic medication (e.g. benztropine)</p>

A number of empirical studies support the assertion that medications that are effective in treating psychiatric conditions in people without learning difficulties are similarly effective in treating these conditions in people with learning difficulties (Sevin et al. 2001). However, other authors note that given the problems that people with learning difficulties might have in self-reporting their symptoms, and the lack of consensus on how to diagnose specific psychiatric conditions in this population, such generalisations are invalid (Stenfert 2001).

Many studies of the effectiveness of psychotropic medication in people with learning difficulties and challenging behaviour have been criticised for poor methodology including the lack of controls, the use of clinical impression rather than the reliable measurement of behaviour to assess outcome, and the failure to measure the effects of medication on other behaviours in order to facilitate a reasonable risk-benefit analysis (Manchester, 1993). Reviews of evidence related to the use of psychotropic medication in people with learning difficulties for aggression (Matson et al. 2000) and for aberrant behaviour (Baumeister et al 1998) have found no evidence for their efficacy. In a review of the evidence from randomised controlled trials, Brylewski & Duggan, (1999, updated in 2003) reported no evidence of the effectiveness or ineffectiveness of psychotropic medication, concluding that the evaluation of these treatments requires '*urgent attention*', and until then, clinical practice will continue to be based on '*opinion, judgement and fashion, rather than evidence*' (1999 p.369. reiterated in 2003).

Concerns about side effects and dubious efficacy have led to litigation in the USA, where prescription rates have fallen (Briggs, 1989; Poindexter, 1989). A more recent study in the UK has found that a substantial proportion of individuals prescribed psychotropic medication for behavioural problems can have their medication reduced or withdrawn with positive results, or at least, no deterioration (Smith et al. 2002; Ahmed et al, 2000; Davis et al, 1998). Another study showed evidence that residential staff training in the preventative and reactive management of severely challenging behaviours reduced the use of emergency medication by 86% over a five year period (Allen, et al, 1997). Studies in the USA and the UK have suggested that when a monitoring system is in operation that includes the use of multidisciplinary review, the identification of target behaviours and the use of alternative strategies, the use of psychotropic medication reduces (Branford, 1996 quoted in Stenfert; Coughlan, 2000). Miller et al (1997) note that by undertaking a clinical audit of prescribing psychotropic medications in people with learning difficulties, they were '*able to target our prescribing of psychotropic medication to patients with mental illness, and with regard to those patients receiving psychotropic medication in the absence of mental illness, to ensure medication was used together with, and not as a substitute for, alternative strategies*' p.288-289.

Over the past decade, and especially since the Bournwood judgment in 1998, more emphasis has been placed on the legal rights of people to be informed

about their treatment and to make decisions for themselves wherever possible. The Mental Health Act (1983) Code of Practice defines consent to treatment as:

The voluntary and continued permission of the patient to receive a particular treatment based on an adequate knowledge of the purpose, nature, likely effects and risks of that treatment including the likelihood of its success and any alternatives to it. Permission given under any unfair undue pressure is not 'consent' (DoH and Welsh Office 1993).

This definition suggests three key factors must be considered for a person to give informed consent – firstly, a knowledge of their medication, the benefits and risks of taking it and any alternatives to it, secondly, the capacity to exercise choice, and thirdly, the right to choose or refuse medication without undue pressure.

Research about the perceptions, knowledge and opinions of carers working directly with people with learning difficulties has suggested that the knowledge and skills deficits of carers appears to represent 'a significant barrier to the appropriate monitoring and management' of treatment with psychotropic medications for this population (Christian et al. 1999; Singh et al. 1996; Aman et al. 1987). However, these carers are critically important to the well-being of the people with learning difficulties they care for because they spend a great deal of time with them, and may provide the information needed by prescribers to make treatment decisions.

We are unaware of any recent studies that have explored what people with learning difficulties understand about why they have been prescribed psychotropic medication and what the implications of this are for them. Studies about non-learning disabled psychiatric patient's knowledge about their medication have suggested that many patients do not know the name or the dosage of the medication they take, what it is for and its side-effects. Tempier (1996) reported that although most respondents in his study could identify the medication they took, almost a half wanted information about their medication repeated, and more than half wanted additional information.

Research about the understanding of people with learning difficulties about any prescribed medication found that only just over 50% of the participants correctly answered questions regarding the time at which medication should be taken, what would happen if it was not taken, the reason for taking it and its action. Participants appeared to find questions regarding the side-effects of their medication, alternatives to medication and other medications which they should not take in conjunction with their prescribed medications the most difficult to answer (Arscott et al, 2000).

The reasons why people with learning difficulties appear to have a poor knowledge of some aspects of their prescribed medication are unclear. It is possible that people are not told about particular things, that they forget or do not

understand what they are told, or that they do not want to know. They also have fewer sources of information to use to supplement their knowledge. Strydom et al, (2001) found that people had difficulties in reading and understanding medication labels and manufacturers' inserts. Accessible medication information leaflets about psychotropic drugs are not commonly available for people with learning difficulties, although the UK Government and National Health Service Guidelines have identified the provision of accessible information as an important function in the healthcare of people with learning difficulties (Strydom et al, 2001). However, in a randomized controlled trial of psychotropic medication information leaflets for people with learning difficulties, Strydom and Hall (2001) found that the leaflets did not significantly improve any aspect of medication knowledge. They recommended that rather than excluding people with learning difficulties from such resources, carers and health professionals should assist them to use the resources and help them to align new knowledge with previous knowledge.

Few studies have examined prescribers perspectives of optimal strategies for communicating medication information. McGrath (1999) reported that prescribers preferred two-way interactions focusing on the specific needs of the patient, rather than simply disseminating more and more information about the prescription. The prescribers also tended to weigh up the benefits of disseminating drug information against the psychological costs of anxiety about possible side-effects. A striking finding from a study by Llewellyn-Jones et al (2001) was the paucity of questions posed by general psychiatric patients to their psychiatrist, reflecting the difficulties that patients had in discussing their symptoms and their medication. Reasons why this was found to be the case were considered to be: patients may fear being judged if they say too much; a restricted experience in adult-adult interactions may be a barrier; they may be discouraged by subtle body language from the doctor; sensitivity to time restraints; not wanting to waste a doctor's time; and a trivialisation of their concerns.

In conclusion, therefore, given the considerable controversy regarding the efficacy and safety of psychotropic medicines in people with learning difficulties, there is a paucity of evidence about what people with learning difficulties understand about why they have been prescribed psychotropic medication and what the implications of this are for them. Yet this knowledge is vital, because if people with learning difficulties and their families or carers are not in full possession of the information about such drugs, it is questionable whether they can be said to be giving informed consent to treatment with psychotropic medication.

Methodology

Shaping the research proposal

The Medication Matters research project was planned and shaped during formal and informal discussions and meetings between researchers at the Norah Fry Research Centre, people with learning difficulties and key personnel from Aspects and Milestones Trust³ and Hft⁴. Ensuring that people with learning difficulties were meaningfully involved in the research process was considered to be an essential part of the project. In part, this reflected the general drive by government to encourage service user involvement in research, and by research governance frameworks for health and social care which were increasingly requiring academic and clinical researchers to demonstrate in funding applications how service users would be involved. To a greater degree, however, was our belief that adopting a participative research methodology would result in a more inclusive, ethical approach to the research, better informed analysis based on issues considered important to people with learning difficulties themselves and a more accurate identification of the needs and experiences of people with learning difficulties.

Despite our good intentions, however, the initial stages of developing and shaping the research proposal, applying for research funding, considering ethical, data protection and best practice guidelines, and formalizing research contracts between the research partners were largely undertaken without the inclusion of people with learning difficulties. Without wanting to appear defensive about this, we felt caught in a double-bind situation. In order to include people with learning difficulties we would have had to explain bureaucratic forms and formal research terminology and concepts. With a research proposal covering 6,000 words to answer potential research funders' questions fully, and new ethical application forms currently 68 pages long and taking over 40 hours to complete (Wald, 2004), time and funding were the resources that we most needed at this stage, yet didn't have. Other researchers have seemingly made more successful attempts at involving people with learning difficulties at this stage of the research than we had (see Burke et al 2003), but there clearly seems to be a need for recognising the practical and financial assistance needed to support this early stage of the research process if service user inclusion is to be meaningful.

Recruitment of co-researchers

Once funding had been awarded, the practicalities of setting up the research project could get underway. Our plan had been to recruit a Service User Advisory

³ A specialist learning disabilities service providing supported housing and residential care in the Bristol and surrounding areas.

⁴ An organization for people with learning disabilities, providing a range of services throughout England.

Group (SUAG) of six to eight people with learning difficulties. Individuals on the group were to be able to have flexible involvement throughout the course of the research, on the understanding that people might be especially interested in one aspect of the research but not necessarily in others, and that their lives and commitments might change over time. Having a *group* of people who were closely involved with the research would, we assumed, mean that best use could be made of their time depending on their interests and availability, and provide some back-up for individuals if necessary. This approach was intended to facilitate an effective balance between good quality research, maximising the participation of people with learning difficulties, and ensuring that the needs of the project were met.

The recruitment process to the SUAG was rather less systematic than we originally hoped for. Our first point of contact was service user-controlled or –led organisations, so that the individuals attending the SUAG had an accessible group of peers with whom they could discuss ideas and issues. Other points of contact were via the research centre and partner organisational networks, personal connections, local and regional services for people with learning difficulties, and accessible leaflets and adverts. We were interested in working with people with learning difficulties who could be representative of others, as well as people who might provide their own individual perspective.

From the start, we needed to be clear about what was needed and what was on offer. Accessible materials were produced and distributed giving information about the Medication Matters project and inviting people to contact us if they were interested in being involved with the work.

- We specified that we needed the SUAG to meet about 3 times, to give general advice on the project. In addition, we welcomed people working with us as co-researchers. Co-researchers could be involved in: helping to make information about the project easy to understand, talking to people with learning difficulties about the drugs they take, helping to undertake data analysis, formulating recommendations from the research, producing research outputs, and/or talking to people about the project.
- In return, what was on offer to members of the SUAG and co-researchers was training and support to do the work, paid work (at a hourly/daily rate) and payment of any expenses (e.g. travel, overnight accommodation, subsistence, personal support) they incurred or required. These had all been budgeted for appropriately in the research proposal.

Five people with learning difficulties were finally recruited to the SUAG. In reality, they all worked as co-researchers and preferred to be known as the co-researchers on the project. Two were male and three female; all were aged between 25 and 50; and they all experienced differing degrees of learning difficulties. One of the co-researchers lived locally, the other four lived

approximately 100 miles away to the west and south west of the research centre. One was a member of a service-user led organization, three were members of organizations for people with learning difficulties, and all brought their own perspectives as people with learning difficulties. One had worked as a researcher before. Their reasons for wanting to be involved with the project varied: for some it was paid work in an area they were interested in, others wanted to learn something new, develop their own self-confidence and/or meet new people and make new friends.

All the co-researchers met together one afternoon to get to know each other, and remind themselves about the Medication Matters project. We discussed how, and how much, each person might like to be involved, any hopes and fears they might have about being a co-researcher, what their own support needs might be and how the researchers could best work with them. Finally, a set of ground-rules was drawn up to describe the ways in which everyone would work together.

Training of co-researchers

Two training days, a week apart, were held following the introductory afternoon. Both were led by people with learning difficulties already working as researchers, with support from researchers at the Norah Fry Research Centre.

Both training days started with lunch. The first training day considered what research is and why it is important to have people with learning difficulties working as researchers. Three researchers with learning difficulties then spoke about the different research projects they had worked with, what they had been involved in doing and what the experiences had been like for them.

The second training day recapped on what had been covered the previous week, and then had sessions on: how to be a respectful researcher, keeping information private and confidential, and keeping themselves safe and well.

Other training, both formal and informal, was ongoing throughout the period of each person's involvement in the project. Most of this training was provided individually and was tailored according to the needs, interests and prior knowledge of the co-researchers, and the needs of the project. Examples included: how to find out what we already know about something, writing a questionnaire, how to do interviews, working with people who have supporters, how to use a tape-recorder, what to do if someone becomes upset during an interview, what we mean by 'consent', having a clear boundary between our work and home lives, using a computer, analysing data, and speaking in public.

Undertaking the research

Fully involving people with learning difficulties in the research process required additional thought, preparation, time and money. As researchers, we needed to be flexible in our approach, committed to the process, and influenced by it. Some of the co-researchers preferred to come in to work at the research centre, others preferred a researcher to travel out to support them with the work; some preferred to work individually, others found they worked best with another co-researcher present; some wanted to be involved in all stages of the research, others wanted to be involved in specific parts; some reduced their involvement for periods of time due to personal reasons, one decided to leave the project altogether. There was no ‘one size fits all’ way to optimising the participation of the co-researchers. Our practice was based on what the co-researchers themselves said, and our own and others’ knowledge and experience of undertaking participatory research with people with learning difficulties.

Interviewing service users

All of the co-researchers had been involved in designing or reviewing the interview questionnaire for service users. The questionnaires were written in accessible formats, using easy language and pictures as prompts. Where necessary, they were further adapted or stylised to the individual co-researchers needs as appropriate.

On reflection, it seems that for the co-researchers who had had the least involvement in deciding on the interview questionnaires, the interviews that they undertook seemed to run less ‘smoothly’ than others. In part, this was because they felt less ‘ownership’ about the questions and were less clear why some were being asked. Those who had had the most involvement with deciding on the interview questions seemed to be, overall, more confident and interested when interviewing service users.

At the beginning of the project, one of the researchers would visit the prospective interviewees to offer a careful explanation of the research, offer them a chance to ask any questions they might have, and complete a consent form. At this stage the researcher would find out whether the person had any preferences about the gender of the co-researcher who would interview them and would give them a photograph of the person that it would most likely be. As the co-researchers lived in geographically spread out areas, and these pre-interview meetings needed to be conducted at least a day or two before the actual interview in order to allow the person sufficient time to think about their involvement, it had seemed logically most appropriate for the researchers to conduct these meetings. However, it soon became apparent that this initial meeting was a vital way of building rapport and a relationship with the person, which then made it a difficult situation for the co-researcher to come into. As a result we changed this policy so that wherever possible the researcher and co-researcher conducted joint visits. It

involved considerable practical and logistical planning at times, but it seemed to make the dynamics of the interview situation more balanced, and the interviewee to consider the co-researcher and researcher as much more of an equal partnership.

Interviews were held with 21 people with learning difficulties living in four different regions of England. They were contacted via voluntary and statutory sector organisations providing support for people with learning difficulties living in those areas. People were selected on the basis that they had learning difficulties and had been prescribed psychotropic medication. They included both males and females, were of a range of ages and backgrounds, and were receiving different levels of support to live in the community. With people's consent, a carer who supported them, and the doctor who prescribed their medication were also invited to participate in the study. Interviews were held on an individual basis with 20 carers and 11 prescribers (who prescribed for a total of 15 of the people with learning difficulties in the study).

All of the interviews with service users were led by the co-researchers, with support where necessary from the researcher. The degree of input from the researcher varied considerably from interview to interview, according to a range of factors. We felt it important that the co-researchers should be able to pitch their involvement at a level they felt happy with, rather than expecting them to match any of our expectations of them. By having a researcher present at each interview, the same minimum level of information could be collected from each research participant, and the quality of the interview be assured. Considerable attention was paid to making the interviews as accessible as possible. Accessible venues were chosen for the interviews themselves and for overnight accommodation; interview timings were chosen that did not require any of the interviewers to conduct more than two interviews a day; the personal support needs of the researchers were considered and external personal assistance funded or provided for non-research related activities and needs.

Data analysis

Stalker (1998) comments that data analysis might not be something which people with learning difficulties could reasonably undertake. Others, however, argue that researchers must believe in the real contribution that people with learning difficulties can make during this stage of the research process, and their role must be to support this as much as possible (Williams, 2004 – personal communication). The latter position was the one that we took in the Medication Matters project. Although there was a tendency for the co-researchers to make their initial focus 'how they did' or 'how the interview went', all were interested in making sense of what people collectively were saying and thinking through the individual responses of people they had interviewed. Our approach in this was to be as flexible as possible, and to build on the experience of other researchers (notably Val Williams) at the Norah Fry Research Centre in doing this.

With the research participant's permission, all of the interviews were tape recorded and transcribed. This allowed the co-researchers to get as close to the original data as possible. Some preferred to listen to the original tapes, and from these, identified key themes that were being spoken about. From the original tapes, some of the co-researchers were also able to pick up on aspects of the conversation itself – such as person not sounding very certain about something, or having left a long pause before answering. One co-researcher preferred to read the transcripts herself, and mark emerging themes on the paper copy. All transcriptions were entered onto the MaxQda qualitative data analysis software to support data analysis. Whilst this intrigued and interested most of the co-researchers, none of them felt confident using MaxQda in isolation from the tapes or transcripts, although one did become involved in entering themes from transcripts to the computer program.

The key challenge with data analysis was in supporting co-researchers to see the wider picture. In discussions about individual transcripts, there was a tendency for the co-researchers to focus on the individual and for the individual's comments to trigger personal feelings of agreement or disagreement. To a large extent, this was a valuable process in itself, in that it enabled the co-researchers to 'position' themselves within the research. We came to see it very much as the first steps along the road of data analysis. The subsequent steps involved standing back and looking at what others were saying about a similar issue and considering the various viewpoints less judgementally. The technique that we found most helpful and productive for this was to cut up copies of transcripts and arrange the cuttings into 'theme folders'. The co-researchers would then look at each 'theme folder' and consider all of the comments made about that issue as a whole. At times, co-researchers did this in pairs. More usually, however, they preferred to work individually, or one-to-one with a researcher in discussing the themes. This did provide the flexibility in that as all of the comments were anonymised, analysis of the themes could be taken to the co-researchers, rather than them travelling to the research centre.

The academic process of 'grounded theory' was the approach underlying the data analysis process. In this, data analysis takes place concurrently with data collection. As ideas concerning the interpretation of the data are formulated, they are tested and redeveloped using a process of constant comparison of the data. It is an approach that worked well in supporting individual co-researchers to think about making sense of what a number of people were saying about their medication.

Being involved in interpreting the findings of the research in this way, enabled the co-researchers to take a further step and become involved in thinking of resulting recommendations to offer. All of these were noted, then checked out with other co-researchers, research participants and the project advisory group.

The preparation and piloting of research outputs

It seemed apparent from many of the interviews that people with learning difficulties, carers and prescribers would welcome practical resources that they could use to support prescribing decisions. In particular, there was a need for:

- a resource to support people with learning difficulties in making the decision about whether or not to take a particular medication
- a resource where all the relevant information about a particular medication could be collected together in an accessible format, to be used by people with learning difficulties
- an information guide about a particular medication, to be used by carers
- a guide to where people could find out reliable information about medications.

Each of these resources was developed and piloted by the research team.

The *Making Decisions about Medication* booklet was piloted with sixteen people with learning difficulties and six carers. All of the people involved in piloting the resource were asked for their comments on the appearance and layout of the booklet, its content, length and ease of use. Carers were also asked about the appropriateness of the booklet and its likely use.

Overall, the people with learning difficulties who commented on drafts of the booklet stressed the need for brevity, the use of easy to understand language, the inclusion of pictures and that they would always require support to be able to complete a booklet such as this. Two of the sixteen did not find the booklet interesting and said they felt bored with it. Other comments included:

I would like to have a book like this.

Some parts were hard.

Just four pages long would be best.

It would have been better with more pictures.

Better when [support worker] went through it [with me].

It's good to have space to write things down.

All six of the carers who piloted the *Making Decisions about Medication* booklet were very positive about its content and appropriateness. One carer commented that it had been a time-consuming process involving three sittings to complete

the booklet with the person with learning difficulties. Another carer suggested that it would mean doctors changing their approach: rather than merely prescribing a particular medication they would need to enter into a dialogue with the person concerned to discuss what their own thoughts or views might be. Other comments included:

It was a useful approach to highlighting issues around medication.

My client had not looked into long-term side-effects before using this booklet – while filling it out he learnt a lot.

Those who have sight impairments would not be able to use it.

It would clarify questions for me.

Initially, one medication information resource booklet was developed, targeted at carers. The *Medication Matters* resource booklet was piloted with ten carers, although some responded on behalf of a group of carers rather than individually. All of the people involved in piloting the resource were asked for their comments on the appearance and layout of the booklet, its content, length, ease of use, appropriateness and likely use.

Overall, the carers who commented on drafts of the booklet stressed the importance of keeping it to a manageable length and of it being a practical, working document. Concern was expressed about the amount of work entailed if a person was taking a number of different medications, or if a carer was supporting a number of people with learning difficulties who were all taking medication. Other comments included:

The language could possibly be simpler without being condescending.

If it were loose leaf, the review pages could be photocopied when the existing ones ran out.

It would be great to have the history of treatment in one place.

This could be used alongside health action plans.

It became clear from the initial piloting that the *Medication Matters* resource booklet could be best used in conjunction with people with learning difficulties, rather than as a separate resource for carers. The issue was raised about the right to, and ownership of information by people with learning difficulties and the importance of them having access to the same information about their medication as their carers had. As a result, the *Medication Matters* resource booklet was modified to become a resource targeted at people with learning difficulties and their carers: more accessible language was used, the use of

pictures and a photograph of the medication considered and only areas of key importance included. The final resource: *My Medication* emerged from these changes.

Dissemination

As researchers we have a commitment to disseminating research findings to service users, their organisations and supporters, as well as to academic and professional audiences. For some co-researchers this was an exciting part of the project and an opportunity to get the message of the research across to different people. One co-researcher spoke very confidently at a large international conference in Rome about the research project and her involvement in it. Others preferred to take a more low-key approach or to write about the research for local or national audiences. New skills to be learnt included: speaking up and talking in public, and working with the media.

Throughout the dissemination process, we are having to be aware that it also heralds the ending of the current relationship between the researchers and co-researchers. There are thoughts about closure of the project and moving on to other things; reflections about what has gone well and what could be improved upon. There are also a range of personal feelings involved, on the parts of researchers and co-researchers which need to be respected and valued.

Reflections of the participative research methodology?

Mention has already been made of the need for explicitly agreed standards about what constitutes 'quality' in participatory research. That is not the direct purpose of this paper, but we hope that by being as honest about this as possible and providing some of the detail of the process this paper can contribute to the debate about what 'quality standards' for involving people with learning difficulties in research might look like. It is a debate that needs to include the perspectives of researchers and co-researchers, organisations of people with learning difficulties and people with learning difficulties themselves. Participatory research is, as its name suggests, a joint enterprise, and the development of quality standards in this field requires joint work.

In the meantime, we can explore the 'results' of involving people with learning difficulties in the Medication Matters project in a number of ways. From the research point of view, the co-researchers contributed to making information easier to understand for other people with learning difficulties; they ensured that appropriate and important questions to them were included in the interview schedule (although, on reflection, some wished to have had more involvement at this stage); they conducted 20 of the 21 service user interviews, and completed all but one of these; they added their own insights to the data analysis stage; were able to propose relevant and useful recommendations from the research

findings and have been involved in writing and talking about the research and their involvement in it.

At a more qualitative level, a great deal of empathy seemed to develop between the co-researchers and those they interviewed. Sometimes this helped the interview process itself:

I think it was easier for people being interviewed because there was less pressure on them to get the right answers and they could ask me if they didn't understand – co-researcher.

At other times, it was in a more generally supportive way as a result of shared experiences or in helping them with the data analysis stage. One co-researcher, for example said that he especially remembered one interview because of the particular difficulties of the interviewee. The co-researcher thought that he had got on well with the interviewee, could see things from his point of view and had been thinking about him and his situation a lot.

At a personal level, most of the co-researchers made significant changes to their own lives during the course of the research. Whilst there is no direct cause and effect here, those involved were clear that working as a co-researcher had fostered in them a degree of personal confidence that might otherwise have taken more time to emerge. Four took a number of steps forward in ‘independent living’ – having choice and control to live their lives as they wanted to - by making changes in their own living, day-time activity, or social arrangements. For three of the co-researchers, these changes were largely sustained.

Things that the co-researchers said they had found most difficult included: keeping to themselves their own opinions about what someone was saying in an interview, maintaining their focus and concentration for periods of time, and making the practical arrangements for their involvement.

From our perspective as researchers, having a pool of people with learning difficulties involved as partners in the research has, at times, tested our capacity to provide the level of support we all needed and presented us with challenges we could not have anticipated. But that, on reflection, has been a small price to pay for the benefits the participative approach has brought to the co-researchers personally and the research project in particular.

Research Findings

What people with learning difficulties said they knew about their medication

Few of the people with learning difficulties could remember what they had been told – or if they had been told anything at all, when they were first given their

medication. Some remembered the name of their medication, some recalled the shape or colour of it, but others had no idea:

Well I know the long one in the morning and the short one in the morning. I don't know the names of them though...One long one and one round one in the night time...If you want the name you'll have to ask one of the staff.

The one that's strongest is the big one, the Venlafaxine one.

Most people seemed to know when their medication was due to be taken, but there was some variation in knowledge about how much to take – with some people completely dependent on their carer for this, and others able to self-medicate, albeit, sometimes under supervision. When asked why they were taking the medication, most people said that it was because it 'made them feel better'. A few were more specific:

To keep me happy and calm and to stop worrying about things.

I take carbamazepine and risperidone...I take it for my mood swings...and risperidone I take that to help me sleep better at night.

One person was of the view that his psychotropic medication was prescribed to make his stomach better.

Very few of the people with learning difficulties were aware of side effects – although a couple of people said they had been told but couldn't remember what was said. When asked if the doctor said if there might be side effects of his medication, one person responded:

They checked the tablets. There is no side effects on the tablets. They say it is safe, it is OK, it is safe. Guarantee it is safe to take.

What carers and prescribers thought the people with learning difficulties knew

When the carers were asked what they thought the person with learning difficulties they supported knew about their medication, some thought the person knew, in general terms, why they were taking the medication - to reduce stress, to keep them calm, or to help them with their moods:

He's well aware of how he used to behave. He doesn't like to talk about it. And I know that he knows that that's what the medicine does for him. You know the other medicines are for other things. But that particular one, he knows helps him keep calm.

I think he understands that sometimes he gets very loud and he loses control of himself. And he shouts and he throws things when he loses control. So I think he understands that, by taking his medication, it helps him to keep in control of himself.

Other carers felt that the person with learning difficulties wouldn't understand about their medication, or that they were not sure:

I don't want to underestimate his understanding, but I doubt it

One of the factors involved in this was the view that some people had been taking their medication for so long it had become part of their daily routine, and something that they wouldn't necessarily think too much about:

He just takes them now because I give them to him, you know.

He doesn't remember why he started taking the tablets, I wouldn't think.

When the prescribers were asked what they thought the person with learning difficulties they prescribed for knew about their medication, they were very much more circumspect. The prescribers were more likely to couch their language in terms of uncertainty or doubt, or to say that they had not assessed the person's knowledge. Some prescribers highlighted that the person's level of understanding had not been recorded anywhere in the notes:

I've not discussed her medications with her. I've not tried to assess what her knowledge is.

I'm not sure, actually. I think I'd be sort of just guessing.

I haven't documented that very well.

What carers said they knew about a person's medication

The carers working in residential homes who were interviewed for the Medication Matters project had been in post for varying lengths of time; some were qualified nurses, others were support-workers with no occupational qualifications. Two recently recruited support-workers were able to reflect on their training in the administration and use of medications. One carer, who had been in post for approximately six months had not yet received any training in medication use or administration:

It should be there in your inductions and things like that but like I said mine – it probably would have been there – it's just that nobody was available to bother with me.

A second carer, who had been in post for a shorter length of time, had had some training from the house manager on the practical administration of medications, and had then been 'signed off' to administer them. When asked what the training covered he replied:

Going through our files, there, to show who has medication and at what times they have medication, and how the charts work...we have to initial them, religiously, each time we administer the drugs. And if we're never ever sure of anything then we've got their care notes to refer to 'cos that's got their medical notes in as well...there's the actual file we give drugs out by. And I was taken through all that. I was shown how to do it by the other members of staff for probably a week, I would imagine.

Apart from this training, which the carer thought was '*a little bit behind*', he had received no information about anything other than the practical task of administering medications. If he wanted to know any further information about the medication, such as what the medication was for, potential side-effects or warnings, he was expected to read up on it, which he felt was impossible given his current working circumstances and time constraints

This carer did not seem to be unusual. Other carers too, commented that they had been taught how to administer the medication, but were provided with little further information:

We don't get information at all...we just administer it.

In general, carers seemed to be well informed about the name of the medication the person with learning difficulties was taking. There was less clarity about the dosage, but most carers were able to provide information about the strength of the tablets or the number of tablets taken, either from the prescription administration documentation in use or from medication packaging. However, as one carer acknowledged:

We know how much he's taking but we don't know if that's an average amount, a lot or a little.

The knowledge about other aspects of the medication that the person with learning difficulties was taking was very varied. Some carers knew whether the person needed to take the medication with food or not, although one carer subsequently corrected herself after looking at the medication packaging. Most of the carers were aware whether alcohol could be drunk or not; but none knew if the medication could be taken during pregnancy. When asked what they would do if the person with learning difficulties forgot to take their medication, or took too much, all the carers said that they would seek advice from elsewhere. Sources of advice mentioned included a doctor, the emergency services, NHS

Direct, the home manager, an on-call staff member or the Care Standards Commission.

When considering how long people had been taking their medication for, the carers' knowledge only seemed to go back as far as they had been involved with the person – family carers were able to give a full history, but carers of people in residential or supported living settings tended to be less sure. Often, the initial reason for starting medication was not known. The question did inspire one residential carer to try and find out, because she thought that the person had changed considerably over time:

I mean its only now you are asking me these questions...I am going to go and find out. I think it would be interesting to see when she was prescribed it but I think it is quite important...she is a different person now so it would be interesting to know when and why.

Despite not always knowing the history of the people they were working with, all of the carers were able to say why the person was currently taking psychotropic medications. Some responses were more sophisticated than others, with carers giving clear reasons why each different medication was given:

His olanzipine we use as a mood stabilizer. I think that's more for the psychiatric side so, like his thoughts and that sort of thing... The depocote and the lithium we use as a mood stabilizer to help him avoid the highs and the big lows. And then the zuclopenthixol we use when he becomes agitated. And then his lorazepam we use when he becomes physically aggressive and then becomes violent.

Other carers were aware of the general purpose of the medication: '*I can only assume it is to stabilize [him] to give a better quality of life*', but did not feel that they knew what each one was for:

Not what I should know and what I would be comfortable with.

I'm handing out the medication but I'm not 100% sure of what I'm handing out.

Knowledge about possible side-effects of the medication was generally limited and with the exception of community nurses (who were the main supporter for a minority of people), most carers said that they weren't aware of any possible side-effects, couldn't remember them, or didn't know which ones to look out for. However, whilst some carers may not have known about the side effects of specific medications, many were alert to the possibility that any physical or behavioural changes in the person could be due to side-effects:

The sort of things that we do always look out for is any sort of vomiting or nausea, anything unusual really. Anything which sort of doesn't feel right you know.

Rather than memorizing that zuclopentixol can cause this, this and this, and lithium can cause this this and this...I tend to look at how the person is...and then, if he's got a problem, you look back at the medication and see if it could be related to it and explore it then.

However, there were a number of circumstances where recognising side effects in a person with learning difficulties was considered to be more challenging. One carer commented that she was aware that one of the possible side-effects of the medication the person was taking was dizziness, but would find it difficult to identify this because the person had ataxia. Another mentioned difficulties in differentiating possible side effects of medication from the aging process. A third carer said that because the person was taking a number of medications it could be difficult to pinpoint exactly which medication might be causing any side effects.

Once possible side effects had been recognised, carers then sometimes faced difficulties in getting their voices heard and appropriate action being taken. One carer said that the prescriber she reported possible side-effects to '*didn't want to know*'; another carer said he was told the person '*would just have to cope*'. As a third carer explained:

The doctor said it was nothing...but...you can't just think it is somebody doing it for attention or they don't know what is going on in their own body. You can't assume that.

What prescribers and people with learning difficulties thought carers knew

When the prescribers were asked what they thought the carers of the people with learning difficulties they prescribed for knew about the medication, there was a mixed response. Some prescribers identified a hierarchy of knowledge ranging from professionally qualified carers, such as community nurses who were thought to be most knowledgeable, through to family carers, and then unqualified carers who were considered to know the least:

I think the family carer's a lot better, often, at knowledge than the residential carer.

The majority of the carers need a lot of information. They need to be educated or informed about medications. Like, some of the carers who are qualified, they seem to know a lot more about medications.

Others considered it to be a matter of personal interest on the part of the carer:

I think you very clearly get a dichotomy between the people who avidly look at the drugs and compare the effects on different people and 'will actually come back to you saying 'Well, why are you trying this and 'not that? They're doing well on it' and other who, sort of, you get the feeling, don't give a damn.

The people with learning difficulties in the study were not specifically asked what they thought their carers knew about their medication. Most made the assumption, however, that their carer would, or should, know about their medication:

On medication I prefer to go to X [community nurse]...I feel sure about asking X... He'll go through it with me.

'They [the staff] would know that.

I talk to mum, not dad.

Knowledge about alternatives to medication

An important aspect of informed consent is the knowledge of possible options available. A number of carers and people with learning difficulties did mention treatment approaches other than medication that had, or were currently being tried. They reported the use of:

- relaxation tapes or classes
- electroconvulsive therapy (ECT)
- art or drama therapy
- occupational therapy
- a light box
- 'talking treatments'
- attendance at a support group
- going to a Snoozelum room
- complementary therapy such as aromatherapy
- a study day for staff about the management of a particular patient.

In general, it seemed that treatment approaches other than medication were not routinely offered to the people with learning difficulties in the study. With a lack of information about what some of these options might be, it would be unlikely that the person would ask for a particular approach to be tried – although this is what seemed to be expected for one person:

If he asked to, then obviously he would. But really, I think we decide as a staff group...we just felt that he didn't really need it.

An explanation for this was given by one carer:

I think most carers, you know, most people, staff in group homes and carers still subscribe to the medical model...I think that there are pockets of new kinds of approaches, but most people kind of think generally it is the first line of treatment [medication] ...and people are generally sceptical about talking therapies and art and music therapies. I mean you get referrals for music therapy because somebody likes music.

Other carers felt that they themselves didn't know enough about alternatives to medication, or were frustrated about the lack of consideration of approaches other than medication:

She doesn't know what's out there, same as we don't. We don't know there's alternatives, apart from being off [medication]. You know? We're solely, really, at the doctors mercy, really.

In reality, at the moment, doctors can write a prescription quicker than psychologists can build up a therapeutic relationship and try and explore if there is any other way of treating the problems they might have.

It was also clear from some carers, that even if the particular therapy was requested or considered to be needed, either they wouldn't know how to arrange this, or that the arrangements would involve several other 'gate-keepers':

I think she needs...counseling. She needs someone to teach her how to lose her temper, teach her how to cry, teach her how to express love, hate, jealousy, whatever she needs to do. But who does it? Where do we turn? Who do we turn to? I don't know.

The current provision of information

The provision of information to people with learning difficulties about their medication varied considerably in quality and quantity. Most of the people with learning difficulties said their doctor had told them verbally about their medication; some had had this backed up with written information, but this tended to be the exception rather than the rule. Almost all of the people with learning difficulties, and many prescribers, relied on this information to be reinforced or repeated by the carer:

The doctor gave me a lot of information, and then my mum explained it – person with learning difficulties

I think I would always talk to the patient and try to ensure they have understood it, but I mean if the carer is there they are going to kind of reinforce it - prescriber

The provision of information for carers about medications was, however, generally poor. When asked if they knew where they could look up information about medication if they wanted to, few of the carers mentioned any up-to-date source of information that was easily available for them to access if they wished. Some carers mentioned that a medication information file or folder was available, although there was some doubt about where these might be located or how up-to-date they might be:

I don't know which file it's in at the moment.

I don't know when it was written or if it's up-to-date.

Others mentioned that they would use the British National Formulary (BNF), ask a pharmacist, use the internet or look things up in books about medication. When asked where she could find out information about medications, one carer simply said: '*I haven't got the time*'.

In general, the fact that carers had to actively search out information about medications was due in part to most medications being dispensed in monitored dose packaging, such as blister packs, nomad cassettes or dosette boxes. The monitored dose packaging only gave guidance about the administration of the medication, and did not contain an information leaflet about each medication which other packaging supplies:

All we get is blister packs. It hasn't got any of the side effects or warnings on it.

On the back of the nomad cassette it tells you...the size of the tablet, the colour of the tablet. It doesn't give you any information about drowsiness or this, that and the other.

Some stuff cannot be blistered like Olanzapine. They don't blister that, so those come up in little cardboard packets and there is an information sheet in that, but as a regular thing we don't have an information sheet.

Information passed on between carers about a person's medication was also limited. When one carer replaced another in a key-working role, it was common for the new key-worker only to be told the name of the medication or where it was stored. If a prescription was changed, one carer said that they recorded the change in the staff communication book, but others only found out about the change when they read the instructions on the packaging or the medication card.

Despite the general lack of information held by carers about the medications, it was not unusual for carers with *some* information to adopt the role of gatekeeper to the little information they had, only informing the person of what the carers themselves thought that it was appropriate for the person to know:

I don't really know if it would sink in. And probably its best she doesn't really know...I'm worried that she would sort of be saying, right, I'm not taking them.

The need for more information

The majority of people interviewed for the Medication Matters project thought that people with learning difficulties should be given the same information about their medication as anyone else – albeit in an easy to understand format. Although this had not always been the case, most of the people with learning difficulties interviewed were satisfied with what they knew. For some, a small amount of information seemed to be enough; for others, they felt there was no need to find out any more information because things were going well for them. Those who did want to know more, wanted information about what the tablets were for, how long they had to take them, what made the tablets 'dangerous' and more general issues such as their own health.

The majority of carers also thought that they didn't know enough about psychotropic medication themselves. Whilst some carers thought that it was a problem '*across the board*', others saw it as being their own individual responsibility:

it is probably my fault in the sense that there are sources of information that I could go to

Specific issues that carers wished they had been told about included: why a person was prescribed the medication, how the medication worked, what the short- and long-term effects (and adverse effects) of taking the medication might be, how long a person might be expected to take medication for, and what the recommended safe limits of the medication were. Other carers wished they had more knowledge generally:

...just to sort of go into a little more depth with the medications that I'm giving out. I could be giving out Smarties at the end of the day.

Some GP prescribers, too, commented on the need for more information to be available to them. Whilst it was generally thought to be relatively easy for psychiatrists to keep up to date with good prescribing practice and newer medications for people with learning difficulties, GPs had fewer opportunities to update themselves.

Supporting people with learning difficulties in obtaining information

When asked about how best to improve the provision of information about medications to people with learning difficulties, four key strategies were highlighted:

- More time to be spent with the person with learning difficulties to provide, repeat and reiterate the key information about their medications:

I think to be honest my preference is actually to have some time set aside, whether it be in surgery or whether it be at the home itself, but just some time set aside with the main key worker and themselves just to go through it. That's what I think is the best. In real terms time just doesn't allow that all the time – prescriber

Having a community nurse who comes and spends the time – person with learning difficulties

It might even help, I don't know, if a psychiatrist was going out and talking to people, going to People First, or going to day centres and giving talks to service users...at least making themselves more accessible - carer

- Up-to-date, accurate information about all of the medications in use – that could be easily accessible for carers and people with learning difficulties to refer to on a day-by-day basis. This included:
 - Accessible information sheets
 - Accessible information sheets to accompany monitored dose packaging
 - Information to be presented in community languages
 - The option of having information provided using symbols, pictures, cartoon strips, video or audio tape.

Although a number of prescribers mentioned initiatives in their localities to produce accessible materials such as these, they were not widely used and not immediately available. Thus the provision of information in accessible formats would need to be supplemented by a dissemination strategy that would ensure that those who wanted or needed the information were able to get hold of it easily.

- Better training for carers about what psychotropic medication is, how it can be used and how to recognise and deal with possible problems in its use. The assumption was that better informed carers would be able to provide more accurate information to people with learning difficulties:

How can I explain something to somebody when I don't really understand it myself? – carer

If I talk to [carers] on a one to one basis and going into people's homes, they're much better – prescriber

- Individually tailoring information for each person's needs. This included using a familiar medium for the information or of modifying already existing information on an individual basis:

With Jack the visual symbols that he uses would be really useful for him. He's quite visual so if he sees something [visually] he remembers it much better and understands it much better.

I don't think that if Alan went out himself to find out information about his medication that he would get it in a format he could understand. It would have to be cut by myself and broken into something that he would be able to comprehend...as long as you broke it down to simple words that he could understand he would take it in.

The question of choice

Most of the people with learning difficulties in the Medication Matters study perceived themselves as having no choice about whether they took their medication or not. The majority suggested that they had to take the medication because their carers gave it to them or because the doctor told them to:

They make me take it

The staff tell me

I've been told I must, I'm forced to take it

For others the need to take the tablets in order to be 'well' was the key issue
'We got to take them, makes us better'

Few people seemed to express any sense of personal agency about the decision to take their medication and just one person indicated that the decision to take medication had been made by him alone:

It is not against the law, but it is just permission by myself. It is OK. It is my choice. It is up to me and it is my choice.

Many carers suggested too that they thought the person with learning difficulties had no real choice when it came to taking medication. Three main reasons were suggested: firstly the person with learning difficulties wanting to please staff,

secondly, that taking medication was part of the daily routine, and thirdly that carers would insist on the person taking prescribed medication because it was in their 'best interests'.

Choosing to refuse medication

Choice, like consent, shouldn't just be something that is done once and then inflexibly adhered to. People should have the chance to change their mind or withdraw their consent at any time. In general, however, there was little attention to decision-making being a process: the pressure of compliance with a medication regime that was ordered for people was far more in evidence than a shared decision-making process (concordance) between the service user, carers and professionals. Few people with learning difficulties said that they ever refused their medication and just one person admitted to sometimes spitting his tablets out in the bin. Another carer acknowledged:

I think he feels that if he wants to be, he can probably be more successful at not taking it if he didn't want to take it, by pretending that he was and keeping quiet about it.

Most of the carers acknowledged that they could not force a person to take their medication. However, they used a number of strategies to encourage them to do so, including repeatedly offering it until the person had taken it, telling the person about the risks of not taking it, and informing the doctor.

You offer them again half an hour later. You're saying, 'Oh, come on. You know you ought to be taking these tablets. We don't know what is going to happen if you suddenly stop taking them like that. You could be very ill. Do you know how ill you could be?

The policy now is that if she refuses her morning dose she should be offered that medication repeatedly throughout the day until she has taken it

In reality, few of these strategies really upheld the person's right to consent, particularly where there was an element of coercion. One carer spoke about an explicitly coercive strategy - that if a person did not take their medication they would not be allowed to go to work.

Supporting people with learning difficulties to make choices about medication

People with learning difficulties had a number of suggestions about what carers and prescribers could do better to help them make informed choices about taking their medication.

Firstly, they wanted easy to understand information to take away and look at in their own time, with support if necessary. The existing provision of information to people with learning difficulties about their medication was generally an ad hoc affair. None of them had seen accessible information leaflets about their medication, although the Elfrida Society in conjunction with Camden and Islington Community Health Services NHS Trust do produce a series of leaflets about different types of psychotropic medications for people with learning difficulties.

Most of the people with learning difficulties had been told about their medication by their doctor, but where doctors had taken the time and trouble to write things down or go through written material with the person it was greatly appreciated. For example one woman found it helpful when her doctor read out from the computer screen a letter that had been sent from her psychiatrist about a change in her medication. Another appreciated going through a medication information leaflet with her community nurse so that she knew that she was taking the medication correctly.

Secondly, people with learning difficulties said that they wanted more time when seeing the doctor. They wanted the doctor to speak directly to them, and not to their carer and they wanted the doctor to listen to their views and concerns. People felt uncomfortable when they knew the doctor was hurried or had other patients waiting, and found it difficult to ask questions if the doctor was not engaged directly with them. There is certainly a role for carers here to ensure that people with learning difficulties are not just 'seen but not heard' in any consultation or review of their medication.

Thirdly, people with learning difficulties said they wanted a chance to think about their choices for a while, and to be able to talk options through with a trusted person or an independent advocate before making their decision.

To some extent carers were in a double bind situation – they were there to support the people with learning difficulties and to promote their rights, but they also had a degree of responsibility to ensure their physical and mental well-being. As one carer put it:

People do find it hard to deal with because you feel like you're not doing your job properly 'cos you're not looking after her properly. But then, also, its taken us quite a while to learn that just 'cos somebody's got a learning disability doesn't mean that they can't make choices and they haven't got rights.

Finding a way through these dilemmas are some of the key challenges for people working with, or supporting people with learning difficulties.

Outcomes from the research

As a result of the research findings, the research team have been working on a number of resources to help people with learning difficulties, their carers and prescribers. These are:

- a booklet for people with learning difficulties, their families or carers where information about a medication can be recorded
- a decision-making tool for people with learning difficulties to help them make informed choices about medications they are prescribed
- information about where to find out more about medications
- a checklist of things to ask the doctor about medication
- a guide for prescribers about the things they should particularly consider when issuing a prescription for psychotropic medication to people with learning difficulties.

Some of these resources will be produced and distributed by the Medications Partnership Agency. Others are available directly from the research team.

For more information, contact:

The Medication Matters team
Norah Fry Research Centre
University of Bristol
3 Priory Road
Bristol BS8 1TX

Tel: 0117 923 8137
Email: mhmyw@bristol.ac.uk
Website: Bristol.ac.uk/Depts/NorahFry

References:

- Ahmed, Z., W. Fraser, et al. (2000). "Reducing antipsychotic medication in people with a learning disability." British Journal of Psychiatry(176): 42-46.
- Allen, D. M., L. Dunn,C. Doyle,T. (1997). "Changing care staff approaches to the prevention and management of aggressive behaviour in a residential treatment unit for persons with mental retardation and challenging behaviour." Research in Developmental disabilities **18**(2): 101-112.
- Aman,M.G., Singh,N.N. White,A.J. (1987) "Caregiver perceptions of psychotropic medication in residential facilities" Research in Developmental Disabilities **8**: 449-465.
- Arscott, K., B. Stenfert Kroese, et al. (2000). "A study of the knowledge that people with intellectual disabilities have of their prescribed medication." Journal of Applied Research in Intellectual Disabilities **3**(2): 90-99.
- Ashcroft, R. F., B. Kerr,M. Ahmed,Z. (2001). "Are antipsychotic drugs the right treatment for challenging behaviour in learning disability? The place of a randomised trial." Journal of Medical Ethics **27**: 338-343.
- Baumeister, A., J. Sevin, et al. (1998). Neuroleptics. Psychotropic Medications and Developmental Disabilities: The International Consensus Handbook. S. Reiss and M. Aman, Ohio State University Nisonger Center: 133-147.
- Bouras N., Kon Y., Drummond C. (1993) "Medical and psychiatric needs of adults with a mental handicap". Journal of Intellectual Disability Research **37** (Pt 2):177-82.
- Bramble, D. (2003). "Annotation: The use of psychotropic medications in children: a British view." Journal of Child Psychology and Psychiatry **44**(2): 169-179.
- Branford, D. (1996). "Factors associated with the successful or unsuccessful withdrawal of antipsychotics prescribed for people with learning disabilities." Journal of Intellectual Disability Research **40**(4).

Briggs,R. (1996) "Monitoring and evaluating psychotropic drug use for persons with mental retardation: a follow-up report" American Journal of Mental Retardation **93**: 633-639.

Brylewski, J. and L. Duggan (1999). "Antipsychotic medication for challenging behaviour in people with intellectual disability: a systematic review of randomized control trials." Journal of Intellectual Disability Research **43**(part 5): 360-371.

Brylewski, J. and L. Duggan (2003). "Antipsychotic medication for challenging behaviour in people with learning disability." Cochrane library.

Burke,A., McMillan,J., Cummins,L., Thompson,A., Forsyth,W., McLellan,J., Snow,L., Fraser,A., Fraser,M., Fulton,C., McCrindle,E., Gillies,L., LeFort,S., Miller,G., Whitehall,J., Wilson,J., Smith,J., Wright,D. (2003) "Setting up participatory research: a discussion of the initial stages". British Journal of Learning Disabilities **31** 65-69.

Christian, L., S. Snycerski, et al. (1999). "Direct service staff and their perceptions of psychotropic medication in non-institutional settings for people with intellectual disability." Journal of Intellectual Disability Research **43**(part 2): 88-93.

Coughlan, B. (2000). "Psychopharmacology in the treatment of people with learning disabilities:a review." Mental Health & Learning Disabilities **3**(9): 304-307.

Davis,S., Wehmeyer,M.L., Board,J.P., Fox,S., Maher,F., Roberts,B. (1998) "Interdisciplinary teams". Psychotropic Medications and Developmental Disabilities: The International Consensus Handbook. S. Reiss and M. Aman, Ohio State University Nisonger Center.

Deb,S. Fraser,W. (1994) "The use of psychotropic medication in people with a learning disability: towards rational prescribing". Human Psychopharmacology **9**: 259-272.

DoH and Welsh Office (1983) "Mental Health Act Code of Practice" HMSO: London.

Fraser,W.W., Leudar,I., Gray,J., Campbell,I. (1986) Psychiatric behaviour disorder in mental handicap Journal of Mental Deficiency Research **30**: 49-59.

Harper,D.C. Wandsworth,J.S. (1993) Behavioural problems and medication utilization Mental Retardation **31**: 97-103.

Havercamp,S. (1996) Psychiatric diagnosis and mental retardation: reliability of rating scales as a function of IQ. Masters thesis, Department of Psychology. The Ohio State University, Columbus, OH.

Holmes,G. Newnes,C. (1996) "Medication – the holy water of psychiatry"
Openmind **82**: 14-15.

Hubert,J. (1992) "Too many drugs, too little care". Values into Action: London.

Jenkins, R. (2000). "Use of psychotropic medication in people with a learning disability." Learning Disability Nursing **9**(13): 844-850.

Kalachnik, J. (1999). "Measuring Side Effects of Psychopharmacologic Medication in Individuals With Mental Retardation and Developmental Disabilities." Mental Retardation and Developmental Disabilities Research Reviews **5**: 348-359.

Llewellyn-Jones, S. J., G. Donnelly,P. (2001). "Questions patients ask psychiatrists." Psychiatric Bulletin **25**: 21-24.

Manchester, D. (1993). "Neuroleptics, learning disability, and the community: some history and mystery." British Medical Journal **307**: 184-187.

Matson,J.L., Bamburg,J.W., Mayville, E.A., Pinkston,J., Bielecki,J., Kuhn,D., Smalls,Y., Logan,J.R. (2000) "Psychopharmacology and mental retardation: a 10-year review (1990-1999)" Research in Developmental Disabilities **21**: 263-296.

McGrath, J. (1999). "Physicians' perspectives on communicating prescription drug information." Qualitative Health Research **9**(6): 731-745.

Miller, H. E. S., N. Foster,S.E. (1997). "Psychotropic medication in learning disabilities: audit as an alternative to legislation." Psychiatric Bulletin **21**: 286-289.

Molyneux, P., E. Emerson, et al. (1999). "Prescription of psychotropic medication to people with intellectual disabilities in primary health care settings." Journal of Applied Research in Intellectual Disabilities **12**(1): 46-57.

Moss, S., E. Emerson, et al. (2000). "Psychiatric symptoms in adults with learning disability and challenging behaviour." The British Journal of Psychiatry **177**: 452-456.

Poindexter,A.R. (1989) "Psychotropic drug patterns in a large ICF/MR facility. A ten-year experience" American Journal of Mental Retardation **93** 624-626.

Pyles, D. A. M. M., K. Cade,A. Silva,R. (1997). "A behavioral diagnostic paradigm for integrating behavior-analytic and psychopharmacological interventions for

people with a dual diagnosis." Research in Developmental disabilities **18**(3): 185-214.

Read,J. Wallcraft,J. (1992) "Guidelines for empowering users of mental health services" MIND/COHSE Publications: Brighton.

Reiss,S. (1994) "Handbook of Challenging Behaviours: Mental Health Aspects of Mental Retardation" IDS Publishing Corporation, Worthington, OH.

Reiss, S. and M. Aman (1997). "The international consensus process on psychopharmacology and intellectual disability." Journal of Intellectual Disability Research **41**(part 6): 448-455.

Robertson, J., E. Emerson, et al. (2000). "Receipt of psychotropic medication by people with learning disability in residential settings." Journal of Intellectual Disability Research **44**(6): 666-676.

Santosh, P. (1999). "Psychopharmacotherapy in children and adults with intellectual disability." Lancet **354**(9174): 233-42.

Sevin, J. (2001). "Integrating behavioural and pharmacological interventions in treating clients with psychiatric disorders and mental retardation." Research in Developmental Disabilities **22**(6): 463-85.

Singh, N. N. E., C.R. Donatelli,L.S. Williams,D.E. Ricketts,R.W. Goza,A.B. Perlman,N. Everly,D.E. Best,A.M. Singh,Y.N. (1996). "Professionals' perceptions of psychotropic medication in residential facilities for individuals with mental retardation." Journal of Intellectual Disability Research **40**(1): 1-7.

Smith, C. F., D. Ahmed,Z. Fraser,W.I. Kerr,M. Kiernan,C. Emerson,E. Robertson,J. Allen,D. Baxter,H. Thomas,J. (2002). "Sedation effects on responsiveness: evaluating the reduction of antipsychotic medication in people with intellectual disability using a conditional probability approach." Journal of Intellectual Disability Research **46**(6): 464-471.

Stalker,K. (1998) "Some ethical and methodological issues in research with people with learning difficulties" Disability & Society **13** 5-19.

Stenfert Kroese, B. D., D. Holmes,G. (2001). "Diagnosis and drugs: help or hindrance when people with learning disabilities have psychological problems?" British Journal of Learning Disabilities **29**(1).

Strydom, A., M. Foster, et al. (2001). "Patient information leaflets for people with learning disabilities who take psychiatric medication." British Journal of Learning Disabilities **29**: 72-76.

Styrdom, A. and I. Hall (2001). "Randomized trial of psychotropic medication information leaflets for people with intellectual disability." Journal of Intellectual Disability Research **45**(part 2): 146-151.

Tempier, R. (1996). "Long-term psychiatric patient's knowledge about their medication." Psychiatric Services **47**(12): 1385-1387.

Vitiello,B. Jensen,J. (1995) "Developmental perspectives in pediatric psychopharmacology". Psychopharmacology Bulletin **31**: 75-81.

Wald,D.S. (2004) "Bureaucracy of ethics applications" BMJ **329**: 282-284.

Wilson,J.G., Lott,R.S., Tsai,L. (1998) "Side effects: recognition and management". Psychotropic Medications and Developmental Disabilities: The International Consensus Handbook. S. Reiss and M. Aman, Ohio State University Nisonger Center.

Young, A. T. H., J. (2002). "Psychotropic medication prescriptions: an analysis of the reasons why people with mental retardation are prescribed psychotropic medication." Journal of Developmental and Physical Disabilities **14**(2): 129-142.