# Guide to Using Psychotropic Medication to Manage Behaviour Problems among Adults with Intellectual Disability

# **Technical Document**

Shoumitro Deb, MBBS, FRCPsych, MD, Clinical Professor of Neuropsychiatry and Intellectual Disabilities and Gemma L. Unwin, BSc(Hons).

University of Birmingham, Division of Neuroscience, Department of Psychiatry, UK.

Acknowledgments: Thanks to the Guideline Development Group members – Gill Bell, Sabyasachi Bhaumik, David Branford, Rob Chaplin, David Clarke, Chris Dale, Caroline Lee, Suzanne Robinson, Ashok Roy, Florence Simon, Ray Smart, Biza Stenfert Kroese, Caron Thomas, Miriam Wilcher, and Linda Woodcock

www.LD-Medication.bham.ac.uk

#### November 2006







# Guide to Using Psychotropic Medication to Manage Behaviour Problems among Adults with Intellectual Disability

# Technical Document Section 6: Multi-centre Audit of Guideline Recommendations

Gemma L. Unwin, BSc(Hons) and Shoumitro Deb, MBBS, FRCPsych, MD, Clinical Professor of Neuropsychiatry and Intellectual Disabilities

University of Birmingham, Division of Neuroscience, Department of Psychiatry, UK.

www.LD-Medication.bham.ac.uk

November 2006









INTRODUCTION	4
METHODS	5
Design Audit Criteria Sample Data Utilised Included Clinics	5 5 5
Trust Approval  Questionnaire and Protocol Development  Data Collection  Data Handling  Data Analysis	6 7 7
RESULTS	8
OBSERVATIONS Target Behaviour Time Until Review Key Worker Medications Prescribed Examinations and Investigations Adherence to the Audit Criteria	8 9 10
DISCUSSION	12
REFERENCESAPPENDIX 1: AUDIT QUESTIONNAIRE	
APPENDIX 1: AUDIT QUESTIONNAIRE APPENDIX 2: AUDIT GUIDANCE NOTES AND PROTOCOL	

#### Introduction

The audit was devised in order to survey current clinical practice surrounding adults with a learning disability for whom medication has been prescribed to manage a behaviour problem with reference to the guideline recommendations. The results are anticipated to act as a baseline with the audit being replicated in three to four years time, at which point the impact of the guideline can be assessed.

In addition, the audit has formed an integral part of the guideline development and largely focussed on assessing the good practice points as outlined in the guideline. Such points include assessment of behaviour, rationale for treatment, consent and capacity issues and information sharing from the prescriber to the individual and/or carer.

Furthermore, the audit was primarily concerned with evidence of clinical practice that can be obtained through patient case notes, as it is becoming increasingly important for clinicians to document all aspects of their practice to provide a written record which verifies the quality of treatment an individual has received. As Marshall (2004) concluded from his own audit of the use of psychotropic medication for challenging behaviour in a community learning disability service, "there is a need to demonstrate well-considered prescribing characterised by describing behaviour well, considering alternative approaches, using outcome measures, discussing risks with clients and carers and monitoring for side-effects".

#### **Methods**

## Design

The design used was a retrospective case note review. A data collection proforma was developed (see Appendix 1) in alliance with the GDG to facilitate the capture of information from service user case notes. Individual service user data were collected on separate data collection proforma.

#### **Audit Criteria**

The audit criteria were selected through discussion within the GDG meetings (see Section 2, Appendix 3 for a list of possible audit questions). It was decided that the audit should focus on the initiation of treatment and therefore examine the current practice surrounding initial assessments in particular. The criteria were specifically chosen to reflect the good practice points outlined in the guideline and therefore measure current adherence to the guideline.

## Sample

Adult (over the age of eighteen years) inpatients or outpatients who were referred to a specialist learning disability psychiatric service within the past three years where they received medication treatment for a behaviour problem without a diagnosis of psychiatric illness such as schizophrenia, depression or bipolar disorder. Inclusion in the audit was determined by inspection of relevant case notes for references of behaviour problems without mention of a confirmed psychiatric diagnosis. Cases where medication was primarily prescribed for any such psychiatric illnesses, epilepsy, brain injury or substance misuse were excluded (see Appendix 3 for list of inclusion and exclusion criteria).

#### Data Utilised

Clinic case notes including handwritten medical notes and clinic letters.

A total of 154 case notes were identified that met the sample criteria for the audit and were subject to data extraction. The included services spanned a large geographical area broadly covering the East and the West Midlands, Oxfordshire and the North East of England (UK) with a total of ten sites involved in data collection.

#### Included Clinics

The clinics and clinicians involved in the audit were selected on an opportunity basis through contacts of the project leader. A total of forty clinicians was initially invited to take part via a postal information pack containing a letter of invitation, the data collection proforma (see Appendix 1) and the audit protocol

(see Appendix 2). Any consultant psychiatrists specialising in Learning Disability were eligible to take part, providing they worked with adults for whom medication had been prescribed to manage a behaviour problem. Those consultants who expressed an interest in the audit were then contacted and local arrangements were established.

# **Trust Approval**

The audit was registered with all the relevant NHS Trust Research and Development (R and D) departments prior to data collection. As the project was deemed a baseline audit/survey, Research Ethics Committee approval was not required.

# Questionnaire and Protocol Development

The methodology employed in the audit was developed over a number of months with input from a number of sources. It was decided by the GDG to concentrate the audit on good practice points surrounding the initiation of treatment rather than specific mechanics of prescribing to reflect the recommendations made in the guideline. The audit criteria were therefore derived directly from the advice offered in the guideline (see Section 2 for the recommendations). The GDG discussed all the criteria, creating a list of audit questions, and establishing what evidence of practice was to be accepted in response to each of the questions. The audit questions were then transformed into a questionnaire design where a range of responses could be ticked in reply. This initial questionnaire was conferred at a local meeting for consultant psychiatrists working in the West Midlands area where suggestions were made towards the framing, wording and layout of the questionnaire; the criteria however remained largely unchanged. The questionnaire was then subject to constant review in regards to its utility with input from the GDG and the local NHS Trust R and D advisor. A local pilot was also conducted on ten case notes to assess the face validity of the questionnaire and address any practical implications with amendments made in the light of experience.

It was decided that the questionnaire should collect both qualitative and quantitative data with scope for written explanations in support of forced choice (tick box) answers. This was deemed important as a more reliable depiction of current clinical practice could be gleaned from both the examination of statistical compliance to the criteria and any additional information surrounding clinical practice.

Once the items on the questionnaire were finalised, a lengthy protocol was drafted to explain, in detail, the nature of the audit and provide clear advice on how the questionnaires should be completed with specific reference to what was deemed adequate evidence for a 'yes' response to be accepted for each of the audit questions (see Appendix 2). The protocol served a number of purposes in that it was sent out to relevant clinicians to inform them of the intended methodology for the audit, to inform relevant trusts of the intended

methodology for the audit when seeking approval and to ensure that each questionnaire was completed in a consistent and reliable manner.

#### **Data Collection**

The data were gathered from careful inspection of the case notes in order to complete one questionnaire (see Appendix 1) for each included set of case notes between the dates of 22<sup>nd</sup> August 2005 and 19<sup>th</sup> February 2006. The data extraction was completed either by Gemma Unwin, a Research Associate of the University of Birmingham or by Senior House Officers (SHOs), Staff Grade Doctors, or Specialist Registrars (SpRs) working within the relevant clinical teams. This approach facilitated a larger yield of included case notes as data collection could be completed at several clinics in parallel.

In order to ensure inter-rater reliability, all external auditors who completed some data extraction were given training by the research associate in how to fill in the questionnaires, either via meetings or over the phone. In addition, the protocol to accompany the questionnaire (see Appendix 2) was designed in such a way as to be extensive and inclusive so that it could provide consistent instructions on how to answer each of the audit questions. Furthermore, the questionnaire was engineered to provide room for written responses with additional space at the back so that any extra information surrounding a question could be noted.

# **Data Handling**

The data collected throughout this study were of a highly sensitive nature and were therefore kept confidential. In addition, anonymity was ensured by the use of identification numbers rather than names on the audit questionnaires.

# Data Analysis

The data from each questionnaire were imported into a database where the answers relevant to each question were tallied. These numbers were then transformed into a proportion of the total number of responses given to each question. By expressing the data as percentages, adherence to the audit criteria was examined. The written responses given in the text boxes on the data collection proforma were closely examined for any re-occurring themes and reported as observations.

#### Results

(All the percentages quoted in this section are correct to the nearest whole number.)

Of the 154 included case notes, 102 (66%) were of male individuals and 52 (34%) female, 125 (81%) were outpatients and 29 (19%) inpatients. The mean age of the cohort was 34 years (range 18 – 69).

#### **Observations**

The qualitative, written responses on the questionnaires demonstrated some trends regarding the prescribing of medication for behaviour problems in adults with a learning disability.

# **Target Behaviour**

Details regarding the specified target behaviours was provided in 141 (92%) completed questionnaires. The most commonly cited target behaviour was aggression (n=113, 80% of those 141 cases providing details of the target behaviour). The breakdown of the different types of aggression specified are as follows:

- 15 cases (13%): verbal aggression
- 26 (23%): physical aggression
- 29 (26%): both physical and verbal aggression
- 43 (38%): did not specify the type of aggression.

A total of 28 cases (20% of those 141 cases providing details of the target behaviour) referred to self-injurious behaviour as the target behaviour, 21 cases (15%) referred to a reduction in anxiety being the target for medication, and 23 cases (16%) referred to destructive behaviour or property destruction.

In the majority of cases that provided details on the target behaviours specified in the case notes, two or more behaviours were cited as the target for the medication-based intervention.

#### Time Until Review

Of the cases that specified a time until review (n=105, 68%), the median time was 3 months (range 3 days – 1 year), an additional 6 cases specified that the review date was 'as needed' and 17 specified that a review date was not applicable as the service user had been discharged from the clinic. A proportion (n=13) of the questionnaires recorded the specific review date rather than the time until review and were therefore not entered into the

analysis of average time until review. As a general rule, inpatients were reviewed at shorter intervals than outpatients.

# Key Worker

A majority of the cases examined identified a key person who would implement the treatment plan (n=120, 78%). Of the 124 cases that gave details of the capacity of this key person, 39 (31% of the 124 cases that provided further details) specified that they were a relative of the service user with 36 cases identifying the key person as a parent of the service user; two were identified as the partner of the service user, and one was identified as the aunt of the service user. 80 cases specified that the key person was a paid care worker or health professional; the breakdown for the primary professional key person is as follows:

n	Capacity of Paid Professional
22	Staff/paid carer/manager at care/residential/nursing home/supported accommodation
20	Ward/inpatient nurse
18	Unspecified care/key/support worker
8	Community nurse
6	Team/service leader/manager
3	Unspecified inpatient staff
3	Social worker
2	Outreach worker
1	Psychologist
2	Other

Where a key person who would implement the treatment plan was identified, this was largely on an informal basis and inferred by the notation of the attendance of the key person with the service user to the clinic. Rarely was the individual explicitly mentioned as the key contact who would implement the treatment plan. Furthermore, in only 4 cases was a key person identified through a formal care plan, Health Action Plan (HAP) or Care Programme Approach (CPA).

Of the cases that identified a key person, 97 (80%) went on to demonstrate that relevant information, including the treatment plan had been passed to that key person. This was largely achieved on an informal, verbal basis as the

treatment plan was discussed during clinic appointments at which the key person would attend with the service user.

#### **Medications Prescribed**

The medications documented in the notes as prescribed after the initial assessment were recorded on the questionnaires. The most commonly prescribed medication for the management of behaviour problems was risperidone which was prescribed in 81 cases (53%). The mean dose of risperidone was 1.85 mgs. Lorazepam was prescribed in 18 cases, as was carbamazepine with the mean dosages being 1.39 mgs and 594 mgs respectively. Polyprescribing (prescribing more than one medication for the same indication) was common amongst the examined case notes.

# **Examinations and Investigations**

A minority of the cases demonstrated that any examinations or investigations had been carried out prior to initiating treatment with medication. 23 (15%) demonstrated that the physical examinations of pulse, blood pressure and all systems had been executed. 7 cases (5%) demonstrated that the clinician had examined weight or body mass index prior to prescribing medication. 36 cases (23%) showed evidence that any routine blood tests had been carried out, namely full blood count, urea and electrolytes, liver function test, and thyroid function test. In 1 case, a folate blood test was conducted and in 1 case, a Vitamin B12 blood test was conducted. In 3 cases, a lipid blood test was carried out.

Other investigations noted were electroencephalogram and electrocardiogram (9 cases each) and brain scans (4 cases).

Overall, only a minority cases provided evidence that any examinations and investigations had been carried out prior to prescribing medication. Many of the above cases overlap somewhat with those conducting any investigations or examinations tending to carry out more than one.

#### Adherence to the Audit Criteria

The percentage of cases demonstrating adherence to the audit questions is presented in the table below in descending order.

Audit Question	Cases Demonstrating Adherence	
	Percentage	Number
Has the treatment plan been communicated with other relevant professionals, including the GP?	94	154
Has there been an assessment of the behaviour?	94	154
Has the assessment covered behavioural, medical, psychological/ psychiatric and social	92	154

issues?		
Has the target behaviour been defined?	92	154
Has a date been set up for review at the time of the last appointment?	91	137 <sup>a</sup>
Has non-medication based intervention been considered?	82	154
Has the prescriber passed all the relevant information to the key person identified as implementing the treatment plan?	80	122 <sup>a</sup>
Has non-medication based intervention been implemented?	72	148 <sup>a</sup>
Has a differential diagnosis been made?	70	154
Has the rationale for the treatment been described?	64	154
Has a risk assessment been completed?	44	154
Has the use of an objective outcome measure been described?	43	154
Has the capacity issues of the service user been assessed?	34	154
Has a written (short term and/or long term) treatment plan been handed over to the service user and/or carer?	30	154
Has the carer's assent to treatment been secured?	26	126 <sup>a</sup>
Has the service user's consent to treatment been secured?	26	135 <sup>a</sup>
Has a written document about the adverse effect been provided to the service user and/or carer?	5	154

a. Not all the criteria were applicable to each case. Where information was documented suggesting that a standard was not relevant to that case, they were not entered into the percentage calculation. For example, where consent to treatment was not obtained due to the individual deemed as unable to provide consent, or where a review date was not established due to the individual being discharged.

#### **Discussion**

A high proportion of cases demonstrated some assessment of the behaviour and similarly of the assessment of behavioural, medical, psychological/psychiatric and social issues. In addition, the majority of the cases examined demonstrated both the consideration and implementation of non-medication based interventions. The target behaviour for the treatment was also well defined in a preponderance of cases and similarly with the establishment of a review date, signifying good, consistent documentation of these areas. Furthermore, a majority of cases showed evidence of a differential diagnosis and description of the rationale for treatment. The most adhered to criterion was that of the treatment plan being communicated with other relevant professionals including the GP, this was largely accomplished through the use of a clinic letter.

However, some areas were identified that revealed poor adherence to the audit criteria. Such areas included the recording of providing the service user and/or carer with a written document containing the treatment plan and information on adverse effects. In line with the guideline development, a series of medication information leaflets for service users and their carers have been produced in an attempt to aid this aspect of information sharing and therefore aid the implementation of the guideline. The issue of provision of accessible information about medications has been subject to investigation in many areas of mental health. Bowler et al. (2000) found that information provision by a community mental heath team to individuals experiencing psychosis was too infrequent, unstructured, often *ad hoc*, and did not take into account the cognitive deficits left by the illness. They suggest that the use of accessible information, using different mediums, and the review of knowledge held by individuals and their carers was needed.

Furthermore, documentation of the assessment of capacity and the acquisition of consent or assent were found to be lacking in the majority of cases. This area is particularly pertinent in the field of learning disabilities and has important legal implications. In addition, only a minority of cases recorded the use of an objective outcome measure for evaluating medication effect or documented the completion of a risk assessment. Indeed, Bhaumik et al. (2005) concluded from their evaluation of the care programme approach (CPA) in adults with a learning disability that there were 'major deficiencies in risk identification, risk management and information sharing'. They suggest that the only way that information sharing regarding risks can be ensured is through the 'meticulous use of written documents', which they found to be insufficient. Furthermore, when contrasted with the high rate of aggression cited as the target behaviour, the low rate of risk assessment appears noteworthy. Moreover, Campbell and Chaplin (2001) found that the documentation of the risk of violence could be greatly improved with no impact on resources, paperwork or time.

Whilst the results appear to be rather striking, particularly in terms of consent and capacity issues, it is important to recognise that these actions may have been carried out but not documented. Therefore, the results demonstrating paucity in the documenting of certain aspects may reflect a 'recording deficit' rather than poor clinical practice. However, the guideline from which the audit criteria were derived places emphasis on the appropriate documentation of clinical practice to provide an account of the level of care an individual receives.

The study suggests that there is scope for improvement in terms of substantiating clinical practice through documentation in case notes. However, there were some methodological issues inherent with the study. Whilst every effort was made to obtain inter-rater reliability through the use of a pilot, a comprehensive protocol including substantial guidance notes and training for external auditors, it is acknowledged that there may be a small amount of variability in the responses to some of the questions. A particular related problem was the wording of the questions, which were extensively refined specifically to probe certain aspects of practice but some may have left a certain level of ambiguity. In addition, there was a specific issue identified due to the difficulty of retrieving some information from the medical case notes. As the audit examined any information from within the case notes, this included handwritten clinic notes that were sometimes difficult to decipher. A suggested solution to this problem is to focus on typed documents such as current clinic letters.

If a follow-up audit is completed, consideration needs to be offered to the changing nature of practice documentation. Computer databases are now becoming more commonly used, therefore any subsequent data collection perhaps should intend to probe these files with less emphasis on written notes. Furthermore, a recent audit of psychotropic medications in community-based individuals with learning and developmental disabilities analysed computerised pharmacy records to establish longitudinal prescribing patterns. This method proved to be very effective and efficient in assessing prescribing patterns in community-based individuals.

#### References

Bhaumik S, Nadkarni S, Biswas AB, & Watson JM (2005). Service innovations: risk assessment and learning disability. *Psychiatric Bulletin*, **29**, 28-31.

Bowler N, Moss S, Winston M, & Coleman M (2000). An audit of psychiatric case notes in relation to antipsychotic medication and information giving. *Clinical Performance and Quality Health Care*, **8**; 212-216.

Campbell M & Chaplin R (2001). Improving the assessment of risk of violence: a clinical audit of case note documentation. *Psychiatric Bulletin*, **25**; 250-252.

Lott IT, McGregor M, Engelman L, Touchette P, Tournay A, Sandman C, Fernandez G, Plon L, & Walsh D (2004). Longitudinal prescribing patterns for psychoactive medications in community-based individuals with developmental disabilities: utilization of pharmacy records. *Journal of Intellectual Disability Research*, **48**; 563-571.

Marshall T (2004). Audit of the use of psychotropic medication for challenging behaviour in a community learning disability service. *Psychiatric Bulletin*, **28**; 447-450.

# **Appendix 1: Audit Questionnaire**

Date of Questionnaire completion:		
Identification Number: Date of Birth: Gender: In-patient/ Out-patient:		
1) Has there been an ass	sessment of the behaviour?	
Yes Not Recorded	[]	
2) Has the assessme (Psychological), and (S)	ent involved B (Behaviour), M (Medical), P Social issues?	
Yes Not Recorded	[]	
Give details:		
3) Has non-drug interve	ntion been considered?	
Yes Not Recorded	[]	
4) Have any non-drug in	terventions been implemented?	
Yes No Not Recorded	[ ] [ ] [ ]	

available reason:		,,	give details of any
	en (short-term and the service user ar		reatment plan been
Yes Not Recorded	[]		
6) Has a written service user and		he adverse effect b	peen provided to the
Yes Not Recorded	[]		
Not Recorded			
Not Recorded			

7) Record the names of the existing psychotropic drugs prescribed (if any) to the service user with daily dosage prior to the initial assessment at the present clinic:
Drug Name Daily Dosage (Milligrams)
a) b) c) d) e) f)
Not Recorded [ ]
8) Record the names of the psychotropic drugs prescribed (if any) to the service user with daily dosage after the initial assessment at the present clinic:
Drug Name Daily Dosage (Milligrams) a) b) c) d) e) f)
Not Recorded [ ]
9) What physical examinations or investigations were carried out prior to prescribing any new psychotropic drugs (please list)?

10) Has the capacity issues of the se	rvice user been assessed?
Yes [] Not Recorded []	
Give Details:	
11a) Has the service user's consent l	been secured?
Yes Consent Sought, Not Secured Not Applicable Not Recorded	[ ] [ ] [ ]
11b) Has the carer's assent been sec	cured?
Yes Assent Sought, Not Secured Not Applicable Not Recorded	[ ] [ ] [ ]
12) If the service user lacks capacity Capacity Act?	y, has the prescriber considered the
Yes Not Applicable Not Recorded	[ ] [ ] [ ]
13) If the service user lacks capacit the prescriber considered the Mental	
Yes Not Applicable Not Recorded	[ ] [ ] [ ]
14) Has the treatment plan been inclu Health Action Plan or Care Programm	
Yes [ ] No [ ] Not Recorded [ ]	

15) Has the rationale	for the treatment been described?
Yes Not Recorded	[]
If yes, give details o	of rationale or why rationale not provided:
16) Has a differential	diagnosis been made?
Yes Not Recorded	[ ]
17) Has a risk assess	ment been completed?
Yes Not Recorded	[]
18) Has the target bel	haviour been defined?
Yes Not Recorded	[ ]
If yes, give details	s of target behaviour:

described?
Yes [ ] Not Recorded [ ]
20) Has a date been set up for the review at the time of the last appointment?
Yes [ ] No, Patient Discharged [ ] Not Recorded [ ]
If yes, give time since last appointment until review:
Time until Review:
21) Has a key person been identified who would implement the treatment plan?
Yes [ ] No [ ] Not Recorded [ ]
If yes, give details of key person. If no, give details of any available reason:
22) Has the prescriber passed all the relevant information to the key person identified above, bearing in mind any issues of confidentiality?
Yes [ ] Not Applicable [ ] Not Recorded [ ]  If no, give details of any available reason:

professionals (including the GP)?
Yes [ ] Not Recorded [ ]
If yes, give details of other professionals:
Any Additional Comments:

# **Appendix 2: Audit Guidance Notes and Protocol**

The Neuropsychiatry and Intellectual Disabilities Research Group based in the Department of Psychiatry, Division of Neuroscience at the University of Birmingham is developing a 'good practice' guideline in association with the Royal College of Psychiatrists and MENCAP to advise Health Professionals and others on the use of medication in the management of behaviour problems among adults who have a learning disability.

Between 1% and 2% of the general population have varying degrees of learning disability<sup>1</sup>. It has been reported that between 20% and 45% of individuals with a learning disability are prescribed psychotropic medication, of which 14% to 30% are taking these to control behaviour problems<sup>2</sup>. Psychotropic medications are indicated in the treatment of psychiatric illnesses, however, research suggests that 36% of people who have a learning disability are prescribed these drugs in the absence of a diagnosis of psychiatric illness<sup>3</sup>. In addition, many of these individuals are receiving such medication indefinitely, in the form of poly-therapy and at a high dose in the absence of any monitoring<sup>2</sup>.

The rate of behaviour problems among adults with a learning disability is high. A recent study indicated that 60.4% of adults in a community setting with severe, moderate and mild learning disability demonstrated behaviour problems of any severity with 11% exhibiting severe challenging behaviour<sup>4</sup>.

Both caregivers and professionals have expressed concern regarding the inappropriate use of psychotropic medication within the learning disabled population, hence the development of the guideline in order to improve the health outcomes whilst optimising resource utilisation.

This audit intends to survey the current clinical practice surrounding individuals with a learning disability for whom psychotropic medication is prescribed to manage a behaviour problem with reference to the present guideline recommendations. In addition, the audit aims to initiate the identification of areas of clinical practice that could be improved in accordance with the guideline and aid in the employment of such targets.

The audit forms an integral part of the guideline development and largely focuses on assessing good practice points as outlined in the guideline. Such points include assessment of behaviour, rationale for treatment, consent and capacity issues and information sharing from clinician to the service user and/or carer.

#### **Methodology**

The audit is primarily concerned with evidence of clinical practice that can be obtained through patient case notes as it is becoming increasingly important

for clinicians to document all aspects of their practice in order to provide a written record which verifies the quality of treatment an individual has received. The audit has been restricted to individuals targeted by the guideline, namely adults (over the age of eighteen) with a learning disability for whom a new referral (within the past 3 years) has been made to a consultant psychiatrist learning disability team whereby medication has been prescribed for the management of a behaviour problem. The case notes may be from both outpatient and inpatient clinics. The identification of case notes for inclusion in the audit will often require investigation into the actual clinic notes for relevant dates of referral, current treatment, and current diagnoses to assess whether they fall within the constraints of the audit population.

#### **Data Collection**

The data is to be gathered from careful inspection of case notes for individuals attending a specialist psychiatric learning disability clinic including existing inpatients. One questionnaire should be completed for each individual's set of notes. The data is to be extracted from the case notes either by a Research Associate of the Neuropsychiatry and Intellectual Disabilities Research Group based at the University of Birmingham (Gemma L. Unwin) or by doctors (Senior House Officers) within the relevant clinical team.

In order to provide some demographic data concerning each of the cases audited, the individual's identification number, date of birth, gender and whether they are an in-patient or out-patient at the time of audit should be recorded on the dotted lines at the top of the questionnaire. In addition, the date of the completion of the questionnaire should also be recorded.

The following notes provide information on how to complete the questions contained within the audit questionnaire. The question numbers refer directly to those on the questionnaire and the details following relate specifically to that question. The general information refers to all questions.

#### **General: All Questions**

Information regarding each question may be located anywhere within the clinic case notes for each individual unless stated otherwise. Therefore, the information may be recorded in case notes written during a consultation, clinic letters, referral letters, investigations, Health Action Plans or any other document within the notes.

Where information cannot be found within the case notes regarding a question, the box titled 'Not Recorded' should be marked. Furthermore, where additional details are requested, they should be recorded in the text box immediately after the corresponding question. It is important that these details reflect those held within the case notes and are not inferred by the auditor.

Where details of other parties or professionals are requested in the questionnaire, they should not include any information alluding to the identity

of that individual such as name and should only reflect their professional category.

Any additional information or comments regarding any of the questions may be recorded in the large text box at the end of the questionnaire; if possible, the relevant question number should also be recorded.

#### Question 1

Where there is evidence within the notes of any assessment of behaviour such as details of the individual's normal and problematic behaviour, the 'Yes' box should be marked. This information may originate from an oral discussion between the clinician, service user and/ or carer or from more formal assessments such as clinical observations or the use of rating scales. However, the behaviour must have been assessed within the clinic, therefore information of assessment of behaviour must be held within the clinic notes or clinic letters and not in the referral letters.

#### Question 2

Where there is evidence of the assessment of any one of the four areas (B, M, P, S), the 'Yes' box should be marked and the relevant areas that have been assessed circled. Any additional information regarding the assessments may be noted in the box following the question. Where the case notes do not indicate that any of the four areas have been investigated, the 'Not Recorded' box should be marked. These four areas of investigation have been defined by the guideline to provide a structure to the assessment of an individual. It is unlikely that a clinician has made specific reference to each of these areas therefore any evidence of an assessment broadly covering any of these four areas would imply a 'Yes' response. However, these assessments must be carried out before treatment initiation or medication prescription.

The four areas should be viewed as follows:

Behaviour (B): Under this heading it is expected that an assessment of the individual's problematic behaviour in relation to the type, frequency and severity of the behaviour along with the impact of the behaviour on the individual and others should be noted.

Medical (M): Under this heading it is expected that an assessment of any comorbid medical condition, such as epilepsy or dementia and effects of medication etc. on the target behaviour should be noted.

Psychological (P): Under this heading it is expected that an assessment of any psychiatric disorder or psychological symptoms that may have an impact on behaviour should be noted.

Social (S): Under this heading it is expected that an assessment of the individual's social circumstances, including day activities, inter-personal relationships and accommodation situations and their relevant impact on behaviour should be noted.

#### **Question 3**

Where there is evidence of a consideration of a non-medication based intervention or a non-medication based intervention has been implemented, mark the 'Yes' box. Where there is no mention of non-medication based intervention within the case notes, mark the 'Not Recorded' box. Where a

service user has been referred to social services or day care, this can be noted by the question or in the text box following question 4.

#### **Question 4**

Where there are details of a non-medication based intervention being implemented, mark the 'Yes' box and record any details regarding the treatment in the text box, details of implementation may include confirmation of such treatment being executed or a referral letter requesting such treatment. Where it is specified that non-medication based treatment has not been implemented, the 'No' box should be marked and any available reason such as service user/ carer choice, non-availability of non-drug treatment or evidence of lack of effectiveness noted in the text box following the question. Where there is no mention of non-medication based treatments, the 'Not Recorded' box should be marked.

#### **Question 5**

Where there is a record of a written treatment plan being handed over to the service user and/ or carer, the 'Yes' box should be marked, if there is no record, the 'Not Recorded' box should be marked. The written treatment plan may be short term (up to one month) or long term (one month to a year). This treatment plan may form part of the service user's Health Action Plan, a copy of which should be kept within the case notes and a copy handed to the service user and/ or carer, or may be a copy of the clinic letter handed to the service user and/ or carer.

#### **Question 6**

Where there is a record of the service user and/ or carer being provided with a written document about the adverse effects of treatment, the 'Yes' box should be marked and relevant details of the nature of the document and any other additional information should be entered into the text box after the question. If there is no mention of such document, the 'Not Recorded' box should be marked. The written document may be a standard drug company produced information leaflet or a similar information leaflet for service users, perhaps specifically designed for those with a learning disability.

#### Question 7

Record the names of any psychotropic medications previously prescribed to the service user before the first assessment within the present clinic (those that were prescribed before referral). In addition, the daily dosages should also be recorded. Where this information is not recorded, the 'Not Recorded' box should be marked. Psychotropic medication may include antipsychotics, antidepressants, mood stabilisers or anti-epileptic drugs etc.

#### **Question 8**

Record the names and daily dosages of all the psychotropic medications prescribed to the service user at the initial/ first assessment at the present clinic. Where no details regarding medications are evident, mark the 'Not Recorded' box.

#### **Question 9**

List any physical examinations or investigations that were carried out before the prescribing of any new psychotropic medication. Such investigations may include blood tests, brain scans, ECG, EEG or psychological evaluations. These investigations must have been carried out, not only requested. Where no investigations have been made, leave the box blank or insert the word 'none'.

#### Question 10

The capacity issues refer to whether the service user has undergone some assessment of their capacity to give informed consent to any treatment or intervention. It is presumed that all individuals have such capacity until evidence to the contrary is indicated. Where some consideration has been made towards the assessment of capacity, with verification in the case notes, the 'Yes' box should be marked and any additional information entered into the following text box. Where the case notes demonstrate no such assessment, the 'Not Recorded' box should be marked. It is not required that evidence of a detailed assessment be present in the notes, rather some mention of the service user's capacity including a subjective assessment prior to the initiation of medication treatment is expected to imply a 'Yes' response.

#### **Question 11a**

Where there is evidence within the case notes, indicating that consent to treatment has been sought and secured by the clinician from the service user, the 'Yes' box should be marked. This reference may be brief but must be explicit, stating that consent has been gained. Where it is noted that consent was sought from the service user but not secured, the 'Consent Sought, Not Secured' box should be marked and where consent was sought but the individual was deemed to lack the capacity to provide consent, the 'Not Applicable' box should be marked. In cases where there is no mention of such consent acquisition, the 'Not Recorded' box should be marked.

#### **Question 11b**

Where there is evidence within the case notes, indicating that the service user was deemed to lack the capacity to provide informed consent to treatment, therefore assent was secured from the carer, the 'Yes' box should be marked. This reference may be brief but must be explicit, stating that assent has been gained. Where it is noted that assent was sought from the carer but could not be obtained, the 'Assent Sought, Not Secured' box should be marked and where the service user was deemed capable of providing consent (having responded 'Yes' to question 11a) the 'Not Applicable' box should be marked. In cases where there is no mention of such assent acquisition, the 'Not Recorded' box should be marked.

#### **Question 12**

Where the service user has been deemed capable of providing informed consent, the 'Not Applicable' box should be marked. However, where the service user has been assessed as lacking this capacity, there should be reference made within the case notes to consideration of the Capacity Act for the 'Yes' box to be marked. If there is no such record, the 'Not Recorded' box

should be marked. The Capacity Act refers to the 'best interests' principle where treatment may be initiated without the service user's informed consent by an agreement between the carer and other health professionals involved that the suggested treatment is in the best interests of the service user.

#### **Question 13**

Where the service user has been deemed capable of providing informed consent, the 'Not Applicable' box should be marked, similarly, where the individual has not been sectioned and does not come within the remit of the Mental Health Act, the 'Not Applicable' box should be marked. Where a service user has been sectioned, there should be proper documentation within the notes regarding this, including a specific form for the application of the Mental Health Act. If this is present, the 'Yes' box may be marked, however if there is no such record, the 'Not Recorded' box should be marked.

#### **Question 14**

Where the treatment plan including medication prescribed, dosage, treatment duration, follow-up time/date and mechanism for assessment of outcome and adverse events is included in the service user's Care Plan, Health Action Plan or Care Programme Approach (a copy of which should be included in the case notes and a copy handed to the service user and/ or carer) mark the 'Yes' box. This may include a mention in the case notes that treatment is part of a broader care plan. In the absence of that, mark the 'No' box. Where there is no such document within the notes, mark the 'Not Recorded' box.

#### **Question 15**

The rationale refers to the reasons for the treatment. These reasons must be comprehensive enough to account for the decision to medicate the individual and should include any indication of the possibility of an underlying psychiatric disorder or anxiety which may be causing or precipitating the behaviour or the need to calm the service user down in order to implement a psychological therapy or behaviour management programme. This information is likely to be located within the case notes at the time of prescription, if this is evident, the 'Yes' box should be marked and details of the rationale should be recorded in the text box following the question. If there is no rationale present within the notes, the 'Not Recorded' box should be marked.

#### Question 16

A differential diagnosis should consider psychiatric disorders or medical conditions manifesting some of the behaviours evident in an individual but should distinguish a disease or condition from others presenting similar symptoms. Where there are comments alluding to this in the notes, the 'Yes' box should be marked, however where this is not present in the notes, the 'Not Recorded' box should be marked. Where the assessment in question 2 has covered all four areas (B, M, P, S) it can be assumed that a differential diagnosis has been completed.

#### **Question 17**

Where a risk assessment has been documented as carried out, with or without details of the outcome of the risk assessment, the 'Yes' box should be

marked. If there is no such mention of a risk assessment being carried out, the 'Not Recorded' box should be marked. A risk assessment may not necessarily be a formal assessment but may include a mention of risks to be considered, for example an instruction to observe the service user whilst swimming or cooking. In addition, where advice has been given regarding any possible risks, it can be assumed that a risk assessment has been completed.

#### **Question 18**

The target behaviour refers to the behaviour problem for which the medication is prescribed. If the target behaviour has been defined, the 'Yes' box should be marked and details of the target behaviour entered in the following text box. Where no target behaviour has been expressed, the 'Not Recorded' box should be marked in response.

#### **Question 19**

Where the use of an objective outcome measure has been documented, the 'Yes' box should be marked. Where there is no record of an objective outcome measure, the 'Not Recorded' box should be marked. Objective outcome measures refers to the use of standardised tools or observations (for example noting the severity and frequency of the target behaviour at baseline and follow-up) rather than relying on subjective self or carer reports to assess intervention effects.

#### Question 20

Where a review date has been set at the time of the last appointment, the 'Yes' box should be marked. In addition, the time until review should be calculated (number of weeks or months from the last clinic visit to date set for review). Furthermore, where there is no date set up for review in light of the individual being discharged, the 'No, Patient Discharged' box should be marked and where there is no evidence of consideration in the notes of a review date, the 'Not Recorded' box should be marked.

#### **Question 21**

A key person who is identified to implement the treatment plan is likely to be the individual's immediate carer, often from within the service user's residential home. Where a key person has been identified, the details of whom that person is such as their profession, relationship to the individual and capacity as implementer should be noted in the text box following the question. This reference may be implicit. Where there is no confirmation of a key person being identified, the 'Not Recorded' box should be marked. Where a key person could not be identified, the 'No' box should be marked and any available reason detailed in the text box.

#### **Question 22**

Where a key person has not been identified in the preceding question, the 'Not Applicable' box should be marked. Where a key person has been identified but there is no record of information being passed on to that individual, the 'Not Recorded' box should be marked. Relevant information denotes information including medication prescribed, dosage, how the medication is to be administered and follow-up time/date. This information

may be contained within the clinic letters. Where there is evidence of this, the 'Yes' box should be marked in response.

#### **Question 23**

The treatment plan must include medication prescribed, dosage, treatment duration, follow-up time/date and mechanism for assessment of outcome and adverse events. This must have been communicated to the individual's General Practitioner (GP) and all other relevant professionals. This will be dependant on the individual case being audited, for example where the service user is an inpatient, the treatment plan must also have been communicated to carers based within the inpatient ward. If a clinic letter is copied to a GP, a community nurse or a clinical psychologist, mark the 'Yes' box. Thus, where there is evidence that the treatment plan has been communicated to relevant professionals, the 'Yes' box should be marked and details of the professional capacity of those communicated to should be noted in the following text box. Where there is no record of such communication, the 'Not Recorded' box should be marked.

#### **Data Handling**

The data collected throughout this audit is of a highly sensitive nature and therefore must be kept confidential. In addition, the audit questionnaires must be anonymous with each case being assigned an identification number which relates to a separate information sheet whereby details such as name, patient number, health centre name and consultant team can be recorded. This information must be kept secure and separate from the audit questionnaires and is required in case additional information regarding a specific case is needed.

#### **Data Analysis**

The analysis of the data requires the calculation of the proportion of the cases relevant to each of the outcome measures for each question. This will provide details of the quantity of cases that have provided evidence regarding the audit criteria and therefore demonstrating the current practice in terms of adherence to the guideline.

Furthermore, a qualitative analysis of the data will be executed from the text boxes on the questionnaire in order to provide more specific information on current clinical practice surrounding the treatment of behaviour problems within an adult population with a learning disability.

#### References

- 1. NHS Health Scotland (2004). Health Needs Assessment Report: People with learning disabilities in Scotland, www.healthscotland.com.
- 2. Deb, S. & Fraser, W. (1994). The use of psychotropic medication in people with learning disability: towards rational prescribing. *Human Psychopharmacology*, 9: 259-272.

- 3. Clarke, D. J., Kelley, S., Thinn, K. & Corbett, J. A. (1990). Psychotropic drugs and mental retardation: 1: Disabilities and the prescription of drugs for behaviour and for epilepsy in three residential settings. Journal of Mental Deficiency Research; 28 (3): 229-233.
- 4. Deb, S., Thomas, M. & Bright, C. (2001). Mental Disorder in adults with intellectual disability. 2: The rate of behaviour disorders among a community-based population aged between 16 and 64 years. Journal of Intellectual Disability Research; 45 (6): 506-514.

# **Appendix 3: Inclusion/ Exclusion Criteria (underline)**

#### **Checklist for Notes for Inclusion:**

- The service user was aged 18 or over when initially referred to the present specialist learning disability psychiatric service.
- The service user has a learning disability, intellectual disability, or is defined as mentally retarded.
- The service user has received medication to manage a behaviour problem.
- The service user was referred to the present clinic within the last three years from the completion of the questionnaire.

If all above points apply, include the case notes in the audit.

#### **Checklist for Notes for Exclusion:**

- The service user was aged under 18 years when initially referred to the present service.
- The service user does not have a learning disability.
- The service user has not received medication to mange a behaviour problem.
- The service user was referred to the present service over three years from the date of completion of the questionnaire.
- The service user was prescribed medication to manage the symptoms of epilepsy, brain injury, substance addiction or a major psychiatric disorder.

If any of the above points apply, exclude the case notes from the audit.