

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

Supported by



UNIVERSITY OF
BIRMINGHAM



The Royal College of Psychiatrists
Let Wisdom Guide

MENCAP
Understanding learning disability

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

Technical Document Section 2: The Recommendations

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

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

Acknowledgments: Thanks to the Guideline Development Group Members - David Clarke, Caron Thomas, David Branford, Miriam Wilcher, Ashok Roy, Linda Woodcock, Ray Smart, Caroline Lee, Sabyasachi Bhaumik, Rob Chaplin & Florence Simon.

www.LD-Medication.bham.ac.uk

November 2006

Supported by



UNIVERSITY OF
BIRMINGHAM



The Royal College of Psychiatrists
Let Wisdom Guide

MENCAP
Understanding learning disability

INTRODUCTION	4
HOW TO IMPLEMENT THIS GUIDANCE	5
GENERAL PRINCIPLES	7
MAIN RECOMMENDATIONS	10
SCHEMA FOR PRESCRIBING	12
GRADING OF RECOMMENDATIONS	13
INITIATION OF TREATMENT^{GPP}	14
ASSESSMENT AND FORMULATION	14
THE MEDICATION TREATMENT PLAN	15
GENERAL RECOMMENDATIONS	17
MONITORING OF TREATMENT^{GPP}	21
ADMINISTRATION OF MEDICATION	21
DISCONTINUATION OF TREATMENT^{GPP}	24
HIGH-DOSE MEDICATION^{GPP}	28
POLY-PRESCRIBING^{GPP}	30
INTRA-MUSCULAR (IM) MEDICATION^{GPP}	32
RAPID TRANQUILLISATION^{GPP}	33
AS REQUIRED (PRN) PRESCRIBING^{GPP}	35
COMMUNICATION AND INFORMATION SHARING^{GPP}	37
INTERDISCIPLINARY WORKING^{GPP}	38
CONSENT AND CAPACITY^{GPP}	39
THE REFERRAL PATHWAY^{GPP}	41
REFERENCES	42
APPENDIX 1: THE ASSESSMENT - BULLET POINTED VERSION	44
APPENDIX 2: THE ASSESSMENT - ADDITIONAL INFORMATION	47
APPENDIX 3: POSSIBLE AUDIT QUESTIONS	56
APPENDIX 4: SAMPLE CLINIC LETTER COVERING THE AUDIT POINTS DISCUSSED IN THIS SECTION	58
APPENDIX 5: SAMPLE CARE PLAN PROFORMA	61
APPENDIX 6: RECOMMENDED INVESTIGATIONS AND MONITORING	62
ANTIPSYCHOTICS	62
MOOD STABILISERS AND ANTIEPILEPTICS	64
APPENDIX 7: GLOSSARY	67

Introduction

This guide has been produced to provide advice to people who are considering prescribing medication to manage behaviour problems among adults with a learning disability. It follows the National Institute for Health and Clinical Excellence's (NICE's) (nice.org.uk) guideline development criteria, and has been assessed using the internationally accepted 'Appraisal of Guidelines for Research and Evaluation' (AGREE, 2001) criteria for guideline development.

This guidance represents the view of the Guideline Development Group (GDG). The GDG considered the evidence available and consulted widely before writing this document. The recommendations in this guide reflect the principles laid down in the Valuing People Document (2001). Health professionals are expected to take it into account fully when exercising their clinical judgment. The guide does not, however, override the individual responsibility of health professionals to make decisions appropriate to the circumstances of the individual situation. Such decisions must be taken after careful consideration of all the possible benefits and potential risks involved with the intervention.

This guide does not consider in any detail the indications for choosing specific medication to manage behaviour problems among adults with a learning disability. Rather, it provides recommendations for clinical practice surrounding the use of medication to manage behaviour problems among people aged 18 years and over with a learning disability. All relevant medication and related issues are considered.

This guide should facilitate the care process, and improve the way that behaviour problems are managed. This should lead to a better quality of life for people with a learning disability.

How to implement this guidance

Use appropriate assessment and review methods

Organisations involved in caring for adults with a learning disability for whom medication is either prescribed or considered to manage behaviour problems should train and encourage prescribers and other relevant people to use appropriate assessment and review methods for the management of behaviour problems.

Use accessible information

Organisations should ensure that information about managing behaviour problems, including the indications and adverse effects of any medication prescribed for this purpose, is available in a format that is accessible to adults with a learning disability and their carers.

Document clinical practice

Organisations should ensure that those involved in managing behaviour problems, including those who prescribe medication for this purpose, document clinical practice in an appropriate manner at the right time and in the right place.

Promote effective communication with the prescriber, the person with a learning disability and their carers, and across organisational boundaries

Organisations should encourage communication about managing behaviour problems, including details of any medication prescribed, in an effective and timely way. Such communication should include all the relevant professionals and organisations, as well as the person with a learning disability and their carers.

Work in partnership with and empower the person with a learning disability and their carers

Organisations should encourage relevant personnel to work in partnership with adults with a learning disability and their carers, allowing them to influence decisions about interventions to manage behaviour problems, including the prescribing of medication.

Develop policies to support the implementation of this guidance

NHS and non-NHS organisations that are involved in managing behaviour problems among adults with a learning disability including prescribing medication, should develop policies to implement the recommendations in this document.

Carry out an audit of guideline recommendations

Organisations should create mechanisms to monitor and audit the implementation of these recommendations regularly. If necessary, they should take remedial action.

Provide training and support to implement this guidance

Organisations should provide training and support to those involved in implementing this guidance.

Training and information sharing about the current evidence at regular intervals

Organisations should have mechanisms for sharing information among the relevant people on a regular basis. Such information should include evidence of the efficacy and effectiveness of different interventions for managing behaviour problems in adults with a learning disability. Where necessary, the organisations should provide training for the relevant personnel to enable them to access timely information about the evidence.

Ensure effective dissemination of the guidance to the relevant stakeholders

Organisations should effectively disseminate information about this guidance to all relevant people and organisations, including local groups of carers and people with a learning disability.

General principles

Assessment and formulation

The primary aim should be not to treat the behaviour but to find out the underlying cause of the behaviour and manage that. However, it is not always possible to find a cause for the behaviour problem. When this is the case, the management strategy should be to minimise the impact of the behaviour on the person, the environment around them and other people.

There may be many reasons for behaviour problems, including physical or mental health problems. Many factors internal to the person – such as negative childhood experiences, maladaptive coping strategy etc – and external to the person – such as understimulating or overstimulating environment etc – may contribute to behaviour problems. Therefore, a thorough assessment of the causes of behaviour and their consequences, along with a formulation, is an absolute prerequisite in managing any behaviour problem (see Appendices 1 and 2). A proper assessment and formulation will often need input from several disciplines and from families and carers. A multi-axial/ multilayered diagnostic formulation, such as the one indicated in the DC-LD from the Royal College of Psychiatrists may be useful in this context. The assessment should include personal, psychological, social, environmental, medical and psychiatric issues. A formulation should be made even in the absence of a medical or psychiatric diagnosis.

For a detailed account of assessments and formulation, it is advised that the following documents are consulted:

- British Psychological Society's (BPS) guideline on the management of challenging behaviour (2004)
- The joint statement produced by the BPS and the Learning Disability Faculty of the Royal College of Psychiatrists (RCPsych) titled 'Challenging behaviour: a unified approach' (2006) (www.rcpsych.ac.uk/college/faculties/learningdisability.aspx).

Input from the person with a learning disability and their families and carers

A proper assessment and formulation will often depend on input from the person with a learning disability and/ or their family and carers. This input should continue at every stage of management. It is important to share information with the person with a learning disability in a way that they can understand. This may require additional time and effort on the part of the prescriber and other members of the multidisciplinary team. It may also involve using innovative methods of information sharing, such as using pictures etc.

Interdisciplinary input

Interdisciplinary input may also be needed during implementation and monitoring of the management options. This may have resource implications and so may not be possible to achieve at the stage of initial formulation. Where relevant, an attempt should be made to secure interdisciplinary input to the process of managing behaviour problems.

When to consider medication

If there is an obvious physical or psychological cause for the behaviour, this should be managed in an appropriate way. If an underlying psychiatric disorder is treated with medication, the current NICE guideline and other appropriate guidelines should be followed.

If no psychiatric disorder can be recognised then non-medication based management should be considered depending on the formulation. Sometimes after considering non-medication based management options, medication may be used either on its own or as an adjunct to non-medication based management.

The exact situation under which medication and/ or non-medication based management strategies should be implemented will depend on individual circumstances, and is therefore not within the remit of this guideline. However, it may be possible to improve the psychological well-being of the person (by providing counselling and improving social and environmental factors, or by finding more enjoyable activities to do during the day) and use medication simultaneously to make the person concerned less anxious. This strategy may be seen as an interim formulation, which then needs to be monitored carefully at regular intervals to assess its effectiveness.

Monitoring the effectiveness of the intervention

Monitoring effectiveness should be carried out at regular intervals. It should include objective assessments with input from the person with a learning disability and/ or their family and carers, and members of other relevant disciplines. Examples of assessments include behavioural monitoring, reports from carers, and direct examination of mental state.

An attempt should be made at each stage of monitoring to revisit and re-evaluate the formulation and the management plan. The aim is to prescribe medication, if necessary, at the lowest possible dose and for the minimum duration. Non-medication based management strategies and the withdrawal of medication should always be considered at regular intervals.

Further advice is available on this matter from the BPS guideline (2004), Joint BPS and RCPsych guideline (2006), and Leicestershire Partnership NHS Trust prescribing guideline (2005).

Prescribing within Person-Centred Planning

Managing behaviours, whether this involves using medication or not, must always take place within person-centred planning. It should be influenced by the person themselves and/ or their carers. The prescribing should take place

within a Care Programme Approach (CPA), Care Plan (CP) or Health Action Plan (HAP). These care pathways should always be considered if the person's care is not already carried out using one of them.

Who should prescribe?

Examples of people who could prescribe psychotropic medication for adults with a learning disability include GPs, psychiatrists, pharmacists, nurses, specialist psychiatrists in learning disabilities and other doctors. This guidance and the general principles it contains apply to everyone who might prescribe. As far as possible, the prescriber should always consider management options within an interdisciplinary forum. Non-specialists should seek specialist advice when necessary.

Communication issues

The management plan should be communicated clearly to the person with a learning disability and/ or their family and carers. All other relevant professionals that are involved in the care of the person should be told about the management plan on a need-to-know basis. This process should be updated at regular intervals. Special care is needed and innovative approaches may be required when information about the management is shared with the person with a learning disability and their family and carers.

Capacity and consent

The assessment of the capacity of the person for whom the medication is prescribed should always be documented, along with all other issues surrounding consent. In the absence of capacity, the best interests principle should be applied and consensus among the multidisciplinary team and the families/ carers should be gathered.

Legal issues

Management options for behaviour problems must comply with the country's legal framework.

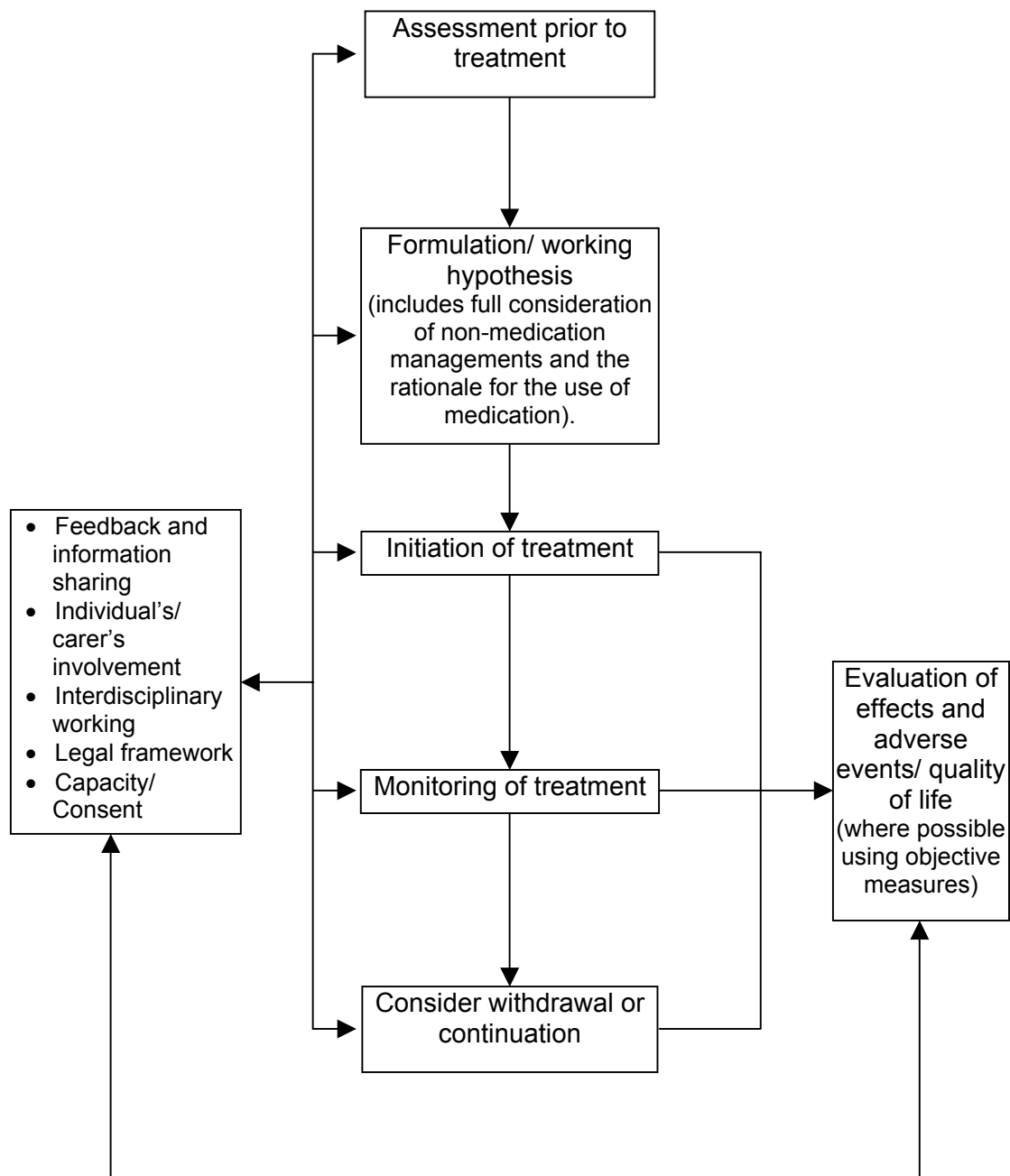
Main recommendations

- The prescriber needs to ensure that an assessment has been conducted and recorded prior to initiating treatment.
- The prescriber should ensure that an appropriate formulation is carried out and a treatment plan drawn up, prior to instigating any interventions.
- The prescriber needs to ensure that appropriate physical examinations and investigations have been carried out.
- The prescriber is responsible for assessing the person's capacity to consent to treatment.
- The prescriber should discuss the formulation and treatment plan with the person and/ or their family or carers.
- The prescriber should allow the person and/ or their family or carers to influence the decisions that are made and included in the treatment plan.
- The prescriber should clarify to the person and/ or their family or carers if the medication is prescribed outside their licensed indication. If this is the case, they should be told about the type and quality of evidence that is available to demonstrate its effectiveness.
- Where possible, and when necessary, the prescriber should discuss the formulation and treatment plan with other relevant professionals.
- The treatment plan should be part of a broader care plan that takes a person-centred approach.
- The treatment plan must comply with the country's legal framework, including the relevant Mental Health Act.
- The formulation and treatment plan should be shared with all the relevant parties, including GPs, as soon as possible.
- The prescriber should identify a key person who will ensure that medication is administered appropriately and communicate all changes to the relevant parties.
- The prescriber should provide the person and/ or their family or carers with a written treatment plan at the time of prescribing. If the prescribing is done over the phone, it should be followed by written confirmation as soon as possible.

- The prescriber should discuss with the person and/ or their family, carer, or key person, common and serious adverse events related to the treatment (where possible, they should provide accessible information in writing). The prescriber should advise what action to take if a serious adverse event takes place.
- The consultation should take into account the communication needs of the person.
- When 'prn'/ 'as required' medication is prescribed, the prescriber is responsible for providing as much information as possible about why and when the medication may be used. The prescriber should monitor this information regularly.
- The method and timing of the assessment of treatment outcome should be set at the beginning of the treatment, along with a follow-up date for review of treatment progress.
- As far as possible, there should be an objective way to assess outcomes (the use of standardised scales is recommended).
- The prescriber should ensure that follow-up assessments have taken place.
- As far as possible, one medication should be prescribed at a time.
- As a general rule, the medication should be used within the BNF recommended range of doses.
- Consideration for withdrawing medication and exploring non-medication management options should be ongoing.
- The prescriber should remember that medication might be used at the same time as non-medication managements.
- The prescriber should document all appropriate information and share it with appropriate individuals when necessary.

Schema for prescribing

Key processes associated with using medication to manage behaviour problems in adults with a learning disability



Grading of recommendations

The grading of recommendations is based on:

- A. Category I Evidence**
Meta-analysis of more than RCT, or at least one RCT.
 - B. Category II Evidence**
At least one controlled study without randomisation, or at least one other type of quasi-experimental study, or extrapolated recommendation from category I evidence.
 - C. Category III Evidence**
Non-experimental descriptive studies, or extrapolated recommendation from category II evidence.
 - D. Category IV Evidence**
Expert committee reports or opinions and/ or clinical experience of respected authorities, or extrapolated from category III evidence and arrived at using formal consensus methods.
- A (NICE)**
Recommendation taken from NICE guideline or health technology appraisal.
- GPP**
Recommended good practice based on the clinical experience of the GDG.

Initiation of treatment ^{GPP}

Assessment and formulation

The guideline recommends that a thorough assessment should be carried out first when an adult with a learning disability presents for the management of reported behaviour problems (see Appendices 1 and 2 for further information on assessments).

The prescriber:

- Needs to ensure that an assessment has been conducted prior to beginning treatment with medication.
- May use a biopsychosocial model of assessment. This may be under the broad headings of assessment of:
 - Behaviour itself
 - The person
 - Medical/ organic conditions
 - Psychological/ psychiatric issues
 - Social/ environmental issues.(See also the British Psychological Society (BPS, 2004) guidelines.)
- Is responsible for assessing the individual's capacity to consent to treatment.
- Should produce a formulation before beginning the treatment.
- Should discuss the outcome of the assessment and formulation with the person involved and/ or their family/ carers.

As a general rule, the formulation should consist of the following:

- A list of the target behaviour(s) to be managed
- A clear description of the behaviour, including frequency and severity
- An assessment of the behaviour(s) and its causes
- A differential diagnosis
- A record of reactions to and outcomes of the behaviour
- An assessment of predisposing, precipitating and perpetuating risk factors
- Consideration of all management options and their outcome
- The rationale for the proposed management option
- A risk assessment
- Possible adverse effects from the proposed intervention(s)
- The likely effect of the proposed intervention(s) on the person's quality of life.

The medication treatment plan

- Once the formulation is carried out and recorded, a **treatment plan** should be drawn up and recorded. A treatment plan can be:
 - **short-term** (usually covering a period of a few days)
 - **medium term** (usually covering a period of few weeks)
 - **long term** (usually covering a period of a few months).
- Arrangements for monitoring outcome and adverse effects should be agreed (including the issue of the person's quality of life and including the method of assessment and time for follow up).
- The outcome should be assessed as objectively as possible (using standardised scales such as MOAS, Sorgi et al, 1991; ABC, Aman et al, 1985, and Positive Goals, Fox & Emerson, 2002, is recommended).
- Objectives and dates for reviews should be set.
- The treatment plan should include the possibility of withdrawing the medication in the future.
- The route of administration, dosage and its titration over a period should be stated clearly.
- The treatment plan should be set in the context of a person-centred care plan (PCP).
- The aim should be to prescribe medication for a minimum period of time necessary and at a minimum effective dose to manage the behaviour problems.
- Where possible, and when necessary, the prescriber should discuss the formulation and treatment plan with other relevant professionals.
- The treatment plan must comply with the country's legal framework, including the Mental Health Act.

The prescriber should also note the following:

- Start new medication at a low dose and gradually increase the dose until there is an improvement in the target behaviour or until any adverse effects are displayed.
- In general, prescribe medication in a dose that does not exceed the BNF recommended maximum (see section on recommendations for the use of high-dose medication).

- During the consultation, remember the communication needs of the person with a learning disability. They may need extra time or additional non-verbal communication to be able to understand.
- Discuss the proposed treatment plan with the person and/ or their carers. Such discussion should include:
 - Information about the potential positive and negative results of using the medication
 - What to do in case of a serious event
 - The outcome of considering managing the behaviours without the use of medication
 - Providing written information in a suitable accessible form as back up.
- If the prescribing is done over the phone, it should be followed by written confirmation as soon as possible.
- Allow the person and/ or their carers to influence the decision-making process that leads to the treatment plan being created.
- Clarify to the person and/ or their carers if the medication is prescribed outside their licensed indication and describe the type and quality of evidence that is available to show its effectiveness.
- Share the formulation and treatment plan with all the relevant parties as soon as possible, including GPs (including any shared care arrangement), day centres etc.
- When 'prn'/ 'as required' medication is prescribed, provide as much information as possible about why and when the medication may be used, and monitor this regularly.
- Ensure that a key person is identified to ensure that the treatment plan is carried through.
- As far as possible, prescribe one medication at a time.
- As far as possible, prescribe the medication at a time of the day that minimises the need for administration in multiple settings (such as day centres).
- Ensure that the appropriate physical examination has been carried out and documented.
- Ensure that the appropriate investigations have been carried out and documented (see South London and Maudsley NHS Trust and Oxleas NHS Trust prescribing guideline, 2005).

Evidence to support prescribing medication in adults with a learning disability and behaviour problems

Primarily, case studies and also some controlled studies have shown that anti-psychotics, antidepressants, mood stabilisers (including lithium and anti-epileptic medication), anti-anxiety medication and beta blockers, opioid antagonists and dietary supplements improve behaviour problems among adults with a learning disability.

However, because of the small number of individuals included in the studies, mixed populations studied, dearth of use of validated outcome measures and the potential for publication bias, no specific recommendation can be made to support prescribing medication in adults with a learning disability and behaviour problems.

The fact that good-quality evidence is sparse does not mean that there is evidence to show that medication is ineffective.

The evidence of effectiveness of non-medication management of behaviour problems is based on case studies, but not on randomised controlled trials (RCTs). The difficulty surrounding conducting RCTs involving adults with a learning disability is well recognised.

In view of the above, the following general recommendations are proposed.

General recommendations

Anyone prescribing medication to manage behaviour problems among adults with a learning disability should follow this good practice:

- Medication should be used only in the best interests of the person
- All non-medication management options should have been considered and medication should be seen as necessary under the circumstances, or alongside non-medication management
- If possible, evidence to show that the medication is cost-effective should be taken into account
- Information about which interventions worked before and which did not should be noted
- If previously, interventions produced unacceptable adverse effects, the details should be noted
- The effect of availability or non-availability of certain services and therapies on the treatment plan should be considered
- Relevant local and national protocols and guidelines should be followed.

Evidence of the risks associated with prescribing medication in adults with a learning disability and behaviour problems

Most medications carry a potential risk associated with adverse events. However, the evidence is largely gathered from studies among non-learning disabled psychotic patients. For example, current evidence shows that atypical antipsychotics carry a certain amount of risk associated with adverse effects relating to weight gain, cardiac abnormalities, and various metabolic abnormalities, including impaired glucose tolerance.

There is no good-quality evidence to either support or refute concerns that people with a learning disability may be at greater risk of the adverse effects of medication than people from the general population.

The shortage of good-quality evidence does not mean that medication is associated with an unacceptable risk specifically for adults with a learning disability.

In view of the above, the following general recommendations are proposed.

Adverse events

- It is recommended that advice about serious and important adverse events is made available to the person and their carer at the time of prescribing, or as soon as possible afterwards.
- This advice should include details of the severity of any potential adverse events, as well as the frequency with which they may occur.
- Information leaflets about adverse medication events should be made available.
- The person concerned, and their carer, should be talked through the adverse events in addition to being given a pamphlet to take away.
- All adverse events should be recorded properly.
- Appropriate physical examinations and investigations should be carried out at regular intervals (see South London and Maudsley NHS Trust and Oxleas NHS Trust Prescribing Guideline, 2005 for a list of physical examinations and investigations).

Evidence for the choice of medication

There is evidence from good-quality RCTs to show that risperidone is effective in improving behaviour problems among adults and children with a learning disability with or without autism. However, most RCTs have shown that using this medication can result in a high rate of adverse effects such as weight gain and somnolence.

The evidence from case studies and small trials that focus on the treatment of particular behaviour problems is inconclusive. However, studies directly comparing the use of different medication to manage specific behaviour problems are absent. Therefore, it is not possible to recommend any specific medication for any specific behaviour problem.

Guidelines based on clinical scenarios are available (see Leicestershire Partnership NHS Trust Guideline, 2005 and South London and Maudsley NHS Trust and Oxleas NHS Trust Prescribing Guideline, 2005). However, these are not evidence-based.

We have carried out a questionnaire-based consensus exercise (see section 4); the findings demonstrate how the expert panel (members of the Learning Disability Faculty of the Royal College of Psychiatrists, UK) ranked a number of intervention options to manage aggression and SIB in order to achieve a consensus order of preference. The findings are summarised below. However, these findings have to be interpreted with caution because the response rate was slightly below 40% and the clinicians were given forced choices. In real situations, they would decide on medication depending on individual clinical circumstances. Also, the current preferences may change in the future when more information becomes available about the efficacy and adverse effect of individual medications, and as new medications arrive on the market.

- Most clinicians (96%) preferred non-medication based management as the first choice and medication was the second choice for managing behaviour problems.
- Clinicians preferred anti-psychotic medication as their first choice, followed by either antidepressants or mood stabilisers depending on whether they were treating aggression or SIB.
- Among antipsychotics, clinicians preferred atypicals to typicals.
- Among antidepressants, clinicians preferred newer generations, such as Selective Serotonin Reuptake Inhibitors (SSRIs) rather than older medication, such as the tricyclics.
- Among atypical antipsychotics, risperidone was the first choice, followed by olanzapine and quetiapine.
- Among antidepressants, citalopram, fluoxetine and sertraline were the preferred choices.
- Among mood stabilisers, carbamazepine, sodium valproate and lithium were the preferred choices.

- Clinicians preferred to prescribe antipsychotics, particularly risperidone, in lower doses than is recommended in the BNF for the treatment of schizophrenia.
- Below are some of the situations under which the clinicians would consider using medications:
 - failure of non-medication based interventions
 - risk/ evidence of harm/ distress to self
 - risk/ evidence of harm/ distress to others or property
 - high frequency/ severity of behaviour problem
 - to treat an underlying mental/ psychiatric disorder or anxiety
 - to calm the person to enable implementation of non-medication based interventions
 - risk of breakdown to the person's placement
 - lack of adequate or available non-medication based interventions
 - good previous response to medication
 - person/ carer choice

Monitoring of treatment^{GPP}

- The requirements for monitoring the treatment should be planned by the prescriber when the treatment begins.
- These details should be recorded in the treatment plan.
- This information should be communicated to all relevant parties.
- The frequency of follow-up should be determined on an individual basis.
- At each visit, an assessment of behaviour should be conducted and documented.
- Treatment effects should be monitored objectively (the use of a rating scales such as MOAS, ABC, and Positive Goals is encouraged).
- Adverse events should be monitored as objectively as possible.
- The quality of life of the person and their carers should be monitored.
- The follow-up should also include a review of the initial assessment, formulation and treatment plan.
- The updated treatment plan should be incorporated within the individual's overall care plan.
- The updated treatment plan should be discussed and agreed with the individual and / or their family or carers.
- The individual's capacity to give consent should be re-assessed.
- At each follow up, non-medication management should always be considered, either as an alternative or an adjunct.
- At each follow-up, withdrawal of medication should always be considered.
- Multi-disciplinary involvement in follow-ups is encouraged.
- All relevant parties need to be kept informed about the updated treatment recommendation, the follow-up arrangements and their outcome.

Administration of medication

All necessary support and monitoring should be provided for those who prefer to self-medicate (e.g. provide with pre-prepared medication dispensing boxes,

etc.). For those who prefer not to self-medicate, the prescriber should identify a key person who will administer the medication and communicate all changes to the relevant parties.

Good practice involving the identified key person responsible for administering medication:

- This person should ensure that they understand why the medication is being used, the common and serious adverse effects associated with the medication, and the necessary actions required under those circumstances.
- This person should ensure that the medication is administered according to available guidelines (see Association for Real Change, ARC, 2005).
- This person should ensure that all relevant people associated with the administration of medication are informed about the treatment.
- This person should ensure that they communicate all the relevant information to the prescriber.

Many people with a learning disability are cared for by people who have had limited training in medication management. The Association for Real Change (ARC) recently produced a guideline and training framework on the management of medication in learning disability services (www.arcuk.org.uk). The guideline highlights the need for standardised training for people who are involved in administering medication to people with a learning disability.

The training package emphasises the need to check the following:

The right person

That the treatment is provided to the right person and that the issues relating to informed consent and capacity for consent are rightly addressed.

The right medication

People administering the medication should have basic knowledge of the purpose of the medication, medication group, common and serious adverse effects and the action necessary to deal with them, and of any contra-indication for not using the medication for the particular person.

The right time

People administering the medication should check that the medication is administered at the correct time of the day, in relation to meal times. The sequence for giving several medications should always be appropriate.

The right dose

The right dose of medication must always be administered. If in doubt, people should always check the instruction given by the prescriber or check with another staff member or the BNF. Communication with the prescriber is very important, particularly if any changes to dosage have been made. All those involved in administering medication should be up-to-date with any recent

changes in the dose. Recent loss or gain in weight, possible allergies and the correct measurement for liquid formula should always be taken into account.

The right method

People should be absolutely sure about the route of administration of medication, and of any changes in the instruction for that before administering it. People should have the right training before administering any medication (for example, administration of rectal diazepam or buccal midazolam).

The right procedure

People should ensure that they have the right level of competence to administer medication. They should always ensure that the correct and safe instruments are used. The right person should be monitored after taking the medication to ensure that they do not spit it out or develop any adverse effects.

The right record keeping

All records should be kept in line with policy, regulations and best practice. The records should be legible and written in an understandable way. The records should be kept confidential and up-to-date, and monitored regularly.

Discontinuation of treatment^{GPP}

- Once a medication is prescribed, the prescriber should continue to evaluate the risk-benefit profile regularly, with particular emphasis on the individual's and their family or carers' quality of life.
- Consideration of a reduction in the dose or withdrawing the medication and exploring non-medication management options should be ongoing.

In instances where the behaviour improves:

- The prescriber should consider withdrawing medication. However, the decision about when to withdraw as well as the rate and timing of withdrawal should be based on individual circumstances and the purpose of the medication. For longer-term treatments, withdrawal should be considered within 6-12 months.
- The rate of withdrawal will depend on the type of medication used, the severity of the behaviour, the availability of non-medication management options, and previous response to withdrawal.
- The decision to withdraw medication should only be made after discussion with the person and/ or their family or carers, and when necessary with other relevant professionals.
- In the case of a difference of opinion, a multi-disciplinary meeting should be organised, bearing in mind the best interests of the individual.
- The withdrawal of medication should be undertaken in a planned and systematic manner, and a contingency plan (relapse plan) should be in place to intervene should a crisis arise (see flow chart on page 52).

In instances where the behaviour partially improves or does not improve, the prescriber:

- Should review the initial formulation and rationale for using the medication.
- Should check that the medication is used at an adequate dosage and for an adequate duration.
- Should check that either the individual with a learning disability or their carer has complied with the instructions.
- Should check carer expectations.
- Should check for tolerability and adverse effects.

- Should assess the impact of other interventions.
- Should consider whether there is a need to increase the dose of the existing medication to the clinically effective maximum dose without causing adverse effects.
- Should also check for any potential medication interactions.
- May consider another medication from the same or a different BNF category or add-on medication in these circumstances (see the section on poly-prescribing).
- Should follow the best method of crossover to the new medication (see South London and Maudsley NHS Trust and Oxleas NHS Trust Prescribing Guideline, 2005).
- Should assess whether the medication is still indicated.
- Should consider planned withdrawal if the medication is no longer indicated.

In instances where the behaviour deteriorates:

- The prescriber should assess the possible reasons for deterioration in the behaviour, including adverse effects of the medication.
- If this deterioration is caused by the medication, the prescriber should withdraw the medication as detailed in the above paragraph.

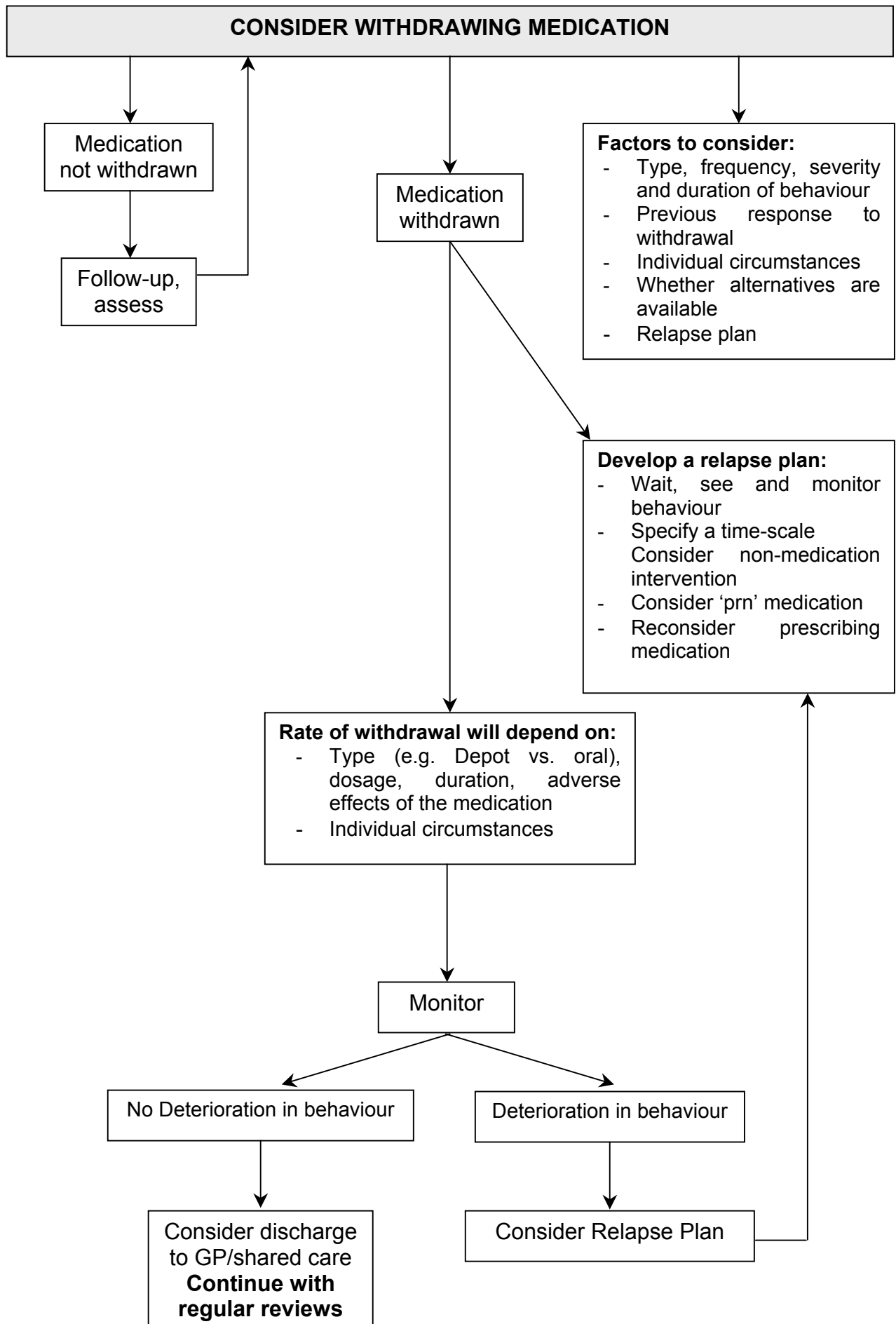
In instances where the behaviour remains stable after reducing the dose or withdrawing medication:

- The prescriber should regularly monitor the individual's behaviour using the flow chart on page 52 and consider when to discharge them to their GP (if the prescriber is not their GP).
- The appropriate time to discharge to the GP will depend on individual circumstances, but a period of 12-18 months of stable behaviour seems reasonable in this context.
- However, the GP should keep monitoring the situation at regular intervals and, if necessary, should consider re-referring to the secondary or tertiary service.

In instances where the behaviour re-emerges after reducing the dose or withdrawing the medication:

- The prescriber should have in place a relapse plan when considering medication withdrawal (see flow chart on page 52).

- The prescriber should be aware of the withdrawal effect of certain medication and allow adequate time for that to settle before reconsidering the use of medication.
- The prescriber should always consider non-medication based interventions and re-assess the initial formulation and rationale for using the medication.



High-dose medication^{GPP}

High-dose medication, in this context, refers to the prescribing of medications at a dose higher than the maximum dose recommended in the BNF.

(Also consider the College Report by the Royal College of Psychiatrists with regard to the use of 'high dose antipsychotic medication'; www.rcpsych.ac.uk.)

- High-dose prescribing should be used only under exceptional circumstances.
- It should be discussed fully with the person and/ or their family or carers and used with their agreement.
- It should be used with full discussion and agreement with the relevant multi-disciplinary team.
- If the individual's and/ or their family or carers' agreement cannot be guaranteed, a second opinion must be sought.
- The differential diagnoses should be reviewed and psychosocial and other risk factors should be considered.
- Alternative non-medication management strategies must be explored and, if available, instigated.
- Alternative medication management strategies, including augmentation with poly-prescribing, should be considered.
- Contra-indications for high doses of medication such as obesity, smoking, heavy alcohol use, cardiac problems, diabetes etc. should be considered.
- The dose should be increased as slowly as possible and both desired and adverse effects should be monitored carefully and at regular intervals.
- This should be instigated by a specialist who has experience of prescribing medication at a dose higher than the maximum recommended dose in the BNF.
- Although above the recommended maximum dose, the dose should be as low as possible.
- A full rationale for using a high dose should be documented.
- It should be reviewed at the earliest opportunity and regularly thereafter.

- Attempts should be made to bring down the dose to within the BNF recommended range as soon as possible.
- The evidence for the effectiveness of high dose medication should be sought and, if available, documented in the notes.
- Appropriate investigation, such as ECG and blood tests, should be carried out before the start of treatment and at appropriate intervals.
- Organisations should regularly audit treatment regimes that involve the use of high dose medication.

Poly-prescribing^{GPP}

It is common for people with a learning disability to take medication for a wide variety of disorders and illnesses. However, the term poly-prescribing in this document is used to describe the prescribing of more than one medication for a particular indication, in this case behaviour problems.

Evidence to support poly-prescribing

There is a lack of studies of combinations of psychotropic medications to manage behaviour problems among adults with a learning disability. Therefore, it is not possible to recommend any combination of medication as enhancing the efficacy of medications prescribed on their own. However, the evidence based on observational studies suggests that the reduction in poly-prescribing not only improves behaviour but also the quality of life of the person for whom medication is prescribed.

In the light of this, the following is recommended.

If an add-on medication is indicated:

- The rationale for using an add-on medication must be recorded.
- The decision to use an add-on medication must be taken after full discussion, and with the consent, if appropriate, of the person, their family or carers and other relevant professionals.
- This should be instigated by a specialist who has experience of prescribing add-on medication to manage behaviour.
- The add-on medication must be used in the best interests of the person and introduced slowly.
- The effectiveness and adverse effects should be monitored in the same way as the first medication.
- If the add-on medication is ineffective, reassess the situation.
- If the first medication is to be continued, the reasons for continuing to use more than one medication simultaneously for the same indication must be recorded.
- The use of an add-on medication from the same BNF category is not recommended (the exception is antiepileptic medications for the treatment of epilepsy).

- If the combination is effective, try to withdraw or at least reduce the dose of one of the medications at a future date.
- Always consider the option of either a non-medication intervention or using such an intervention in combination with the medication.
- Try to return to monotherapy as soon as possible.

If more than two medications need to be used simultaneously:

- Avoid using more than two medications simultaneously for the same indication.
- More than two medications should only be used under exceptional circumstances.
- Try to secure another clinician's opinion if more than two medications are to be used simultaneously.
- All the steps mentioned in the above paragraph for using more than one medication must be followed.
- The use of more than three medications simultaneously is difficult to justify unless they are used for other indications, such as simultaneous epilepsy or psychiatric disorder.

Evidence to support the withdrawal of medication in the person who is on more than one medication for a long period of time

Studies of withdrawing medication show that, in a proportion of cases, the medication can be successfully withdrawn after a long period of use. In a proportion of cases, the dose can be reduced, although total withdrawal is not possible, and in some cases, it is difficult to even reduce the dose of medication after a long period of use. Many factors affect the success of withdrawal of medication, including non-medical factors such as the training and the attitude of care staff. However, based on such evidence it is not possible to recommend which medication to withdraw and how, but the following general recommendations are proposed.

The person on one or more medication for a period to manage behaviour problems:

- Try to stabilise the person's behaviour on a minimum number of medications prescribed at the lowest possible dose, or no medication.
- Follow the recommendations given in the 'Discontinuation of treatment' section of this guide.
- Withdraw one medication at a time.

- Withdraw medication slowly.
- If necessary, allow time (sometimes a few weeks) after withdrawing one medication and before starting to withdraw another.

Intra-muscular (IM) medication^{GPP}

- All medication should be given orally unless there are special circumstances that mean this is not possible, or this is contra-indicated.
- Depot or long-acting injections can be used if non-compliance is an issue.
- Consider Depot injections if the person with a learning disability and/ or their family or carer chooses this approach.

Rapid tranquillisation^{GPP}

Evidence to support using rapid tranquillisation

The evidence from RCTs conducted on the general population shows that IM benzodiazepines, such as lorazepam 1-2 mgs, and anti-psychotics, such as haloperidol 5-10 mgs, are as effective as a rapid tranquilliser either used individually or as a combination. Some studies have shown that combining a benzodiazepine such as lorazepam with an antipsychotic such as haloperidol achieves a marginally better result than using each medication alone. However, other studies have suggested that the reverse is the case.

However, there is no specific data relating to people with a learning disability. There is no evidence from RCTs to show that rapid tranquillisation is more or less appropriate or risky when used in the short term to manage aggressive or violent behaviours of people with a learning disability than for people without a learning disability.

Therefore, the recommendations made in the NICE guideline on the management of imminent violence in psychiatric settings (2005) are appropriate for people with a learning disability. They are summarised here.

(Please note that rapid tranquillisation is only required in this form in a minority of situations involving adults with a learning disability, particularly within a hospital setting.)

- The aim of rapid tranquillisation is to achieve a state of calm sufficient to minimise the risk posed to the service user or to others.
- Try to predict a violent episode by using 'risk assessment', by considering appropriate 'risk factors', and looking for 'antecedents and warning signs'.
- Try to avoid a violent episode by using appropriate preventative strategies such as 'de-escalation' and appropriate 'observations'.
- Rapid tranquillisation, physical intervention and seclusion are management strategies and are not regarded as primary treatment techniques. Rapid tranquillisation should only be used once de-escalation and other strategies to control the violent episode have failed.
- Clinical need, the safety of service users and others and, where possible, advance directives should be taken into account when deciding whether to use rapid tranquillisation and other interventions.
- The intervention selected (e.g. rapid tranquillisation or physical restraint or seclusion) must be a reasonable and appropriate response to the risk posed by the service user.

- Rapid tranquillisation with intramuscular or intravenous injections should only be used in healthcare settings and a crash bag should be available within three minutes.
- The crash bag should include an automatic external defibrillator, a bag valve mask, oxygen, cannulas, fluids, suction and first line resuscitation medication.
- The crash bag should be maintained and checked regularly.
- When using intramuscular or intravenous injections to implement rapid tranquillisation, a doctor should be available at all times to quickly attend an alert by staff members.
- The prescribing and administration of rapid tranquillisation must take place within the current legal framework, particularly according to the relevant Mental Health Act or its equivalent.
- Any departures from the legal guideline must be clearly recorded and justified in the service user's best interests, and reviewed as soon as possible.

Service user's concern:

- When administering the rapid tranquillisation try to ensure that the service user does not feel humiliated or perceive this as a punishment (the prescriber should respect their need for dignity and privacy and balance this against the need to administer the rapid tranquillisation).
- Explain the reasons for using the interventions to the service user at the earliest opportunity.
- Reassess the service user's care/ treatment plan and help them to reintegrate into their living environment at the safest opportunity following the rapid tranquillisation.

As required (PRN) prescribing^{GPP}

(Please note that in most cases PRN medication, particularly when taken orally, is used instead of rapid tranquillisation for the management of an acute episode of behaviour problem, particularly for those who live in the community.)

- The prescribing of 'as required' medication should be part of an overall treatment care plan and, when possible, should be prescribed after discussion with the individual and/ or their family and carers and other relevant care professionals.
- If possible, the prescriber should use the individual's and/ or their carer's preferred route of administration (e.g. oral or IM).
- The reason for prescribing 'as required' medication must be recorded clearly in the notes and objectives should be set at the outset for measuring the outcome over an established period of time.
- The 'as required' prescription must be monitored at regular intervals, the time period for which should be set at the time of prescribing.
- The prescriber must clearly note the indication for administration of 'as required' medication, the minimum interval between doses and the maximum dose allowed in a 24-hour period.
- The 'as required' medication that may be administered by more than one route (e.g. orally or IM) should be prescribed separately with clear direction as to why one should be preferred.
- Unless there is a clear clinical reason (which should be clearly noted), the prescriber should consider discontinuation of any 'as required' medication that has not been used for six months or longer (the exception to this is rescue medication for status epilepticus or prolonged seizures or prolonged cluster of seizures).
- The prescriber should not prescribe at any one time medication from more than one BNF therapeutic category without stipulating the reasons.
- The prescriber should not prescribe more than two medications for any one indication.
- If the prescriber wishes to offer more than one medication as 'as required' treatment they should stipulate the order in which they should usually be administered.

- The prescriber must review and re-write medication as regular prescriptions if it is needed regularly but was originally prescribed as 'as required' medication.
- The prescriber should be careful to monitor medication from the same therapeutic category that is used simultaneously as regular and 'as required' prescription in order to avoid inadvertently overdosing (the prescriber should ensure that the total daily dose of the regular and the 'as required' prescription does not exceed the maximum BNF recommended dose).

Communication and information sharing^{GPP}

Communication between professionals, carers and service users and the sharing of information is an underlying thread of this guideline and will form a very important principle of care when managing people with behaviour problems and a learning disability.

- The prescriber is responsible for ensuring that all the information necessary for the administration of medication has been explained properly and passed on to the person who will administer the medication.
- This may include handing over a written treatment plan including medication dosage and timing of administration, and enlisting of common and serious adverse effects to the individual and/ or an appropriate carer at the time of prescription.
- This should be done as well as, not instead of, verbal explanation at the time of prescribing.
- Similarly, adults with a learning disability and those supporting them also have a responsibility to the prescribers – they should attend appointments on time, with the appropriate information (most up-to-date medication records or charts, notes or records regarding issues or problems, and an understanding of the reason for the appointment and any special issues related to medication treatment and administration).
- The individual accompanying the person with a learning disability should know the person and all relevant issues well. They should be confident in communicating and able to understand all the relevant information relating to a prescription.
- If necessary, the prescriber should mention on the prescription where the medication can be obtained, e.g. community pharmacy, hospital pharmacy or, if it is unusual medication, who can supply it.
- The primary care service should inform the secondary care service when secondary care has made a suggestion on a particular intervention and primary care has not followed that suggestion.
- Information about treatment should be passed on to all relevant people as soon as possible on a need-to-know basis, including the other members of a community multi-disciplinary team who are involved with the individual's care including Day Centres and Respite Carers and where Shared Care Agreements are in place.

Interdisciplinary working^{GPP}

Throughout this guide, inter-disciplinary team working has been emphasised as good practice. In areas of care that are potentially controversial, or where it has not been possible to reach an agreement, (for example, between the prescriber and individual with a learning disability and/ or their family or carer) the interdisciplinary team approach may play a particularly important role.

Inter-disciplinary working helps to ensure a comprehensive assessment of the problem behaviours, their causes and effects. It also provides opportunities to use alternative approaches to managing the behaviour, and alternative and supportive views about the options. It may also provide technical support about medication options and enhances the possibility of making complementary intervention strategies more successful.

Consent and Capacity^{GPP}

Carrying out an assessment of capacity should involve the following important points:

- Whether the person has an understanding that they have a problem.
- Whether the person has an understanding of the consequences of having or not having the intervention.
- Whether the person has the ability to take in and retain information for a reasonable length of time.
- Whether the person needs to be allowed enough time to assimilate the information.
- Whether the person needs to be provided with different forms of information to allow them to understand the information.

When capacity to consent to treatment is being assessed, the prescriber should consider following important points:

- The relevant regional or national laws and guidelines governing capacity or incapacity.
- Every adult has the right to make his or her own decisions and be assumed to have capacity to do so, unless it is proved otherwise.
- People must be given all appropriate help before anyone concludes that they cannot make their own decisions.
- Anything done for or on behalf of people without capacity must be in their best interests.
- Anything done for or on behalf of people without capacity should be the least restrictive of their basic rights and freedoms.
- An assessment of capacity should be specific to that point in time and should be assessed by the person who is proposing the intervention. However, the prescriber can obtain assistance regarding the individual's understanding in order to assess capacity (perhaps from a psychologist or a speech therapist).
- Involve a multidisciplinary team in the assessment of capacity, if necessary.

- No one can be labelled 'incapable' because of a particular medical condition or diagnosis.
- Most people with a learning disability can make many of their own decisions, even if they may lack capacity in relation to some complex issues.

The Referral Pathway^{GPP}

An adult with a learning disability and behaviour problems who lives in the community may be referred to one or more of the following:

- General Practitioner (GP)
- NHS Direct
- Community Learning Disability (Psychiatric) Nurse
- Community Learning Disability (Psychiatric) Team
- Crisis Resolution (Intervention) Team
- Psychiatrist
- Clinical Psychologist
- Voluntary Service
- Independent Sector Service
- Social Services
- Hospital
- Police

The person may already be known to the appropriate service providers and therefore may be part of a Care Programme Approach (CPA), a Care Plan (CP), a Health Action Plan (HAP), or a Person-Centred Plan (PCP) with a designated CPA co-ordinator or an identified key person. Alternatively, there may be no CPA/ CP/ HAP/ PCP and in such cases, there may or may not have been an identified CPA co-ordinator, care-worker or key contact.

If they are not already, the person should be considered for inclusion in one or more of the care programmes mentioned in the preceding paragraph. Where possible the management of behaviour should be part of one of these programmes. Local or national Care Pathways should guide the prescriber in this; one such Care Pathway has been developed by the Birmingham and Black Country Strategic Health Authority (NHS West Midlands, 2003).

References

Association for Real Change (ARC, 2005). *Managing medication in learning disability social care settings: A guide and training framework for social care organisations*. Available www.arcuk.org.uk/388/en/managing+medication.html

Aman MG, Singh NN, Stewart AW, & Field CG (1985). The Aberrant Behaviour Checklist: a behaviour rating scale for the assessment of treatment effects. *American Journal of Mental Deficiency*, 89, 485-491.

Birmingham and Black Country Strategic Health Authority (BBC StHA, 2003). *Care Pathway for adults with learning disabilities who are displaying challenging behaviour: Implementation Guide*. NHS West Midlands, Partnership for Developing Quality (PDQ).

British Medical Association and Royal Pharmaceutical Society of Great Britain (March, 2006). *British National Formulary*, Number 50. London: Author. Available www.bnf.org

British Psychological Society (BPS, 2004). *Psychological interventions for severely challenging behaviours shown by people with learning disabilities: Clinical Practice Guidelines*. Leicester: Author.

British Psychological Society and Royal College of Psychiatrists (BPS & RCPsych, 2006). *Challenging behaviour: a unified approach*. Available www.rcpsych.ac.uk.

Fox P & Emerson E (2002). *Positive Goals; Interventions for People with Learning Disabilities whose Behaviour Challenges*. Brighton: Pavilion Publishing Ltd.

Leicestershire Partnership NHS Trust (2005). *The Frith Prescribing Guidelines for Adults with Learning Disability* (edited by S Bhaumik & D Branford). Oxfordshire: Taylor & Francis

National Institute for Health and Clinical Excellence (NICE, 2005). *Violence; The Short-term Management of Disturbed/ Violent Behaviour in In-patient Psychiatric Settings and Emergency Departments*. London: Author. Available www.nice.org.uk/CG025NICEguideline

Royal College of Psychiatrists (RCPsych, 2001). *Diagnostic criteria for psychiatric disorders for use with adults with learning disabilities/ mental retardation* (DC-LD, Occasional Paper OP48). London: Gaskell.

Sorgi P, Ratey J, Knoedler DW, Markert RJ, & Reichman M (1991). Rating aggression in the clinical setting; a retrospective adaptation of the Overt

Aggression Scale: Preliminary Results. *Journal of Neuropsychiatry*, 3, 552-556.

South London and Maudsley NHS Trust & Oxleas NHS Trust (2005). *The Maudsley 2005-2006 Prescribing Guidelines* (8th Edition). D Taylor, C Paton & R Kerwin. Oxon: Taylor & Francis.

Appendix 1: The assessment - bullet pointed version

(This list is not a comprehensive, but a broad scheme. Not all assessments will be required in all cases.)

An assessment should address:

- the behaviour
- the person
- medical and organic factors
- psychological and psychiatric factors
- social and environmental factors.

Assessment of the actual behaviour should take the following factors into account:

- the type and nature of the behaviour(s)
- past history of behaviour problems
- baseline behaviour prior to the onset of behaviour problems
- the onset of the behaviour(s)
- the frequency, severity and duration of the behaviour(s)
- associated behaviours
- the impact of the behaviour(s) on the person's life, other's lives, and the environment
- reactions to the behaviour by the person/ others/ services
- the function of the behaviour.

Risk assessment:

- the type and the nature of risks:
 - risk to others
 - risk to the individual
 - risk to the environment
 - other risks including offending history
- methods of risk assessment
- previous risk assessment
- review of risks
- record of reviewing reduction of risks.

Guidelines on the assessment of risks are available from the National Patient Safety Agency. Other local risk assessment guidelines may also be available. The prescribers may follow any of these guidelines.

Assessment of the individual (BPS, 2004):

- their strengths – abilities, opportunities, resources

- their needs – impact of disability, service and resource gaps in their lives, mental and physical health needs
- their likes, dislikes and preferences and how they express these
- their history – social, developmental, psychological and history of use of services
- difficulties in developing fulfilling relationships.

In this context, it is helpful to have a description of the individual's current and past weekly routine.

Medical and organic factors:

- chronic physical conditions
- medical conditions
- epilepsies
- other neurological conditions
- genetic conditions
- sensory impairment
- communication problems
- physical disabilities
- illicit drug and alcohol-related factors
- prescribed drugs
- relevant developmental and medical history.

Psychological/ psychiatric factors:

- psychiatric disorders
- relevant history of psychological development
- psychological emotional issues, such as bereavement, relationship, abuse etc.
- new/ ongoing/ recurrent stress
- difficulty in developing fulfilling relationships
- developmental disorders, like Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD), including impulsivity
- neuropsychological factors
 - impaired intelligence
 - impaired memory
 - impaired attention
 - impaired or abnormal communication skills
 - impaired executive function
 - impaired frontal lobe function, such as lack of initiative and apathy
 - lower threshold of stress tolerance.

Social and environmental factors

- description and assessment of the environment and daily activities
- factors relating to other people around the person, including staff/ carers
- change in the environment

- influence of life events
- relationship with peer group, friends, family members and care staff (including any changes)
- effect of the daily activities (including any changes)
- effect of (or lack of) leisure and day activities (including any changes)
- the organisational setting – systems and procedure
- absence of appropriate/ adequate support for the person and their family or carers
- under- or over-stimulating environment
- lack of (or opportunity for) appropriate social exposures
- issues relating to integration within the wider society, stigmatisation and discrimination
- carer issues, including levels of stress and lack of support for carers.

Appendix 2: The assessment - additional information

Description of the actual behaviour

Clear and unambiguous

In all circumstances, the target behaviour(s) should be clearly described. As much detail of the behaviour(s) as possible should be recorded. In an emergency, at least the target behaviour(s) should be listed and a full description be provided as soon as possible after that.

Measurable (by observation or self report)

In some situations, it will be possible to use standardised methods of measuring the behaviour(s) by using validated instruments. In all situations, a baseline measurement of behaviour(s) should be recorded even in the absence of the use of a standardised assessment tool.

Capable of future replication

Standardised methods of measuring behaviour(s) will always facilitate future replication. In the absence of standardised tools, the baseline measurement method should be such that this could be used at future dates for monitoring the behaviour(s), and as much as possible the same methods of measurement should be used at the baseline and at subsequent assessments.

Assessment of the actual behaviour

History of behaviour problems

In many circumstances, the reported behaviour(s) will be the recurrence of previous behaviour(s). Such information of history will help to assess the cause(s), management, impact and outcome of such behaviour previously. Even if the behaviour has occurred before, the severity, frequency and the nature of the behaviour may somehow differ in the current episode as compared with the previous episodes.

Baseline behaviour prior to the onset of behaviour problems

It is always worth assessing baseline behaviours in an individual with a learning disability. This may be done by asking about the person's behaviour before the onset of the current target behaviour(s). This could be facilitated by taking a pen-picture of the person's daily/ weekly life before and after the onset of the target behaviour(s). This will detect new behaviour problems as well as the exacerbation of previously existing behaviour problems.

The onset of the behaviour(s)

The behaviour(s) may develop gradually or over a period. This may give an indication about the cause of the behaviour. Some people may show a cyclical nature in their behaviour in that they show an intense behaviour problem for a

period and then show no problem for a few weeks. This may help to assess the cause and choice of appropriate management option. Behaviour may have a sudden onset but may occur many times during the day or over a period of few days. It is also worth keeping in mind that although the behaviour may appear sudden, it may have been caused by an accumulation of events or emotional stress over a period. In some cases, there may be an apparent delay in sudden occurrence of the behaviour and the event that may have precipitated the behaviour.

The frequency, severity and duration of the behaviour(s)

It is always important to make a note of the frequency of the target behaviour(s). This can be done by direct observation or taking an account of observation by staff. A chart of behaviour(s) should be kept or an assessment tool that uses frequency may be used. Severity is often difficult to define because it may depend on the perception of the carer or any other person reporting the behaviour. However, there are standardised tools available to measure the severity of behaviour as well. The total duration of occurrence of the target behaviour(s) should also be recorded.

A behaviour problem may be a one off occurrence but be serious in nature for example causing serious harm to the individual or others. In this case, immediate action may be required. Therefore, it is important to take into account both the frequency and the severity of the behaviour(s).

Associated behaviours

The target behaviour may be, for example, aggression but the person may show other behaviour problems simultaneously. A record has to be made of both the target behaviour(s) and other associated behaviours. It is possible to use a specific measure for aggression (for example MOAS) and another broad measure for the assessment of all types of behaviour problems simultaneously (for example ABC, see Section 5 for further detail on behaviour assessment instruments).

The impact of the behaviour(s)

It is of utmost importance to assess the impact of the behaviour(s) on an individual's self and others. The behaviour(s) may lead to reduced quality of life for the individual. Similarly, the behaviour(s) may lead to poor physical/mental health, including continuing stress or headache or injury to the person etc. The behaviour(s) may lead to reduced access to services including education, day service and employment opportunity. For example, the behaviour may lead to a threatened or actual loss of placement in a residential setting or day placement. The behaviour(s) may lead to reduced social activities including leisure activities, access to friends etc.

In severe cases, the individual may end up being physically restrained, medicated or taken to a hospital or police station. All these scenarios may subsequently have their impact on the individuals, their behaviour and their carers. For example, some of these outcomes may work as perpetuating factors for the ongoing behaviour(s). They may be seen as inappropriate or

excessive and the individual or their carer may perceive them as punishments.

The behaviour(s) may have impact on others. For example, this may lead to reduced quality of life for the immediate carers including loss at a financial or employment level or loss of leisure and social activities. The behaviour may upset other people living in the house with the service user and subsequently perpetuate the current behaviour(s). The behaviour(s) may cause damage to property or physical harm to other people. The behaviour may have impact on the physical and mental health of the carers or other people who encounter the individual. This may eventually lead to a breakdown of the relationship.

The impact on the carer may implicate the training needs for the carer in the management of behaviour problems.

The ultimate aim of the management of behaviour problems is to eliminate or reduce these impacts of behaviour on the self and others but not only a mere reduction in the frequency and severity of the target behaviour(s). Contrary to the expectation that a reduction in the frequency and severity of target behaviours would minimise the impact of the behaviour(s), this does not always happen in practice.

Risk assessment

The type and the nature of risks

Risk to others: The individual may pose a risk to others if they display verbal or physical aggression to other people. This may require specific measures such as supervision, treatment and support for its prevention. However, the risk could be more long standing and less obvious, which may cause physical and psychological harm to others.

Risk to the individual: In some cases the individual may harm themselves by either producing tissue injury of different degrees of severity or internal injury by ingestion or putting objects inside various bodily orifices. In severe cases self-harm may lead to fatality or long-term morbidity.

Risk to the environment: In some cases the behaviour may produce damage to the immediate environment (e.g. destruction of property or other type of damages to the wider community).

Other risks: In some circumstances the individual may display other unacceptable social behaviours (e.g. smearing faeces, spitting, inappropriate sexual behaviour, repetitive ritualised behaviour).

Methods of risk assessment: The risks may be classified as immediate risks or long-term risks, risks to the individual, risk to others or risk to the environment, according to the frequency and severity of risks depending on the impact of the behaviour(s) on the individual, environment and other

people. In some cases, it may be possible to use standardised methods for risk assessments including the use of validated instruments. In the absence of standardised tools, some measure of risk assessment should be recorded in all cases.

Previous risk assessment: In some cases, there may be a record of previous risk assessment, which will allow comparison of previous risks, their impact, their management and outcome with the current risks. It is often said that the best predictor of future risk is the history of previous risk. In these circumstances, lessons could be learned from the previous management of risks.

Review of risks: After the initial assessment of the risks they should be monitored during subsequent assessments using, where possible, the same methodology. The date and method of the future assessment of risks should be set at the time of the initial assessment.

Record of reviewing reduction of risks: There should be a record of the assessed risks accompanied by a risk reduction or a risk management plan with evidence of this being reviewed.

Medical and Organic Factors

Chronic physical conditions

Many physical conditions may lead to behaviour problems. For example, toothaches, headaches or pain in any part of the body may cause stress and lead to behaviour problems. Those who cannot communicate pain may express the stress associated with pain through behaviour problems. The prescriber should always check for such physical conditions.

Medical conditions

The prescriber should check for any acute, chronic or recurrent medical condition involving the major systems such as cardiovascular, respiratory, gastrointestinal, musculoskeletal, dental, skin and renal.

Epilepsies

The prescriber should assess the relationship between epilepsy and behaviour problems. The relationship between epilepsy and behaviour problems among adults with a learning disability is rather complex. Some individuals may show emotional and behaviour problems in between seizures (inter-ictal) or around the time of the seizure (peri-ictal, including pre-ictal, ictal and post-ictal). The underlying brain pathology that causes epilepsy, recurrent epileptic discharges in the brain, antiepileptic medication, stigma attached to the condition, and other psychosocial issues may all lead to behaviour problems. In some cases, the effective treatment of epilepsy will show improvement in the associated behaviour problems but in others, a deterioration in the behaviour problems may occur.

Other neurological conditions

The prescriber should assess any link with neurological disorders and behaviour problems. Some individuals with a learning disability have cerebral palsy and spasticity, which may indirectly lead to behaviour problems. Other neurological conditions such as movement disorders, multiple sclerosis, brain tumour etc. may be difficult to diagnose in an individual with a learning disability but may have impact on the person's behaviour.

Genetic conditions

Many genetic disorders cause a learning disability and are associated with a high rate of behaviour problems. One such example is Lesh Nyhan syndrome. The prescriber should check out for any genetic syndromes and also family history of stillbirths, medical and neurological conditions, mental illnesses, behaviour problems, learning disability and developmental disorders e.g. autism spectrum disorder.

Sensory impairment

Sensory impairments, particularly problems with vision and hearing may lead to behaviour problems. It is therefore essential to assess sensory capacities (including excessive sensitivity to sound and light) in people who show behaviour problems.

Communication problems

Difficulty with proper communication can lead to behaviour problems. Communication difficulty may involve expressive speech, comprehension or a discrepancy between the two. The communication difficulty may involve the social aspect of speech and language, for example abnormalities of reciprocal social interaction with problems in the area of eye contact, turn taking, empathy and rapport. The prescriber should assess how much expressive speech the person with a learning disability has and how does the person express him/herself, for example, do they use any sign language? The prescriber should also assess whether or not there are difficulties in understanding verbal, signed or symbolic communication. The prescriber should assess the level of understanding on the part of the person with a learning disability (environmental cues, single or increasingly complex groups of words, signs or symbols, concrete or abstract meaning).

Some people with a learning disability may have better expressive speech than comprehension and as a result may give an erroneous impression that they understand complex instructions. An inability to detect this may raise expectations on the part of care staff and eventually lead to misunderstanding and the expression of behaviour problems. Dysarthria may also cause frustration and lead to behaviour problems.

Physical disabilities

The prescriber may find evidence of physical disabilities that produce difficulties in self-care, mobility and psychological well being in a person with a learning disability and may lead to behaviour problems.

Illicit drug and alcohol related factors

The extent of illicit drugs, solvents and alcohol use among people with a learning disability is not known but it will be expected that as in a population without a learning disability, drug and alcohol use will remain an important factor for causing behaviour problems among adults with a learning disability. It is therefore important to explore these possibilities among adults with a learning disability who show behaviour problems.

Prescribed medications

Behaviour problems may be the adverse effects of some prescribed and over the counter medications. Therefore, this possibility should always be considered in an adult with a learning disability who demonstrates behaviour problems.

Developmental history

The developmental history including a history of assessment for sensory processing abnormalities is an important part of the assessment and is likely to provide clues for the aetiology and prognosis of behaviour problems in a person with a learning disability.

Psychological/ psychiatric factors

Psychiatric disorders

Psychiatric disorders may lead to behaviour problems among adults with a learning disability. It is not always easy to diagnose psychiatric disorders in this population. However, in the absence of other known symptoms and signs the prescriber should not assume the presence of a psychiatric disorder because of mere changes of behaviour in a person with a learning disability. The prescriber should distinguish carefully between behaviour associated with the developmental disorder from that of genuine psychiatric symptoms. For example, if an adult speaks to a tree or looks around indiscriminately and shouts, these should not be declared as hallucinations in the absence of a more reliable diagnosis. Similarly if a person with autism spectrum disorder speaks about an imaginary person this does not necessarily mean that this person has delusions.

However, psychiatric disorders such as schizophrenia, depression, anxiety disorder and phobia should always be considered in a person with a learning disability who shows behaviour problems. Conditions such as autism and attention deficit hyperactivity disorder (ADHD) are common among adults with a learning disability. It is not clear whether these conditions constitute psychiatric disorder or not but they are associated with a high rate of behaviour problems. Therefore, the prescriber should investigate for these conditions because the management of behaviour problems may vary depending on their presence or absence.

The prescriber should look for evidence of persistent enduring abnormalities of personality that are contributing to difficulties in interpersonal, occupational and social domains (e.g. paranoid, psychopathic). However, the prescriber

should be careful of using a diagnosis such as a personality disorder, which may simply be a way of describing behaviour problems in people with a mild to moderate learning disability, whereas the same behaviour problems among adults with a severe and profound learning disability may not attract the diagnosis of a personality disorder.

Psychological and emotional issues

The prescriber should also look for other contributory psychological and emotional factors such as bereavement, psychological trauma, new, ongoing or recurrent stress and relationship difficulty leading to a loss of self-esteem and isolation that may be perpetuating behaviour problems.

Neuropsychological Factors

Impaired intelligence: Impaired intelligence lowers the cognitive threshold to deal with problems in day-to-day life but particularly to deal with problems under stress because of the reduced cognitive reserve. This may lead to behaviour problems. Similarly the certain events may be perceived as stressful to people with impaired intelligence whereas these events may not appear stressful to people who do not have impaired intelligence.

Impaired memory: Underlying brain damage in some adults with a learning disability may lead to impaired cognitive function in the form of impaired memory. This may lead to behaviour problems indirectly because in many cases the carers will be unaware of this possibility. It is therefore important to assess this aspect of cognitive function in all adults with a learning disability who show behaviour problems.

Impaired or abnormal communication skills: This important aspect of assessment has been discussed under the previous heading.

Impaired executive function: Impairment in executive function may take the form of a lack of planning ability, ability to think in abstract terms, multi-tasking abilities and sense of judgement. A lack or impairment of these functions is likely to cause stress and inability to address problems in day-to-day life and as a result lead to behaviour problems. Some adults with a learning disability are likely to show impairment in their executive function. This impairment may remain subtle and undetected and indeed there are practical difficulties in reliably assessing these aspects of cognitive function in many adults with a learning disability. However, in the absence of an understanding of this process, the potential for behaviour problems increases and therefore it is important to keep this in mind while assessing a person with a learning disability and behaviour problems.

Impaired frontal lobe function such as lack of initiative and apathy: Many people with a learning disability may just appear lazy to their carers and more and more demands may be placed on them in order to rectify these behaviours. However, the carers may not realise that these behaviours are caused by the impaired function of the pre-frontal cortex of the person with a learning disability. Furthermore, the individual with a learning disability may

not therefore have any control over these behaviours. A lack of understanding of this process may lead to behaviour problems. Therefore, this possibility should be considered during the assessment.

Lower threshold of stress tolerance: People with a learning disability may have a lowered tolerance of stress and this may lead to behaviour problems. The lower threshold can be caused by many factors including: a) the cognitive factors that are discussed above, b) lack of social support, c) lack of self-esteem, d) poor self-image, e) learned maladaptive behaviour from the past, f) lack of psychological and social reserve including the inability to use advanced psychological defences as opposed to using more primitive psychological defences, and g) an inability to think in abstract terms. All these areas need careful consideration in the assessment.

Social and environmental factors

Description and assessment of the environment and daily activities

Such factors may play a major role in predisposing, precipitating, and perpetuating behaviour problems. Some individuals may perceive their environment as too demanding. For example, an individual may not want to carry out certain activities that are required of them and are seen as necessary for their personal welfare by the care staff. Similarly, some individuals may find the lack of space around them, other people around them, and many activities around them overwhelming and stressful. It is important to keep in mind that certain activities that may not seem demanding to a person who does not have a learning disability may be perceived as demanding by some individuals with a learning disability. Similarly, some individuals may perceive their environment as under-stimulating and lacking in appropriate activities. Both under and over-stimulation in the environment may lead to behaviour problem(s).

Personalities of other people

Personalities of other people around the individual including that of care staff are likely to affect the person's behaviour. Similarly, the way a person with a learning disability is managed is also going to have impact on their behaviour. The lack of respect for the person with a learning disability will be evident and can lead to behaviour problems. The lack of support from others including carers and other residents in a house may lead to behaviour problems. Although these are important causes for behaviour problems and must be considered during assessment, at times these issues will have to be dealt with sensitivity and caution.

Change in the environment

Changes in the environment may also lead to behaviour problems. The change may include a change in a staff member in the house, change in accommodation, change in day activities, change among the other residents in the house etc. In a person with autistic tendency, for example, a change in the colour of the room may constitute a significant change and lead to behaviour problems.

The prescriber should also look for any changes in the following:

- the level and quality of activities of daily living at home (e.g. washing, cleaning)
- the level and quality of activities of daily living outside home (e.g. shopping)
- the number and quality of relationships with friends, family, other residents, other day placement attendees, and care staff
- the level of occupation and activities including leisure activities that the individual participates in
- the financial situation
- any changes required in the level of supervision and support to maintain previous levels of these activities.

Influence of life events

The prescriber should also assess whether the individual has experienced significant life events in the recent or distant past (e.g. loss, change). This should include history or evidence of sexual, emotional and physical abuse in the past or ongoing. The individual may not feel part of an inclusive service or wider community or experience stigmatisation and discrimination. They may also lack appropriate social exposure and support.

Carer issues

An important area to assess is whether the carers are adequately supported (including training) and involved in the provision of the service, and support for stress and fatigue amongst carers.

Other important areas to assess are the organisational setting-systems and processes in place to support the person, and possible absence of adequate support (including social and therapeutic).

Appendix 3: Possible audit questions

Names of existing psychotropic medication prescribed (if any) with daily dosage at commencement of intervention and names of medication prescribed after the initial assessment should be noted.

1. Has the behaviour been assessed?
2. Did the assessment involve B (behaviour), M (medical), P (psychological) and S (social) issues?
3. Has a formulation, including a rationale for prescribing, been carried out?
4. Has a treatment plan been documented?
5. Has non-medication based intervention been considered?
6. Has a written (short-term and long-term) treatment plan been given to the individual and/ or their family or carer?
7. Has a written document about the potential adverse effects of the prescribed medication(s) been provided to the individual and/ or their family or carer?
8. Were appropriate physical examinations carried out before the prescription?
9. Were appropriate investigations carried out before the prescription?
10. Has the capacity of the individual been assessed?
11. Has the individual's and/ or their carer's consent/ assent to treatment been secured?
12. If the individual lacks capacity, has the prescriber considered the Capacity Bill and/ or the Mental Health Act?
13. Has the treatment plan been included in the individual's Care Plan, Health Action Plan, or Care Programme Approach?
14. Has a risk assessment been completed?
15. Has the target behaviour been defined?
16. Is there a plan to measure outcome using objective measures?

- 17.** Has a date been set for the review?
- 18.** Has a key person been identified to implement the treatment plan?
- 19.** Has the prescriber passed all the relevant information to this person?
- 20.** Has the treatment plan been shared with other relevant professionals (including the GP)?
- 21.** Is there evidence of inter-disciplinary involvement?
- 22.** Has a review taken place as per the original treatment plan?

Appendix 4: Sample clinic letter covering the audit points discussed in this section

(This sample provides a guide to prescribers, but not a definitive format. Prescribers should format each letter depending on individual circumstances.)

(Numbers in the parentheses correspond to the numbered audit questions in Appendix 3. Appendix 5 covers audit questions 6 and 7, 22 is not included in this letter as this is the initial assessment.)

Dear Dr.

Re: Alan Smith

Diagnoses: Severe learning disability with problem behaviour (F72.1).
Atypical autism (F84.1).

Thank you for referring Mr. Alan Smith. I assessed him on 31 June 2005 in my outpatient clinic. He has a severe learning disability and I was unable to take much of the history from him directly. His carer, Ms Jane Williams, who has known him for the past five years, accompanied him.

The problem is with impulsive aggressive behaviour **(15)**. This has been a problem for many years, and influences on the behaviour include tiredness, frustration, having to wait for things, being in pain and anxiety provoked by changes in routine. At present, he is aggressive to either carers or to other residents in the group home in which he lives. This occurs between two and three times per week on average. Members of the care staff have sustained injuries, usually as a result of biting, hitting or kicking **(1, 14)**.

He has received various interventions to try to help with the behaviour – including an assessment of sensory needs and a plan of how to meet these, a reward-based behavioural intervention and, most recently, anger management work co-ordinated through the psychology department at Towers Road **(5)**.

The developmental history was consistent with an autistic spectrum disorder, but it was not possible to date the onset to before 36 months on the basis of the information available. I did not find evidence of any associated physical or psychiatric illness and so I felt the problem was one of impulsive aggressive behaviour of quite long standing, associated with severe learning disability **(2)**. A quick physical examination in the clinic did not reveal any obvious abnormalities **(8)**. I have arranged for Mr. Smith to have blood tests, including FBC, renal and liver and thyroid function tests, serum prolactin, and fasting blood glucose. An EEG was performed about six months ago and did not

show any abnormality **(9)**. Ms Williams has agreed to keep a weekly weight chart on Mr. Smith and I will assess blood pressure each visit.

We agreed that physically aggressive behaviour would be the target for intervention, and that verbally abusive or other challenging behaviours could be dealt with by other means. In particular, the objective was to avoid further injuries to staff or other residents **(3)**. Ms Williams has agreed to keep a weekly chart of the frequency and severity of Mr Smith's aggressive behaviour until the next follow up. Ms Williams will also complete a weekly MOAS chart and a monthly ABC chart on Alan to quantify the problems and measure change **(16)**. I have promised to supply them with a copy of the MOAS and ABC as soon as possible.

I think it may be helpful for the anger management work to continue, so I am copying this letter to Mr Smith's psychologist and community nurse **(21)**.

In view of the fact that Mr Smith lacked capacity to consent due to his severe learning disability and lack of speech, I was unable to meaningfully get his agreement to the proposed treatment plan **(10)**. Ms Williams agreed to liaise with his psychologist and community nurse to ensure that they were in agreement **(20)**.

After discussion, it was agreed with Ms Williams **(11)** that, in Alan's best interests **(12, 13)**, it would be appropriate to prescribe risperidone 0.5 mg daily. If there are no adverse effects and the treatment seems at least partially beneficial, I may advise further increases in the dose of risperidone gradually by 0.5 mg a day every two weeks as necessary **(4)**. I have asked Ms Williams to let me know about any change in Alan's health and especially any problems with sedation, movement disorders or weight gain **(7)**.

I explained to Ms Williams that this decision was based on the RCT-based evidence for risperidone's efficacy in the treatment of aggression associated with learning disability. The rationale is that risperidone may reduce anxiety and help impulse control **(3)**.

I explained to Ms Williams that most of the other approaches that could be taken seemed already to have been adopted with only limited impact on Mr Smith's aggressive behaviour. We agreed that treatment with risperidone was in Mr Smith's best interests **(12)**. I have given Ms Williams some brief written information about risperidone, including the principal adverse effects (which could include weight gain, sedation and more early movement problems). I am also sending her a copy of this clinic letter as a summary of the consultation **(7)**.

The short-term objective of treatment is to reduce the number of injuries to other people caused by Mr. Smith's aggression. The rationale for the treatment is to decrease anxiety and the impulsive nature of Mr. Smith's aggressiveness so that non-medication-based management strategies could be implemented **(3)**. I would also hope that the reduction in aggression would

be sufficient to increase the number and type of activities in the community that Mr Smith is able to take part in.

Ms Williams agreed to be responsible for monitoring Mr. Smith taking the medication, and for reporting any potential adverse effects **(18, 19)**. In the clinic, I handed Ms Williams a short-term and long-term treatment plan for Mr. Smith, which should form part of Mr. Smith's overall Health Action Plan **(13)**.

We agreed that we would review the situation in outpatients in six weeks, or sooner if necessary **(17)**.

Yours sincerely,

Dr. D Turner
Consultant Psychiatrist in Learning Disability

cc Ms Williams
Psychology **(20)**
Community Nurse **(20)**

This material could be confined to the case notes to produce a shorter letter, if required.

Appendix 5: Sample care plan proforma

(A copy should be given to the person at the time of prescribing, which should be kept in their health action plan file.)

Name of patient: Mr. Alan Smith

Date: 31/06/2005

Short Term Plan:

Risperidone 0.5 mg/ day.

Continue with the anger management programme.

Watch out for excessive daytime sleepiness, weight gain and stiffness in the body or tremor.

Investigations:

FBC, Fasting blood glucose, blood pressure, serum prolactin, weekly weight chart, U&Es, LFT.

Objective Measurement of Target Behaviours:

Frequency and severity of aggression chart + weekly MOAS and monthly ABC and Positive Goals assessment.

Long Term Plan:

If necessary increase risperidone by 0.5 mg/ day increment every 2 weeks to up to 2mgs/ day dose.

Try relaxation exercise if required.

Date of the next appointment: 15/09/2005

Name of the prescriber: Dr. D. Turner

This plan was discussed with and given to: Ms. Jane Williams

Appendix 6: Recommended investigations and monitoring

Antipsychotics

Medication	Baseline	Continuation	Time Interval	Actions
Amisulpride*	FPG/HbA _{1C} FBC Prolactin U&Es Weight Blood Lipids	FPG/HbA _{1C} FBC Prolactin U&Es Weight Blood Lipids CPK	- 12 monthly - monthly - if symptoms occur - 6 monthly - as needed - after 3/12 then yearly - if NMS suspected	Perform FPG if HbA _{1C} raised Stop if prolactin-related effects intolerable Stop if NMS suspected
Aripiprazole*	FPG/HbA _{1C} BP FBC LFTs U&Es Weight Blood lipids	FPG/HbA _{1C} BP FBC LFTs U&Es Weight Blood lipids	- 12 monthly - frequently during initiation - 12 monthly - 12 monthly - 12 monthly - as required - after 3/12 then yearly	- Perform FPG if HbA _{1C} raised - Stop if FBC shows pathological change - Stop if PT or bilirubin change
Clozapine*	FPG/HbA _{1C} FBC BP ECG (Optional) LFTs U&Es Weight Blood Lipids	FPG/HbA _{1C} FBC BP CPK ECG (Optional) EEG LFTs U&Es Weight Blood Lipids	- at 1 month; 4-6 monthly - monthly - 4 hourly during titration - if NMS suspected reached - when maintenance dose is reached - if myoclonus or seizures occur - every 6 months for first year - every 12 months - as needed - 3 monthly then yearly	- Perform FPG if HbA _{1C} raised - Stop if neutrophils below 1.5x10 ⁹ /l - Refer to specialist care if neutrophils below 0.5x10 ⁹ /l - Stop if ECG shows important changes or if signs of heart failure noted - Use valproate if EEG show epileptiform changes - Stop if LFTs indicate hepatitis or reduced hepatic function

Key: ACE inhibitors= Acetylcholinesterase inhibitors BP= Blood Pressure CPK= Creatinine Phosphokinase ECG= Electrocardiograph EEG= Electroencephalograph

FBC= Full Blood Count FPG= Fasting Plasma Glucose HbA_{1C}= Glycosylated Haemoglobin LFTs= Liver Function Tests

PT= Prothrombin Time TFTs= Thyroid Function Tests U&Es= Urea and Electrolytes NMS = Neuroleptic Malignant Syndrome NSAIDs= Non-Steroid Anti Inflammatory Drugs

Olanzapine*	FPG/HbA _{1C} BP FBC LFTs U&Es Prolactin Weight Blood lipids	FPG/HbA _{1C} BP CPK FBC LFTs U&Es Prolactin Weight Blood lipids	- at 1 month; 4-6 monthly - frequently during initiation - if NMS suspected - 12 monthly - at 3 and 6 months then yearly - 12 monthly - if symptoms occur (rare) - as needed - 3 monthly then yearly	- Perform FPG if HbA _{1C} raised - Stop if NMS suspected - Stop if neutrophils below 1.5x10 ⁹ /l - Stop if PT or albumin change
Quetiapine*	FPG/HbA _{1C} BP FBC LFTs U&Es Weight Blood lipids	FPG/HbA _{1C} BP CPK FBC LFTs U&Es Weight Blood lipids	- 12 monthly - frequently during titration - if NMS suspected - at 3 and 6 months, then yearly - 12 monthly - 12 monthly - as needed - 3 monthly then yearly	- Perform FPG if HbA _{1C} raised - Stop if NMS suspected - Stop if PT or bilirubin change
Risperidone*	FPG/HbA _{1C} BP FBC LFTs U&Es Weight Blood lipids	FPG/HbA _{1C} BP CPK FBC LFTs U&Es Weight Blood lipids	- 12 monthly - frequently during titration - if NMS suspected - 12 monthly - if symptoms occur - 12 monthly - as needed - after 3/12 then yearly	- Perform FPG if HbA _{1C} raised - Stop if NMS suspected - Use with caution in hepatic/renal failure - Stop if prolactin-related effects intolerable
Zotepine	FPG/HbA _{1C} BP ECG LFTs Prolactin U&Es	FPG/HbA _{1C} BP CPK EEG ECG LFTs Prolactin U&Es	- 12 monthly - frequently during titration - if NMS suspected - if seizures occur - if necessary when maintenance dose reached - 12 monthly - if symptoms occur - 12 monthly	- Perform FPG if HbA _{1C} raised - Stop if NMS suspected - Use valproate if EEG shows epileptiform changes - Stop if ECG shows important changes - Stop if renal function deteriorates

Key: ACE inhibitors= Acetylcholinesterase inhibitors BP= Blood Pressure CPK= Creatinine Phosphokinase ECG= Electrocardiograph EEG= Electroencephalograph
 FBC= Full Blood Count FPG= Fasting Plasma Glucose HbA_{1C}= Glycosylated Haemoglobin LFTs= Liver Function Tests
 PT= Prothrombin Time TFTs= Thyroid Function Tests U&Es= Urea and Electrolytes NMS = Neuroleptic Malignant Syndrome NSAIDs= Non-Steroid Anti Inflammatory Drugs

Zotepine Cont'd*	Weight Blood lipids	Weight Blood lipids	- as needed - after 3/12 then yearly	
Ziprasidone*	FPG/HbA _{1c} BP FBC LFTs U&Es Weight Blood lipids	FPG/HbA _{1c} BP FBC LFTs U&Es Weight Blood lipids	- 12 monthly - frequently during initiation - 6-12 monthly - 6 monthly - 6 monthly - as required - after 3/12 then yearly	- Perform FPG if HbA _{1c} raised - Stop if FBC shows pathological change - Stop if PT or bilirubin change

*Source: The Maudsley Prescribing Guidelines 2005-2006

Mood Stabilisers and Antiepileptics

Lithium#	Thyroid function Liver function Renal function FBC FPG/HbA _{1c} Blood lipids profile BP ECG Weight Smoking/Alcohol EEG Serum lithium	Thyroid Function FBC FPG/HbA _{1c} Blood lipids BP Weight Smoking Serum lithium Serum creatinine U&Es	- 6 months - Only if clinically indicated - Annually (over 40s only) - Annually - If the patient gains weight rapidly - Annually - Within 7 days of starting treatment, then 3 monthly - 6 monthly - 6 monthly	- Monitor for signs of neurotoxicity including: Paraesthesia, ataxia, tremor and cognitive impairment. Neurotoxicity can occur at therapeutic levels. - Maintain serum lithium concentration at 0.6- 0.8mmol/l - More frequently if patient starts taking drugs such as ACE inhibitors, diuretics or NSAIDs
----------	---	--	---	--

Key: ACE inhibitors= Acetylcholinesterase inhibitors BP= Blood Pressure CPK= Creatinine Phosphokinase ECG= Electrocardiograph EEG= Electroencephalograph
FBC= Full Blood Count FPG= Fasting Plasma Glucose HbA_{1c}= Glycosylated Haemoglobin LFTs= Liver Function Tests
PT= Prothrombin Time TFTs= Thyroid Function Tests U&Es= Urea and Electrolytes NMS = Neuroleptic Malignant Syndrome NSAIDs= Non-Steroid Anti Inflammatory Drugs

Valproate**	U&Es Creat. FBC LFTs Pancreatic enzymes	U&Es Creat. FBC LFTs Pancreatic enzymes	- Annually - Annually - Initially - 2 monthly for 1 yr - Initially	- Also check before any surgery - Measure if acute abdominal pain suspected
Carbamazepine**	U&Es Creat. FBC LFTs Pancreatic enzymes	U&Es Creat. FBC LFTs Pancreatic enzymes	- All Annually	
Topiramate**	U&Es Creat. FBC LFTs Pancreatic enzymes	U&Es Creat. FBC LFTs Pancreatic enzymes	- All Annually	
Levetiracetam**	U&Es Creat.	U&Es Creat.	- All Annually	
Lamotrigine**	U&Es Creat. LFTs Pancreatic enzymes	U&Es Creat. LFTs Pancreatic enzymes	- All Annually	
Phenytoin**	Phenytoin blood levels FBC Serum calcium LFTs Serum folate FPG	Phenytoin blood levels FBC Serum calcium LFTs Serum folate FPG	- 2 weeks then annually - Annually - Annually - Annually - Annually - 6 monthly - Annually	- Monitor to avoid toxicity or drug interactions - Give folic acid supplements if necessary

Key: ACE inhibitors= Acetylcholinesterase inhibitors BP= Blood Pressure CPK= Creatinine Phosphokinase ECG= Electrocardiograph EEG= Electroencephalograph
FBC= Full Blood Count FPG= Fasting Plasma Glucose HbA_{1c}= Glycosylated Haemoglobin LFTs= Liver Function Tests
PT= Prothrombin Time TFTs= Thyroid Function Tests U&Es= Urea and Electrolytes NMS = Neuroleptic Malignant Syndrome NSAIDs= Non-Steroid Anti Inflammatory Drugs

Oxcarbazepine**	U&Es FBC Weight	U&Es FBC Weight	- All annually	- In patients with pre-existing renal conditions assoc with low sodium, or if treated concomitantly with sodium lowering drugs (e.g. diuretics, desmopressin, NSAIDs), check prior to initiating therapy, at 2 weeks, 1mth, 2mths and 3mths, then annually. - If cardiac insufficiency or secondary heart failure.
Gabapentin**	U&Es Creat.	U&Es Creat.	- All Annually	
Tiagabine**	FBC LFTs	FBC LFTs	- All Annually	
Ethosuximide**	FBC U&Es Creat. LFTs	FBC U&Es Creat. LFTs	All Annually	- Blood count determinations should be performed if symptoms or signs of infection develop (e.g. sore throat, fever).
Clobazam**	U&Es Creat. LFTs Respiratory function	U&Es Creat. LFTs Respiratory function	- Annually - Annually - Annually	- Measure in patients with acute severe respiratory insufficiency
Phenobarbitone**	U&Es Creat. LFTs Serum folate FBC	U&Es Creat. LFTs Serum folate FBC	- All annually	- Give folic acid supplements if necessary - Monitor for hypothyroidism

Source: ESCA – George Eliot Hospital, Warwickshire PCT, Coventry & Warwickshire Partnership Trust

** Source: North Warwickshire PCT Recommended Blood Monitoring

Key: ACE inhibitors= Acetylcholinesterase inhibitors BP= Blood Pressure CPK= Creatinine Phosphokinase ECG= Electrocardiograph EEG= Electroencephalograph
FBC= Full Blood Count FPG= Fasting Plasma Glucose HbA_{1c}= Glycosylated Haemoglobin LFTs= Liver Function Tests
PT= Prothrombin Time TFTs= Thyroid Function Tests U&Es= Urea and Electrolytes NMS = Neuroleptic Malignant Syndrome NSAIDs= Non-Steroid Anti Inflammatory Drugs

Appendix 7: Glossary

British National Formulary (BNF)

A thorough prescribing guide for clinicians produced under the joint umbrella of the British Medical Association and the Royal Pharmaceutical Society of Great Britain.

Care Programme Approach (CPA)

A systematic approach to assessing the health and social needs of people accepted into specialist mental health services. It has four stages – the assessment of the individual's health and social care needs, the development of a care plan, the identification of a key worker and the regular review of the individual's progress and the care plan.

Care Plan (CP)

A document that is drawn up after the assessment of the individual. It contains information about the individual's health needs and arrangements for meeting those needs.

Health Action Plan (HAP)

A personal plan about what a person with a learning disability can do to be healthy. It helps people with a learning disability access the services and support that they need to be healthy.

Person-Centred Planning (PCP)

Refers to the idea that it is the person rather than services or systems that should drive planning. It ensures that healthcare provision is directed by what is important to the individual – from their own perspective. It emphasises the importance of partnerships in healthcare.

Modified Overt Aggression Scale (MOAS)

A practical and effective tool to assess aggressive behaviour and the effectiveness of interventions. It rates aggressive behaviours according to their type and frequency using a five-point Likert scale system.

Aberrant Behaviour Checklist (ABC)

A widely used scale to assess behaviour problems and assess the effectiveness of interventions. Measures the type and frequency of a range of behaviour problems including aggression, SIB and property destruction.

Positive Goals

An aid to help evaluate the effectiveness of interventions. It addresses the personal and social consequences of behaviour problems rather than just focusing on the behaviour itself. It contains 38 potential outcomes that are tailored to suit the individual. It is consistent with the principles of person-centred planning.