

Challenging Behaviours

Psychological interventions for severely challenging behaviours shown by people with learning disabilities

Clinical Practice Guidelines

St Andrews House
48 Princess Road East
Leicester LE1 7DR, UK

Tel 0116 254 9568
Fax 0116 247 0787
E-mail mail@bps.org.uk
<http://www.bps.org.uk>

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This paper was written by:

Tina Ball

Director, Psychological Health Sheffield
Sheffield Care Trust, Fulwood House, Old Fulwood Rd, Sheffield S10 3TH.

Alick Bush

Consultant Psychologist, CAISS Team
Sheffield Care Trust, 45 Wardsend Rd North, Sheffield S6 1LX.

Eric Emerson

Professor of Clinical Psychology
Institute of Health Research, Lancaster University, Lancaster LA1 4YT.

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Preface

I am delighted to write a foreword for these guidelines regarding interventions for severely challenging behaviour shown by people with learning disabilities. Challenging behaviour, in the wide range of ways in which it presents to families, care staff, and not least to other people with learning disabilities, may be threatening, or may lead to actual assault. Any well formulated guidance that helps to minimise the probability of such behaviour, and thereby to increase the likelihood that the person showing the behaviour will be more able to be accepted and included in a fuller range of social activity, is welcome.

The guidelines are very carefully constructed to follow the path from first presentation of a behavioural problem, through to evaluating the outcome of an intervention. They include both core guidance for a wide range of people to use, and more detailed guidance for specialist staff working with people with learning disabilities. They are based on a thorough review of the most relevant literature. Perhaps most importantly of all, they have been developed by psychologists with a thorough understanding of the day-to-day realities of working with people with challenging behaviour.

A wide range of clinical practice guidelines is now being produced by a range of statutory and professional bodies. These guidelines take their place alongside other guidelines developed by clinical and other applied psychologists that can be used by members of other professions, and to guide other workers in the field. They also contain useful information that is applicable to those other fields of practice where severely challenging behaviour may be displayed, such as people with behavioural difficulties arising from an acquired brain injury, or from serious mental disorder.

The best recommendation for these guidelines will be that they are widely used by a range of people in a range of settings. I commend the authors for designing them for that purpose, and hope that they will become a gold standard for work in this field.

Professor John Hall FBPsS

Chair, QUEST (The Quality and Clinical Effectiveness Sub-committee of the Division of Clinical Psychology of the British Psychological Society)

Executive summary

These Clinical Practice Guidelines have been prepared for clinical psychologists who provide psychological interventions to people with learning disabilities who also display behaviours that severely challenge services. They have been prepared by a small group of experienced clinical psychologists following a process that has included a detailed review of the relevant literature, a conference of clinicians, advice from acknowledged experts in the field, and an extensive consultation process within the profession.

This area was selected for guidelines development on account of the level of clinical need, the existence of an evidence-base, the potential contribution of clinical psychologists to this group of people, and the potentially serious consequences for people when services do not respond appropriately to their challenging behaviour.

Currently there are only a limited number of well-designed randomised controlled trials in this area, and many of the guidelines are based on case controlled studies and clinical consensus. Bearing this in mind, the guidelines make a distinction between 'good' practice and 'essential' practice, with the majority of the recommended practices falling into 'good' practice. There is therefore an emphasis in the language of the document, on 'should' and 'ought', with only a minority of the guidelines using 'must' to describe essential practice. It is the intention of the authors that the guidelines will be used in local services and by individual psychologists. They will need to be adapted for local use, especially where local policies and procedures are already available covering key aspects of the guidelines.

The guidelines lean heavily on the literature contained within the applied behaviour analysis field. This reflects the current state of research in this area. However, it is emphasised that the guidelines are applicable to psychologists from any theoretical or philosophical background.

The guidelines recommend a process that is a) person centred; b) takes account of the three elements- the person, their environment and their behaviour and the

interaction between them; and c) adopts a series of stages that include:

1. Pre-assessment

Preliminary information gathering in order to identify risk and priorities, and hence to shape the initial focus of a psychological assessment.

2. Assessment

Structured and systematic gathering of information concerning the person, the social, interpersonal and physical environment and the behaviour which is challenging.

3. Formulation

The integration of the assessment information into a hypothesis that can lead to an appropriate intervention plan and means of evaluating the accuracy of the hypothesis.

4. Intervention

An intervention for working with people who present extreme challenges that is likely to include: a) reactive behaviour management strategies that aim to contain the behaviour which presents a risk of harm or injury while; b) proactive intervention and treatment strategies are implemented through planned interventions.

5. Evaluation

Measures of change are required in order to determine the impact or effectiveness of the selected interventions.

6. Feedback

Information about the process of intervention and its effectiveness will need to be communicated to all relevant parties.

I. Introduction

These guidelines have been developed by a group of clinical psychologists who work with people who have learning disabilities (Tina Ball, Alick Bush and Eric Emerson). The basis of the guidelines has been a detailed review of the relevant literature, which provided an extensive evidence base. This process was supported by a wide reference group of experts in the field and a conference of specialist psychologists that was convened specifically to look at what constitutes current good practice in this area.

Draft guidelines were presented at the annual national conference of the Learning Disabilities Special Interest Group (now the Learning Disabilities Faculty) of the British Psychological Society's Division of Clinical Psychology (DCP) and circulated for comment within the profession. This consultation led to an amended version being submitted for peer review through the British Psychological Society Centre for Clinical Outcomes Research and Effectiveness and for circulation as a draft document. The guidelines were further updated in 2002, following a second review of the literature.

During this process, contributions have been made to key sections of the guidelines by acknowledged experts in the relevant areas. We are grateful to David Allen, Nigel Beail, David Felce, Sara Fovargue, Ian Gray, John Hall, Theresa Joyce, Glynis Murphy, Janet Robertson and Peter Wheeler. Funding and moral support for the development of the guidelines have been provided by the British Psychological Society (BPS) through the Quality and Effectiveness Subcommittee (QUEST), the Service Development Subcommittee, and the Faculty for Learning Disabilities. Colleagues in the Trent Region Faculty for Learning Disabilities have been interested and helpful throughout the process of guideline development. We would also like to acknowledge the support of colleagues in Sheffield Care Trust (previously Community Health Sheffield NHS Trust), particularly the Clinical Effectiveness Department and Psychological Health Sheffield for their flexible and practical help.

The development of the guidelines has only been possible with the input of numerous contributors. There are too

many to name everyone individually, but particular mention must be made of Karen Moore (who carried out the initial literature search), Martin Burke, Sarah Heke and Linda Lambert (who made the conference possible), Clare Burnell (who carried out detailed critiques of various drafts from very different perspectives), Katia Allchurch (who organised the final draft), Fiona MacDonald, Anna Mitchell, Sophie Heason and Karen Bartle.

These are national guidelines for clinical psychologists which will need to be adapted to local conditions. It is anticipated that local groups of psychologists will use them as a framework for developing more detailed guidelines for their own work, to inform clinical audit and the training of clinical psychologists.

Other professionals, service providers and purchasers may find them helpful in clarifying what to expect from clinical psychology and what constitutes good practice. They are not intended to advise other professionals on their practice.

We believe that psychologists have a particular role to play in working with people whose behaviour is challenging. Challenging behaviour is in itself a psychological concept, and interventions derived from psychological principles have been demonstrated to be the most effective over a number of years.¹ It is our responsibility as a profession to ensure that people with learning disabilities, their families and carers can have access to the most effective remedies for psychological distress and behaviour which is disturbing.

Although these guidelines have been derived specifically for psychologists, this is not meant to imply that only psychologists can or should provide a service for people who challenge. Good practice must be multidisciplinary and draw on the skills of the full range of clinicians. It is also absolutely essential that psychologists work in close partnership with people with learning disabilities who show challenging behaviour, and their families and carers.

These guidelines need to be read within the context of *Valuing People: A New Strategy for Learning Disabilities for the*

21st century (2001).² This White Paper sets out how the UK Government intends to provide new opportunities for children and adults with learning disabilities and their families to live full and independent lives as part of their local communities. There is a requirement to 'ensure that all agencies commission and provide high quality, evidence-based and continuously improving services which promote both good outcomes and best value' (p.90).

The White Paper recognises that commissioning and providing services for people who present significant challenges is one of the major issues facing learning disability services. Learning Disability Partnership Boards are directed to 'ensure that local services develop the competencies needed to provide treatment and support within the local area.' (p.103). These guidelines may help to achieve this.

References: Section 1

¹ Didden, R., Duker, P. & Korzilius, H. (1997). Meta-analytic study on treatment effectiveness for problem behaviours with individuals who have mental retardation. *American Journal on Mental Retardation* 101, 4, 387–399.

Within Scotland, a review of services for people with learning disabilities (*The Same As You?*)³ conducted by the Scottish Executive, outlines a vision for modernising community care, including the provision of specialist support to people who challenge services.

The guidelines have largely been prepared within a policy context relating to adults who have learning disabilities. However, the clinical evidence-base generally relates to both children and adults, and except where indicated, the guidelines should be interpreted as applying to psychologists who work with either children or adults. Psychologists who work with children are directed to the forthcoming Children's National Service Framework and the website⁴ that provides emerging findings from the NSF.

² See DoH website at www.doh.gov.uk/vpst/papers.htm

³ See the Scottish Executive website at www.scotland.gov.uk/ldsr/default.asp

⁴ See the DOH website at www.doh.gov.uk/nsf/children.htm

2. Development of the guidelines

2.1 The need to develop guidelines

The area of challenging behaviour shown by people with learning disabilities was recognised as a clear priority for the development of clinical practice guidelines by the British Psychological Society when it agreed to fund this project. There are three major reasons for this:

1. clinical need;
2. the presence of a strong evidence base describing successful interventions;
3. problems with the successful application of effective interventions.

2.1.1 Clinical need

Challenging behaviour is an area of immense clinical need. It can directly cause pain, injury and distress to people with learning disabilities, their families and care staff and other professionals working with the people concerned.

The consequences can include physical injury and even death as a result of self-injury,⁵ injury to others,⁶ distress to families,^{7 8} and stress to care staff.^{9 10}

The occurrence of such behaviour leads to people being the last to leave inappropriate hospital accommodation and the first to return to it, often out of district and at considerable expense.¹¹ Parents are more likely to look for residential care if their sons or daughters are challenging.¹² People whose behaviour is challenging are at greater risk of abuse¹³ and of living in deprived and damaging environments.¹⁴ People who are challenging are more likely to be medicated^{15 16 17} or physically restrained¹⁸ or to be subject to abusive techniques in the name of 'behavioural interventions' such as being spanked, pinched, suddenly shouted at or being given painful electric shocks.^{19 20}

Challenging behaviour is relatively common among people with learning disabilities. Numerous prevalence studies have been undertaken in the UK. Stress has been placed on the importance of social processes in leading to particular behaviours being seen as challenging. One implication of this approach is that attempts to measure the prevalence of challenging behaviour are themselves

bound by social processes. Estimates of the prevalence of challenging behaviour are influenced by such factors as: (1) the constraints and expectations of particular contexts and cultures which combine to define particular behaviours as challenging; and (2) methodological factors such as the selection of operational definitions, methods of case identification (e.g. review of case notes vs. interview with care staff) and the overall sampling strategy adopted within the study (e.g. total administratively defined population of people with intellectual disabilities, children with intellectual disabilities at school). Nevertheless, UK studies suggest that between 5 and 15 per cent of all people with learning disabilities who are known to services show behaviours which present significant challenges to carers.^{21 22 23 24 25} Similar prevalence rates have been reported in North America.²⁶

Qureshi, Kiernan and colleagues²⁴ conducted a survey in 1987 in seven administrative areas in the North West of England with a total (general) population of 1.54 million. They screened approximately 4200 people with learning disabilities and identified people as showing serious challenging behaviours if they had either:

- at some time caused more than minor injury to themselves or others, or destroyed their immediate living or working environment; or
- showed behaviours at least once a week that required the intervention of more than one member of staff to control, or placed them in danger, or caused damage which could not be rectified by care staff, or caused more than one hour's disruption; or
- showed behaviours at least daily that caused more than a few minutes disruption.

Using this definition, 1.91 people per 10,000 of the general population (range 1.41 to 2.55 per 10,000 across the seven areas) were identified as having learning disabilities and serious challenging behaviour. This translates to an estimated prevalence rate of 7 per cent of all people within these areas who had been administratively defined as having learning disabilities. In a follow up study, Emerson *et al* (2001)²⁷ repeated the procedures used in

the 1987 study in two of the original areas (total population, 0.47 million). Using a slightly amended definition of 'serious', they reported overall prevalence rates of 3.62 people per 10,000 of the general population as having learning disabilities and serious challenging behaviour (equivalent to 8 per cent of the people with intellectual disabilities who were screened). Combining the results of these studies gives an overall prevalence for serious challenging behaviour of 2.40 per 10,000 of the general population or 7.3 per cent of people administratively defined as having learning disabilities.

People who show one kind of challenging behaviour are likely to show other kinds as well.^{27 28 29 30 31 32} For example, people who self-injure are likely to engage in more than one type of self-injurious behaviour. Oliver *et al.*²⁹ found 54 per cent of their population showed two or more types of self-injurious behaviour. Murphy *et al.* (1993),³⁰ in a study of people whose self-injury was severe enough for them to be given protective devices, found that 40 per cent were also physically aggressive and 36 per cent were destructive to property. A sizeable minority of people with learning disabilities therefore show severe and multiple forms of challenging behaviour.

2.1.2 Evidence base demonstrating successful interventions

Extensive literature searches and meta-analyses^{33 34} have demonstrated that interventions which are based on psychological principles derived from learning theory, are currently the most effective interventions for reducing the incidence of challenging behaviour in people with learning disabilities. The meta-analysis by Didden³³ and colleagues in particular, argues that the literature demonstrates a convincing level of change in terms of reducing challenging behaviour through the use of systematically applied behavioural approaches. The impact is much more effective than that demonstrated by medication, for example.³⁵

There is some evidence to support the effectiveness of cognitive behavioural interventions for the management of anger and impulsiveness in people with learning disabilities who have the motivation and the cognitive and communication skills to use such approaches.³⁵

There are also a few studies which indicate that changes to the service environment can reduce the incidence of challenging behaviour in that setting.³⁶

2.1.3 Problems with the application of effective interventions

The application of these techniques in everyday clinical practice and as reported in the literature is neither as systematic nor as effective as might be hoped. The majority of people whether in institutions, in the community or at home with their families are not receiving any effective psychological interventions for their challenging behaviour.^{37 38 39}

A related problem is that punitive and aversive techniques of behavioural control have been misused with people with learning disabilities. Attempts are still made to justify bad practice and abuse by calling it a 'behavioural programme'.

Clements⁴⁰ has suggested that one reason for the failure to use applied behavioural techniques of demonstrable effectiveness is that the scientific approach lost favour among some psychologists because of its identification with a narrow behaviourism which was 'cold, mechanistic, manipulative and non-humanistic'. Certainly some of the older studies of interventions for challenging behaviour are aversive to read because of their apparent lack of empathy with the 'subjects', but in more recent work in the applied behavioural tradition, humanity and creativity are very evident.⁴¹ Clements argues against a narrow view and urges the reapplication of mainstream psychological thinking to work with people who challenge services. Mainstream psychological thinking would of course include thinking about cognitions, emotions and organisations, for example, as well as behaviour.

Another possible reason suggested by colleagues during the consultation period for these guidelines was that effective work was intensive and time consuming. Many clinical psychologists feel under pressure to work rapidly and see large numbers of people to maintain high activity counts. Challenging behaviour creates its own pressures too – the severity of the problem can lead to a need for interventions to be in place rapidly. But speed of response and the need to work with as many people as possible should not be at the cost of being effective. Applied behavioural approaches – functional analysis, setting up and evaluating appropriate interventions – are time-consuming but clinically effective. The other approaches for which there is some evidence of effectiveness in reducing challenging behaviour – cognitive behavioural interventions

and organisational change – also take time to be carried out effectively. Perhaps psychologists need to develop more confidence in the effectiveness of what they do so that they can invest the time that is necessary to be effective.

A third possible reason is that the work is difficult and involves spending time with people who are challenging to psychologists as well as to services, and with groups of

staff who may be demoralised and demotivated. As well as the evidence demonstrating the effectiveness of psychological interventions for challenging behaviour, there is also a literature which shows the persistence of many challenging behaviours.^{42 43} We need to look to support and development systems for psychologists, and how we motivate ourselves as well as others to persist with difficult and enduring problems.

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3. Definitions

3.1 Learning disability

People with learning disabilities do not constitute an homogeneous group. However, in terms of diagnosis and classification there are a number of features of learning disability which have gained widespread acceptance across professional boundaries within the UK and America. Irrespective of the precise terminology, or the wording in the various definitions, there are three core criteria for learning disability:⁴⁴

- significant impairment of intellectual functioning;
- significant impairment of adaptive/social functioning;
- age of onset before adulthood.

This definition is consistent with the ones provided in the *Valuing People* White Paper,⁴⁵ American Association on Mental Retardation,⁴⁶ ICD-10 (World Health Organisation),⁴⁷ DSM-IV (American Psychiatric Association)⁴⁸ and Department of Health.⁴⁹

The term 'learning disabilities' is not being used in these guidelines for people with specific areas of learning difficulty (e.g. dyslexia) who do not meet the criteria above.

3.2 Challenging behaviour

The definition of challenging behaviour most commonly used in services is:

*Severely challenging behaviour refers to behaviour of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or delay access to and use of ordinary community facilities (Emerson et al., 1988).*⁵⁰

The behaviour needs to be seen as abnormal in the context of the person's culture.

Felce and Emerson⁵¹ elaborated on this definition in 1996 when they said:

One of the reasons for the adoption of the term 'challenging behaviour' was to provide a reminder that severely problematic

or socially unacceptable behaviour should be seen as a challenge to services rather than a manifestation of psychopathological processes. In order to respond to this challenge services need to promote positive behavioural development, reduce the occurrence of damaging behaviour and maintain people's access to a decent quality of life despite continuing behavioural difficulties

The usual definition of challenging behaviour raises as many questions about the design and flexibility of support services as it does about people with learning disabilities themselves. There is also the concern that the people who challenge should be seen in terms of their strengths, skills, development and quality of life as well as their challenging behaviour.

Any review of the literature on challenging behaviour demonstrates how broadly the term can be used. The database developed by Didden⁵² and his colleagues lists over 50 different behaviours, ranging from adipisia to vomiting. Many authors have dealt with the problem of definition by concentrating on a particular sub group of behaviours, such as self injury or aggression.^{53 54} But prevalence studies that have looked at a wide range of challenging behaviours have indicated that such behaviours often coexist.^{55 56 57}

As already discussed in Section 2.1.1, one approach has been to define the behaviour in a more precise operational way. Hazel Qureshi, for example, in her survey of the incidence of challenging behaviour in the North West of England defined people as showing challenging behaviour if they:

- Had at some time caused more than minor injuries to themselves or others or destroyed their immediate living or working environment; or
- Showed behaviours at least once a week that required the intervention of more than one member of staff to control, or placed them in physical danger, or caused damage which could not be rectified by care staff, or caused more than one hour's disruption; or

- Showed behaviours at least daily that caused more than a few minutes disruption.⁵⁵

This was revised in follow-up studies, when Emerson and his colleagues defined people with ‘more demanding challenging behaviour’ as meeting at least one of four criteria:

- they showed challenging behaviour at least once a day;
- their challenging behaviour usually prevented the person from taking part in programmes or activities appropriate to their level of ability;
- their challenging behaviour usually required physical intervention by one or more members of staff;
- their challenging behaviour usually led to major injury (i.e. injury requiring hospital treatment) to either the person themselves, carers or other people with learning disabilities.⁵⁸

Clements⁵⁹ has suggested that behaviour should be identified as ‘problematic’ if it meets two of the following three criteria. The behaviour should be:

- unacceptable by the social standards relevant to the person’s age, class and cultural background;
- imposing (or threatening to impose) a significant cost on the person himself (e.g. physical damage, social rejection, limiting opportunities for learning);
- imposing (or threatening to impose) a significant and unreasonable cost on the lives of others.

Other more qualitative researchers have asked parents or care staff to identify what is challenging or problematic for them and worked from that basis, building up a shared understanding of what is challenging behaviour. Hastings⁶⁰ showed that care staff he interviewed defined challenging behaviour in a variety of ways:

- challenging/difficult for others;
- not the norm/not acceptable;
- extreme reaction to ‘normal’ events;
- defined by examples;
- to be controlled/changed.

His work is illuminating for its consideration of how staff beliefs can affect their actions in containing or working with challenging behaviours.

‘Challenging behaviour’ is a term that has been widely adopted since its first introduction to the United Kingdom

in 1987. This may be partly because of the ever-present wish to provide new euphemisms for disturbing experiences.⁶¹ However, it seems to be a useful concept to many people providing services for people with learning disabilities because of the emphasis it places on the social and interactive nature of such behaviours. There is a risk that this emphasis can be lost if it subsumed under more biological based headings such as ‘mental health’ as in the NHS Executive paper *Signposts for Success*.⁶²

Some psychologists have argued that an excessive focus on the challenging behaviour can divert attention away from important issues of how people with learning disabilities can be supported to live full and valued lives. These guidelines will indicate that priority must be given to helping people with learning disabilities who show challenging behaviours to learn new skills, participate in their communities and reach their full potential. But we do a disservice to these individuals and to those living with them or caring for them if we do not address the behaviours which can become such an enormous barrier to individual development and result in social exclusion. Fox and Emerson⁶³ have shown that a range of different stakeholders rate a reduction in the severity of challenging behaviour to be the most important outcome of interventions. The complexity of the definition of challenging behaviour reflects the nature of work with people who are challenging. The definition needs to be both tangible, so that the behaviours can be measured and worked with, and dynamic, so that the social and interactive elements are not lost. The use of the term ‘challenging’ to describe behaviours is an attempt to make this clear.

3.3 Clinical practice guidelines

Clinical practice guidelines are defined as:

*systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances.*⁶⁴

Guidelines refer specifically to the process of clinical care. They need to be both scientifically valid and relevant to day-to-day practice.⁶⁵

Scientific validity can be measured by the use of a thorough and systematic review of the relevant literature. Some research is of higher quality than others and care needs to be taken that this factor is recognised and taken account of in the literature review. In the development of clinical practice guidelines in the North of England project, for

example,⁶⁶ evidence was categorised according to three levels:

Level 1: evidence from well-designed, randomised controlled trials, meta-analyses or systematic reviews;

Level 2: evidence from well-designed cohort or case controlled studies;

Level 3: evidence from uncontrolled studies or clinical consensus.

We have chosen to adopt these same three levels when weighing up the different degrees of evidence to support these guidelines.

Guidelines are seen as an important element of 'clinical governance' in the new NHS (Department of Health, 1998). National guidance on good practice in health services for people with learning disabilities states that:

*'Whenever possible interventions and services should be based on evidence of effectiveness. When this is not available a consensus view of good practice is used.'*⁶⁷

The National Institute for Clinical Excellence (NICE)⁶⁸ was set up as a Special Health Authority for England and Wales

in 1999, with a role to provide patients, health providers and the public with authoritative, robust and reliable guidance on current best practice, for a range of procedures and clinical conditions. NICE has not yet commissioned the development of guidelines relating to people with learning disabilities who challenge services. However, a guideline on 'disturbed (violent) behaviour: the short-term management of disturbed (violent) behaviour in adult psychiatric inpatient settings' is due for completion in August 2004. This is likely to have some applicability to psychologists in this field, although adults with learning disabilities are not covered by the guidelines.

Parallel to NICE is the Social Care Institute for Excellence (SCIE)⁶⁹ launched in 2001 with a remit to improve quality in social care services across England and Wales. SCIE, with links to the electronic library for social care⁷⁰ is in the early stages of developing a range of Best Practice Guides.

Other useful links are the National Electronic Library for Health Website⁷¹ and the Centre for Evidence Based Social Care.⁷²

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- ⁷² See Centre for Evidence Based Social Care website at www.ex.ac.uk/cebss/

4. Process of developing the guidelines

The process of developing these guidelines has had five main components:

1. An extensive review of the literature on psychological interventions for challenging behaviour.
2. The organisation of a conference of clinical psychologists working with people with learning disabilities and with an interest in good practice in the field of challenging behaviour, with a view to identifying clinicians' views on good and bad practice.
3. The presentation of draft guidelines at the annual national Special Interest Group (Learning Disabilities) Conference of the British Psychological Society (now the 'Faculty for Learning Disabilities') and subsequent dissemination of the draft guidelines to psychologists working with people with learning disabilities for comments.
4. The revision of the guidelines following comments received.
5. Peer review of the revised guidelines and final amendments.

4.1 Literature review

A key component of the process of developing the guidelines was the systematic literature review of the PsychINFO database (1982 to 2001) and Medline database (1982 to 2001). The review included 'clinical practice guidelines', 'challenging behaviour' and its synonyms and 'psychological interventions' in people with 'learning disabilities'. We have had access to the Problem Behaviour Database designed by Didden, Duker and Korzilius in Holland which holds summaries of 1000 studies from 31 international journals over 25 years (up to 1995). We have been very grateful for the many review articles, edited collections or collections of key articles, and the meta-analyses^{73 74} which have made it easier to come to grips with the evidence base of interventions for challenging behaviour, within the resources available to us. We have not been able to go back to all the original material over the last 40 years and re-analyse it in a systematic, weighted way, and so have been dependent on the meta-analyses, reviews and key articles (identified by frequent citation) as the basis of the review.

We have also been interested to see other attempts to provide a systematic framework for looking at psychologists' work in the area of challenging behaviour. There have been many debates about the ethics and effectiveness of behavioural interventions.^{75 76 77} Previous attempts have been made to provide systematic statements of acceptable practice in the USA and Australia.⁷⁸

A special edition of the *American Journal on Mental Retardation* describes⁷⁹ the development of seven guidelines for the treatment of psychiatric and behavioural problems in mental retardation. They adopted a process of surveying 48 experts on the psychosocial treatment and 45 experts on the medication treatment of mental retardation.

In the British context, Clements⁸⁰ suggests five criteria that should be applied to judging a framework to guide interventions for challenging behaviour. Such a framework should include:

- derived from mainstream psychology;
- extensive;
- generative;
- humanistic;
- disseminable.

We have found these suggestions helpful in the development of these guidelines, and have used them as guiding principles.

4.2 Clinical consensus

Relevance to day-to-day practice can be assessed by consulting with clinicians in both formal and informal ways (e.g. by questionnaire, at conferences, by monitoring the implementation of the guidelines). Involving practising clinicians in the development of guidelines has been found to be particularly helpful in ensuring that they are relevant. These guidelines were developed by psychologists working with people with learning disabilities and challenging behaviour, with support and comments from many other practising psychologists. This is similar to the approach used by Rush and Frances.⁸¹

Academic and clinical experts with experience of working with people who present extreme challenges, were invited to a consensus conference. Various presentations provided an overview of current 'best practice' in the field, and gave an opportunity to check the validity of the information derived from the literature review, against current expert opinion. Identifying clinical consensus has been particularly important in those areas of psychological practice where the literature is least extensive.

Draft guidelines were drawn up, based upon the systematic literature review and consensus conference. These were presented to the Division of Clinical Psychology's Special Interest Group and through circulation within the profession. This generated 30 detailed comments from both individuals and groups of psychologists. Specific comments were sought from acknowledged experts. On the basis of the feedback, the guidelines were redrafted with a further updating of the literature.

The revised guidelines were submitted for peer review by members of the Division of Clinical Psychology of the British Psychological Society through the Service Development subcommittee and the Quality and Effectiveness subcommittee.

4.3 The scope of the guidelines

These guidelines focus specifically on interventions that are designed to provide effective help for people who are challenging. They have been guided to a considerable extent by the published literature, because of a need to be able to evaluate interventions critically and establish whether a particular approach can be replicated. We have not included the more general literature about working

effectively with people with learning disabilities as that is beyond the scope of these guidelines. However, we would like to make it very clear that we consider that the literature on creating positive environments and supporting people with learning disabilities in reaching their full potential as members of society must be applied to people who are described as challenging. The guidelines indicate that it is unethical to attempt to prevent challenging behaviours without looking at the social and organisational environments in which they occur, and attending to the individual's needs for growth, development and safety.⁸²

Although some of the feedback to us has suggested that these guidelines should be applied only to those psychologists working in the behavioural tradition, this is not our intention. Those of us working on the guidelines come from a variety of therapeutic backgrounds, and are keen that people with learning disabilities should benefit from the full range of psychological interventions available to anyone else in this country. These guidelines are intended to be of use to all clinical psychologists working with people with learning disabilities who present challenges to services.

We would also direct psychologists to the relevant specialist clinical psychology literature for work on mental health and forensic issues. We believe it is important for psychologists working with people with learning disabilities to keep up to date with more general psychological thinking and to seek to apply developments in the mainstream to work with people with learning disabilities.

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5. Ethical, professional and legal context

People with learning disabilities are disempowered and potentially vulnerable to abuse or neglect in our society. Their lack of power reduces their ability to challenge poor practice and restricts their access to redress. Psychologists' professional transactions with this group must therefore be informed by a strong set of ethical standards and values. These values need to be stated clearly, so that they are open to challenge and can be developed further.

The clinicians' conference identified many areas of ethical concern about working with people with challenging behaviours and groups of staff who may feel very challenged. For example, psychologists face ethical dilemmas about whether to continue working in particular settings which they believe may be causing challenging behaviour or be deleterious to the psychological or physical health of staff or people with learning disabilities.⁸³

The question of aversiveness – while often simplified by service bans on the use of any aversive procedures – remains a dilemma when both formal and informal interventions are assessed carefully on an individual basis. What is reinforcing for one person (e.g. physical contact) may be highly aversive for another. A programme which is non-aversive in theory (e.g. voluntary time alone 'to calm down') may be aversive in practice (enforced seclusion for someone who enjoys time with staff).⁸⁴

It is essential that ethical considerations as well as the evidence base and clinicians' consensus on good practice inform guidelines in the field of challenging behaviour.

There are four possible components to an ethical framework that can be used to inform psychologists' decision-making about interventions for challenging behaviour:

1. the law – legal requirements, duties and restrictions;
2. professional standards and advice such as the British Psychological Society Code of Practice;
3. local standards, policies and procedures (e.g. Trust statements on use of aversive procedures; local

authority adult abuse policies);

4. personal ethical beliefs and principles.

Psychologists need to ensure that they are familiar with the law and local and national policies and procedures, and also that they have the opportunity for expert advice and discussion with experienced colleagues in areas where these more formal sources of guidance are lacking or unclear.

5.1 The Law

Duty of Care

A psychologist, like any other health professional, has a common law duty of care towards people with learning disabilities with whom he or she is working.⁸⁵ This means

*taking reasonable care to avoid acts or omissions which are likely to cause harm to another person.*⁸⁶

Where challenging behaviour is causing harm to the person or others (as is clearly the case with aggressive behaviour or self-injury), it can be argued that the psychologist's duty of care is to intervene as effectively and appropriately as possible. There is no legal guidance as to positive interventions for challenging behaviour – this is a clinical rather than a legal issue – but the law does specify what is unlawful.

Formal and informal interventions run the risk of being against the criminal or civil law if they constitute assault, battery or false imprisonment.⁸⁷ *Assault* is when a person is in fear of being attacked by another (e.g. the threatened use of restraint). *Battery* is inflicting unlawful violence on another (e.g. touching, holding, pushing). *False imprisonment* is the unlawful or reckless restraint of victims' freedom of movement (e.g. seclusion or use of a 'time-out' room, preventing someone from leaving a room or building through locks or physical restraints).

The law recognises that there are occasions when actions which may be illegal may be justified if there is an overriding need to prevent a greater harm, for example, to prevent suicide or to prevent other people being harmed

or to prevent damage to property. People with learning disabilities can be detained lawfully under the Mental Health Act 1983 if they are deemed to have a 'mental disorder'. They may be detained under Section 2 for assessment for a mental disorder. A treatment order (Section 3) requires identification of the disorder as mental illness, mental impairment, severe mental impairment or psychopathic disorder.

Following the Bournemouth ruling there is debate about the legality of restricting the movements of people with learning disabilities who can not easily give consent, and are not detained under the Mental Health Act. In the Bournemouth issue, patient L was compliant about remaining in hospital, but unable to consent to this, due to incapacity. He was therefore not formally detained but he did not consent to the admission. This deprived him of the rights that detained patients have, to have their detention considered. It is not clear that the Draft Mental Health Bill, 2002, will resolve this, although the Draft Mental Incapacity Bill might be more useful. This case is currently being considered by the European Convention of Human Rights.

Psychologists should ensure that they are aware of the legal status of their clients, in relation to the Mental Health Act (1983) and the new Act when it appears, and also to the Mental Incapacity Bill.

Capacity and consent to treatment

If a patient is touched without their valid consent, the health professional involved may be liable to civil or criminal proceedings. For consent to be valid the person must: i) have the capacity to consent to or refuse the treatment/intervention in question; ii) give their consent voluntarily; and iii) be appropriately informed.⁸⁸

The law is concerned about the ability of people with learning disabilities to consent to treatment, which includes psychological treatment for challenging behaviour. All adults (people over 18 years old) are presumed to be able to consent to treatment⁸⁹, but doubts may be raised about the capacity of a person with a learning disability to give consent. To be competent to make their own decisions, patients have to i) be able to take in and retain the treatment information; ii) believe it; and iii) be able to weigh up that information, balancing its risks and benefits.⁹⁰ This is a functional approach to the assessment

of capacity which means that mental incapacity attaches to specific, thus

*a person may be considered capable of making a decision in one set of circumstances (but not in another) and at one point in time (but not at another).*⁹¹

Intellectual ability is not regarded as a good predictor of capacity to treatment,⁹² and a psychologist making a decision about someone's capacity to consent to an intervention needs to look at the particular individual and their specific circumstances. The individual's capacity to consent will have to be assessed anew for each occasion as the complexity of the decisions (and the person's capacity) may vary.⁸⁷ Furthermore, as the Department of Health has noted:

*Care should also be taken not to underestimate the capacity of a patient with a learning disability to understand. Many people with learning disabilities have the capacity to consent if time is spent explaining to the individual the issues in simple language, using visual aids and signing if necessary.*⁸⁸

The British Medical Association has recently produced a Consent Tool Kit which suggests that to demonstrate capacity, individuals should be able to:

- understand in simple language what the medical treatment is, its purpose and nature and why it is being proposed;
- understand its principal benefits, risk and alternatives;
- understand in broad terms what will be the consequences of not receiving the proposed treatment;
- retain the information for long enough to make an effective decision; and
- make a free choice (i.e. free from pressure).⁹³

These may be useful practical tips in determining capacity; however, it is important to note that these are guidelines and are not legally binding. Thus, the psychologist must ensure that they comply with the *Re C* test.⁹⁴

A joint working party of the BPS, DCP Faculty for Learning Disabilities and Faculty for Older People is developing guidelines on consent for clinical psychologists. In the meantime it would seem appropriate to apply these same criteria to psychological interventions for challenging behaviour. The psychologist has a duty of care which means they may be negligent if they do not provide an

intervention when it is required to preserve the life, health or well-being of the person.

If, following the use of the *Re C* test,⁹⁴ it is decided that a person is unable to consent to or refuse treatment, *no one else* can provide consent for that person.⁹⁵ The common law doctrine of necessity is used to provide or withhold treatment in this situation, thus health professionals may carry out treatment/interventions which are in the best interests of that patient. Such treatment will be in a person's best interests only if it is carried out to save life, or ensure improvement or prevent deterioration in their physical or mental health. The 'best interests test' dictates that health professionals will not be liable for providing or withholding treatment that they believe to be in the patient's best interests if that belief is supported by a responsible body of medical opinion.⁹⁶ No further legal guidance is provided on the 'best interests test'; however, the General Medical Council⁹⁷ has suggested that in deciding what may be in the best interests of a patient, account could be taken of:

- options for treatment or investigation which are clinically indicated;
- any evidence of the patient's previously expressed preferences, including an advance statement;
- your own and health care team's knowledge of the patient's background, such as cultural, religious or employment considerations;
- views about the patient's preferences given by a third party who may have other knowledge of the patient, for example the patient's partner, family, carer ... or a person with parental responsibility;
- which option least restricts the patient's future choices, where more than one option (including non-treatment) seems reasonable in the patient's best interests.

The British Government has also examined how the best interests of a person should be determined and suggested that the following should be considered:

- the ascertainable past and present wishes and feelings of the person concerned and the factors the person would consider if able to do so;
- the need to permit and encourage the person to participate or improve his or her ability to participate as fully as possible in anything done for and any decision affecting him or her;
- the views of other people whom it is appropriate and

practical to consult about the person's wishes and feelings and what would be in his or her best interests;

- whether the purpose for which any action or decision is required can be as effectively achieved in a manner less restrictive of the person's freedom of action;
- whether there is a reasonable expectation of the person recovering capacity to make the decision in the reasonably foreseeable future;
- the need to be satisfied that the wishes of the person without capacity were not the result of undue influence.⁹⁸

Again it is important to note that the GMC guidelines and the suggestions in *Making Decisions* are *not legally binding*, although they may be of help in practice. Further suggestions are also provided in the *BMA Consent Tool Kit* and *The Lord Chancellor's Department*.⁹⁹

The decision-making process about providing treatment must be carried out in a thoughtful way and the reasons for proceeding with an intervention should be well-documented.¹⁰⁰ Normally, psychologists would be expected to have considered the person's capacity to consent and, if they think the person not able to take a decision, they should ensure that alternatives are discussed in a multidisciplinary meeting, preferably including the person's family, GP, advocate, paid carers and others. As well as 'capacity' for consent to be valid it is necessary to demonstrate that the person gave their consent *voluntarily* and that they were appropriately informed:

Voluntariness – Consent must be freely and voluntarily given, without pressure or undue influence being exerted by partners, family members, or health professionals. The Department of Health notes that there is a potential for the offer of treatment to be perceived as coercion in situations where involuntary detention may be an issue. However, it emphasises that there is a distinction between coercion and reassuring a patient about the benefits of a treatment, but notes that withdrawal of privileges, for example, or using other ways to induce consent is unacceptable and coercion will invalidate the consent.¹⁰¹

Information – For consent to be valid, a patient must be informed in broad terms of the nature of the procedure intended.¹⁰² A health professional will be considered negligent if they do not provide information which a responsible body of medical practitioners would provide (the *Bolam* test – see above).¹⁰³ Health professionals

should try and ensure that patients are able to make a balanced judgement on whether to give or refuse consent, but it is advisable to inform the patient of any 'material' or 'significant' risks in the proposed treatment/intervention, any alternatives to it, and the risk incurred by doing nothing. The health professional will normally be responsible for informing a patient of 'a significant risk which would affect the judgement of a reasonable patient'.¹⁰⁴

Both the GMC and BMA have considered the question of information provision, and have provided extensive guidance, not legally binding, on this issue.^{105 106}

Further guidelines on assessing a person's capacity to consent are presented in Section 9.

Human Rights Act

The Human Rights Act 1998 brings the rights outlined in the European Convention of Human Rights into English Law for the first time. It is designed to protect individuals from abuse by state institutions and people working for these institutions. Several of the articles will have particular relevance to psychologists involved with people who are challenging. These include 'no torture, inhuman or degrading treatment' (article 3), 'the right to liberty and security' (article 5), 'no punishment without law' (article 7). It is likely that the inappropriate use of procedures with people who present challenges, would potentially contravene article 3.

Physical interventions

For the first time, joint guidance on the use of restrictive physical intervention has been prepared by the Department of Health and the Department for Education and Skills.¹⁰⁷ This guidance covers all areas of service that children and adults with learning disabilities and difficulties will use throughout their lives. Physical intervention refers to direct physical contact between one person and another, or to physical contact mediated by an instrument or device. This guidance is specifically concerned with restrictive physical interventions which involve the use of force to restrict movement or mobility or the use of force to disengage from dangerous or harmful physical contact initiated by pupils or service users. The purpose of the Guidance is to ensure that restrictive physical interventions (which employ force) are used as infrequently as possible, that they are used in the best interests of the service user,

and that when they are used, everything possible is done to prevent injury and maintain the person's sense of dignity. Restrictive physical intervention should be seen as one part of a broader strategy to address the needs of children and adults whose behaviour poses a serious challenge to services.

The inappropriate use of physical intervention may give rise to criminal charges, action under civil law or prosecution under health and safety legislation. As a general rule, restrictive physical interventions should only be used when other strategies (which do not employ force) have been tried and found to be unsuccessful or, in an emergency, when the risks of not employing a restrictive intervention are outweighed by the risks of using force.

Any restrictive intervention should employ the minimum reasonable degree of force to prevent injury or avert serious damage to property. Its use should be minimised by the adoption of fully documented risk assessment and preventative strategies whenever it is foreseeable that the use of force might be required.

All organisations that provide a service to adults or children with a learning disability or autistic spectrum disorder should have a policy on the use of restrictive physical interventions. Psychologists and others who work with someone when restrictive physical interventions may be utilised, are strongly advised to familiarise themselves with local policies and the Joint Guidance.¹⁰⁸ Other publications that provide advice and guidance on its use should also be referred to.^{109 110 111}

At present there is clearer guidance on the legal position of children with learning disabilities.¹¹² The legal situation for adults with learning disabilities is less clear and at the time of writing is under review.¹¹³

It is particularly important at present for psychologists working with adults to have access to legal and other expert professional advice over difficult cases. The advice of the Official Solicitor can be sought in difficult and complex cases.

Disclosure of an offence by a client

A psychologist may be in the situation of a client disclosing information about an offence. This may occur

when a psychologist is working within a forensic setting or when the client's challenging behaviour includes offending behaviour. This can present the psychologist with a potential dilemma regarding issues of confidentiality. Generally there is no requirement in English law to take steps to prevent a crime. However, in some legislation there are offences concerning such things as 'knowingly suffer'.¹¹⁴ Additionally there are offences of complicity such as 'accessory' or 'assisting'. Whilst the Sex Offences Act 1956 creates no such offence in relation to the situation described, case law and the 1967 Criminal Law Act may.¹¹⁵

Since 1967, the offence of 'assisting' has been defined in s.4(1) Criminal Law Act 1967. This provides that:

Where a person has committed an arrestable offence, any other person who knowing or believing him to be guilty of the offence or some other arrestable offence, does without reasonable authority or reasonable excuse act with intent to impede his apprehension or prosecution shall be guilty of an offence.

As yet there is no case law directly relating to a psychologist withholding information about an offence that was described by a client, and it is likely that for an offence to be committed it would require a positive act on behalf of the psychologist intended to impede the apprehension or prosecution of the offender.¹¹⁶ In common law, inaction by a psychologist may be regarded as 'complicity through omission to exercise control'. This recognises that in certain limited circumstances a person may be incriminated by their failure to act. Once again there is as yet an absence of relevant case law. It is likely that whether or not a psychologist was guilty of an offence would rest on whether they had a right to control the client. This may occur if the offender was detained under section of the MHA and the therapist was the responsible medical officer or nurse using the powers invested in them under the Act. Although this may not currently impact on psychologists, proposed MHA reforms and the potential introduction of the 'clinical supervisor' role could change this situation.

5.2 BPS Code of Conduct

In addition to the law of the land, chartered clinical psychologists are also bound by the British Psychological Society Code of Conduct¹¹⁷ and should make sure that they are familiar with it.

The Division of Clinical Psychology of the BPS has published a supplement to the Society's Code of Conduct, in the form of *Professional Practice Guidelines*,¹¹⁸ providing specific guidance to clinical psychologists. These guidelines describe the components of good standards of practice that will ensure the delivery of the highest quality services by clinical psychologists. Psychologists who work with people who show challenging behaviours should be familiar with the *Professional Practice Guidelines*.

The *Code of Conduct* (BPS, 1991) makes a general statement:

In all their work psychologists shall value integrity, impartiality and respect for persons and evidence and shall seek to establish the highest ethical standards in their work. Because of their concern for valid evidence, they shall ensure that research is carried out in keeping with the highest standards of scientific integrity. Taking account of their obligations under the law, they shall hold the interest and welfare of those in receipt of their services to be paramount at all times and ensure that the interests of participants in research are safeguarded.

As people with learning disabilities who show challenging behaviour are in receipt of psychologists' services, it is clear that their interest and welfare must be paramount.

The Code of Conduct then goes on to provide more detailed guidance on four areas:

- competence;
- obtaining consent;
- confidentiality;
- personal conduct.

Competence

Psychologists need to maintain and develop their professional competence, and recognise their limitations, ensuring that they work within the limits of their skills. The BPS has published a set of enabling guidelines¹¹⁸ in order to facilitate the continued professional development of Chartered psychologists.

Consent

Psychologists can only carry out interventions with the valid consent of participants. This requires providing accurate and not exaggerated information to the service user, ensuring that the person is giving free and informed consent and that they know that they can withdraw their

consent at any time. Detailed discussion on these issues can be found in Sections 5.1 and 9.

The Code of Conduct recognises that it may be difficult for people with learning disabilities, those living in institutions or people detained under provision of the law to give valid consent and urges psychologists to recognise and uphold their rights. After consultation with colleagues, the psychologist needs to weigh up the balance between the duty of care (i.e. to provide an effective intervention for a challenging behaviour that puts the person or others at risk) and the obligations to intervene only with a person's valid consent. It is important that the service user is involved in the process as far as is possible.

Confidentiality

Psychologists must take all reasonable steps to preserve the confidentiality of information acquired through their professional practice or research, and protect the privacy of individuals or organisations about whom information is collected or held. Confidentiality is to be kept subject to the requirements of law.

The Code is clear that confidentiality may be breached in exceptional circumstances where there is sufficient evidence to raise serious concerns about the safety or interests of recipients of services, or about others who may be threatened by the recipients' behaviour. In such circumstances, prior consent to disclosure should be sought if possible. Failing that, the psychologist should consult with an experienced and disinterested colleague, unless the delay caused by seeking this advice would involve a significant risk to life or health. Within each NHS Trust there will be a 'Caldicott guardian' whose advice may be sought. The identity of individuals and organisations should not be revealed either deliberately or inadvertently without their express permission. The ability of people with learning disabilities to give valid consent to disclosure is again problematic. Similar considerations should be applied as with ability to consent to treatment.

It should be noted that the confidentiality of organisations is to be respected as well as that of individuals. The majority of psychologists in learning disability services work in teams, where it is common practice to share information about both individuals and organisations. People with learning disabilities (and perhaps especially those whose behaviour is challenging to services) are often

known to teams for many years and it is too easy for them to acquire 'reputations' which are not respectful. Psychologists must beware the dangers of gossiping about people who use their services. They must also ensure, however, that they do pass on accurate information (e.g. about risky behaviour presented by the person, or of abuse perpetrated on them) when this is necessary to prevent harm.

Personal conduct

The BPS Code of Conduct also provides guidance about a psychologist's personal behaviour and conduct:

*Psychologists shall conduct themselves in their professional activities in a way that does not damage the interest of the recipients of their services ... and does not undermine public confidence in their ability to carry out their professional duties.*¹²⁰

Specifically, psychologists should not work when their practice is impaired through alcohol, drugs, illness or personal stress. They should not exploit their professional relationship with people to gratify their personal desires or to secure financial benefits. They will take steps to maintain adequate safety standards at work. They will not allow their professional responsibilities or standards of practice to be swayed by considerations of religion, race, age, nationality, party politics, social standing, sexual orientation, class or other extraneous factors. A client's learning disability would clearly be relevant here: a psychologist must not apply lower standards of practice because of a person's disability.

Psychologists also have the responsibility to act when they suspect misconduct by a professional colleague. If this cannot be addressed by discussion with the person concerned, then the psychologist must bring it to the attention of those with the responsibility to investigate it. In addition to the BPS *Code of Conduct*¹²⁰ and the DCP *Professional Practice Guidelines*,¹²¹ psychologists should also be aware of other relevant documents from the professional body. These include:

- DCP – *Guidelines for Clinical Psychology Services*.¹²² This document sets out to clarify the standards that can be expected of psychology services. These concern the generic non-clinical aspects of services rather than specific clinical interventions and procedures.
- DCP – *Core Purpose and Philosophy*.¹²³ This includes sections on the philosophy, purpose and aims of the profession.
- DCP – *Guidelines for Continuing Professional*

Development.¹²⁴ This sets out guidelines that will facilitate the continuing professional development of all qualified clinical psychologists to ensure that they maintain their professional competence to provide the psychological services they are offering or agreeing to offer.

- DCP – *Clinical Psychology and Case Notes: Guidance on Good Practice*.¹²⁵ This provides specific guidance for clinical psychologists based upon the requirements outlined in *HSC 1999/53 – For the Record*.¹²⁶ It sets out to ensure that clinical records are properly controlled, readily accessible, available for use, and disposed of or archived properly.
- *DCP Information Leaflet No.6 – Guidance on clinical psychology workforce planning*.¹²⁷ This document provides guidance on the development of an appropriate clinical psychology workforce within local health services. Recommended staffing levels are provided for services for people with learning disabilities which would include people whose behaviour challenges services.
- BPS – *Working in Teams*.¹²⁸ This document sets out guidance for clinical psychologists in terms of responsibility and accountability issues in the delivery of multidisciplinary health and social care.
- DCP – *Policy and Guidelines on Supervision in the Practice of Clinical Psychology (2003)*. This document sets out guidance to assist psychologists in their understanding of supervision, the general context in which it takes place, what is involved in supervision, its relationship to CPD, who needs it and how often. It is the responsibility of clinical psychologists to ensure that they keep themselves professionally updated.

5.3 Local policies

The psychologist must ensure that he or she is familiar with local policies and procedures and has ready access to them for reference. The kinds of local policies that are likely to be relevant to interventions for challenging behaviour include:

- adult protection policies
- child protection procedures
- policies on the use of restraint
- policies on the ethical use of behavioural approaches
- policies on the ethical use of medication

It is recommended that local groups of psychologists adapt this section of the guidelines in line with their local situation.

5.4 Personal ethical beliefs

Psychologists need to be familiar with all the formal and legal requirements, but they must also be self aware, self-questioning and open to constructive criticism. A personal sense of ‘something being wrong’ is essential at times to alert us to possible bad practice or abuse. Neglect and various other forms of abuse are risks faced by many people with learning disabilities, and particularly those who are challenging.^{129 130} The clinicians’ conference identified the importance of attending to ‘uneasy feelings’ about the work of other people or ourselves. Challenging behaviour may be a response to a damaging environment or relationship and this possibility should be considered when working with people who are challenging.

Psychologists must also be alert to the possibility that they may be mistaken or simply wrong in their assessments and interventions. People who are challenging may evoke difficult feelings in psychologists just as much as anyone else and such feelings may influence judgements. As articulate, paid employees with relatively high status in the settings in which we work, we must recognise that we are in a position of considerable power in comparison with people with learning disabilities and many of the people who work directly with them. People may acquiesce or be reluctant to challenge our views directly because of this inequality in power and status. We need to be proactive in seeking out both positive and negative feedback on the assessments and interventions we carry out.

Local psychology departments need to implement policies of clinical supervision and audit in order to ensure good ethical practice. Where clinical psychologists work alone, they should take particular care to ensure that their work is regularly and frequently reviewed by experienced colleagues.

We recognise from our clinical experience the difficulties of working within constrained resources, when the urgency of clinical need can sometimes drive us to working at the limits of our competence or beyond. Nevertheless, we believe it is particularly important under these circumstances to be clear about our minimum standards, so that we are able to provide a service which is both realistic and competent.

We would recommend that psychologists are clear about their limits with referrers and colleagues, and negotiate with them about what can or cannot be provided with the skills and resources available.

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6. Structure of the guidelines

The guidelines are presented in two parts:

1. Core guidelines

The first part describes the *process* of working with individuals who present challenges. This section (Section 7) contains three core guidelines which can be used to provide a structure or framework for the psychologist's work.

2. Detailed guidelines

The second part (Sections 8–14) describes the *content* of what might be done in greater detail. Guidelines are presented for each stage of the pre-assessment (Section 8), assessment (Section 10), formulation (Section 11), intervention (Section 12), evaluation (Section 13), and feedback process (Section 14).

6.1 Format of the guidelines

The actual guideline is presented first, followed by an indication of the level of evidence to support it and whether it should be seen as 'good' or 'essential' practice.

6.2 Level of evidence

For each guideline, there is an indication of the level of evidence that supports it, using the categories from the North of England project.¹³²

Level 1: evidence from well-designed randomised controlled trials, meta-analyses or systematic reviews.

Level 2: evidence from well-designed cohort or case controlled studies (this includes well designed single case (n=1) experimental studies).

Level 3: evidence from uncontrolled studies or clinical consensus.

6.3 Good and essential practice

Bearing in mind the limitations of the literature which has been outlined in the section on the evidence base above, and because of the ethical concerns of clinical psychologists, we have chosen to make a distinction between *good practice* and *essential practice*, in addition to describing the level of evidence from the literature.

The majority of the guidelines describe *good practice* that should be followed by a competent psychologist. The language used is 'should' or 'ought'.

There are some guidelines, however, which we believe are *essential practice* and must always be followed. If they are not adhered to, there is a risk of bad practice. These guidelines use the term 'must' or the definition of a minimum acceptable standard. The essential practice guidelines can be seen as constituting a minimum standard of practice for psychologists.

Each guideline is therefore followed by the statement that it is either 'good practice' or 'essential practice.'

Where necessary, there is a definition or clarification of terms used in the guidelines. There is also a brief review of the evidence base and clinicians' views, together with a discussion of ethical concerns.

References: Section 6

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7. Core guidelines – a framework for working with challenging behaviour

7.1 Core guideline A: An individualised process

In order to work effectively with someone whose behaviour is challenging services, a clinical psychologist must take into account that person's unique strengths and needs, and their unique social context.

Level of evidence to support this guideline: 3

Essential practice

In practice it is difficult to assess the level of evidence to support this guideline. There is negative evidence to indicate that failure to work in an individualised way leads to ineffective or even harmful practice. For example, failing to identify or misidentifying the function of a behaviour can lead to the reinforcing and hence increasing of a behaviour which is harmful to the person or others.^{133 134} Two of the commonest functions of challenging behaviour are thought to be social contact and social avoidance.^{135 136} These are opposites and to provide the same response to the behaviour (regardless of the person and the context) would result in completely different outcomes.¹³⁷

There is a strong belief among clinicians that effective and ethical work must focus on individual needs and circumstances. Again this is perhaps based on the experience of difficulties caused by failure to work in an individualised way, as well as a commitment to seeing people with learning disabilities as unique individuals. Equally, clinicians believe that an assessment and intervention should not just focus on the challenging behaviour and its consequences. The person's opportunities for development, quality of life, choice, happiness and respect from other people must also be considered.

Person Centred Planning has been adopted as a cornerstone of the recently issued Department of Health policy for the health and social care of people with learning disabilities in the UK: 'A person-centred approach will be essential to deliver real change in the lives of people with learning disabilities' (p.5).¹³⁸ Other sections of the White Paper identify Person Centred Planning as a key

means of implementation in respect of service co-ordination, improving outcomes, and achieving better partnerships between professionals and people with learning disabilities and their families.

Set in this policy context, it is perhaps surprising that whilst there have been anecdotal reports on the usefulness of Person Centred Planning, there have been few formal evaluations.^{139 140 141 142 143 144 145 146}

Within the literature, there is an increasing use of the term 'Positive Behaviour Support' (PBS).¹⁴⁷ This approach has emerged from three major sources: applied behaviour analysis, the normalisation/ inclusion movement, and person-centred values. PBS integrates the following elements into a cohesive approach: comprehensive lifestyle change, a lifespan perspective, ecological validity, stakeholder participation, social validity, systems change and multi-component intervention, emphasis on prevention, flexibility in scientific practices, and multiple theoretical perspectives. The application of many of these characteristics will be evidenced in the development of the guidelines.

This guideline does not imply that the intervention will necessarily be an individual one. Assessment of the individual and his or her environment may indicate that the intervention needs to take place at a systemic or organisational level.

7.2 Core Guideline B: The basic process

When clinical psychologists work with people who show challenging behaviours, they should follow a coherent basic process, consisting of the stages shown in Figure 1.

This process should be seen as cyclical, with new information refining the formulation and making the intervention more focused and effective.

Given the persistence of severely challenging behaviours, work with people whose behaviour is severely challenging is likely to be long term.

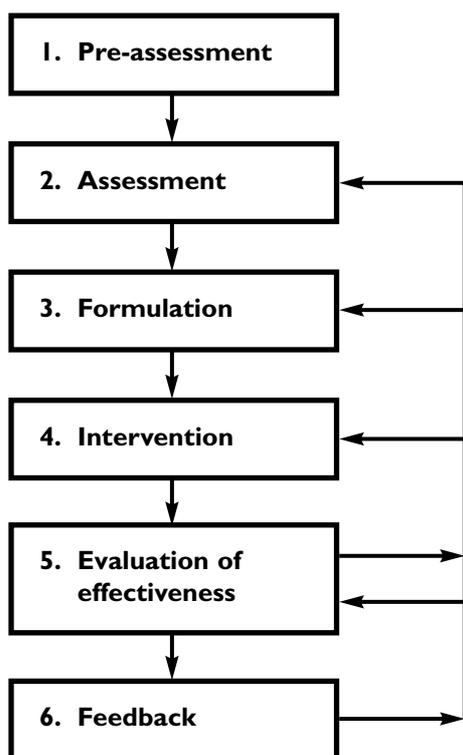


Figure 1.

Level of evidence to support this guideline: 3

Good practice

This guideline is presented as a useful schema to help structure assessment and intervention for challenging behaviour. It has not been evaluated other than through clinical practice and the consultation processes for these guidelines.

There is evidence to support the persistence of much severely challenging behaviour, but also evidence to show some variability over time and over settings.^{148 149 150}

This model is of course a restatement of the familiar ‘scientist practitioner’ model,¹⁵¹ where the psychologist defines the problem, investigates it, develops a hypothesis, tests the hypothesis, revises it etc. There has been a recent re-emphasis on this model in the literature on challenging behaviour, with new descriptive accounts of functional analysis.^{152 153} Repp,¹⁵⁴ for example, describes three stages:

1. hypothesis development (e.g. by interview and rating scales);
2. hypothesis confirmation (e.g. by direct observation and descriptive analysis);

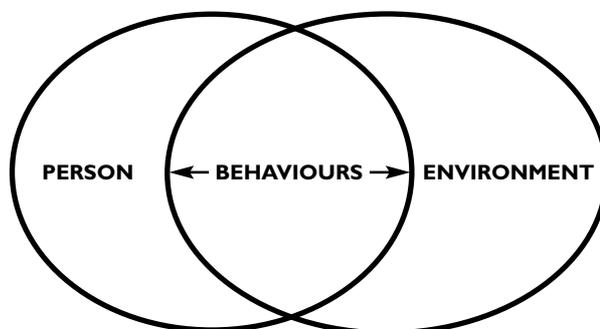
3. hypothesis testing (by analogue assessment or by intervention).

In this approach, the accuracy of an assessment and the effectiveness of an intervention is tested out systematically case by case. Practice is guided by the evidence as it is collected.

7.3 Core Guideline C: Essential elements

Any psychological assessment and intervention for challenging behaviour must include consideration of three elements:

1. the person;
2. his or her environment;
3. the behaviours which are challenging, and the interaction between these elements.



Level of evidence to support this guideline: 3

Essential practice

‘The person’ is used to mean all aspects of that individual, including developmental, social and interpersonal history; abilities and disabilities; acute or long-term medical conditions, and physical and psychological characteristics.

‘Environment’ is used to mean the social and interpersonal milieu as well as the physical environment. It includes family and carer relationships, staff structures and organisations, timetables and programmes, buildings and facilities within them, neighbourhoods and the wider social context.

‘Behaviours’ need to be understood and defined precisely, given the very broad sweep of the term ‘challenging behaviour’. At times the absence of an expected or necessary behaviour may constitute the challenge, as well as or instead of a behaviour which is overtly disturbing.

The nature and definition of challenging behaviour is that it is behaviour that occurs in a social context, in an environment. It is not acceptable clinical practice to ignore environmental factors in the creation and maintenance of challenging behaviour. Equally, individual characteristics, whether inherited or acquired, must be recognised and incorporated into the assessment, formulation and intervention.

For example, a common explanation of challenging behaviour is that 'they are doing it for attention'. There is evidence from analogue studies¹⁵⁵ that challenging behaviour may be maintained by social reinforcement. However, there are clear individual differences. For some individuals, perhaps because of autism or a history of abuse, inappropriate social reinforcement is highly aversive, whereas other individuals appear to crave a great deal of social reinforcement and become distressed and lonely when alone. There are also great differences in environments. It is essential to assess the amount of social contact or social deprivation in a person's environment. Few people had the chance to become satiated with social

reinforcement in the learning disability institutions of the 1960s, and the level of social interaction in many community settings, particularly for more disabled people, remains frighteningly low.^{156 157 158} If social attention is believed to be reinforcing someone's challenging behaviour, both individual and environmental characteristics need to be assessed – and the interaction between the two is likely to be very significant.

Where there is an underlying individual genetic cause for a particular behaviour, environmental factors can be used to reduce the frequency, severity and impact of the problem. An example of this would be work with people with Prader-Willi syndrome. Their biological make-up gives them an overwhelming desire to eat; this desire often leads to challenging behaviours related to food; but the challenging behaviours are still amenable to psychological and environmental interventions.¹⁵⁹

Challenging behaviour may be secondary to physical or mental illness in the individual, which needs to be treated.

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8. Detailed guidelines – Pre-assessment

8.1 Pre-assessment

Definition: Pre-assessment is defined as that stage of preliminary information-gathering which helps shape the initial focus of a psychological assessment. Information may be given in a referral form or letter, but often needs to be supplemented by eliciting further details from the referrer or other key people.

The term ‘pre-assessment’ was used by Toogood and Timlin (1996)¹⁶⁰ in their review of functional assessment measures. They advocate the use of a pre-assessment stage to help create a systematic and efficient assessment.

As a new concept, it has not been evaluated in the literature and has no formal evidence base. Nevertheless, for psychologists working primarily in community settings it is a necessary and frequently time-consuming part of their work. We are recommending that this stage should be recognised as essential good practice.

Many services find it helpful to have a form to collect pre-assessment information at the referral stage.

8.2 Content of pre-assessment

The psychologist should make sure that he or she has essential, basic information available at the start of working with someone who challenges.

This information should include key facts about the person, their environment and the challenging behaviour. This is likely to include information to help with the ‘risk screening’ process.

Records of previous assessments and interventions should be acquired.

Level of evidence to support this guideline: 3

Good practice

As well as the person’s name, address, telephone number, date of birth, it is helpful to have a brief description of how to communicate with the person (whether they use a

signing or symbol system; first language; whether they can read appointment letters; whether they can talk to the psychologist about themselves.) Toogood and Timlin¹⁶¹ suggest that an awareness of factors such as degree of disability, presence of sensory impairment and verbal ability will help the psychologist select the most appropriate combination of assessment methods.

It is also useful to know what kind of setting the person is living in – family home, group home, hostel, supported living etc.; whether there are any arrangements for respite care; whether the person attends a day centre, school or college; whether they carry out any paid or voluntary work or are on a training project. It is helpful to have an indication as to whether the challenging behaviour is occurring in all or just one or several settings. Variations between settings can be useful in generating ideas about possible environmental factors contributing to the behaviour.

Names of keyworkers and service managers, important family member and other professionals involved with the person should be elicited. All these people are potentially important informants about the person and the behaviour, and interventions which may have been tried earlier. There is some evidence that levels of training and education in staff make a significant difference to their ability to complete questionnaires, ABC charts etc.¹⁶² Staff attitudes to the behaviour are also likely to impact on how they record or report it.¹⁶⁰ An awareness of the skills and experience of staff in different settings can help a psychologist select appropriate assessment methods.

A referral for ‘challenging behaviour’ needs further clarification – what are the behaviours and who is being challenged by them? Has there been one specific serious incident or is there a history or pattern of incidents? Is it a new behaviour or a well-established one? An idea of the severity of the problem can help determine level of risk and urgency. Frequency can also be used in considering what kind of recording methods are likely to be useful to elicit assessment information. High frequency behaviours can be assessed by direct observation, for example, whereas low frequency but high cost behaviours will

probably need to be assessed by reports from others.¹⁶³ It is likely that some of this information will be gathered as part of a process for risk assessment.

Previous work with the person who is challenging should always be reviewed; at the pre-assessment stage old notes and records should be obtained.

8.3 Purpose of pre-assessment

Pre-assessment should provide practical information about how to make contact with the person who challenges and other key people who live or work with him or her.

It should enable the psychologist to make a constructive and focused start to an assessment.

Level of evidence to support this guideline: 3

Good practice

The psychologist needs to know the best way to approach an individual who has been referred because they present challenges, in order to establish a good rapport with the person and the important people in his or her life. The psychologist also needs to know, very practically, where to meet them and when.

It is important for the psychologist to identify other staff who are working with the person concerned, so that a consistent and coherent multi-disciplinary approach can be implemented.

8.4 Risk assessment

The degree of risk to the person and others must always be assessed.

Level of evidence to support this guideline: 3

Essential practice

The psychologist must not lose sight of the fact that much challenging behaviour presents a serious risk to the person and others – to physical and mental health; to leading a full, valued and rewarding life. High level of risk is a compelling indicator of the need to ensure that a reactive behaviour management strategy^{164 165} is in place as soon as possible. The level of risk will influence the urgency of the response, but the psychologist must not make recommendations on the basis of a very incomplete assessment, and needs to

make sure there is enough time to develop a good behaviour management strategy. During this time, the psychologist must be sure that the person is in an environment that is as safe as possible for everyone.

In many authorities the Care Programme Approach (CPA)¹⁶⁶ has been adopted as the mechanism for ensuring the co-ordination of the care provided to people with learning disabilities who display severely challenging behaviours. Risk assessment and risk management are central to the CPA process. CPA forms a key component of the Mental Health National Service Framework.¹⁶⁷ Although it is often a matter of debate amongst psychologists and psychiatrists as to whether 'challenging behaviour' should be included within a mental health framework, there are potential advantages of adopting the CPA framework for people with learning disabilities who present significant challenges. Each service should have a robust risk assessment and risk management process, whether or not it is as part of CPA. Psychologists must ensure that they follow local procedures.

The psychologist needs to work in collaboration with other professionals and service managers when there are situations where people are at risk, and take responsibility for ensuring that there is a mutual clarity about roles and expectations of what will be done by whom.

If a situation appears to be unsafe with an immediate risk of injury to the person or others, there are other possible courses of action, depending on the structure of local services:

- Additional members of staff can be brought in to either a family home or a residential setting to relieve stress on carers and provide a safer environment
- Emergency respite care may be available in a safer environment.
- Admission to a hospital unit on a voluntary basis or under section of the Mental Health Act 1983 if this is appropriate. In this case the psychologist needs to involve other professionals who have the statutory responsibility for admission under the Mental Health Act. All psychologists must ensure that they are familiar with the workings of the Mental Health Act 1983.

If the person has committed an offence such as assault, there must be clarity about the legal situation, and whether a prosecution can or should be brought.

Similarly, where the person has breached local agreements or policies, such as adult abuse policies, there needs to be clarity about what procedures are being followed.

As well as a direct physical or psychological risk to the person or others, there may be a risk of the loss of a valued part of a person's life, such as a job, college place or day or residential placement. There may be a risk of restrictive practices being applied, or the person's quality

of life suffering through negative attitudes created in staff or families as a result of the challenging behaviour.

The psychologist should also be aware that there may be a risk to himself or herself and that there is a need to keep oneself safe and not take unnecessary risks. Local health and safety or violence at work policies should be available to cover these areas.

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9. Guideline on consent

9.1 Consent

Whatever form of assessment and intervention is proposed, the capacity of the person with challenging behaviour to give valid, informed consent must be assessed.

As far as possible, the person with learning disabilities must be asked to give their consent to assessment and intervention.

Family members and staff should also be provided with information and asked for their consent if they are the focus of an assessment or intervention.

*Level of evidence to support this guideline: 3
Essential practice*

This guideline is derived from an ethical imperative, rather than the evidence base, but must be clearly seen as good practice. Detailed discussion concerning the legal position with regard to 'capacity and consent' to treatment can be found in Section 5.1.

Information about psychological interventions must be presented in a clear and user-friendly manner.

The information should include:

- a full description of the procedures or techniques;
- an explanation of what is expected of the person with the learning disability, the psychologist and any others involved;
- any risks of the intervention;
- its likely effectiveness (from the literature and from the psychologist's clinical experience);
- alternative approaches and their costs and benefits;
- the consequences of not carrying out the intervention.

Where a person with learning disabilities is thought to be unable to give informed consent because of cognitive or communication difficulties, it may be helpful to seek the views of a fully informed advocate. It is accepted good practice that in such circumstances, professionals should

consult with the person's family, other professionals, and an advocate, in a multi-disciplinary meeting. However, it should be noted that at present no one may give proxy consent for another adult, whatever the level of disability, although this situation is under review.^{168 169 170}

The psychologist should also ensure that his or her work is supervised and reviewed by experienced colleagues. Particular care should be taken when the psychologist is using innovative techniques or approaches that have not previously been used with people with similar learning disabilities, or where established procedures raise ethical concerns or unease.

For consent to be valid,

- the person must be given the information (as described above),
- they must understand the information
- they must give their consent without any kind of coercion.

In order to enhance a person's ability to understand the information relating to a decision, consideration will need to be given to how the information is put across. This will need to be provided in accessible language, perhaps in small chunks, with pictures, and on repeated occasions.¹⁷¹ It is important that the service user understands the information in broad terms, rather than needing to be able to understand all the details. The Department of Health has funded the Norah Fry Research Centre to produce evidence-based guidance on accessible information for people with learning disabilities. The project 'Information for All' is due to be completed in 2004. Their early review of the evidence identifies a number of potentially useful resources to help psychologists make the information more accessible to people with learning disabilities.^{172 173 174 175 176 177}

A similar level of informed consent should be sought from staff or families where they are the focus of a planned assessment or intervention. Written contracts are recommended as a way of ensuring that staff or families know what is happening and are clear about expectations of both them and the psychologist.

References: Section 9

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10. Detailed guidelines – Assessment

10.1 Assessment

Definition: Assessment for challenging behaviour is the process of collecting and evaluating information about the person, the social, interpersonal and physical environment and the behaviour which is challenging. The information needs to be reliable and pertinent.

Assessment is a distinct and essential stage in the process of working with people who show challenging behaviour.

It is a necessary precursor to any psychological intervention. There may be an urgent need to ‘do something’ about the challenging behaviour. Psychologists may feel themselves to be under a variety of pressures to carry out an intervention. However, if such an intervention is not based on an assessment and formulation, it is unlikely to be effective and may even result in the challenging behaviour becoming worse.

When the challenging behaviour presents a severe risk to the person or others, it may sometimes be necessary to suggest a reactive behaviour management strategy on the basis of a brief assessment, including a review of previous interventions, and a preliminary formulation. If this is the case, it needs to be made clear that further assessment and reformulation will lead to a review of the original reactive strategy, and revision if necessary.

An argument has been put forward that assessment may not always be essential, and the delay to starting interventions may be unacceptable to parents.¹⁷⁸ However, in this study, interventions were not randomly assigned and there was in practice a shortened period of assessment.

The weight of the evidence available in the literature indicates that the most effective way of assessing challenging behaviour is to carry out a functional assessment.^{179 180} Functional analysis may be one format used for a functional assessment. The outcome of meta-analyses is that prior

functional analysis correlates with a successful behavioural intervention.¹⁸¹

10.2 Purpose of the assessment

Assessment should serve three purposes:

- 1. It should collect enough information to lead to a coherent psychological formulation.**
- 2. It should lead to the selection of an intervention plan which fits the person and their environment.**
- 3. It should establish a baseline so that the effectiveness of any intervention can be measured subsequently.**

Level of evidence to support this guideline: 3

Good practice

Assessment for formulation

Assessment is part of the process of working with people who show challenging behaviour. Enough information needs to be found and evaluated for the psychologist to be able to make sense of what is happening and come to a psychological formulation.

Being able to reach a reasonable hypothesis about the function of a behaviour is one sign that the assessment process has been adequate.

Assessment leading to an intervention plan which fits the person and their environment

The concept of ‘goodness of fit’ has been applied recently to interventions for challenging behaviour.^{182 183} An intervention needs to fit with the values and characteristics of the person with a learning disability, the people around him or her and their social, cultural or organisational environment.

Definition: ‘Goodness of fit’

When contextual fit is high or good, a support plan and its components are consistent with, or highly compatible with, the values and skills of key stakeholders and plan implementers; readily sustainable given the resources and constraints

of the environments, conditions and systems where the plan is implemented; and suitable to the unique needs of the person with problem behaviors. Put simply, the support plan works well for (i.e. makes a good fit for) the person and the environments where it is being implemented.¹⁸⁴

It follows from this that a necessary part of the assessment process is getting to know the person and the values and skills, resources and constraints of the environments which support him or her. There is some evidence that failure to do this will limit the initial effectiveness and longer term maintenance of interventions.¹⁸⁵

Baseline measure

The third purpose of assessment is to establish a baseline measure before any intervention so that the effectiveness of the intervention can be assessed.

Definition: A baseline is a measure of a person, a behaviour or an environment which is taken before an intervention starts.

The measure should be of something that is:

- clearly specified;
- observable or subject to reliable reporting by the person or others;
- replicable by other colleagues;
- relevant to the perceived need or target for intervention.

The baseline measures should match the targets for intervention. If for example, an intervention is aimed at changing staff attitudes, then those attitudes should be measured before the intervention. If an intervention is aimed at reducing challenging behaviours, then those behaviours should be measured before and after an intervention.

Self-report can be used to establish a baseline measure of psychological health or well-being, when the person is able to communicate information about his or her inner experiences.

If baseline measures are not taken, then the success or failure of an intervention can only be guessed at.

It can be helpful to take additional baseline measures of behaviours or attitudes that are not being targeted in a

specific intervention, so that there is an internal control for measuring the effectiveness of the intervention, and any generalisation effects or 'symptom substitution' can be identified.

When the challenging behaviour is having an impact on other areas of the person's life, as is almost invariably the case, then it is important to assess that impact. This could involve taking baseline measures of aspects of the person's life, such as quality of life, levels of engagement in positive activities or use of restrictive practices by staff.

Successful outcomes for psychological interventions may be demonstrated if there is an improvement in quality of life, for example, or in a reduced use of physical restraint by staff, even if the frequency of the behaviour has not significantly changed.¹⁸⁶ Consideration should be given to obtaining the views of the individuals themselves regarding their perspectives on the impact of their behaviour.¹⁸⁷

10.3 Extent of the assessment

Assessment should collect relevant information about the person, the environment or settings they live or work in, and the behaviours that are challenging to services and families.

Where a particular person or service setting is already well known to the psychologist, existing information should be reviewed and its current accuracy checked by interview and observation.

Level of evidence to support this guideline: 3

Good practice

An assessment for challenging behaviour needs to encompass all three elements of the person, the environmental setting and the behaviour. A partial assessment will be much less effective.¹⁸⁸

There needs to be a multidisciplinary assessment of an individual who is challenging, which will identify any medical, psychological or other difficulties. Consideration needs to be given to the potential roles of the different members of the team in the assessment of people who show self-injurious or aggressive behaviour.¹⁸⁹ The psychologist may have a role in acting as an advocate for the person with learning disabilities if they are unable to access appropriate specialist

health care. The psychologist may also have a role in advising on psychological aspects of healthcare in people with learning disabilities (e.g. by the use of desensitisation techniques for fears or phobias of medical procedures).

Previous assessments and interventions should always be reviewed.

Although it can be helpful to know a person or family or a service setting well, it is important to review this information and see if any changes have taken place. The psychologist should guard against hearsay – many people with severely challenging behaviour develop reputations within a service, which can be prejudicial to an accurate assessment. Similarly, day or residential settings can acquire an image of being a good or bad service, which needs to be checked against the current reality.

10.4 Selecting a focus

Given the complex lives of some people living in community settings, and the likelihood that people will demonstrate more than one behaviour which is challenging, a focus should be selected for the initial stages of the assessment and this focus made explicit to the referrer and other key people.

The pre-assessment stage should help determine the initial focus for the assessment.

Relevant factors to consider in choosing an initial focus would include:

- 1. The degree of risk of physical harm to the person and others which a particular behaviour presents.**
- 2. The risk of loss of access to services or other opportunities for development and participation.**
- 3. The levels of distress being experienced by the person and others because of particular behaviours in particular settings.**
- 4. The hopes, capacity and motivation for change in the person and the settings.**

Level of evidence to support this guideline: 3

Good practice

There is some evidence to suggest that work with challenging behaviour is more likely to be successful if it is focused. For example, research which has looked at the effectiveness of teams working with people who present challenging behaviours suggests that teams with a clearer model of working and clearer management structure and leadership were more successful.^{190 191}

Research that has looked at the effectiveness of an applied behavioural approach in some detail, would also indicate that specific behaviours need to be worked with in a focused way. For example, the function of a particular behaviour at a particular time in a particular setting needs to be assessed – the same behaviour may serve different functions under different circumstances.¹⁹²

Given the prevalence of challenging behaviour in people with learning disabilities it will be necessary to prioritise work in some way. This needs to be considered at the stage of taking up referrals and also when prioritising work with a particular individual.

One of the challenges faced by clinicians is to balance the need to work effectively – which needs very intensive work at some stages – with the demand for a quick and accessible response to a large number of people. Good practice would indicate being transparent about resources and priorities in such a situation and discussing the criteria for setting priorities. Attention needs to be paid to how widely accessible services are.

This guideline suggest that prioritisation should be based primarily on severity of clinical need – the risk to the client and others and the distress that they are experiencing – but that the capacity of the person with a learning disability and families or carers to change the behaviour should also be considered.

Similarly, when a specific target for intervention is being selected, the severity of risk (including the risk of losing a good service) together with the scope for change should be used to help decide where to start.

Although a focus on just one challenging behaviour is often the most appropriate and straightforward way of starting an assessment, there is a risk that other challenging behaviours may increase as one decreases during the intervention stage. There is also the possibility that other challenging behaviours will decrease if the intervention is

able to generalise. If there are concerns about a range of different behaviours, it is helpful to collect at least outline data on more than the one target behaviour.

10.5 Assessment of the person who is challenging

Assessment of individuals should include:

1. **Their strengths – abilities, opportunities, resources.**
2. **Their needs – impact of disabilities, service and resource gaps in their lives, needs for further development, mental and physical health needs.**
3. **Their likes, dislikes and preferences and how they express these.**
4. **Their history – developmental, social, medical, history of use of services.**

Level of evidence to support this guideline: 3
Essential practice

Assessment of strengths

Assessing a person's strengths is important for identifying possible strategies for change. For example, if a person can express their thoughts and feelings verbally or in written or pictorial form, then this strength may be utilised in a psychological intervention. Strengths need to be identified so that they can be built on to promote positive behavioural change.

Identifying strengths can also help increase motivation to work together to make changes. Staff groups with strong positive values about people with learning disabilities can find it difficult and painful to look at problematic behaviour or the person's disabilities, and may need the opportunity to talk about the person's positive aspects and have these valued before looking at areas of difficulty. Conversely, where staff groups have developed a negative view of a person, helping them look at the positive side is an essential first step towards developing a positive intervention.

The need to assess strengths is based on clinical consensus and values held by psychologists, as it has not been evaluated in the literature.

Assessment of needs

Identifying an individual's needs for support because of underlying difficulties or disabilities should never be omitted from the assessment of challenging behaviour. In general terms, certain disabilities have been shown to be associated with challenging behaviour. There is a

correlation between severity of learning disability and prevalence of challenging behaviour.¹⁹³ For example, in one study it was found that 33 per cent of people with profound learning disabilities also showed challenging behaviour. Impairment of communication, hearing, vision and mobility have also been shown to be associated with an increased risk of challenging behaviour.¹⁹⁴

An increase in the prevalence of some particular forms of challenging behaviour has also been reported to occur in association with specific syndromes associated with learning disabilities. These include:

- occurrence of self-injurious behaviour, specifically hand and lip biting, among all people who have Lesch-Nyhan syndrome;^{195 196 197}
- very high prevalence of self-injurious hand-wringing in Rett syndrome;¹⁹⁶
- greater than expected prevalence of various forms of self-injurious behaviour in the Cornelia de Lange, Riley-Day and Fragile-X syndromes;¹⁹⁶
- greater than expected prevalence of hyperkinesia, attention deficits and stereotypy in Fragile-X syndrome;^{198 199 200 201 202}
- greater than expected prevalence of self-injury among people with autistic spectrum disorders;^{203 204}
- high prevalence of challenging behaviours in Prader-Willi syndrome.^{205 206 07 208 209 210}

The recent explosion of interest in the 'new genetics' is likely to lead to a substantial growth in knowledge about the behavioural manifestations or 'phenotypes' of a range of syndromes.^{211 212 213}

Psychiatric diagnosis may be associated with challenging behaviour for some people with learning disabilities.²¹⁴ This is a complex area where definitions of terms are crucial (e.g. 'conduct disorder' in childhood may be used as a synonym for challenging behaviour). Different types of mental health problems produce very different types of challenging behaviour, ranging from the apathy and withdrawal of depression to wild excitement and over activity in hypermania. If someone is dually diagnosed, it is essential for the psychologist to have a clear understanding of the emotional, cognitive and behavioural components of his or her specific mental health problems. A similar level of awareness is required when a person is diagnosed as autistic as well as learning disabled.

There are three possible ways in which mental health problems may be associated with challenging behaviour.²¹⁵

Challenging behaviour may be the atypical presentation of a mental health problem. It is possible that psychiatric disorders may be manifested in unusual ways among people with highly restricted language and adaptive behaviours. For example, circumstantial evidence suggest that some forms of self-injurious behaviour may constitute the atypical presentation of obsessive-compulsive disorder among people with severe learning disabilities.²¹⁶

Challenging behaviour may be a secondary feature of a mental health problem. A range of challenging behaviours (including aggression and self-injurious behaviour) may occur as secondary features of affective disorders among people with severe learning disabilities.^{220 221} For example, a variety of clinical features may be indicative of depression among people whose level of disability makes it difficult for them to verbalise their feelings.²²² These features include somatic symptoms (e.g. headache and stomach ache), agitation, disturbances of sleep, appetite and bowel movements and loss of self-care skills.^{223 224 225 226}

Mental health problems may establish a motivational basis for the expression of challenging behaviours which are then maintained by behavioural processes. Some mental health problems may create an enhanced sensitivity to stimuli, or interpersonal difficulties or other factors which may create a climate in which challenging behaviour starts. Once started, other factors come into play to maintain the challenging behaviour. Depression, for example, may be associated with an unwillingness to participate in educational or social activities, thus establishing such activities as negative reinforcers (i.e., events whose termination is reinforcing). If the person has previously learned that challenging behaviours can terminate such aversive events, we would expect an episode of depression to be associated with an increase in challenging behaviour. In such a case it would be necessary both to treat the person's depression and to change the 'functionality' of the person's challenging behaviour.

It is also good practice to have a clear picture of any specific neuropsychological difficulties the person may have as a result of brain injury or impairment. Problems of attention, memory, problem-solving, etc. can contribute to the likely development of challenging behaviours. Epilepsy is very common in people with learning disabilities^{228 229}

and its effects on the individual need to be understood and evaluated as part of the assessment process. Indeed, some evidence suggests an increased prevalence of challenging behaviour among people with epilepsy, both in general²³⁰ and in relation to specific forms of epilepsy,^{231 232} Sleep problems may be associated with significantly increased challenging behaviours during the day.²³³

There is no evidence in the literature to confirm or disconfirm this part of the guideline. It is based on clinical consensus and the clinical experience of the problems caused by the failure to recognise the impact of someone's mental state or disability on their behaviour.

Assessment of individual likes and dislikes

It is important to assess a person's likes and dislikes for several reasons. A psychologist needs to be able to recognise how people, especially those with the most severe cognitive and communication disabilities, express their preferences.

One reason for this is in order to identify potential reinforcers which can be used to motivate changes in a person's behaviour and teach new skills. Another reason is so that aversive stimuli can be avoided.

'Aberrant motivation' should be considered in work with people with learning disabilities i.e. that individuals may be unusually sensitive to some reinforcers or desire large amounts of reinforcement.²³⁴ This may be because of the person's inherent characteristics (as with the desire for food in Prader-Willi syndrome or sensitivity to noise in people with autism) or may be because of personal history and experience.

Being able to assess reliably how a person reacts to an intervention is an important component of assessing consent.

Families and staff who know a person with severe disabilities well, are often able to explain how they judge likes and dislikes. Facial expression and physical movements such as reaching towards or turning away, can be reliably used to assess preference in even the most disabled people.^{235 236}

The psychologist also needs to be aware of potential difficulties when assessing the likes and dislikes of more able people with learning disabilities, who may be overly

acquiescent, particularly with people in positions of power in their lives such as psychologists and other members of staff.^{237 238}

Assessing the person's history

Taking a history puts the behaviours into a context and helps establish a 'good fit' between any proposed interventions and the person's life experiences. It may even help to avoid making the same mistakes twice.

History can be assessed by reviewing old case notes and by talking to the individual and to family members or staff who have known the person for a long time. The history should include:

1. a medical history which includes an account of the diagnosis or identification of learning disabilities and other medical or psychiatric conditions;
2. genograms (family trees) and accounts of family history;
3. history of contact with services and institutional care;
4. educational and employment history, including attendance at day centres;
5. social history – friendships and other relationships;
6. a historical account of challenging behaviours, where this is appropriate, including any offences;
7. an account of previous interventions and their effectiveness.

Taking a history is an important part of the assessment process, but a psychologist needs to be sensitive to the experience of parents or people with learning disabilities who may be asked to repeat their 'stories' to many different professionals.

There are no studies where the effectiveness of history taking has been evaluated, so this part of this guideline is based on clinical practice.

10.6 Meeting the person who is challenging

When at all possible, the person who is challenging should be interviewed as part of the assessment process.

As a minimum standard, the person must always be met face to face, and enough time spent with them for the psychologist to have a sense of them as an individual.

Level of evidence to support this guideline: 3

Good practice

This guideline is both a practical suggestion about how to assess a person effectively and reliably and a statement of an ethical principle.

The views of people with challenging behaviour about themselves, the people who live and work with them, their environment and the services they receive, and the reasons for their challenging behaviour should all be actively sought.

Where the person uses a signing or symbol system or a language which the psychologist does not understand, a competent interpreter should be sought. Where severe expressive or receptive communication difficulties make interviewing extremely difficult, additional time should be spent observing the person in different settings.

Studies have shown that depending on other people's reports of individuals alone, particularly when those individuals are challenging, is not a reliable method for collecting information.²³⁹ Staff attitudes to the person and to their challenging behaviour tend to colour their reporting. This is particularly the case with retrospective reporting, with non-specific information (interpretation of events rather than detailed accounts) and with distance in time from events or characteristics being recalled.

There are well known difficulties with interviewing people with learning disabilities, including acquiescence,^{240 241} suggestibility to leading questions²⁴² and feeling obliged to please an interviewer who is perceived to have high status.²⁴³

There is, however, a growing body of literature which addresses these difficulties and provides useful guidance. Interviews need to avoid closed yes/no questions and leading questions.²⁴⁴ Pictures and symbols can be used to supplement the verbal content of questions and answers, although it should not be assumed that these are necessarily easier to understand for everyone. For reviews of these issues, consult the following references.^{245 246 247 248}

Where the person with learning disabilities does not have the communication or cognitive skills to participate in

these kinds of measures, it is still important to get to know him or her. Observation of facial expression and other forms of non-verbal communication can provide reliable information about how a person thinks and feels, what they like and don't like and so on.²⁴⁹ Packages such as 'Getting to know you' have been used to help structure this kind of assessment.

10.7 Assessing the environment – what to assess

Assessment of the environment should include:

1. **The physical environment**
2. **The interpersonal setting – relationships and values**
3. **The organisational setting – systems and processes in place to support the person.**

Level of evidence to support this guideline: 3

Essential practice

This guideline is based primarily on clinical consensus and the belief that challenging behaviour, by its nature, derives from an interaction between a person and the physical and interpersonal setting they are in. It follows that the environment needs to be assessed just as carefully as the individual. However, there are a number of studies which either describe the inter-relationships between challenging behaviour and aspects of the person's environment, or suggest mechanisms through which environmental variables may impact on challenging behaviour.

Any assessment of the environment that a person lives or works in needs to include psychological and organisational factors as well as the physical environment.

The *physical environment* may have an important influence on a person's behaviour. Elements to assess would include:

- size;
- comfort – heat, light, noise;
- location – access to community facilities, open spaces;
- safety.

Published evidence to support the need to assess the physical environment has highlighted the potential salience of noise and temperature,²⁵⁰ crowding,²⁵¹ location,²⁵² music,²⁵³ the presence of such idiosyncratic variables as small balls, puzzles and magazines,²⁵⁴ and general environmental conditions.²⁵⁵

In assessing the *interpersonal and organisational setting*, a

psychologist needs to take into account the network of people and relationships around the person whose behaviour is challenging. This might include:

- relationships with staff or family members and other service users;
- their beliefs about the person and the challenging behaviour;
- effects of the behaviour on them;
- interaction and engagement with the person;
- routines and practices;
- values and attitudes about disability and challenging behaviour, including cultural values;
- skills and resources available;
- organisational culture;
- family culture.

The evidence for the importance of assessing the interpersonal environment and its relevance to challenging behaviour comes from a wide range of studies. Behavioural studies have commonly identified social contact or social avoidance as common functions of challenging behaviour.^{256 257 258 259 260}

In addition, evidence points to the possible role of a range of interpersonal and organisational variables, either as immediate precursors to episodes of challenging behaviour or as influencing people's capacity to work constructively with people with challenging behaviour.^{261 262 263 264 265 266 267}

These include:

- *preceding interactions* such as preceding compliance,^{268 269 270} task repetition,²⁷¹ critical comments from others,²⁷² the cancelling or delay of previous activities,²⁷³ immediately preceding interactions,^{274 275 276} temporally distant social interactions,^{277 278} physical exercise,²⁷⁹ the route taken to a setting²⁸⁰ and time of awakening.²⁸¹
- the *current context* for behaviour including such factors as preference and choice regarding concurrent activities,^{282 283 284 285 286 287 288 289 290 291 292} the amount of non-contingent reinforcement available in the setting^{293 294 295 296 297} and concurrent social interactions and the nature of surrounding activities.²⁹⁸

Studies of small houses supporting people with severely challenging behaviour in the community have indicated the importance of good management which provided support and motivation for staff as well as a positive environment for people with learning disabilities.^{299 300}

Assessment of the person's environment before and after an intervention for challenging behaviour can look at the intervention's effectiveness in improving the person's quality of life as well as reducing challenging behaviour. Several authors have argued that these wider issues should also be assessed as 'meaningful outcomes'.^{301 302 303 304}

10.8 How to assess the environment

Information about the environment should be sought from interviews with key informants. Views should be sought from more than one perspective in a service setting (e.g. managers and direct care staff.)

Relevant documentation should be accessed (care plans; person centred plans; individual program plans; activity timetables; statements of values; policies and procedures etc.)

Information from interviews and documentation should be supplemented by observation of the relevant environment or settings in action, preferably while the person is there.

Where the individual lives with his or her family for all or part of the time, the family member who is mostly responsible for the care of the person should be interviewed, and attempts made to meet and interview other family members who are significant in terms of the amount of time and influence that they have with the person.

Level of evidence to support this guideline: 3

Good practice

This guideline is derived from clinical consensus of good practice.

Environmental factors can be assessed by:

- direct observation;
- structured record keeping;
- interviews with key informants;
- questionnaires;
- reviews of relevant documentation.

There is no substitute for the structured and careful observation of the person with learning disabilities in the setting where the challenging behaviour occurs.

This can be done by the psychologist or by others (e.g. families, care staff) who have the skills and the opportunity

(space and time) to do it.

Direct observation should look at both long-term, consistent features of the environment (such as the physical building) and those factors which fluctuate from day to day or even minute to minute (e.g. engagement or social interaction)

Concurrent recording of challenging behaviours by staff (using ABC charts) has been shown to be particularly unreliable where staff do not see the target behaviour as challenging.³⁰⁵ It seems likely that the identification and recording of relevant environmental factors may also be affected by staff beliefs. Staff skill and level of training both generally and in the specific task of recording behaviours seem to impact on the reliability of recording.³⁰⁶

Using intensive techniques such as time sampling (when details of the person's behaviour and of the social and physical environment can be recorded to a pre-set format at a fixed time interval) or event sampling (when each time a certain event happens a series of data on concurrent activities or setting details can be collected) should help to reduce response bias in comparison with a more free-floating recording of an observation session.³⁰⁷ However, these types of technique are onerous even with the use of a hand-held computer and care needs to be taken to avoid observer fatigue and loss of concentration. Video recording can identify activities and patterns of interaction but may miss some features of the physical environment such as room temperature.

Interviews with key informants – the people who spend most time with the person whose behaviour is challenging – are another valuable way of assessing environmental factors.^{309 310} Several authors have produced structured or semi-structured interview schedules for the purpose of assessing challenging behaviours which include questions about environmental factors.^{311 312 313 314 315}

The results from retrospective reporting accessed through interview may be no less accurate than concurrent recording³¹⁶ but is also likely to reflect the informants' beliefs about the challenging behaviour and attitudes to the person with a learning disability. This may have the disadvantage of biasing the accuracy of the recording, but potentially enables the beliefs and attitudes to be assessed at some level and taken into account in the full assessment process.

There are some standardised or systematic tools available for the assessment of aspects of the environment :

- broad aspects of quality of life;^{317 318 319 320}
- quality of care;³²¹
- family climate;^{322 323}
- how much an organisation might meet targets informed by particular values;³²⁴
- social climate;³²⁵
- community attitudes to people with learning disabilities;^{326 327}
- staff knowledge, skills and beliefs;^{328 329}
- choice and autonomy for people with learning disabilities;³³⁰
- activity levels. ³³¹

It can also be helpful to review the documentation held about people and their environments – care plans, policy statements, guidelines etc. The presence of competent and comprehensive written information is obviously desirable, and its absence may be indicative of a range of managerial or resource difficulties. However, an assessment of the written material must always be supplemented by an assessment of actual practice, which is best carried out by personal interview and observation.

Assessment of quality of life and the person's well-being in a particular setting can serve three purposes:

1. It may help identify factors in the environment which are contributing to the challenging behaviour.
2. It may identify restrictions and losses of choice or opportunity, which are occurring as a consequence of the challenging behaviours.
3. It can suggest other or alternative meaningful targets for change (as well as the challenging behaviours) and provide a baseline measure of such targets.

10.9 Assessing the challenging behaviours – what to assess

Specification

The challenging behaviour(s) to be assessed must be specified clearly.

The behaviour must be described in terms which are:

- **clear and unambiguous**
- **measurable (by observation or self report)**
- **capable of future replication**

Onset

The onset of the challenging behaviour should be ascertained where this is possible.

Significant life events and changes of or within the environment should be noted.

The ways in which family or care staff responded to the challenging behaviour when it first started should be identified – if possible with the support of contemporary documentation.

Frequency, severity, duration

As a minimum standard, the frequency of the challenging behaviours must always be measured.

The severity and duration of the behaviour(s) should be measured too, especially when there are definite fluctuations in either factor. Fluctuations over time and over setting should be identified and then recorded.

Level of evidence to support this guideline: 2

Essential practice

There is good evidence in the literature and from clinical practice to support the need to carry out a thorough and detailed assessment of the challenging behaviour as described in this guideline.

The behaviours to be assessed need to be described in unambiguous, observable, measurable terms. Another person needs to be able to replicate the measurement – and may well have to if anyone other than the psychologist is going to be collecting data in the various settings where the person with challenging behaviour lives and works.

Identifying the start of a behaviour can help suggest possible functions for it or may indicate how the person learnt a particular way of being challenging. Looking at fluctuations over time and setting can also be helpful in generating ideas of the function of a behaviour.

A baseline measure of the challenging behaviour must be established. If it is not, the impact of any intervention cannot be measured. This is relevant whether the intervention targets the behaviour directly or attempts to alleviate the

pain, boredom or distress, which may underlie it.

The most basic measure of incidence of challenging behaviour is a simple frequency count. See Guideline 10.11 below for methods of taking a baseline measure of behaviour.

10.10 Assessing the challenging behaviours – where to assess

Challenging behaviour should be assessed in the everyday settings of the person’s home, school, workplace or community – wherever the behaviour may occur – unless this presents too great a risk to the person with challenging behaviours or others.

Level of evidence to support this guideline: 3

Good practice

It is very important to assess challenging behaviour in its social context. If this cannot be done because it is too risky, then important data may be lost. The psychologist will need to go to additional lengths (e.g., contacting additional informants) to compensate for this.

10.11 Taking a baseline measure of challenging behaviours

A baseline measure of the frequency, severity, duration etc. of challenging behaviours can be taken by

- **direct observation which is simultaneously recorded;**
- **direct observation which is recorded subsequently;**
- **self-reported accounts of past behaviour;**
- **accounts of past behaviour which are reported by others (e.g. carers).**

Attempts should be made to be as accurate as possible, using observation rather than post-hoc accounts and recording behaviours as closely as possible to the time when they occur.

The information may be collected either by the psychologist or by others such as care staff or family members in day-to-day contact with the person who is challenging. If other people are being asked to observe or complete recording sheets, the psychologist must make sure they have clear instructions and that they understand the rationale for recording the information and are

well motivated and able to do so.

When psychologists ask other people to collect information about incidents of challenging behaviour, they must make sure that they retrieve the information collected regularly, reliably and frequently. It is not acceptable practice to set a task such as data collection and not follow it up.

People with learning disabilities who have the motivation and skills to monitor their own behaviour should be supported in doing this.

Level of evidence to support this guideline: 2

Essential practice

This guideline is based on a number of studies which looked at a range of questions about the most accurate and effective ways of collecting information about the incidence and functions of challenging behaviour.^{332 333 334 335}

Once a decision has been made about which behaviours are to be assessed (see Guideline 10.9 above) the psychologist needs to decide on the best method of collecting accurate data for a baseline measure.

The relevant factors to consider are:

- the expected frequency of the behaviour:
 - high frequency behaviours can best be recorded by simultaneous observation and recording – the closer the recording is to an event, the more likely it is to be accurate;
 - very low frequency behaviours will probably need to be assessed by reports from the person with learning disabilities, if possible, carers who know the person well, people present at the time of the incident etc.;
 - information about low frequency challenging behaviours should be collected as near as possible to the time at which the behaviour occurred, while memories are still relatively clear.
- the impact or saliency of the challenging behaviour on the people being asked to record or describe it:
 - people will remember a highly salient incident of challenging behaviour more, but their memories of it are more likely to be coloured by their emotional reaction to it;
 - staff attitudes and beliefs about the person and the behaviour have been shown to effect the accuracy

- of their reports.³³⁶
- the education, training and experience of staff members who are potential informants:
 - there is some indication that levels of training and general education in staff make a significant difference to their abilities to keep accurate records, complete charts, questionnaires etc.³³⁷
- the technology available to support observation and recording:
 - highly accurate frequency measures can be taken using hand-held computers,^{338 339}
 - videos can be used effectively to record behavioural data for subsequent analysis by trained observers.³⁴⁰
- the possibility of collecting information from more than one informant:
 - if data can be collected independently from more than one source, then accuracy can be checked by inter-rater reliability checks.

It will be most appropriate to ask staff or family members to keep records of behaviour when people are skilled and motivated to carry out the recording, and when the behaviour occurs less frequently and less predictably (so that it is difficult for the psychologist to observe it). Where staff or family members are not experienced in this kind of work, the psychologist needs to provide clear instructions and sufficient training for them to be able to complete the task satisfactorily.³⁴¹ The psychologist can help motivate people by explaining the rationale for recording, but especially by ensuring that he or she comes back to collect the records promptly and gives feedback to people on the work they have completed. (These points were identified at the conference on good practice.)

People with learning disabilities can reliably keep records of their own behaviour if, like family members or care staff, they have the skills and the motivation to do so.^{342 343 344}

The person with learning disabilities should be involved in the selection of a target behaviour to be monitored – the behaviour must be observable, measurable and meaningful to the person. The psychologist needs to be sensitive about asking a person to record behaviour of which they are ashamed or about which they feel angry or guilty.

A range of creative recording systems for people with learning disabilities have been suggested in the literature:

- tallies using pegs (like a cribbage board) or beads (as in

an abacus) or marks on paper;³⁴⁵

- using pictorial representations of the target behaviours;³⁴⁶
- using verbal prompts, or automated tones, timers or other signals to cue recording using a time-sampling methodology.^{347 348}

Some authors have suggested directly reinforcing the behavioural recording. However, for some people the feedback from reviewing the recording sheets may have a self-motivating aspect – challenging behaviours may reduce as they are being monitored and recorded.³⁴⁹

Formal measures developed for use with the mainstream population³⁵⁰ can be of use but have to be adapted either verbally or in presentation format for all but the most borderline learning disabled client, thereby losing the benefits of standardisation. They are still useful however when given to the same person before and after an intervention (i.e. as an individualised measure).³⁵¹ Standardised psychometric tools have been used to measure the outcomes of cognitive behavioural and psychodynamic therapy with people with learning disabilities. People have been asked to complete the questionnaires before and after therapy. They are particularly appropriate in these therapies because the locus of intervention is the person's thoughts and feelings, which are perhaps most effectively measured by self appraisal. Examples of the use of questionnaires and inventories for pre- and post-intervention measures with people with learning disabilities include psychodynamic psychotherapy³⁵² and cognitive behavioural approaches.³⁵³

The process of collecting data for recording the frequency etc. of a challenging behaviour can also be usefully applied to collecting additional data to generate hypotheses about the function of the behaviour. (See guideline 10.12 below.)

10.12 Assessing the function of challenging behaviours

It is essential that a psychological assessment attempts to establish the function of challenging behaviours, in order to determine the correct basis for an intervention.

The most appropriate way of doing this will usually be through a functional analysis.

Level of evidence to support this guideline: I

Essential practice

Definition Functional analysis is a term which is used with different degrees of precision by different authors. The two main usages in psychological approaches to challenging behaviour are:

1. The attempt by a range of methods, including interview and recorded observation, to identify the function (used in its everyday sense of purpose or utility) of a particular behaviour in a particular context.
2. The specific behaviour analytic procedure where structured observation and other methods of assessment (interview of people in frequent contact with the person, use of standardised questionnaires) are employed to generate hypotheses about the challenging behaviour, antecedents which might be acting as stimuli for the behaviour and consequences which may be reinforcing it. These hypotheses are then tested out by experimental trial in either a real life or a more controllable analogue setting. The hypotheses that can be supported by experimental evidence are then used to derive interventions to reduce or eliminate the challenging behaviour.

The evidence base supports the use of functional analysis (in its second, stricter meaning) for interventions where the primary focus is the reduction or elimination of severely challenging behaviours in people with moderate, severe or profound learning disabilities. A correlation has been found between carrying out a functional analysis and successful outcome, measured by reduced challenging behaviour.^{354 355 356 357}

This should therefore be the approach of choice where challenging behaviour is severe and the most urgent target for intervention.

There is general agreement that a functional analysis should follow three stages.^{358 359 360}

Stage 1 Hypothesis development

Interviews or rating scales are used to generate hypotheses or rule out areas for further

investigation;

Stage 2 Hypothesis testing

Direct observation and more detailed interviews are used to assess the accuracy of the hypotheses and identify contextual factors;

Stage 3 Hypothesis refining

Either experimental analysis is used to refine the working hypothesis or there is a direct move to intervention strategies which are used to check the accuracy of the hypothesis about the function of the behaviour.

Stage 1 – Hypothesis development

A good place to start is with interviewing the person with learning disabilities, care staff and family members about the challenging behaviour. People will have their own explanations of the behaviour which it is helpful to identify at an early stage – if they seem accurate then a lot of work is saved, but if not, going through the ideas together and working out ways of checking their accuracy is a useful process which can help people develop skills in working with people with challenging behaviour.

Interviews can follow a structured format^{361 362 363 364} and may incorporate rating scales.³⁶⁵

However, the scales need to be used with caution because of difficulties with reliability.^{366 367} A number of studies have been conducted to measure the reliability of scales such as the Motivation Assessment Scale,^{368 369} the Verbal Behaviour Assessment Scale,³⁷⁰ the Questions about Behavioural Function Scale.³⁷¹ A structured interview format can be helpful to generate a range of hypotheses about the function of the challenging behaviour and prevent premature closure.

Stage 2 – Hypothesis testing

Once hypotheses have been generated, these can be tested by monitoring behaviour in the person's everyday environment. A common way of doing this is by ABC chart.³⁷²

ABC charts, when used reliably and accurately, can be used to identify:

- **Antecedents to the behaviour:**
 - setting conditions, particularly recent and immediate

ones;

– specific triggers for the behaviour.

- **B**ehaviour – a record of the target behaviour and of variations (in severity, frequency etc.) in different settings and contexts.
- **C**onsequences of the behaviour
 - possible reinforcers (both positive and negative).

If people such as family members or care staff are being asked to keep ABC charts, the same considerations about motivation and skills apply as in the Guideline 10.8 above.

There are difficulties however with the reliability of ABC charts.^{374 375 376}

They should be used with caution and mainly to measure basic information such as the rate of occurrence of challenging behaviour or broad variables in the environment such as time of day or location.³⁷⁷

The usefulness of ABC charts can be enhanced by:

- providing training in how to complete them;³⁷⁸
- having more than one person complete them independently and checking inter-rater reliability;³⁷⁹
- being very specific about what is to be recorded.³⁸⁰

Direct observation can be used with greater confidence, particularly with high frequency behaviours, to check out different hypotheses about the function of the behaviour.^{381 382}

It is advisable to structure direct observation using either time sampling or event sampling techniques. Because of the amount of data to be collected and analysed, it is also advisable to use a hand-held computer to collect the data^{383 384 385} and either a standard spreadsheet package or purpose-designed software to analyse it.

Presentation of the data is another factor to consider. Simple bar charts and pie charts can be generated by standard computer spreadsheets and the visual representations of variation in behaviour can be vivid and easy to understand. Scatter plots^{386 387} are another graphic way of presenting data.

Multiple methods of data collection are generally

recommended for the purpose of hypothesis confirmation.^{388 389 390 391 392} This is because any one strategy has its flaws and biases. Attempts to check the validity of one approach against another have generally shown unsatisfactorily low levels of agreement,^{393 394} with different methods of assessment tending to identify different functions.

Stage 3 – Hypothesis refining

The hypotheses which have been generated can be tested out either by further direct observation of naturally occurring variables in the person's normal environments³⁹⁰ or by manipulating factors in a controlled analogue setting to test out the hypotheses.³⁹⁴

In analogue assessment, the supposed antecedent (setting event or trigger) or reinforcer is either withheld or presented in a controlled way (perhaps interspersed with other conditions in an ABA type design), and contingent changes in the target behaviour are measured. The hypothesis about the behaviour is thus tested out in a classic experimental fashion. For example, rates of self injury might be assessed in different conditions such as with and without social interaction of different types such as disapproval, praise or demand.³⁹⁵

Although elegant, this can be difficult in practice:

- it requires a high level of control over the environment;
- it may miss contingencies which are operating in the person's 'real' environment;
- it requires skilled staff;
- it may take a very long time to identify the relevant functions;
- the results may not generalise outside the analogue setting (there may be unique contingencies operating there);
- the setting may be stressful and the process may be aversive for the person with challenging behaviour.

Testing out the hypotheses in the person's usual environment also requires a high level of skill and considerable time. Real environments are usually much less easy to control and unexpected variables can intrude. But there is a considerable advantage in working with the real settings where the challenging behaviour occurs.

Both forms of hypothesis testing are valuable and should

be used where there is behaviour which presents a major challenge in terms of its consequences for the person and others and when it has not proved amenable to less intensive forms of assessment.

Another way of testing out a hypothesis is by measuring the effects of an intervention. This is probably the approach most commonly used by British psychologists in day to day practice. Once a hypothesis has been confirmed through observation, an intervention is tried. The success of the intervention is seen as supporting the hypothesis. This has the advantage of being relatively quick. However, if the intervention has been based on the wrong premise and the challenging behaviour does not improve, the psychologist risks losing the confidence of the person with a learning disability, families and care staff and reducing their motivation to persevere with other interventions. This risk may be reduced if the psychologist makes it clear in advance that the intervention is based on a hypothesis and not a confirmed theory.

A recent development in functional analysis has been the greater refinement or 'fine tuning' of possible functions of challenging behaviour from broad categories such as 'social contact' to much more specific factors such as the verbal content of social interaction with particular individuals.³⁹⁶

The functional analytic approach was used traditionally for strictly observable behaviours, but has more recently been expanded to include cognitions or emotions or historical setting events (the person's history and experiences).^{397 398} There is a growing clinical belief that especially in people with milder or borderline learning disabilities, a behaviour analytic approach needs to be supplemented by work with cognitive and emotional factors.

Clinical consensus indicates that functional analysis in the

first sense – the attempt to understand the purpose or meaning of a particular challenging behaviour – is always necessary, whatever the therapeutic stance of the clinician.

With systemic or organisational interventions, where the challenging behaviour is more likely to be conceptualised as an indicator of difficulties in a system which prevent the person's needs and choices from being attended to in a more helpful way, understanding the functional aspect of the challenging behaviour is illuminating. What the behaviour demonstrates about a system is likely to indicate focal points for interventions.

The process of psychotherapy is also a struggle for establishing meaning, and needs to address areas such as challenging behaviour which cause significant problems for a person in relating to others. In psychotherapeutic approaches, the challenging behaviour is likely to be read as a symptom of underlying interpersonal and intrapersonal difficulties. The function it plays in a person's life and relationships provides a key to understanding his or her psychological difficulties.

10.13 Assessing Risk

The psychologist must continue to assess the risks that the challenging behaviour may present to the person showing the behaviour and other people.

Level of evidence to support this guideline: 3

Good practice

This guideline is based on current clinical consensus rather than the literature on effectiveness.

Most NHS Trusts have developed their own methods of assessing risk, with which psychologists must comply.

References: Section 10

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II. Detailed guidelines – Formulation

II.1 Formulation

Definition: Formulation is best regarded as a hypothesis (or set of interconnected hypotheses) about the nature of the clinical problem and its development. It usually contains informed guesses about causal or functional relationships between variables/events and the central problem. It has two main functions: (a) it tells you what to do, i.e. guides your clinical action within an explicit rationale, and (b) it helps you set up criteria for evaluation of your intervention.³⁹⁹

The formulation of a clinical problem is taught on clinical psychology training courses as an essential element of the process of psychological interventions for a whole range of problems. The DCP's *Core purpose and philosophy of the profession* highlights 'formulation' as one of the four core skills of a clinical psychologist.⁴⁰⁰ The dangers of trying to intervene without having a clear enough understanding of what is happening are seen as self evident, and there are no studies that compare interventions with and without formulation. The nearest thing to this in the field of interventions for challenging behaviour would be the meta-analytic studies which have demonstrated that positive outcome is correlated with the carrying out of a functional analysis.^{401,402} In the traditional behaviour analytic model, identifying the function of a behaviour is the formulation.

It is essential that a thorough and comprehensive assessment guides the development of a formulation. The formulation should gather together the relevant information from a variety of sources, clarify the central issues and provide a starting point for intervention. The formulation is more than a mere summary of the facts. Information should be prioritised and integrated using an appropriate theoretical model, research evidence-base and clinical experience.^{403 404 405 406}

There is, therefore, strong (level 1) evidence to support the carrying out of a functional analysis in interventions for challenging behaviour.

Where psychologists may be considering an individual (psychotherapeutic or cognitive behavioural) approach, it would also be seen as good practice to formulate the nature of the problem and the intervention plan.

If an organisational intervention is being considered, the organisation, its strengths and difficulties and a proposed plan for organisational change needs to be formulated using techniques from management studies and organisational psychology. There is no one single 'correct' way to carry out a formulation. How this will be presented will depend upon the context and particular purpose of the formulation.⁴⁰⁷

A formulation should be seen as a working model or map, which can be changed as new evidence emerges to disconfirm it, as the intervention moves along. Formulations are often useful within the multidisciplinary team as a way of helping to co-ordinate and organise thinking and understanding about the individual and how they interact with the wider system.

II.2 Integrating different factors into a formulation

The formulation should include an understanding of the onset and reasons for the development of the challenging behaviour.

It should identify personal, environmental and interpersonal factors which have increased or maintained the challenging behaviour, and also factors which prevent or reduce its occurrence.

It should present a hypothesis, which can be tested through interventions or further assessment, about the function or meaning of the behaviour for the person in his or her environment.

The psychological formulation should integrate the three basic elements of the person, the environment and the behaviour into a coherent and dynamic whole.

Level of evidence to support this guideline: 3

Good practice

If the formulation is to be inclusive, and to make sense to people living or working with the person who is challenging, then it needs to consider all the above factors. The psychologist needs to look for changes in the challenging behaviour – whether this is the onset or fluctuations in the severity or frequency of the behaviour. By seeing how the behaviour changes, and what other factors are associated with those changes, the psychologist can make a hypothesis or series of hypotheses about the behaviour and how it might be reduced.

The formulation is the stage at which the relative contributions of individual factors, environmental factors and the behaviour itself can be brought together and integrated with each other. The aim should be to reach an inclusive and coherent understanding of the challenging behaviour and the different contributions of biological, learned, interpersonal and organisational or systemic factors.

Although there is compelling evidence that both behavioural and biological processes may be involved in the development and maintenance of challenging behaviour, formulations have frequently been drawn up within, rather than across these different frameworks. Psychologists should be aiming to integrate different models within the formulation. There is a growing literature on integrating cultural, social, behavioural and biological processes into formulations.^{408 409 410 411}

Models that integrate behavioural and biological mechanisms are becoming increasingly sophisticated and there are clear benefits of developing a multi-disciplinary approach to formulation.^{412 413 414}

11.3 Intervention plan

The formulation should indicate a proposed intervention, making clear the reasons for the choice of a particular strategy or treatment approach. This should apply with a systemic or organisational intervention, just as much as with an approach which focuses on individual change. It should clearly indicate the target for intervention and will usually involve a multi-component plan to bring about change.

Selection of a target for intervention should be based on the following criteria:

- **capacity to change and motivation of the person with learning disabilities;**
- **the area of greatest clinical need;**
- **evidence on effectiveness of different possible interventions;**
- **skills and the people in his or her immediate environment.**

Level of evidence to support this guideline: 3

Good practice

An essential component of the psychological formulation is the plan for an intervention. The intervention should follow on seamlessly from the formulation of the problem. Consideration will need to be given to:

a) Identifying the area of greatest clinical need

A detailed risk assessment should be carried out in order to help to prioritise potential targets. Clinical need in the person with learning disabilities should be assessed by:

- interview of the person and carers;
- observation;
- data collected from records.

Factors to be assessed include:

- physical or mental ill health
- pain;
- injury or risk of injury;
- distress;
- blocks to further development;
- blocks to participation in a valued life/social inclusion.

The same needs of carers must also be considered.

Where there is conflict between the needs of a person with a learning disability and a carer, the needs of the person with learning disabilities are paramount. Every effort should be made to resolve such a conflict in a way that is acceptable to both parties – a conflict between a person with learning disabilities and those closest to him or her can be highly distressing to both.

b) Evidence of effectiveness

Where challenging behaviour is the major clinical problem, the evidence is that an applied behaviour analytic approach

is likely to be effective and should be the intervention of first choice.^{415 416 417}

There is growing evidence to indicate that this approach needs to be interpreted broadly and should include the cognitions and emotional responses of people with learning disabilities, families and carers as well as strictly observable behaviour in the traditional behavioural sense.⁴¹⁸

An applied behavioural analytic approach requires the focus of change to be in the systems and services which support the person with challenging behaviour, so that they can meet the person's needs more effectively.

Where challenging behaviour is seen as related to other problems which require intervention in their own right (e.g. mental health problems, psychological distress, lack of opportunities to communicate, living in a damaging or deprived environment) these problems need to be addressed, either by the psychologist or by referral to the more appropriate member of the multidisciplinary team. These underlying problems would then be the primary target for intervention. The evidence for the effectiveness of approaches which address these problems is beyond the scope of these guidelines, but has been covered within the AAMR Expert Consensus Panel for Mental Retardation.⁴¹⁹

c) Skills, capacity to change and motivation of the person with learning disabilities and the people in his or her immediate environment

Choice of an intervention plan must depend on an assessment of its likelihood of successful implementation. There must be a 'goodness of fit'⁴²⁰ between the intervention and those who need to be involved in its implementation. Preliminary work may need to be done (e.g. providing staff training; teaching a person with learning disabilities a self-monitoring technique) before certain interventions are feasible.

During the development and consultation process of these guidelines, there was considerable debate concerning the level of psychology input that should be provided into different settings. The experience of many psychologists is that despite intensive inputs, some organisations have such limitations that there may be only a limited impact on outcomes. This presents an ethical dilemma as to whether further input is justified. There was generally more

confidence in being able to work effectively in situations where there was a skills deficit which could be remedied, than in situations where there was a problem of motivation. There are reports of successful skills training in the literature^{421 422 423} but few of changing staff morale. Although studies have shown that there is an association between challenging behaviours and staff psychological well-being^{424 425 426} there is only limited evidence of the effectiveness of intervening to change staff caring strategies in this area of work.^{427 428}

What this guideline indicates is that a psychologist must take a hard and non-blaming look at the capacities both of the person with learning disabilities and the staff or family members around him or her.⁴²⁹ It may be helpful to start with the intervention which would be indicated on grounds of effectiveness and ethics and see what is required to implement it. If possible, the psychologist should discuss the requirements with family members at home or service managers and get their views on its feasibility.

The psychologist must also consider his or her own skills and capacities in the situation. The British Psychological Society⁴³⁰ is clear that psychologists must not work beyond their capabilities, while being responsible for maintaining and developing their professional skills to the best of their abilities.

11.4 Format of formulation

The psychological formulation must always be written down for future reference. It should be anticipated that it will be revised and extended after further assessment or intervention. The formulation may be presented as a flow-chart or described in ordinary paragraphs. It should be presented in a way that can be readily understood.

*Level of evidence to support this guideline: 3
Good practice*

Clinicians have found that a formulation can be lost sight of, if it is not written down and kept readily accessible. Given the persistence of much challenging behaviour,^{431 432 433} and the fact that there can be a high turnover of staff in many services where people are challenging,⁴³⁴ it is good practice to make sure that the details of the formulation and the basis on which it was developed are kept and not lost.

In the best services, formulations will not be seen as fixed and static, but as working theories which can be extended or revised as further information becomes available.^{435,436}

Equally, formulations should be presented in a way which people who need to work with the client can understand. Often this will be in a visual format, and will enable the psychologist to develop a comprehensive package of intervention.

11.5 Process for developing the formulation

The psychological formulation should be the outcome of a collaborative process. This will often include the input of other clinicians.

The person with learning disabilities and anyone who is likely to be involved in the intervention must be involved in the development of the formulation.

*Level of evidence to support this guideline: 3
Good practice*

If steps are not taken to include the person with learning disabilities and people living and working with him or her, there is a serious risk the formulation will not be practical or socially valid. It will not fit its purpose of providing an agreed sense of direction and a shared understanding of the nature of the problem being addressed.

There is a growing research literature which focuses on the beliefs of care staff about challenging behaviour.^{437 438 439}
^{440 441} Ideas derived from common sense notions of ‘bad behaviour’, or from staff experience of parenting will tend

to be applied, especially in the absence of alternative explanations. Sometimes this leads to staff or families inadvertently reinforcing the very behaviours they find most challenging.^{442 443}

An essential part of the formulation is the creation of a shared understanding of the behaviour and how it needs to be worked with.⁴⁴⁴

Many clinicians have found problems of implementation in working with staff and challenging behaviour. If the process of formulation is shared, then practical problems caused by resources and skills available should be identified – and hopefully overcome – before the intervention stage. This can substantially reduce frustration and mutual blame.

Similarly, it is important ethically and practically to involve the person who is challenging services as much as possible in the process of formulation. Particularly where a proposed intervention is focused on individual change (e.g. with anger management) the person concerned needs to feel motivated and empowered by the formulation. Techniques such as self-monitoring have been used successfully with some people with learning disabilities to facilitate their involvement.

There is another practical reason for involving others in a shared formulation. It is likely to be better – more inclusive and more comprehensive. If colleagues from other professions, families and care staff are not involved in developing the formulation, it risks being impoverished. There are a number of examples of interdisciplinary assessments leading to formulations and intervention plans that combine neurobiological and behavioural processes.^{445 446}

References: Section 11

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12. Detailed guidelines – Intervention

12.1 Intervention

Definition: Psychological interventions are defined as attempts to make changes in people, their behaviour, the systems around them or their interpersonal relationships, using methods derived from a psychological knowledge and understanding of individuals and their world.

These guidelines refer specifically to interventions where the primary focus is on challenging behaviour.

Interventions for challenging behaviour can be divided into two groups:

1. Reactive behaviour management strategies

These are interventions which focus on containing behaviour which presents a risk of harm or injury to the person or others, at the time when that behaviour occurs or seems about to occur.⁴⁴⁷

2. Proactive prevention and treatment strategies

These strategies focus on the prevention, reduction or elimination of challenging behaviour through planned interventions.^{448 449}

The guidelines for interventions for challenging behaviour are presented in three sections:

- ethical issues and priorities;
- reactive behaviour management strategies;
- proactive strategies.

12.2 Ethical issues and priorities

Managing risk

Where aggression or self-injurious behaviour presents a serious risk to the person who is challenging or others, effective and ethical reactive strategies for managing the behaviour as it happens or seems about to happen need to be in place as a matter of urgency. At minimum, the psychologist has the responsibility to check that such a strategy is in place and that it is being used ethically.

Duty of care to provide effective interventions

There is an obligation on the psychologist working with behaviour which presents a severe risk to the person or others to use his or her skills and knowledge to provide the most effective interventions, available in order to reduce the incidence and severity of the challenging behaviour.

Prevention of abuse

No interventions for challenging behaviour should be abusive. A psychologist must not use interventions which constitute ‘cruel, inhuman or degrading treatment or punishment’.⁴⁵⁰ Psychologists have a duty to report colleagues (of whatever discipline) who are using such interventions, in order to prevent their use.

Where the assessment indicates that challenging behaviour is likely to be a response to a neglectful or abusive environment or relationship, the psychologist has a primary duty of care to the welfare of the person with learning disabilities. The psychological intervention should endeavour to protect the person with learning disabilities by changing the environment or relationship rather than stop the behaviour and thereby silence the person’s protest.

When abuse is suspected, local policies (e.g. on abuse of children or adults; on quality of care) and the BPS Code of Conduct must be consulted and followed. Psychologists must consult with experienced colleagues especially if they are in any doubt as to what course of action to take.

Level of evidence to support these guidelines: 3

Essential practice

These guidelines have been informed by the discussions held at the clinicians’ conference in January 1997, and by feedback and further discussions during the consultation process. They are not based on evidence for effectiveness but on the views of experienced clinicians supported by

reference to the British Psychological Society *Professional Practice Guidelines*⁴⁵¹ and *Code of Conduct*.⁴⁵²

Guidelines on reactive strategies

These guidelines need to be considered in the light of local and national guidelines, policies and procedures on managing violence and aggression. Each clinical psychology department should ensure that such policies are being implemented in the places where they work.

National guidelines,^{453 454 455 456} have been developed which provide a clear framework for staff who work in situations in which the implementation of physical interventions may be considered.⁴⁵⁷

12.3 An individual approach to reactive strategies

An effective and ethical reactive strategy for managing challenging or potentially dangerous or offensive behaviour needs to be based on an understanding of the individual and devised on a case-by-case basis.

The information collected through functional assessment should be used to guide the choice of a strategy.

Where there is a need to have a strategy in place quickly because of a high and immediate risk of harm to the person or others, hypotheses about the function of the behaviour should be collected from people (families or staff) who know the person well and from records. These should be used to guide the choice of a strategy.

*Level of evidence to support this guideline: 3
Good practice*

Because of the different functions of challenging behaviour, a reactive strategy which is effective for one person will not necessarily be effective for another. For example, one person may start to self injure in an attempt to engage staff in dialogue, whereas another person may show the same behaviour in order to be left alone or be taken to a 'quiet room' away from interaction with other people. In this case, different strategies will be necessary for the immediate management of the self-injury as well as a longer-term intervention strategy. Psychologists must avoid using reactive

strategies which will reinforce the challenging behaviour in the longer term. It is possible for self-injurious behaviour to increase in response to staff and family reactions to the behaviour.⁴⁵⁸ Similarly, psychologists should not support the use of reactive procedures that could potentially act as punitive stimuli for service users (e.g. via the infliction of physical pain) or as a vehicle for retribution.

The results of functional analyses can also be used to directly inform reactive management plans⁴⁵⁹ in that they should generate data on:

- the specific forms of challenging behaviour that need to be considered;
- how these behaviours may link together in a behavioural chain;
- their frequency, intensity and duration;
- their historical and current triggers;
- the individuals at risk;
- the escalatory pattern of the challenging behaviours;
- immediate indicators that the behaviours are about to occur.

There has been some debate among psychologists about the possible conflict between the need to act quickly to reduce the risk of harm caused by challenging behaviour and the need to assess thoroughly enough to ensure that the strategy selected will be effective. Doing nothing until a full assessment is completed may carry too high a risk of injury caused either directly by the person with challenging behaviour or by staff or families resorting to dangerous physical interventions, for example, when attempting to prevent injury. When formal advice is not provided, carers will tend to devise their own responses. In a study of 5- to 18-year-olds⁴⁶⁰ who displayed high rates of aggressive behaviour, physical interventions were already in place for 56 per cent of the children at the time of referral to a specialist support service. These interventions had been improvised by carers.

In the absence of safe, effective procedures for responding to high-risk behaviours, the chances of carers implementing or maintaining positive behaviour change strategies are significantly reduced⁴⁶¹ and the potential for service user abuse is significantly increased.^{462 463} There is limited evidence to suggest that the provision of training in reactive management may be a key variable in sustaining placements for severely challenging individuals^{464 465} and in reducing the use of anti-psychotic medication.⁴⁶⁶

It may, therefore, sometimes be necessary to introduce reactive procedures in advance of detailed functional analyses or behaviour change strategies being in place; in such circumstances, appropriate analyses or interventions must be initiated in parallel to the reactive procedures.

In all cases, the risk of using an inappropriate reactive behaviour management strategy must be weighed against the risks of harm or injury arising from the challenging behaviour itself.

Where the risk is high, and a strategy needs to be implemented quickly, it will be particularly important to monitor the effects of the strategy in practice. Procedures should be reviewed and changed if they are seen to be having a deleterious effect on the person with learning disabilities or others.

12.4 Purpose and limitations of reactive strategies

The focus of reactive strategies should be to ensure the safety of the person who is challenging, other people with learning disabilities, staff, family members and any bystanders.

Reactive strategies are therefore concerned only with managing difficult episodes of behaviour; they are not designed to produce long-term changes in behaviour.⁴⁶⁷ For this reason, reactive strategies should not be used in isolation, but must be embedded within a broader programme of interventions designed to produce behavioural change.

Written reactive management plans should be in place for all service users whose behaviour poses risk to the person themselves, their carers or members of the public.

Reactive management plans must always co-exist alongside positive strategies for achieving behaviour change.

*Level of evidence to support this guideline: 3
Essential practice*

Local policies on managing violence and other challenging behaviours should contain a statement about the primary purpose of any techniques used.

12.5 Selecting a reactive strategy

Reactive strategies should follow the principle of least intrusiveness and least restrictiveness. A reactive plan should offer advice on responding to lower levels of challenging behaviour in ways that may help to defuse further behavioural escalation as well as guidance on responding to severe behavioural outbursts.

Strategies that are restrictive or intrusive (e.g. physical interventions) should only be used in conjunction with a written service policy and be carefully monitored and reviewed.

The severity of risk presented to the person or others should be considered when deciding on an appropriate reactive strategy.

Non-physical reactive strategies which may be effective include:

- **not responding to challenging behaviours;⁴⁶⁸**
- **at the same time attempting to cue in or reinforce alternative more positive behaviours;⁴⁶⁹**
- **removing demands;⁴⁶⁹**
- **diversion to a reinforcing or compelling event or activity;⁴⁶⁸**
- **strategic capitulation;⁴⁶⁸**
- **low arousal approaches where others stay calm, quiet and non-threatening (e.g. by maintaining appropriate interpersonal space) and try to avoid escalating arousal and the risk of physical violence.^{470 471}**

Only when these approaches have proved ineffective, and where the behaviour presents a serious risk to the person or others, should the planned and well-monitored use of physical intervention procedures be considered. These should contain the challenging behaviour while avoiding injury to the person or others. It is recommended that if physical interventions are required, they should:

- **be appropriate to the needs of children and adults with intellectual disabilities**
- **be used for the shortest time possible**
- **employ the minimum reasonable force**
- **not inflict pain**
- **not impede the process of breathing**

- avoid vulnerable parts of the body e.g. neck, chest and sexual areas
- avoid hypertension, hyperflexion and pressure on or across joints
- not employ potential dangerous restraint holds
- avoid unsupervised modifications to taught strategies

Level of evidence to support this guideline: 3

Good practice

These guidelines are derived from clinical views of good practice, informed by ethical considerations; there is an urgent need for a systematic review of the effectiveness of different reactive strategies.^{472 473}

It is recommended that local policies are used to inform good practice in the field of reactive strategies for challenging behaviour. Local management groups or ethical committees should review reactive behaviour management strategies. There is some evidence to suggest that where there is no guidance, staff are left having to make rapid decisions at a time when they may feel highly stressed, angry or afraid – conditions under which poor practice, abuse or injury are more likely to occur.^{474 475}

12.6 Recording and review of reactive strategies

All reactive strategies for managing challenging behaviour must be written down and in a format and location that is readily accessible. They must be updated and reviewed regularly and frequently. Their use must be recorded and monitored.

Level of evidence to support this guideline: 3

Good practice

This guideline is based on the clinical consensus on good practice, supported by the published guidelines on managing challenging behaviour.⁴⁷⁶ Sample formats for reviewing reactive strategy usage are available.⁴⁷⁷

12.7 Training in the use of reactive strategies

Everyone who is likely to use the reactive strategy (including the psychologist) should receive training which includes opportunities to practice implementing the strategy. This training must be updated on a regular basis while the strategy is in

place. Training should always include both preventative and reactive components.⁴⁷⁹

Level of evidence to support this guideline: 2

Good practice

There is evidence of a need to include reactive behavioural training for carers as part of an overall intervention package. While there is some evidence to suggest that such training can have beneficial effects, outcomes can be highly variable, and the overall quantity and quality of research in this area is poor.⁴⁷⁹ Positive results reported to date include improved carer knowledge and confidence; enhanced competence in physical intervention skills; and reduced rates of challenging behaviour and physical interventions. Minimal or negative results have also been reported in each of these areas. It has been suggested that training in physical interventions will be enhanced if skills are taught one at a time and subject to repeated practice,⁴⁸⁰ and that acquired skills will fade if there is no opportunity to practice.⁴⁸¹

Guidelines on proactive strategies

12.8 The context of interventions

Interventions, which aim to reduce or eliminate challenging behaviour, should be implemented in the context of a positive environment with programmes in place for the person's development and enhanced quality of life.

Level of evidence to support this guideline: 3

Good practice

There is a risk that interventions may be used to ensure that a person conforms to an unacceptable or damaging environment. This is not an ethical use of psychological techniques. In order to prevent this happening, the psychologist should ensure that the person's needs are being addressed in a positive way and that reducing the challenging behaviour is not the sole focus of concern.

12.9 Service policies and procedures

It is recommended that local guidelines or policies should be in place for the use of controversial or restrictive procedures, that staff should receive adequate training in any such policies and that there should also be access to an ethical committee or similar support for the consideration of difficult cases.

Level of evidence to support this guideline: 3

Good practice

Many services have position statements about the use of restrictive or potentially aversive procedures. We would commend this practice. However, it is extremely important that staff understand both what is meant by the term 'aversive' and what is or is not aversive for people on an individual basis.

Any policy on the use of restrictive or aversive procedures, including policies which say such procedures are unacceptable, must be backed up with comprehensive training for existing staff and for new staff as they are inducted. Staff are likely to revert to parental or 'common sense' models of coping with challenging behaviour – including 'telling them off' or 'not letting them get away with it' – if they are not trained in alternative approaches and supported in their use.

12.10 Considerations in service interventions

Changing aspects of the environment in which the person is supported is often a central component of intervention strategies. Interventions which aim to change environmental factors in a service setting include:

- **consultancy and advice;**
- **staff training;**
- **supporting staff and managers in organisational change processes.**

It is recommended that in a service setting, a written contract is made with managers and staff groups. The contract should:

- **define the target for intervention**
- **indicate the plan of action**
- **make clear what is expected from staff and the psychologist.**

The contract must be monitored and reviewed.

In a family, there should also be clarity about the target for change and what is expected of the psychologist and of family members.

Level of evidence to support this guideline: 2

Good practice

It is important that there is clarity about the relative

roles of the psychologist and a service manager in instituting and sustaining organisational change.

Experience from small houses for people with challenging behaviour has shown the importance of management commitment to creating and maintaining a positive environment and provides an indication of the type of supportive role which a psychologist might play.^{482 483 484}

12.11 Selecting a proactive strategy

The intervention strategy should focus on the chosen target for change. It should follow on logically from the functional assessment. Strategies that prevent the challenging behaviour should be considered first.

Choice of strategy should be based on the following criteria:

- **known effectiveness in reducing or preventing challenging behaviour;**
- **other benefits for the person with learning disabilities;**
- **capacity for long-term maintenance;**
- **capacity for generalisation;**
- **ethical considerations;**
- **social validity – acceptability to families, staff, the general public;**
- **ease of use or application.**

Level of evidence for this guideline: 3

Good practice

This guideline is based on clinical consensus on good practice.

Proactive strategies may focus on the person, the behaviour or the environment as the target for change. The locus of intervention may be before the challenging behaviour occurs, while it is happening, or after it has happened. It is self evident that preventing the behaviour from starting in the first place is more desirable than responding to it after it has happened.

Potential approaches to prevention which focus on the *person* include:

- **altering the person's bio-behavioural state**
- **cognitively-based interventions for psychosocial problems**
- **developing the person's capacity to cope with potentially stressful events or to communicate more effectively**

Preventative approaches which focus on the *behaviour* include:

- changing the nature of preceding activities;
- changing the nature of current activities;
- differential reinforcement

Preventative approaches which aim to change the *environment* include:

- introducing a range of positive environmental changes;
- increasing the person's choice and control.

Approaches where different responses to the challenging behaviour are systematically introduced include extinction and punishment. The preceding preventative strategies should be considered before these, and in preference to them.

12.12 Altering the person's bio-behavioural state
Where the assessment has indicated that bio-behavioural factors in the individual are related to challenging behaviour, these need to be addressed.

Referrals should be made to the appropriate clinician if medical or other problems are suspected.

Participation in physical exercise has also been shown to reduce challenging behaviour.

Level of evidence to support this guideline: 2
Good practice

There is some evidence from case studies for the effectiveness of altering bio-behavioural states through addressing illness, pain or discomfort, and by increasing physical activity.

A range of bio-behavioural states have been shown to be correlated with the occurrence of challenging behaviour. These include such factors as alertness, fatigue, sleep/wake patterns, hormonal changes, drug effects, seizure activity, psychiatric disorders, mood and illness or pain.⁴⁸⁵ Examples of this are menstrual pain linked with aggression⁴⁸⁶, otitis media making ambient noise aversive and leading to self injury.⁴⁸⁷ Approaches to intervention include the treatment of sleep disorders,^{488 489 490 491 492} appropriate treatment of medical conditions^{493 494} and changes to medication regimes.⁴⁹⁵

Suspected medical factors should be brought to the attention of the appropriate doctor. As well as the obvious benefit of treating illness or pain, a reduction in the challenging behaviour may also be the outcome.

Numerous studies have reported that physical exercise may result in reductions in stereotypic,^{496 497 498 499 500} self-injurious,^{501 502} aggressive or disruptive behaviours.^{503 504 505} Greater reductions in challenging behaviour have been reported for more strenuous activities (e.g. jogging compared with ball games).⁵⁰⁶ The accumulated evidence points to a consistent, although not inevitable, short-term effect of aerobic exercise on subsequent activity.⁵⁰⁸

12.13 Cognitively-based interventions for psychological problems

When challenging behaviour appears to be a response to a person's psychological distress or a mental health problem, this needs to be treated by the most effective means possible.

Psychological problems such as anxiety, phobias and depression can be treated effectively with cognitive behaviour therapy in people with learning disabilities who have the motivation and skills necessary for cognitive techniques.

Level of evidence for this guideline: 2
Good practice

Where early experience or previous neglect or trauma is thought to have led to current challenging behaviour, psychotherapy, cognitive behaviour therapy or counselling should be considered. These approaches have been demonstrated to be effective for people without a learning disability.⁵⁰⁹

People should not be excluded from effective therapeutic approaches because they have a learning disability; their capacity to benefit must be assessed on a case-by-case basis.

Suggested factors to consider include:⁵¹⁰

- verbal communication skills;
- cognitive skills (e.g. autobiographical memory; capacity to reflect on inner experiences; capacity to understand metaphor);
- capacity to tolerate distressing emotional states;

- suggestibility and assertiveness;
- capacity for interpersonal relationships.

Current environmental factors must be assessed as well as the person's intrapsychic or interpersonal strengths and difficulties; the environment needs to be able to support a person who is in psychotherapy and may experience distress and intrusive memories as a result.

There is a growing literature demonstrating that cognitive behavioural approaches can be effective with people with learning disabilities.^{511 512 513 514}

There is a very small body of literature concerning the provision of psychotherapy for people with intellectual disabilities.^{515 516 517} The majority of reports are case reports, and as yet there are no controlled studies. A number of studies report on the outcome of psychodynamic psychotherapy with adults who have a learning disability and co-morbid mental health problems^{518 519} or have offended.^{520 521}

The person's environment will need to be assessed as well as the individual's ability to make use of cognitive behavioural approaches. Families or services need to be able to reinforce new skills and attitudes developed by cognitive-behaviour therapy.

Where a group rather than an individual approach is indicated, the person's ability to tolerate being in a group, to express themselves in a group setting and to listen appropriately to others should also be considered. Again, there is evidence from research with non-learning disabled people that group approaches can be effective – this needs wider and more systematic replication with learning disabled groups. A few accounts of therapeutic groups with people with learning disabilities exist, but there is little evidence to support their effectiveness.⁵²²

12.14 Developing the person's capacity to cope with potentially stressful events, or to communicate effectively, through psycho-educational approaches or skills training.

Where challenging behaviour appears to be a response to stressors in the environment, people with learning disabilities can be taught alternative ways of coping or problem solving. Anger

management techniques can also be learnt.

Where challenging behaviour has a communicative function, functional communication training can be of benefit.

Level of evidence for this guideline: 2

Good practice

There is a substantial body of literature on effective ways of teaching skills to people with even the most severe learning disabilities.^{523 524} There is an extensive literature too on teaching new skills to people with learning disabilities and challenging behaviour.^{525 526 527}

A review of 16 published reports on interventions based upon anger management approaches⁵²⁸ suggests that intervention packages can be effective, but the differential effectiveness of the components has not been established.⁵²⁹

12.15 Principles of functional equivalence

Behavioural interventions are most likely to be both effective and ethical if they follow the principle of functional equivalence. Once the function of the behaviour has been identified through functional assessment, the challenging behaviour can be replaced with a functionally equivalent but more positive behaviour. This, in effect, enables the person to exercise control over important aspects of their day to day life, without resorting to challenging behaviour.

Level of evidence to support this guideline: 1

Essential practice

This guideline is based on clinical views of ethical practice, supported by the literature which indicates the importance of carrying out a functional analysis (see *Guideline 10.12*), and on the evidence for effectiveness of intervention techniques that are based on the idea of functional displacement (e.g. functional communication training).

Functional displacement: Intervention through functional displacement seeks to introduce a new behaviour (or increase the rate of a pre-existing behaviour) which will tap in to the existing contingencies of reinforcement and displace the challenging behaviour.^{530 531 532 533} A number of

studies have demonstrated the viability of the procedure across a number of settings, participants and challenging behaviours.^{534–562} In addition, studies have indicated that the treatment gains achieved may generalise across settings and therapists^{563 564} and may be maintained over time.^{565 566} Functional displacement will only be effective if the replacement response is equivalent to the challenging behaviour and is also a relatively more ‘efficient’ response.⁵⁶⁷ Response efficiency is a complex construct reflecting the combined effects of response effort and the rate, delay and quality of reinforcement contingent upon the response. As a result, in order to maximise the impact of intervention, it may be important to increase the response efficiency of the replacement behaviour and decrease the response efficiency of the challenging behaviour. That is, it is likely to be necessary to combine functional displacement or functional communication training with more traditional reactive strategies (e.g. extinction, time-out) to weaken the challenging behaviour.^{568 569 570}

12.16 Changing the nature of preceding activities

Changing the behaviours which have been identified as leading up to challenging behaviour can reduce the likelihood of it happening to a significant extent. New activities or patterns of behaviour may be introduced, or triggers or pre-disposing factors may be taken away or diminished.

When the assessment has identified clear and specific triggers for serious challenging behaviour (e.g. exposure to prior activities or events) it is recommended that these triggers are removed where possible and appropriate.

Level of evidence for this guideline: 2

Good practice

The nature of preceding activities may have a significant impact on people’s responses to ongoing events. Studies have examined the relationship between a variety of types of preceding activities and subsequent rates of challenging behaviour.

These include studies of the effects of:

- behavioural momentum in increasing compliance and reducing challenging behaviours associated with non-compliance;
- choice making;

- task variety and stimulus fading;
- exercise; and
- a variety of idiosyncratic establishing operations.

Behavioural momentum⁵⁷¹ is a phenomenon that has been applied to the reduction of challenging behaviour. Following repeated reinforcement, behaviour appears to gain a ‘momentum’ which makes it temporarily resistant to change. For example, preceding a request to take medication (which often led to challenging behaviour) with a series of requests to ‘give me five’ resulted in increased compliance and reduced challenging behaviour.⁵⁷² A number of studies since then have illustrated the viability of this procedure across a range of settings.^{573 574 575 576}

Increasing task variety^{577 578} (and decreasing repetition) was shown to be associated with immediate and significant reductions in aggression and tantrums, but it should be noted that one participant in these studies showed a preference for task repetition. This highlights the need for interventions to be based on individualised functional assessments.

The use of *neutralising routines* has been shown to be an effective intervention.⁵⁷⁹ When an activity or event has been shown likely to precede challenging behaviour (e.g. having a disturbed night’s sleep, or the cancellation of an activity), a ‘neutralising routine’ can be introduced to compensate (e.g. an hour’s nap, or taking part in another enjoyable activity). This can then prevent the challenging behaviour from occurring.

The effectiveness of physical exercise as a preceding activity has been discussed already (Guideline 12.9).

A number of studies have presented data to link other *idiosyncratic* events (e.g., difficulty getting up, the choice of route to school) with an increased probability of challenging behaviour.^{580 581} Clearly, a thorough functional assessment is essential for identifying the operation of such idiosyncratic associations.

Reducing exposure to events or activities which appear to be aversive to an individual, and so generate challenging behaviour (‘triggers’), is self-evidently good practice. It is both an ethical and an effective way of reducing challenging behaviour. For example, a person may demonstrate distress and challenging behaviour in large

group settings. In such a situation it would be more ethical to help rearrange the person's activities to avoid such settings, rather than to make the person comply with routines that have been derived for the convenience of staff or organisations. In such situations a judgement needs to be made as to whether a particular necessity is driven by staff needs or the needs of a person with learning disabilities.

12.17 Re-introducing triggers

If the potential triggers for challenging behaviour need to be reintroduced because they will benefit the person with a learning disability, then a programme should be devised to introduce them carefully and positively using techniques such as embedding or stimulus fading (systematic desensitisation).

Level of evidence for this guideline: 2

Good practice

There are circumstances in which a person may be experiencing a particular event or activity as aversive but nevertheless needs to learn to cope with it as: (1) avoidance may not be practically possible; (2) the activity may be of considerable benefit in itself. There is evidence to indicate how this might be achieved. In such situations it can be effective to eliminate exposure to the activity and then gradually reintroduce it (stimulus fading) in a positive context (embedding).

'Stimulus fading'^{582 583} refers to the temporary withdrawal and gradual reintroduction of stimuli which set the occasion for challenging behaviour. This technique has been combined with the use of negative extinction in the treatment of escape-motivated self-injurious behaviour. The results of these studies suggest that while stimulus fading may help avoid the occurrence of an extinction burst,⁵⁸⁴ it does not necessarily appear to increase the effectiveness of the extinction procedure itself.⁵⁸⁵ The technique of stimulus fading is procedurally similar to the techniques of systematic desensitisation and reinforced graded practice in the treatment of fears and phobias.⁵⁸⁶ This suggests that the effectiveness of stimulus fading may be increased if combined with procedures incompatible with arousal (e.g., relaxation, massage, eating). While there have been no tests of this specific hypothesis, a few case studies have reported the

beneficial effects of including relaxation training or massage as a component of more complex treatment packages.^{587 588 589}

'Embedding' has been defined as 'a procedure that involves placing demands in a positive context, which is any situation that puts the person with disabilities in a good mood.'⁵⁹⁰ Sometimes changing relatively superficial aspects of the context in which challenging behaviours occur can have a significant impact.⁵⁹¹ Similarly, a number of studies have shown that increasing the availability of positive reinforcers or preferred materials in 'high-risk' situations may significantly reduce escape-motivated challenging behaviour.^{592 593 594 595} Substantial reductions in challenging behaviour and reduced negative affect (measured through ratings of facial expression) have been reported⁵⁹⁶ when 'fast-paced' music was incorporated into situations that were associated with high rates of challenging behaviour.

12.18 Strategies for positive environmental change

There are a number of preventative strategies which focus on changing the environment. These include positive curriculum design, increasing choice, and environmental enrichment. Creating an environment which is more adapted to the person's needs and preferences can reduce challenging behaviour as well as being beneficial in its own right.

Level of evidence for this guideline: 2

Good practice

The evidence for these interventions comes from a number of studies.

Curriculum design and supported routines

Several studies have reported reductions in challenging behaviour as a result of using assessments of participant preferences to design educational or vocational curricula.^{597 598 599 600 601 602 603 604 605 606 607} The results indicated significantly greater occurrence of challenging behaviours during activities that were non-functional, age-inappropriate or non-preferred. Replacing them with activities which were meaningful, appropriate and preferred led to reductions in challenging behaviour.

Increasing choice: A small number of studies have also

suggested that the actual act of choosing may be important in increasing participation^{610 611 612 613} and reducing challenging behaviour.⁶¹⁴ It was found that when the children chose tasks they showed greater engagement and less challenging behaviour than when simply presented with identical tasks at other times, although the results of other studies should be noted.^{615 616}

Environmental enrichment and non-contingent reinforcement:

A number of studies have indicated that generally enriching the environment by, for example, increasing interaction with materials or introducing materials into barren environments may lead to a reduction in the rate of challenging behaviours. Thus, for example, increasing social contact,^{617 618} providing toys,^{619 620 621} individually preferred activities,^{622 623} visual stimulation,⁶²⁴ leisure activities⁶²⁵ and music⁶²⁶ have been associated with increased compliance,⁶²⁷ reduced rates of stereotypy^{617 618 621 624 626} and self-injury.^{619 620 622 623} Similarly, moving from materially and socially deprived institutional settings into enriched community-based residential provision is commonly associated with a reduced rate of stereotypic (although not more seriously challenging) behaviour.⁶²⁸ However, other studies have indicated that increasing the level of stimulation in the environment through visual displays,⁶²⁹ television⁶³⁰ and crowding⁶³¹ can lead to *increased* rates of stereotypy,^{629 630} aggression⁶³¹ and decreased task performance.⁶²⁹ The results suggest that for some individuals environmental enrichment may be associated with increased rates of negative reinforcement (e.g. overarousal, increased rates of negative peer contact). The contradictory nature of the results again highlights the importance of basing interventions on prior functional assessment.

Non-contingent reinforcement means increasing the background rate of the specific reinforcer maintaining the challenging behaviour. Several studies have indicated that this procedure may be effective in reducing challenging behaviour.^{632 633 634 635 636 637 638 639 640 641 642 643 644 645 646}

However, given the generalised importance of our ability to exercise control,⁶⁴⁷ and the very limited opportunities for control available to people with severe disabilities, the use of non-contingent reinforcement *on its own* should be advocated with some caution.

12.19 Increasing other behaviours

It is possible to reduce the incidence of challenging behaviour by reinforcing (and thereby increasing

the rate of) other behaviours. This is differential reinforcement. This strategy is more likely to succeed if the new behaviour requires less effort than the challenging behaviour, or if the reinforcers for it are more immediate and powerful.

Level of evidence for this guideline: 3

Good practice

Differential reinforcement seeks to intervene indirectly on challenging behaviour by increasing the rate of other behaviours.^{648 649 650 651} These include: the *differential reinforcement of other* behaviour (DRO) and the *differential reinforcement of alternative* (DRA) or *incompatible* (DRI) behaviour. The differential reinforcement of other behaviour, also known as omission training, is a non-constructural procedure involving the delivery of a reinforcement contingent on the non-occurrence of the targeted challenging behaviour during an interval of time or, more unusually, at a specific point in time. The differential reinforcement of alternative or incompatible behaviour involves the delivery of reinforcement contingent on the occurrence of a specified alternative behaviour (DRA) or a behaviour which is physically incompatible with the challenging behaviour (DRI).

Individual studies have reported marked variability in the outcomes associated with differential reinforcement procedures, with results ranging from complete suppression, through marginal improvements to increases in the rate of challenging behaviour over baseline.⁶⁵³ In general, however, it would appear that such procedures may not be particularly effective in reducing severely challenging behaviours.^{654 655} An effective procedure should aim to ensure that:

1. the alternative behaviour requires less effort than the person's challenging behaviour;
2. the rate of reinforcement delivered contingent on the alternative behaviour is greater than the rate of reinforcement maintaining the challenging behaviour;
3. reinforcement is delivered immediately upon occurrence of the alternative behaviour;
4. the reinforcers selected are more powerful than those maintaining the challenging behaviour, preferably through the use of empirical procedures to identify reinforcer selection.

12.20 Directly altering the consequences of challenging behaviour

Behavioural techniques that manipulate the consequences of behaviour have often been misapplied. They are often restrictive and solely seek to eliminate challenging behaviour. As a result, they need to be used with caution. Nevertheless, there is evidence that such reactive strategies as extinction and punishment can be effective in reducing challenging behaviour.

12.20.1 Extinction

Extinction should only be considered as a treatment option in situations where the following apply:

- **in conjunction with sufficient other opportunities for positive reinforcement and not in a deprived environment**
- **in conjunction with a constructional approach (e.g. functional communication training);**
- **when the consistent application of the technique can be assured;**
- **when the possibility of an ‘extinction burst’ (i.e. marked increase in the behaviour before it decreases) does not hold a serious risk to the person with challenging behaviours or others;**
- **when the possibility of increased behavioural variability (as the person tries other ways of achieving his or her goals) can be contained or worked with in a constructive way.**

Level of evidence to support this guideline: I

Good practice

If the functional analysis has demonstrated that a particular behaviour seems to occur because it is being reinforced by consequences that are positive for the individual, then removing the reinforcer after the behaviour should stop the incentive for the behaviour. Extinction is the technique of taking away the reinforcer. Sometimes extinction will involve not taking away negative reinforcers. For example, if a challenging behaviour seems to have a function of enabling the person to get away from an unwanted demand (escape function), an extinction programme would stop them getting away (escape extinction).

There is strong evidence from a meta-analysis to demonstrate that extinction can be an effective intervention for challenging behaviour.⁶⁵⁶

However, most studies were carried out under very controlled institutional conditions, thereby limiting their applicability to current practice. They also involved considerable physical risk. For example, in one successful case a child stopped self-injuring after eight treatment sessions, but during that time he hit himself 9000 times.⁶⁵⁷

There are three practical difficulties with applying this technique in typical community settings:

Consistency: Extinction needs to be applied very consistently by everyone with whom the person comes into contact. When behaviour is challenging, this can be very difficult for staff or families in the heat of the moment. Similarly, the responses of members of the public in a community setting cannot be controlled. Without such consistency, the behaviour will be on an intermittent reinforcement schedule, where the behaviour is sometimes reinforced and sometimes not. This tends to lead to a strengthening rather than a reduction in the target behaviour.

Extinction burst: An extinction burst refers to the temporary increase in behaviour frequency and variability during the early stages of the extinction process. This creates obvious risks with aggressive or self-injurious behaviour.

Environments with few reinforcers: There is an obvious ethical problem associated with withholding reinforcing activities, especially when a person may have little access to sources of reinforcement. When people live in impoverished conditions, extinction should be only used with extreme caution.

Extinction should therefore not be used on its own without another constructional programme such as skills training or a non-contingent increase in access to other reinforcing items or activities. There is some evidence to support the effectiveness of such a combined approach.⁶⁵⁸

If staff or families are to use extinction as a technique, the psychologist must ensure that they are familiar with the technique, happy to use it and can apply it consistently and when under pressure. Staff in community settings report difficulties of feeling ‘on show’⁶⁵⁹ which mean that programmes where they are asked not to respond to a challenging behaviour can be particularly difficult to implement in public settings.

12.20.2 Punishment

There are many clear ethical objections to the use of punishment as a technique and many services expressly forbid the use of any aversive techniques, in which case punishment can never be used.

It is important to be clear about the idiosyncratic nature of aversives and recognise that responses that may be pleasurable and reinforcing to some people (e.g. physical contact), may be aversive to others, and vice versa. The psychologist needs to consider whether the use of teaching techniques or other strategies might constitute aversive approaches. For services which allow the use of aversive techniques in limited and controlled circumstances, the following guidelines are suggested:

- punishment must never be used as a sole intervention strategy, without additional measures being taken to ensure a high standard of care, individualised plan for the person's development and improved quality of life;
 - there are some punishment strategies which should never be used because they constitute 'cruel and unusual treatment'. Examples of this would include painful electric shock, beatings and other assaults on the person;
 - punishment must only be considered as an intervention where the challenging behaviour presents a serious risk to the person or others;
 - it should never be used without a detailed functional analysis and a review of all other treatment options, including a critical review of previous intervention attempts;
 - a decision as to whether or not it should be used should not be taken by an individual. The use of punishment should always be referred to a service ethical committee or similar review body which has multidisciplinary and informed lay membership;
 - every effort should be made to obtain the person's informed and free consent to the procedure. If this is not possible, the views of an independent advocate for the person with learning disabilities should be sought prior to treatment. Consideration should be given to the question of whether the same technique would be applied to a person without a learning disability in similar circumstances.
- if punishment is agreed to be appropriate under these constraints, then its use must be reviewed and monitored closely:
 - every instance of its use must be monitored in writing;
 - possible effects of punishment on the individual must also be monitored (e.g. signs of distress, social withdrawal);
 - there must be frequent reviews of its use;
 - a date should be set at the outset for a major review, at which the use of punishment would be discontinued unless there was very strong evidence to support its continuation;
 - the client (or independent advocate) should have the right to appeal (to an independent authority and not those responsible for carrying out the technique) against the use of punishment at any time.
 - Where the psychologist witnesses or has reported to him or her the informal use of a punishment strategy, they must challenge its use and follow the local child or adult abuse procedures and report the incident to the appropriate person.

*Level of evidence to support this guideline: 1
Essential practice*

Definition: Punishment is defined as the application of a response which is aversive to the individual immediately after the target challenging behaviour has occurred. Punishment may be 'positive' (in the technical sense of adding a stimulus). Examples would include telling the person 'No' or scolding them, causing physical pain or discomfort or psychological distress. Alternatively it may be 'negative' (in the technical sense of taking away a stimulus) – taking away something reinforcing (e.g. time out; screening one's face to prevent visual contact). It needs to be distinguished from giving feedback or information to the person about their behaviour (e.g. saying 'No, that is hurting,' in a calm and quiet manner).

Punishment has been demonstrated to be effective in the meta-analyses^{660 661} although this has been strongly contested because of the ethical unacceptability of many of the studies. Several writers give a flavour of this debate.⁶⁶²
^{663 664} Most of these studies were carried out under very controlled institutional conditions, thereby limiting their applicability to current practice. They also tended to use highly aversive or abusive procedures (such as contingent powerful electric shock) which would never be acceptable

under current circumstances. There are, however, studies that report effective interventions using 'mild' punishment strategies (e.g. visual screening, verbal reprimand).⁶⁶⁵

Given the ethical considerations and the availability of other interventions that are effective without being aversive, there should be very little need to use punishment.

References: Section 12

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13. Detailed guidelines – Evaluation

13.1 Evaluation

Definition: Evaluation is the measurement of change in order to determine the impact or effectiveness of interventions.

13.2 Evaluation of effectiveness

Interventions for severe challenging behaviour should be routinely evaluated for their effectiveness.

Level of evidence to support this guideline: 1

Good practice

It is accepted by clinicians that evaluating the effectiveness of interventions for challenging behaviour should be routine good practice.

There is also evidence from the meta-analyses to suggest that those studies that are more thoroughly evaluated are more likely to demonstrate a positive outcome.^{666 667}

13.3 Content of evaluation

As a minimum, the evaluation should consider

- the severity, frequency and duration of the target challenging behaviour;
- the person's quality of life and range of activities or opportunities;
- the person's development of positive skills and abilities;
- the person's well-being and satisfaction with the intervention;
- the well-being and satisfaction of carers or family members in close contact with the person.

An evaluation will usually repeat baseline measures from the start of an intervention and look for any evidence of change.

Level of evidence to support this guideline: 3

Good practice

When a person is referred to a psychologist because of challenging behaviour, the psychologist must measure the

impact of any intervention on that behaviour. This is an ethical obligation because the nature of challenging behaviour is such that by definition there is a threat to the health and well being of the person concerned or those close to him or her.

Measuring challenging behaviour alone, however, is seen by many clinicians as an excessively narrow focus. Successful outcome can also be measured by increased quality of life and enhanced well being of the person who is challenging and that of other people in the person's life. These factors, which are threatened by the existence of the challenging behaviour, should therefore also be measured.

For guidance on methods that can be used to evaluate the effectiveness of interventions for challenging behaviour, see the extensive discussions in the guidelines on assessment above (Section 10).

13.4 Evaluation of the specific intervention

The evaluation should measure the impact of a specific intervention. For example, interventions that are focused on environmental change should evaluate the success in achieving environmental targets, whereas anger management techniques should measure the reduction in anger.

Level of evidence to support this guideline: 3

Good practice

The psychologist needs to make a specific evaluation of those factors that he or she is attempting to change. If an intervention attempts to teach new skills, for example, then the acquisition of those new skills should be measured. If the intervention is hoping to change an environment, then measures of the environment need to be taken before and after the intervention.

It is particularly important to measure the effectiveness of new or relatively under-researched interventions, and to disseminate the results.

13.5 Follow-up evaluation

The effectiveness of the intervention should be measured over a period of time.

It is recommended that the outcome should be re-assessed after one year if an intervention is completed.

If the intervention is ongoing, then its impact should be re-assessed regularly, at least on an annual basis and more often if necessary.

Level of evidence to support this guideline: 3

Good practice

There is now considerable evidence to suggest that challenging behaviours can be highly persistent over long periods of time. As a result, it is essential that progress is monitored repeatedly over extended time periods. This allows for (1) measurement of the impact of interventions; and (2) the early identification of potential deterioration or relapse.

Work on relapse prevention with people with learning disabilities is at a very early stage. The literature however, indicates that relapse is a very real problem: 'patterns of severe challenging behaviour do not simply disappear'.⁶⁶⁸

In a study of 179 people,⁶⁶⁹ it is reported that 63 per cent of them who were identified as showing 'more demanding' challenging behaviour in a total population survey undertaken in 1987, were still showing 'more demanding' challenging behaviour when followed up seven years later. Persistence rates of over 80 per cent over a 10 year period for many categories of challenging behaviour were shown by children with Down's syndrome.⁶⁷⁰ A number of studies have examined the persistence of specific forms of challenging behaviour among cohorts of people with learning disabilities.

- *Self-injury*: Reported persistence rates for self-injury have varied from 54 per cent over a three-year period^{673 674} to 90 per cent over a 10-year period, with the majority of studies reporting persistence rates of approximately 75 per cent.^{675 676 677}
- *Aggression*: In a two-year follow-up of 118 adults with intellectual disabilities, extremely high levels of persistence of aggression were reported.⁶⁷⁸

Other studies have found a similar pattern of persistence of aggressive behaviour.^{679 680}

While there is ample evidence that behavioural interventions may bring about significant reductions in challenging behaviour over the short to medium term, evidence from long-term follow up studies indicates that such gains rarely involve the elimination of challenging behaviour and may be difficult to sustain. All of the 52 individuals who had received treatment in a specialised facility for people with severe self-injurious behaviour still required 'high-level behaviour management programmes' eight years later, for example.^{681 682} Single case studies show a similar pattern.

Very few studies have attempted to identify personal or environmental characteristics associated with variations in the persistence of challenging behaviours. One study⁶⁸⁵ reported that persistence of 'more demanding' challenging behaviour among 179 people between 1988 and 1995 was associated with participants in 1988 showing: more severe challenging behaviour; more severe self-injurious behaviour (and specific topographies of self-injury); more frequent stereotypy; more severe intellectual disability; poorer communication skills, self-care skills and less ability to use money; lower ability to occupy themselves constructively or to behave appropriately in social situations.

Another found⁶⁸⁶ that self-injury status at follow-up was predicted by three variables: site of injury (higher persistence being shown by people exhibiting head directed self-injury); reported (greater) stability of self-injury when first identified; and (younger) age. A further study examined the personal and environmental characteristics associated with people being re-referred to a crisis intervention service.⁶⁸⁷ It was reported that, among younger participants, not living with their family and exhibiting self-injurious behaviour were the strongest predictors of re-referral. Among older participants, aggression was the strongest predictor of re-referral.

As a result, even where an intervention has proved very successful – perhaps changing radically the environment in which a person lives and how the challenging behaviour is responded to – it will still be vulnerable to changes over time. A member of staff leaving, for example, may not only reduce the available skills in the staff team, but may also cause a grief reaction in the person with learning

disabilities. In such a situation it is very easy to revert to old, familiar and effective challenging behaviours.

For these reasons, it is essential to monitor psychological interventions for people with learning disabilities and challenging behaviour over the long term.

13.6 Evaluating generalisation

If an intervention is carried out in one setting or over a restricted time period, then attempts should be made to assess whether there has been any impact in other settings or at other times.

Level of evidence to support this guideline: 3

Good practice

If the challenging behaviour is presenting as a problem in other settings or at other times, then a specific programme

to ensure generalisation may need to be set up.

There is evidence from the applied behavioural literature that generalisation is a persistent area of difficulty. This may be because of the specialist setting in which many of the interventions were researched. Interventions in the community where people live or work seem to have fewer problems.⁶⁸⁸

There is some evidence to suggest that people with milder learning disabilities can generalise through self-monitoring and self-management.⁶⁸⁹ But many people with learning disabilities appear to have a difficulty with this skill.⁶⁹⁰ Further research on how people with learning disabilities can learn, should help to develop this area of clinical work.

Evaluating whether there has been any generalisation is the first step towards a new set of work in the new setting.

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14. Detailed guidelines – Feedback

14.1 Feedback

Definition: Feedback in this context is the communication of information about the process and the effectiveness of an intervention for challenging behaviour.

Many services have guidelines on the timeliness and content of psychological reports and letters, which need to be adhered to as one essential element of good practice.

The term ‘feedback’ should be understood more broadly to include verbal and informal communication – both person-to-person and over the telephone, e-mail or fax.

14.2 Providing Feedback

Feedback should be provided at several stages:

1. **at the end of the assessment period, when the psychological formulation has been arrived at;**
2. **after interventions, whether these are successful or not;**
3. **when there is a substantial revision to the psychological intervention or the proposed intervention plan;**
4. **on completion of work with an individual.**

This is a minimum standard: it is good practice to provide feedback on a more regular and frequent basis.

Level of evidence to support this guideline: 3

Good practice

This guideline is based on clinical consensus. There was a strong feeling at the conference that good communication about the work with challenging behaviour was a very important part of the process, and that when it was neglected, poor relationships could develop and the effectiveness of the psychologist’s work was greatly undermined.

Most services have guidelines for when letters or reports should be sent. This guideline may therefore need to be

adapted to fit into local standards and expectations. It does present a minimum standard and we would suggest that a significantly lower local guideline might not meet the requirement to keep colleagues, carers and people with learning disabilities adequately informed.

Perhaps because it is seen as basic good practice, there seem to be no studies which look at the effectiveness of providing different amounts of feedback (or none at all).

14.3 Recipients of feedback

Feedback should be given to the person with learning disabilities in a form that can be understood and is respectful.

People who are involved in the assessment or intervention should receive regular and routine feedback.

The referrer and other important people in the life of the person with learning disabilities should also receive regular and appropriate feedback.

Level of evidence to support this guideline: 3

Good practice

The guideline on ‘meeting the person who is challenging’ (Guideline 10.6) provides advice on communicating with people with learning disabilities.

There is some evidence for the effectiveness of presenting feedback in different modalities or formats. Visual presentations, for example, are very important for people with autism.^{691 692} The use of video feedback to help a person understand their own behaviour can be very helpful.

The most important factor in providing feedback for staff and families appears to be ‘goodness of fit’ with the environment, recognising the skills, preferences and styles of the people being communicated with. For example, the use of visual representations (graphs, bar charts, pie charts or scatter plots) can be very helpful for some people, while others find numbers or narrative easier.

14.4 Confidentiality of feedback

Psychologists must ensure that they respect the confidentiality of the person with learning disabilities when they are giving feedback.

Level of evidence to support this guideline: 3

Essential practice

This guideline is agreed by clinicians to be essential practice. Confidentiality is an essential component of the British Psychological Society Code of Conduct and any other statement of ethical practice by health practitioners.

It is particularly important for psychologists working with people who are not socially valued and often not seen as active agents in their own lives to be mindful of the requirement to respect confidentiality. There is anecdotal evidence to suggest that breaches of confidentiality are more likely to occur with more disabled and more disadvantaged groups of people.

Sometimes clinicians are perplexed about whether family members or paid carers should be provided with personal information about the person with learning disabilities.

The following factors should be considered:

- The person with a learning disability should be asked, when possible, what information they do or do not wish to share with other specified people. The tendency for people with learning disabilities to be acquiescent to requests of this sort should be allowed for in assessing someone's consent to sharing information.
- There is no obligation to pass on information unless there is a serious risk to a person or others for whom

they have some responsibility. A parent, for example, does not have a right to know everything about their adult son or daughter.

- Where there is a serious risk to the person with a learning disability or others, the psychologist does have an obligation to tell those who need to know so that they can take steps to protect others or themselves.
- The relationship with a close family member is often of central importance in the life of a person with learning disabilities. The psychologist needs to consider this when making a decision to share or to withhold information. It may be necessary to work alongside the family to strengthen relationships so that they can offer mutual trust, safety and the capacity for development.
- It may be helpful to consider what information would be shared in similar circumstances if the person did not have a learning disability.

14.5 Eliciting feedback

As well as providing feedback to others, the psychologist should also make serious attempts to elicit feedback from other people on his or her own performance.

Level of evidence to support this guideline: 3

Essential practice

Feedback must be conceptualised as a two-way process. Psychologists should welcome feedback from other people about their work with individuals, family carers and staff teams that support people who present challenges, and use it to improve their practice.

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15. Conclusions

The aim of these guidelines is to act as a stimulus to improve clinical practice. The process of producing the guidelines has helped improve the practice of the authors (we believe), but we hope they will be of wider usefulness.

We have tried to make the guidelines clear, unambiguous, measurable and achievable.

They must be clear and unambiguous if they are to be useful in clinical practice.

We hope that they are measurable enough to act as the basis for an audit tool. The audit cycle is one way of looking at what we do and trying find ways of improving it.

One of the most active debates during the development of the guidelines has been how to set a standard in the guidelines, which is high but still achievable. We are aware that trying to assess what we actually do against what we think we should be doing can be a negative and demotivating experience. But we do believe very strongly that when we are working with people with severe and enduring difficulties, it is important to motivate ourselves and maintain our commitment by setting goals

and standards that we should be aiming to achieve. As with our clinical experiences of setting goals for clients, it is of course essential to monitor our success in achieving the goals after we have set them.

During the consultation period for these guidelines, concerns were raised that defining effective clinical practice might lead to less innovation and creativity in responding to challenging behaviour. We would be very reluctant to see this happen, as using our psychological skills creatively is a great source of satisfaction in our daily work, and we believe this to be true of many of our colleagues.

However, we also recognise the drive to be 'hero innovators'⁶⁹³ can lead us into continually 'reinventing the wheel' and searching after new panaceas, rather than learning from previous experiences. As there is a relatively good evidence base for interventions for challenging behaviours, we believe this should be our starting point. From this point it is important to expand and develop our knowledge by evaluating and disseminating new ideas and new practices, as well as expanding and refining the old ones.

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- provides a service for the news media and the public;
- has an Ethics Committee and provides service to the Professional Conduct Board;
- maintains a Register of more than 11,100 Chartered Psychologists;
- prepares policy statements and responses to government consultations;
- holds conferences, workshops, continuing professional development and training events;
- recognises distinguished contributions to psychological science and practice through individual awards and honours.

The Society continues to work to enhance:

- recruitment – the target is 50,000 members by 2006;
- services – the Society has offices in Scotland, Wales, Northern Ireland and England;
- public understanding of psychology – addressed by regular media activity and outreach events;
- influence on public policy – through the work of its Boards and Parliamentary Officer;
- membership activities – to fully utilise the strengths and diversity of the Society membership.