

**OUT OF AREA
PLACEMENTS**

**USERS, CARERS AND
STAFF HURT
CARERS LEFT TO
STRUGGLE ALONE
STAFF DEMORALISED
INCREASED RISK OF ABUSE
BAD CARE PRACTICES**

**CRISES AND PLACEMENT
BREAKDOWNS
REINSTITUTIONALISATION
'SILTING-UP' OF
SPECIALISED SERVICES**

**LESS CHOICE AND CONTROL
OF SERVICES
LOWER EFFICIENCY
PUBLIC CRITICISM**

SERVICES FOR PEOPLE WITH LEARNING DISABILITIES AND CHALLENGING BEHAVIOUR OR MENTAL HEALTH NEEDS

(REVISED EDITION)

The hidden cost of failing to develop local services

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**SERVICES FOR PEOPLE WITH
LEARNING DISABILITIES AND
CHALLENGING BEHAVIOUR
OR MENTAL HEALTH NEEDS:
REPORT OF A PROJECT GROUP**

(CHAIRMAN: PROF J L MANSELL)

**Revised edition
October 2007**

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Parliamentary Under Secretary of State for Care Services
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9 March 2007

Dear Minister

I present the report *Services for people with learning disabilities and challenging behaviour or mental health needs*, which I have revised and brought up-to-date.

The analysis set out in the first version of this report and its recommendations remain relevant today. The goal of all services for people with learning disabilities should be to provide sufficiently skilful support to prevent problems arising in the first place, to manage them when they occur and to implement relatively sophisticated long-term arrangements for management, treatment and support. Specialised challenging behaviour services will then be able to focus on people who present the most complex and difficult challenges.

Although there has been good progress on many fronts since the publication of *Valuing People*, progress in respect of challenging behaviour has lagged behind. The failure to develop appropriate services has led to an increase in the use of placements which are expensive, away from the person's home and not necessarily of good quality.

The main reason for this is that commissioning has been too reactive and has therefore become dominated by trying to manage crises. What is needed is for Councils to strengthen their commissioning to combine expertise about challenging behaviour with the ability to actually develop services for individuals so that they are ready when needed. This is entirely consistent with the Government's focus on personalisation and prevention in social care.

Yours faithfully



(Prof) J L Mansell

Foreword from the Parliamentary Under Secretary for Care Services

Since the publication of *Valuing People* in 2001, progress has been made in a number of areas to improve the lives of people with learning disabilities. There are a great number of people committed to delivering its principles of rights, independence, choice and inclusion.

However, while good progress has been made, challenges still remain and this is perhaps particularly evident in making real changes for people with learning disabilities who are considered to have challenging behaviour.

We are finally reaching the end of the closure of the remaining old long-stay hospitals and are embarking on our programme of work to close all NHS residential accommodation or 'campuses' by the end of the decade. Real progress is being made in giving people back their independence and control and I am always delighted to hear people's stories of how their lives have changed for the better when they get back the control that we all have a right to. Person-centred planning is a vital component in delivering this independence and control, ensuring that in providing for a person's needs, that their wishes and aspirations for their own life form a central part of the plan.

Good quality commissioning and service provision is also vital in delivering that vision. There are positive examples from across the country demonstrating progressive thinking and innovative ideas. It is important that that knowledge and learning is shared and developed to the benefit of people with learning disabilities and those who work with them.

Valuing People clearly states that good quality services will ensure that people with additional and complex needs are appropriately cared for so that their needs are well managed and they lead fulfilling lives. It acknowledged that commissioning and providing services for people who present significant challenges is one of the major issues facing learning disability services. This revised and updated version of the report by Professor Jim Mansell and his project team will be invaluable in meeting that challenge. I encourage all those involved in services for people with learning disabilities and challenging behaviour or mental health needs to develop those services in line with the best practice set out in this report.

I am committed to reinvigorating the learning disability agenda and this good practice guidance supports us in that goal.



Ivan Lewis
Parliamentary Under Secretary of State for Care Services
October 2007

Preface

This report is issued as best practice guidance to councils with social services responsibilities and health bodies. It is not mandatory and no extra resources will be provided for its implementation. Councils and health bodies should take it into account in setting their own priorities and policies. It will also be useful to people using services, their families and representatives, staff and service-providing organisations as a statement of best practice.

Key recommendations

The following key recommendations are crucial to developing and sustaining quality services to meet local needs. These recommendations provide a means to plan strategically; to develop preventative strategies that avoid crises; and to make the most effective use of available funding.

Aims

1. Better use of investment is required to achieve two aims:
 - ◆ to develop and expand the capacity of local services for people with learning disabilities to understand and respond to challenging behaviour
 - ◆ to provide specialist services locally which can support good mainstream practice as well as directly serve a small number of people with the most challenging needs (paragraph 48).
2. Commissioners should give priority to improving services for people with learning disabilities whose behaviour presents challenges to services (paragraph 70). They should demonstrate value for money through improvements in the outcomes identified in *Valuing People* – rights, inclusion, independence and choice – as well as on the specific treatment of challenging behaviour (paragraph 73). At service system level, value for money should be demonstrated by a low number of placement breakdowns and of out-of-area placements (paragraphs 73 and 76). Low-value high-cost services should be replaced by better alternatives (paragraph 74).
3. Commissioners should avoid increasing the burden on family carers by reducing levels of service (paragraph 75).

Service models

4. Councils should re-examine the continued use of residential special schools away from people's homes in the light of identified problems, to explore the provision of local services which offer at least as good education and care (paragraph 24).
5. Commissioners should ensure that opportunities for short breaks tailored to individual needs are available to every family supporting a person whose behaviour presents a challenge at home (paragraph 49).
6. Direct payments and individual budgets should always be considered in planning for individuals and should be made more widely available (paragraphs 51 and 78).
7. Commissioners should stop using services which are too large to provide individualised support; serve people too far from their homes; and do not provide people with a good quality life in the home or as part of the local community, in favour of developing more individualised, local solutions which provide a good quality of life (paragraph 52).
8. Whether people are living in their family home or in accommodation with support, they should have access to innovative day opportunities (paragraph 54). Where people are excluded from day services because of their challenging behaviour,

commissioners should ensure that they provide alternative day services which can offer good services in spite of the challenges people present (paragraph 55). Supported access to further education should be available to everyone, alongside supported employment and other day opportunities (paragraph 56). Commissioners should take the lead in developing a much wider range of alternative models (paragraph 57).

9. Additional specialist multi-disciplinary support teams focused on challenging behaviour are an essential component of modern provision (paragraph 61). Specialist services need to use their skills to help managers in the provider network lead their staff in the provision of effective local services. This requires closer co-ordination between the commissioners paying for services, the managers providing services and the professional specialists advising on the support people need, to ensure that advice is both practicable and is acted upon. (paragraph 63).
10. Emergency support for people whose behaviour presents a challenge should be available 24 hours a day, seven days a week (paragraph 64).
11. The appropriate role for psychiatric hospital services for people with learning disabilities lies in short-term, highly focused assessment and treatment of mental illness. This implies a small service offering very specifically, closely defined, time-limited services. (paragraph 59)
12. Commissioners should allocate a budget to be used to fund a much wider variety of interventions as an alternative to placement in a special unit (paragraph 67).

Commissioning for service development

13. Learning Disability Partnership Boards should monitor that local agencies are working together to provide effective services for people whose behaviour presents a challenge to services and report when they are not. (paragraph 72).
14. Planning ahead is required for everyone. As a priority, councils should fund the independent advocacy and co-ordination required to ensure at least that every person whose behaviour presents serious challenges to services has a proper person-centred plan for the services they need now and in the coming years. Planning ahead also implies building in some capacity in the system to cope with demand as it emerges, rather than waiting until crises occur. (paragraph 82).
15. Councils should strengthen their commissioning to combine expertise about challenging behaviour with the ability to actually develop the services needed. This is required at both strategic and operational levels. At strategic level, Councils should
 - ◆ *Garner resources*: work with other relevant agencies to identify all current expenditure on learning disability, including resources accessed in emergency or crisis, and obtain agreements to pool these resources and to work together to improve outcomes for people whose behaviour presents a challenge.
 - ◆ *Audit provision*: find out which services are good at supporting people whose behaviour presents a challenge and which are not, and why.
 - ◆ *Assess need*: find out how many people have behaviour which presents a challenge, including

- Young people approaching transition from school
 - People placed in the area funded by other authorities
 - People living at home not receiving services
 - People placed out-of-area
- ◆ *Develop partnerships*: work with provider organisations who are committed to developing good services to support people whose behaviour presents a challenge to agree commissioning and funding arrangements that will achieve value for money while sustaining investment and development in local services.
 - ◆ *Plan services*: forecast the amount of new housing, day opportunities and support that will be required in the years ahead; map the staffing and staff training implications of this; and plan how this will be financed (paragraph 83).
16. At operational level, councils should
- ◆ *Create service development resource*: identify people who know about challenging behaviour and services, to work with people to implement their person-centred plans. Such a team should combine aspects of commissioning and care management and work alongside professionals providing specialist support.
 - ◆ *Identify people as a first priority*: these should be people whose behaviour presents a serious challenge to services, focusing on those people where problems are serious enough that intervention could make an important difference but where the context is supportive enough to allow the greatest impact.
 - ◆ *Develop services*: support the person-centred planning process for these people and deploy resources to implement the plans developed.
 - ◆ *Provide back-up*: notice when problems being to emerge (before they reach crisis-point) and intervene to provide moral and material support to sustain arrangements through difficult periods.
 - ◆ *Extend development to more people*: as successful arrangements become established, take on the support of additional people (paragraph 84).
17. The role of the National Health Service is
- ◆ To keep contributing the financial resources needed to sustain the transfer of specialist learning disability services to councils.
 - ◆ Not to undermine the strategy set out in this report by commissioning poor-quality services, especially out of area, themselves.
 - ◆ To continue to provide sufficient levels of the professional support required to sustain good practice in community based services.
 - ◆ To provide specialist psychiatric assessment and treatment on a short-term basis, but only as part of an integrated pathway of care for the individual that gets them back into the community.
 - ◆ To enable fair access to generic health (including mental health) services for people with learning disabilities whose behaviour presents a challenge to services (paragraph 86).
18. The Sector Skills Councils should support service development by recognising more specialised and advanced courses in challenging behaviour and specialised training at a more advanced level than NVQ2 should be a requirement where people present challenging behaviour (paragraph 92).

19. The Commission for Social Care Inspection, the Healthcare Commission and the Care Services Improvement Partnership (through the Valuing People Support Team) plan work which will help local authorities and health bodies to improve services for people with learning disabilities whose behaviour presents a challenge (paragraph 93).

Introduction

1. The first version of this report¹, published in 1993, provided guidance for councils and health bodies on the development of services for adults with learning disabilities whose behaviour or mental health problems present a challenge to services. The guidance was focused particularly on commissioners, because there was already ample information about service models available for providers. In 2001, the Government White Paper *Valuing People*² reaffirmed this guidance.
2. A great deal has changed since 1993. The old long-stay hospitals are nearly closed. Most people with learning disabilities – including most people who present challenging behaviour - live in the community either with their families, in small residential homes or in their own homes, with varying levels of support. The idea that services should be designed around the individual, relatively new in the first report, is now central to government policy in the 2006 White Paper *Our health, our care, our say*³.
3. These changes have posed new problems for people with learning disabilities whose behaviour or mental health problems present challenges. Often, community-based services have not been sufficiently well-developed and well-organised to serve them. Placements break down as people whose behaviour presents a challenge can no longer be supported. For those who have been living with their families, there are insufficient local placements prepared to take them. For people already in supported accommodation or residential care, the placement is unable to cope⁴. For some individuals, this means they are required to move from one place to another over and over again, causing distress to them and their families.
4. The shortage of suitable local services is often remedied by finding placements outside the local area, sometimes a long way from home. There are over 11,000 people supported out of area by local authorities in England⁵, 31% of all people with learning disabilities supported by local authorities. Challenging behaviour is a common reason for such placements, which can be very expensive⁶⁻⁹ and the increasing number of such placements probably contributes to the dramatic rise in social services expenditure on learning disability services¹⁰.
5. A third problem is that poor quality institutional services persist, either locally or in out-of-area placements. Sometimes these are assessment and treatment units, as in the recent inquiry in Cornwall¹¹; a quarter of people placed in such units by primary care trusts have finished treatment¹² but presumably have nowhere to go. Institutional practice also exists in long-term placements in the community; these can be smaller-scale placements (such as supported living arrangements in Cornwall) but they are often larger settings where every resident has challenging behaviour¹³. There is some evidence that people placed out-of-area may experience worse services^{7 14}.
6. Thus, despite the progress that has been made for people with learning disabilities in general, there has been a failure to deliver the benefits of previous policy to people who present a challenge to services. These problems were foreseen in the first version of the report and the guidance it contained remains relevant now. This revised version

updates the report to reflect recent experience and changes in the organisation of social and health care. As before, the report is heavily based on evidence from research, but the revision was also informed by further discussions with families, services, commissioners and other experts.

7. The report focuses on people whose behaviour presents a significant challenge to services, whether mental illness is implicated or not. It includes people who are on the autistic spectrum and a learning disability. It applies to services for adults, except in so far as issues of the transition from children's to adult services are involved.
8. The phrase "challenging behaviour" is therefore used in this report to include people whose behaviour presents a significant challenge to services, whatever the presumed cause of the problem. Wherever it is used, it includes behaviour which is attributable to mental health problems. As a working definition, that proposed by Emerson *et al*¹⁵ has been used

"Severely challenging behaviour refers to behaviour of such an 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."

When the term 'challenging behaviour' was introduced, it was intended to emphasise that problems were often caused as much by the way in which a person was supported as by their own characteristics. In the ensuing years, there has been a drift towards using it as a label for people. This is not appropriate and the term is used in this report in the original sense.

9. One of the major changes since *Valuing People* is the recognition that all public services have responsibilities towards people with learning disabilities. Although this report focuses mainly on health and social services, other services are increasingly important. People with learning disabilities have the same rights to housing as other people, and housing providers need to support people who present challenges. Education services (particularly schools and further education colleges) are also important partners in serving people with learning disabilities whose behaviour presents a challenge. Ordinary health services too need to be able to serve people whose behaviour challenges. In all these areas, both statutory and independent sector services are involved. For example, social services are commissioned by local councils but largely provided by the independent sector; health services are commissioned by National Health Service bodies and provided both by the NHS and by independent health care providers.
10. The Reed Committee¹⁶ produced guidance specific to people with learning disabilities classified as mentally disordered offenders. More recent advice for commissioners has been produced by the North West Regional Task Force on Learning Disability¹⁷. Further national guidance is provided by the Care Services Improvement Partnership¹⁸ and by the Department of Health¹⁹.

The people involved

Individuals themselves

The client group

11. People with learning disabilities whose behaviour presents a challenge form an extremely diverse group, including individuals with all levels of learning disability, many different sensory or physical impairments and presenting quite different kinds of challenges. The group includes, for example, people with mild or borderline learning disability who have been diagnosed as mentally ill and who enter the criminal justice system for crimes such as arson or sexual offences; as well as people with profound learning disability, often with sensory handicaps and other physical health problems, who injure themselves, for example by repeated head banging or eye-poking. Some brief illustrative examples of individual problems and service responses are given in Appendix 1.

The needs of individuals

12. People whose behaviour challenges have the same needs as anyone else, in addition to special needs for help to overcome the problems their behaviour presents. They do not surrender their needs for personal relationships, for growth and development or for anything else because their behaviour presents a challenge to services. They have the same human and civil rights as anyone else.
13. In considering individual need, the same attention to issues of race and gender as required in other services should apply. There is evidence from mental health services of different, more restrictive, treatment of service users from ethnic minorities. Similar problems may exist in services for people with learning disabilities. Women whose behaviour presents a challenge may also experience a different standard of service. In mixed-sex houses they may be more vulnerable to sexual harassment and assault; they may experience greater restrictions in the expression of their sexuality than men; and aggression by them may be interpreted as a greater challenge than the same behaviour from a man.

Factors contributing to challenging behaviour

14. Challenging behaviour is *socially constructed*; it is the product of individual and environmental factors interacting together. Individual factors are the characteristics people bring with them – the severity of their learning disability, the presence of additional sensory or motor disabilities, mental health problems, communication difficulties, their personal history of relationships and experiences and so on. Environmental factors are the characteristics of services – the number, training and experience of staff, how they work with the people they serve and with each other, the quality of the material environment and the opportunities it presents.
15. Where individuals with problems are cared for in environments which do not respond well to their needs, challenging behaviour is likely to develop and then to remain in the person's repertoire. The individual risk factors (such as communication difficulties or a history of abuse) are quite widespread among people with learning disabilities: for example, between 10 and 46% of adults have additional mental health

needs²⁰; 12-15% have significant impairment of sight²¹, 8-20% of hearing²², 27% have autistic spectrum disorders²³ and at least 45% have significant impairments of communication²⁴. Environmental risk factors (such as poorly organised and trained staff) are widespread among services. The dominant model of support in services for people with learning disabilities is relatively unskilled caring and ‘minding’. The evidence is that staff do not generally interact with the people they support in a way that enables them to achieve greater levels of independence, participation or integration. The amount of support received is relatively low (about 9 minutes in every hour) and facilitative assistance much less (1-4 minutes an hour on average)²⁵. Front-line staff often overestimate the receptive language ability of the people they support²⁷. Psychological treatment for challenging behaviour remains difficult to get²⁸. There is substantial turnover of staff with the associated difficulties of recruitment and training²⁹. The potential for challenging behaviour arising and becoming more severe is therefore greater among less well organised services.

16. In general, transfer from institutional to community services (ie the provision of enriched environmental, physical and social circumstances) has not reduced challenging behaviour or mental health problems^{25 30-32} - and given the functions served by some challenging behaviour, there are good reasons to expect increases in some cases³³. It is not therefore simply a matter of switching the service model and expecting the problem to disappear.
17. Neither is it usually possible to treat and cure challenging behaviour. Biomedical intervention is only effective where there is an underlying mental health problem which has been correctly diagnosed. The use of anti-psychotic medication as a means of behaviour control may mask the problem but does not cure it^{34 35}. Psychological treatments have the strongest empirical support³⁶. However, even where staff are sufficiently well-organised to undertake psychological treatment of challenging behaviour, the results are often short-lived. One reason for this is the difficulty staff often have of maintaining appropriate levels of organisation and skill in their interaction with the service user over time³⁷. Once challenging behaviour has become useful for the person, it remains as an option in the individual’s repertoire to appear again whenever alternatives cease to be as effective³⁸.
18. None of this is to deny that effective intervention can make a difference. Of course services should aim to help people overcome their challenging behaviour, and there are many examples of how this is being achieved. The point is that good practice is fragile, and it is not sensible to plan on the basis that challenging behaviour can be readily ‘fixed.’ Thus, the potential for challenging behaviour exists for many service users in many situations; and the problem of challenging behaviour is not likely to go away. The implication is, therefore, that the appropriate goal of learning disability services is to support the individual in achieving as good a quality of life as possible *in spite of* their problems. In practice, challenging behaviour will be an enduring characteristic of the lives of many service users. There will always be a large pool of people who present some challenging behaviour, which can be better or worse depending on how well services support them.
19. A proportion of this ‘at risk’ population at any one time present an exceptional challenge to services because of their behaviour. Estimates depend on definitions, but over the whole country it is likely that about 24 adults with a learning disability per 100,000 total

population present a serious challenge at one time³⁹. This means that there are over 12,000 people with learning disabilities in England whose behaviour presents a serious challenge at one time. This includes people with mild as well as severe learning disability. A few of these people will present such a challenge more or less all the time and will become well-known to local services (as well as, in some cases, other agencies like the police and housing departments); but many people will move into and out of this group depending both on changes in their characteristics and on how well services meet their needs over time.

Implications for services

20. The implications of the nature of challenging behaviour for services are that
 - ◆ service planning and delivery should be highly individualised, to meet the widely differing needs of people in this group
 - ◆ the special help that services provide in response to challenging behaviour should be in addition to, not instead of, the same standard of service to meet the needs that people whose behaviour presents a challenge have in common with others
 - ◆ services should be planned on the basis of accurate information about individuals, rather than on the basis of norms, since needs vary so much and depend on service capability
 - ◆ services should be designed and provided to reflect available research evidence about best practice, since poor quality services are likely to be ineffective even if expensive
 - ◆ the reduction of challenging behaviour is likely to require attention to other factors (such as communication) than just the behaviour itself
 - ◆ assessing need should involve assessing service competence as much as individual characteristics
 - ◆ preventing the development and worsening of challenging behaviour is a priority because of the costs (to the individual, family and society) of problems escalating or becoming ingrained
 - ◆ maintaining local links by providing local services is also a priority because once people are placed far away it is difficult to organise their return and expensive to support them

The needs of family carers and staff

21. Services exist to meet the needs of their users; but, within this framework, the needs of carers should also be considered to be very important, both because services cannot succeed without the contribution made by carers and because as a matter of principle one group of people's needs should not be met at the expense of another. Of course there will be important conflicts of interest between service users and their carers which will need to be faced up to at an individual level. But services should not be provided by exploiting the personal commitment and dedication of carers.
22. Families who care for individuals whose behaviour presents challenges are subject to considerable and continual stress, both physical and psychological. Although staff are not permanently on duty as family carers can be, they are still subject to the same stresses when supporting people whose behaviour challenges. This is true even in settings which aim to do no more than contain people. Similar concerns apply to staff as to carers. The higher aspirations often found in progressive services impose extra

strain on staff and here too it is important to balance the demands of working constructively with people who can be very difficult, day in and day out, with the needs of individual staff for emotional and practical respite and ongoing support.

Additional pressures on services

23. Demographic changes and rising expectations will increase the demand for accommodation with support for adults with learning disabilities⁴⁰. Increased numbers of people with specific conditions (especially autistic spectrum disorders) is already placing extra demands on services. The tightening of eligibility criteria for social services has led to a larger number of people staying in their family home well into adult life⁴¹ and to reductions in opportunities for short breaks for families supporting people with profound learning disabilities^{42 43}. Since challenging behaviour is one of the common reasons why people need to leave the family home, pressure on families to manage without these options is also likely to be increasing. This is unlikely to be in the best interests of either the disabled person or their family, and may end in crisis.
24. Challenging behaviour is often implicated in the placement of children with learning disabilities in residential special schools^{44 45}. These placements are often disruptive of ties with family and community, so that families face particular problems getting local services which can provide the level of support needed when responsibility passes from children's to adult services^{46 47}. The continued use of residential special schools away from people's homes needs to be re-examined in the light of these problems, to explore the provision of local services which offer at least as good education and care.
25. There has been an increased focus on the management of risks to health and safety in social and health services, including 'zero-tolerance' for violence against staff⁴⁸. Where inappropriately applied, these initiatives can lead to people with learning disabilities who may present challenging behaviour being denied opportunities to live their lives, in order to avoid risks to individuals and to organisations. It is important that such risks are appropriately managed, balancing the risks of challenging behaviour against the risks of reduced quality of life. It is not an appropriate or achievable goal that the risk of challenging behaviour be completely eliminated.

Characteristics of exemplary services

26. The first version of this report was based on the experience of four exemplary services. All were specialist services designed to support learning disability services to support people whose behaviour presents a challenge. The Additional Support Team, Exeter⁴⁹ provided specialist advice, extra help in community settings and some backup provision in the form of specialised small staffed houses for people whose behaviour presents a challenge (used mainly by people with mild learning disabilities). The Special Projects Team, Sunderland⁵⁰ was based on a team of skilled community support workers, supplemented by a six-place alternative day service and a specialised staffed house in the community; it focused on people whose learning disability (rather than mental health) was the primary problem. The Mental Impairment Evaluation and Treatment Service⁵¹⁻⁵⁸ was a hospital-based assessment and treatment service for people with mild learning disabilities, the majority of whom had criminal convictions and additional mental health needs. The Special Development Team^{59 60} provided advice and help to enable local services to establish housing placements for people with severe or profound learning disabilities who presented challenging behaviour.
27. Since cost is sometimes given as a reason why adequate services for this group of people are not developed, it is worth noting at the outset that these services were all developed within the existing resource framework available to their host agencies. Resources are a question of priorities as well as of the amount available. It is also worth noting that the available evidence suggests that the small-scale residential services involved are not more expensive than higher priced institutional placements. They are more expensive than low-staffed hospitals or private homes, but the research suggests that the outcomes achieved in low-staffed services are much poorer⁵⁹.
28. The extent to which exemplary services have been successful depends on a number of factors discussed below. These are grouped under five headings: commitment, individualisation, effective models of care, good management and investment in relationships. No-one involved in such services would claim that they are perfect: but their experience does illustrate some of the issues which must be attended to if services are to meet the needs of people who have challenging behaviour.

Commitment

29. Successful services have typically been built up by a committed group of professional and front-line staff, working with the sustained support of senior policy-makers and managers. As in many innovations, they have tended to work outside existing structures and relationships and this has enabled them to develop new ways of working which have had considerable success.
30. A key observation made to the Committee* was that the senior managers of local service agencies could be classified by their intentions in relation to services for people whose behaviour presents a challenge, and that this helped explain different approaches to service development for this client group.

* By George Gaskell and Julie Dockrell of the London School of Economics; the classification presented here is a modified version of that they proposed.

- ◆ ‘Removers’ do not want to develop locally the competence to serve people whose behaviour presents a challenge (perhaps because they perceive the task as too difficult, or not worth the effort). They seek instead to place people who cannot be served locally in out-of-area residential placements, often at considerable expense.
 - ◆ ‘Containers’ do seek to provide local services (perhaps because of the cost of out-of-area placements) but seek only to contain people in low-cost (and therefore poorly-staffed) settings.
 - ◆ ‘Developers’ seek to provide local services which really do address individual needs, and therefore give higher priority to funding services which, with more staff and more training and management input, are more expensive than ordinary community services.
31. The knowledge and skills needed to develop effective local services are increasingly widely available; it is the extent to which policy-makers and senior managers want to do this which may be the key limiting factor.

Individualisation

32. Successful services are individualised, in a number of ways. First, they recognise that individuals need to experience well-coordinated services, committed to meeting their complex needs over the long term: so they tend to ignore professional or organisational boundaries, trying to construct packages of care that meet individual needs rather than making people fit into existing services; and they ‘stick with’ individuals in spite of the difficulties experienced in meeting their needs.
33. Secondly, the way packages of care are constructed really is based on thoroughly knowing and understanding the individual and their experience. Partly this is done through sophisticated assessment of different kinds (for example, functional assessment or detailed assessments of communication), but more than this staff get to know the individuals and their backgrounds well. The current framework for doing this is person-centred planning⁶¹.
34. Coupled with individualised planning and operation of the services received by an individual, costs are represented, and the case for resources made, at an individual level. Services are therefore in a much better position to demonstrate the value for money they achieve for individuals than services set up for notional client groups or in response to norms or categories of people.
35. This approach is entirely consistent with the Government’s focus on personalisation. Of course individualised approaches are often difficult to arrange (for example where day care is organised on a ‘take it or leave it’ basis in large, poorly-staffed centres, or where general psychiatric services operate a blanket exclusion on treating people with learning disabilities). For social care services, direct payments^{62 63}, the ‘In control’ project^{64 65} and individualised budgets³ are all important mechanisms to help people organise services that provide what they need, when they need it. They will need to be complemented by a new approach to commissioning which promotes and sustains the new kinds of services people will need whatever mechanism they use to get them⁶⁶. Individualised approaches are also promoted by specific legal obligations to provide

services (eg aftercare) and a growing emphasis in law on human rights and freedom from discrimination on the grounds of disability.

Effective service characteristics

36. Specialised services should have a clearly defined role. As extra resources, they offer specific services in support of mainstream local services for people with learning disabilities. In contrast to some institutional services which seemed willing to take anyone and unconvinced that any other agencies could possibly cope, modern services focus on a limited range of functions and are explicitly concerned to improve the capacity of local services to manage well. So, for example, services should not provide respite for people in crisis alongside a home for life.
37. Within this framework, the care and treatment offered to individuals is based on clearly stated assumptions and beliefs about what causes the individual's problem behaviour and what the service needs to do to prevent it, to manage it when it does occur, to treat it over the longer term and to stop it interfering with the quality of life of the individual concerned and those around them. Decisions about these issues are made in a genuinely multi-disciplinary context. This approach extends to all areas of the person's life and all relevant disciplines. It is in contrast to services which offer a general regime into which people are expected to fit irrespective of the different reasons they present a challenge. Guidance on these issues has been produced jointly by the Royal College of Psychiatrists, the British Psychological Society and the Royal College of Speech and Language Therapists³⁴.
38. Coupled closely with this is an emphasis on collecting and using good quality information both in assessment and to maintain a high standard of ongoing support to the individual. Good services focus on outcomes for the individual - independence, inclusion, choice and rights. They attend both to the challenge the person presents and to supporting the person to achieve a good quality of life in spite of their problems.

Good management

39. Services which have high aspirations need good management if their goals are to be realised in practice.
40. First-line and middle managers of the staff providing direct care need good understanding of the reasons for an individual's challenging behaviour and of how this interacts with the everyday organisation of the service. Thus, for example, someone learning greater self-control needs consistent feedback from different staff; a person who cannot tolerate complex spoken commands needs staff to monitor the way they approach them in line with a clear plan. This requires a greater degree of skill among staff and particularly good management (especially first-line management) to keep the service on track. Management is also crucial in ensuring that professional specialists and front-line staff work together; that specialist advice is available, practicable and sensible and that staff follow it.
41. In particular, managers need to distinguish the middle ground between pessimism about models of care ('you can't do anything with these people') and naive misinterpretations about normalisation ('only values matter - all structure is oppressive'); life for people with major disabilities supported by good services will

often look quite ordinary, but this ordinariness will be the product of a great deal of careful planning and management.

42. Since virtually all services claim to provide individualised care based on the latest assessment methods it is essential that service managers, commissioners and regulators can really discriminate between good and mediocre performance. This can be a particular problem for services providing long-term residential or day care, where a successful service looks like an ordinary home or occupation, when in fact it is a carefully designed and organised service dependent on a great deal of skill and management. It is important therefore to look directly at the lives of the people served (how they spend their time, how much help they get from staff, what relationships they have and so on) and not just to rely on the statements and beliefs the service has about itself.

Investment in relationships and networking

43. The last group of defining characteristics of examples of good practice is that they pay particular attention to the relationships between the service, the users, their families and the staff involved.
44. For individual service users, a history of challenging behaviour is also often a history of discontinuity in relationships and of bad experiences in relating to other people. Good services all make particular efforts to involve individuals in their care, to use advocates and to involve family members in person-centred planning.
45. These services also invest heavily in training for the direct care staff of the service. Most of this is specially designed in-service training, reflecting some dissatisfaction with the very limited competence in work with people who have challenging behaviour produced by traditional professional training and also emphasising the importance of training all staff, and training them all together as a team. Training includes not only understanding and responding to challenging behaviour but also the organisation of support in the person's home, day or leisure activity to provide good quality care in spite of a person's problem behaviour and in ways which minimise its likelihood and severity.
46. Each service also emphasises technical (ie about care and treatment) and emotional support for these staff. Technical support is largely provided from professional staff. The scarcity of some categories of staff (eg clinical psychologists, speech and language therapists) presents an obstacle to wider service development, particularly given the specialised nature of the expertise required. Emotional support, in recognition of the heavy demands that working with people who present very serious challenging behaviour make on staff, is equally important. Good team working, supervision, debriefing and counselling are important. Making good use of this support is also obviously dependent on achieving genuinely multi-disciplinary working.

Service models

47. Most people with learning disabilities whose behaviour presents a challenge to services are already living in the community receiving support from ordinary learning disability services. Those who are not could be, given the right kind of support. Effective support does not require different kinds of service but it does require more skilled staff support that is well organised to meet the person's individual needs.
48. Investment is required to achieve two aims:
- ◆ to develop and expand the capacity of local services for people with learning disabilities to understand and respond to challenging behaviour
 - ◆ to provide specialist services locally which can support good mainstream practice as well as directly serve a small number of people with the most challenging needs.

Thus in practice a local service would include

- ◆ a range of small-scale housing, work, education and other day placements into which markedly different levels of staff support could be provided on the basis of individual need at a particular time
- ◆ a sufficiently skilled workforce to reduce the probability of challenging behaviour emerging or worsening throughout the service, and to provide a pool of sufficient skill to help services work through difficult periods
- ◆ skilled professional advice from a full range of specialists, working in a coordinated and genuinely multi-disciplinary way, and backed-up by good access to generic services (including mental health services)
- ◆ management commitment to and focus on service quality and the staff training and support to achieve this.

Supporting people living with their family

49. People with learning disabilities who have challenging behaviour living at home with their families need two main kinds of service at home:
- ◆ Practical support. This may include equipment (for example adequate continence materials where the individual uses more than average because of their challenging behaviour), advice and training for family members in how to understand, interpret and manage situations the person finds challenging and staff support to work with the individual and give the rest of the family time to themselves. The results of giving families resources to organise their own support, through self-directed services such as 'In control', seem to be much better than those achieved by traditional home care services provided to older people^{65 67}.
 - ◆ Short breaks to give the person and their family time away from each other. A particular problem for people with learning disabilities who present challenges is that, although their needs for a short break may be very high, local authorities may discriminate against them because traditional local respite services find it hard to provide the support required. They may therefore be excluded from short breaks. Commissioners should ensure that opportunities for short breaks tailored to individual needs are available to every family supporting a person whose behaviour presents a challenge at home.

Supporting people in other accommodation

50. Members of the Committee were persuaded that the best model of residential service was likely to be support to enable people to live in ordinary housing. The available research evidence showed consistently poor quality of life in hospital (whether old or new campus-style hospitals); on other large-group models of care there is little quantitative research but since they share many of the resource and organisational characteristics of hospitals there are no grounds for believing they will achieve very different results. Research since 1993 has confirmed this judgment. Decisions will of course need to be made on the basis of what is best for each individual; but for most people supporting them in a home (their own home or a small residential home) near their family and friends will be the right decision. An important development since the first version of this report has been the recognition of housing rights, so that once people have a proper home they cannot just be moved from one place to another because services have difficulty providing the support they need.
51. Direct payments and individual budgets provide important new opportunities to provide housing and support in a way that is tailored to the individual needs of the person whose behaviour presents a challenge. These options should always be considered in planning for individuals.
52. The growth of residential homes which specialise in supporting people whose behaviour presents a challenge has not always brought the benefits which research and demonstration projects have shown can be achieved. Some of these services are too large to provide individualised support; serve people too far from their homes; and do not provide people with a good quality life in the home or as part of the local community. Commissioners should stop using such services in favour of developing more individualised, local solutions which provide a good quality of life.
53. Although the quality of community-based services varies widely, the factors that make for good services are relatively well-understood and there are many examples of good practice. The key to the difference between good and indifferent community services lies not in resources, but in the quality of management (especially first-line management).

Education, work and day opportunities

54. Studies of large-scale development of community services for people with learning disabilities in the United States show that the availability of a day service is associated with successful community placement for people whose behaviour presents a challenge⁶⁸. Whether people are living in their family home or in accommodation with support, they should have access to day opportunities.
55. Traditional day centres have limited experience of serving people whose behaviour presents a challenge and, given relatively low staffing ratios, the limited curriculum and the use of large groups these services are in any case likely to face considerable difficulty. In contrast, small-scale alternative day services providing supported employment or innovative leisure or educational pursuits, seem to offer particular promise. This is consistent with the Government's agenda to modernise day services and people whose behaviour presents a challenge are likely to benefit particularly from this programme. Commissioners should therefore purchase day care in these

kinds of services, rather than in large day centres. Where people are excluded from day services because of their challenging behaviour, commissioners should ensure that they provide alternative day services which can offer good services in spite of the challenges people present.

56. People whose behaviour challenges have the same right to continued education as anyone else. Supported access to further education is an important opportunity which should be available to everyone, alongside supported employment and other day opportunities.
57. These different options may not be available in each area. If commissioners only purchase services that exist they are likely to perpetuate traditional models. They should therefore take the lead in developing a much wider range of alternative models.

Access to other health and social services

58. *Valuing People* set out a clear framework for people with learning disabilities, including people whose behaviour presents a challenge, using health and social services available to the whole community. It said that the government will ensure that people with learning disabilities have the same right of access to mainstream health services as the rest of the population; that health facilitators will be appointed from each local community learning disability team to support people with learning disabilities in getting the health care they need; that all people with learning disabilities are registered with a family doctor and have their own Health Action Plan.
59. In respect of mental health services, it is important that services available to the whole community increase their ability to meet the needs of people with learning disabilities whose behaviour presents challenges and who have a diagnosed mental illness. Making services responsive to the needs of these people is part of making them more personalised and capable of meeting the needs of all parts of society. Within this overall framework, some specialised mental health provision may be needed. The appropriate role for psychiatric hospital services for people with learning disabilities, where these will have a continuing existence, lies in short-term, highly focused assessment and treatment of mental illness. This implies a small service offering very specifically defined, time-limited services. The Department of Health intend shortly to issue guidance on specialist health services for people with learning disabilities.

Specialist support to services

60. The first line of specialist support to people with learning disabilities living with their families, or supported in their own homes or in residential care, is the community learning disability team. This should provide social work, psychiatry, psychology, speech and language therapy, physiotherapy, nursing (and sometimes other relevant disciplines).
61. Improving ordinary learning disability services so that they can better support people whose behaviour challenges is not a substitute for proper specialist services. In many areas, additional specialist multi-disciplinary support teams focused on challenging behaviour have been developed, recognising that the intensity and complexity of help required may be more than community learning disability teams can provide. Such

services are an essential component of modern provision. Basing their approach on recent research and development, such teams expect to analyse the challenging behaviour in the situation in which it is occurring and develop a package of intervention components which include ‘ecological manipulation’ (managing the situation to avoid triggering challenging behaviour while still supporting people to engage in meaningful activity and relationships), ‘positive programming’ (helping the individual learn functionally equivalent alternatives to challenging behaviour to get what they need), ‘direct treatment’ (responding to the challenging behaviour in a way that will reduce its functional effectiveness) and ‘reactive management’ (how to work with the person safely during episodes of challenging behaviour)⁶⁹. This kind of approach requires careful, consistent, sustained implementation by staff, often over many days or weeks. They will need to work together as a team, to understand the principles underlying the professionals’ prescription so that they can sensibly adapt to changing circumstances, to manage their interaction with the individual and keep careful record of events and incidents.

62. Given the level of training, turnover and the prevailing ethos in some services staff are not always able to respond to these demands. A common reaction is therefore a kind of stand-off. Staff providing direct support to people with learning disabilities say that professionals do not understand the practical constraints they face and generate action plans that are impossible to implement. Professionals report that staff are simply not able to carry out the necessary assessments and intervention⁷⁰. They may lower their expectations but thereby risk plans being ineffective.
63. The way forward is that specialist services need to use their skills to help managers in service-providing organisations shape up the skill and quality of the service they provide. This requires closer co-ordination between the commissioners paying for services, the managers providing services and the professional specialists advising on the support people need, to ensure that advice is both practicable and is acted upon.
64. Given the importance of avoiding poor placement decisions made in a crisis, emergency support for people whose behaviour presents a challenge should be available 24 hours a day, seven days a week. Services that only work ‘office hours’ or which have waiting lists for support will not be able to provide an effective service to the individuals concerned, their families or the paid staff who support them.
65. When crises do occur, instead of the single solution of admission to a ‘challenging behaviour unit’, there needs to be a pool of staff and money which can be used more imaginatively to meet the particular needs of the situation. Special units fulfil a range of roles:
 - ◆ Short breaks: to give the individual person using services a break from a difficult situation, or to give other residents or family a break from the person
 - ◆ Intervention: to try out new way of working with the individual in a safer situation, to carry out biomedical investigation or to provide a high level of observation
 - ◆ Breathing space: to provide a ‘holding area’ while a new placement is found

Fulfilling these different roles in the same setting is difficult. If the unit is a long way from the person’s home, transferring any benefits of assessment and treatment may be impracticable^{71 72}.

66. The difficulty of bringing people back home once they have been placed a long way away is so great that every effort should be made to avoid such placement. What is needed is a much wider range of options locally so that the individual needs of the person in crisis can be better met. For example, options for respite can be expanded by
- ◆ funding a short hotel break for the individual or those they live with
 - ◆ providing more help at home
 - ◆ staying with staff identified as having a particularly good relationship and skills with the individual
 - ◆ spending less time in the house during the day
 - ◆ using a local house or flat before it is permanently occupied
 - ◆ staying in a designated short break care service

Options for intervention can be expanded by

- ◆ Extra skilled leadership/support for staff ('getting back on track')
- ◆ Extra skilled staff ('extra pairs of hands' or 'new pairs of eyes')
- ◆ Telesupport; phone or visiting checks
- ◆ Extra help to enable access to ordinary settings
- ◆ Stay in a designated assessment and treatment unit

Options for a breathing space can include

- ◆ Having services available for the individual when needed through proper person-centred planning
- ◆ Staying with staff identified as having a particularly good relationship and skills with the individual while a new property is found
- ◆ Turning property designated to provide individualised short break care into someone's home (and developing new short break places)
- ◆ Having spare capacity in anticipation of growth

67. Allocating a budget to be used to fund a much wider variety of interventions than placement in a special unit, often expensive and a long way away, would represent good value for money and good preventative action by commissioners.
68. All these elements of good practice are well understood and have been used to support people whose behaviour presents a challenge. However, they are not widespread in services. The central challenge is for commissioners to direct their investment to develop good practice, instead of continuing to fund services which, while they may solve some problems in the short-term, do not contribute to long-term solutions.

Commissioning

69. Combining the different elements of services to ensure that people with learning disabilities whose behaviour presents a challenge are served well is the job of commissioning. Models of good practice have been demonstrated and service providing organisations committed to good practice exist. However, in the period since 1993 development has not kept pace with need. Placement breakdown continues to be a widespread problem in community services; people are excluded from services; assessment and treatment facilities cannot move people back to their own home; some of the placements eventually found are low value and high cost. What is it that commissioners need to do to tackle these problems?

Commitment

70. The Cornwall Inquiry traced the abuse of people with learning disabilities, including people whose behaviour presents a challenge, to lack of focus and commitment by commissioners¹¹. It is therefore worth restating the reasons why commissioners should give priority to these services:
- ◆ *These individuals have the greatest needs for services.* People with learning disabilities and challenging behaviour present the most complex and difficult problems, both at individual and service organisation levels. Although their numbers may be relatively small, unless services respond well they occupy disproportionate amounts of time and money.
 - ◆ *Quality services achieve marked improvement.* Current research suggests that good quality services already make a substantial difference to the quality of life of individuals whose behaviour presents a challenge, and therefore by implication to their carers and staff. If the characteristics that make these services work were more widespread and better supported by management it would be possible to apply even more of the available knowledge at the individual level and to achieve even better results for individuals.
 - ◆ *Failure to develop local services threatens the policy of community care.* Doing nothing locally is not an option. Out-of-area placements will 'silt up' and reinstitutionalisation (through emergency admissions to psychiatric hospitals or via the prisons) will occur. Special institutions and residential homes for people whose behaviour presents a challenge will be expensive but of poor quality and will attract public criticism. Overall, the efficiency of services will decrease because of the widespread lack of competence in working with people who have challenging behaviour. Commissioners will have less control over and choice of services. Individuals, carers and staff will be hurt and some individuals whose behaviour presents a challenge will be at increased risk of abuse. Staff will be at increased risk from the consequences of developing their own strategies and responses and managers will be held accountable where well-intentioned staff operate illegal, dangerous or inappropriate procedures.

Agency responsibility

71. The development of joint commissioning between health and social services has removed some barriers and in many areas there is a record of health and social services, and to some extent housing, working together to make decisions about services for individuals whose behaviour presents a challenge.

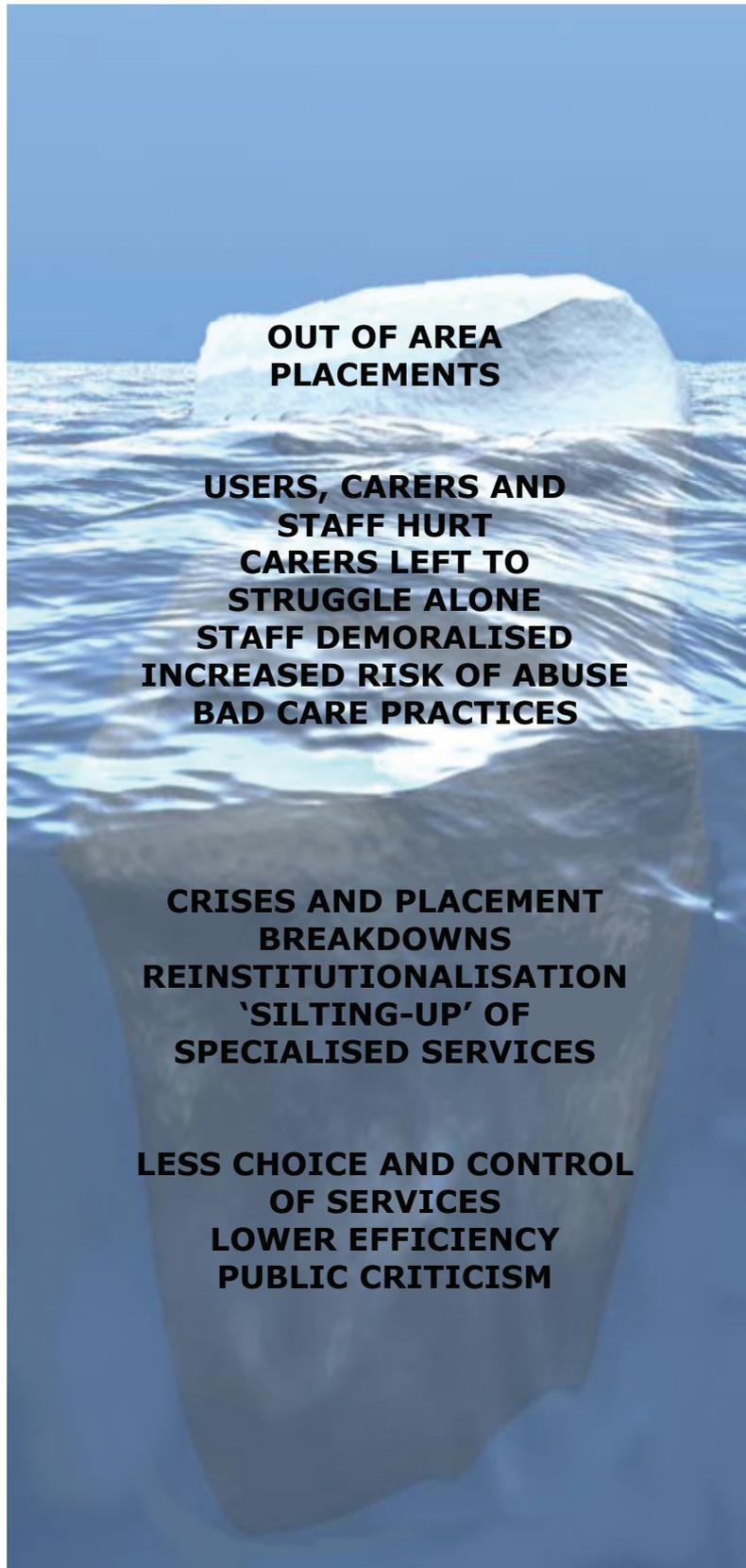
72. However it is clear that problems remain, particularly in
- ◆ the perception that there is unilateral withdrawal of Primary Care Trust finance from joint initiatives when there are financial pressures elsewhere in the health service
 - ◆ the reduction of Supporting People finance for individuals with relatively high needs for support
 - ◆ the continued use of residential special schools a long way from home for children given the importance of maintaining local links for services in adult life.

The government is taking steps to improve the co-ordination of policy between the Department of Health, the Department for Education and Skills and the Department for Communities and Local Government to ensure that people with learning disabilities whose behaviour challenges are not disadvantaged. One of the key roles of Learning Disability Partnership Boards is to monitor that local agencies are working together and to report when they are not.

Value for money

73. All public services are required to demonstrate value for money. This does not mean providing services at the lowest possible price. Value for money requires a judgement about the benefits and outcomes produced as well as the costs incurred. In the context of challenging behaviour, commissioners should focus on the outcomes identified in *Valuing People* – rights, inclusion, independence and choice – as well as on the specific treatment of challenging behaviour. Commissioners should also consider adopting a Charter for people with learning disabilities who have challenging behaviour such as that in Appendix 2. At service system level, value for money needs to be demonstrated by the low number of placement breakdowns and of out-of-area placements.
74. Given that many services performing quite differently use the same language and make the same claims it is particularly important that commissioners are able to distinguish good outcomes from window-dressing. In particular, careful scrutiny is required of expensive services which appear to provide containment rather than a good quality of life: such low-value high-cost services should be replaced by better alternatives.
75. In considering costs, commissioners should take account of the hidden costs of failure to develop local services, such as the costs of handling crises and placement breakdowns (Figure 1). They should also pay attention to the financial and other costs borne by carers and should avoid increasing the burden on carers by reducing levels of service. As one parent said

“They never think about the costs of not doing it”



The hidden cost of failing to develop local services

Figure 1

76. Commissioners should individualise costs to remove the confounding effect of averaging across clients and settings. In the short-term, they should certainly look to redirect resources from relatively expensive out-of-area placements to local service development, although it is clear that a very small number of individuals will be very expensive to serve wherever they live and it would be naive to expect cost savings as a matter of course. Such transfers will also incur the development costs of new placements and the transitional costs of replacing out-of-area with local provision. These cannot be avoided if the job is to be done properly.
77. They should also take care to identify all the current expenditure. It may be that adequate services for people whose behaviour presents a challenge will take more resources than currently allocated (since there is no logical basis to existing resource levels) but there are probably more resources in use than is apparent at first. For example some agencies spend substantial amounts of contingency reserves held at agency level on this group, while failing for want of money to develop the local capacity to serve.
78. It is already clear that most people using self-directed services find they provide much more value for similar costs⁶⁵. Making this option available to more people with learning disabilities whose behaviour presents a challenge is therefore important.

Service development

79. Current commissioning practice is too reactive. The problems are summed up in this mother's account of her family's struggle to get services for her son:

“At a fairly early stage, it was recognised that he was difficult. No one knew quite what to do. Education just wanted to put him somewhere at minimal cost. They took ages to go through bureaucratic processes - either complete incompetence or delaying tactics. Eventually they agreed a residential school placement and told me to find somewhere. Once he was there [over 250 miles away], they had no interest, sending a representative maybe three times in 10 years. When he was 15 I wrote to social services to tell them about him and ask them to plan for his return. They wrote back and said he was not their responsibility until he was 18. The default position was to find a residential home somewhere willing to take him. Setting up a new local service to meet his needs was not an option. The reasons for the lack of local service development are that it is too complicated, there is no set-up funding, no one to take responsibility for leading it - care managers know there is a need, but can't make it happen. Separate children's and adult teams are not helpful; children's team don't have responsibility beyond 18/19, so don't plan; adult teams are already overworked, so don't want to take responsibility before they have to. There is a culture of crisis management and a lack of creative thought. This all seems very negative but there are some good people trying to change things - but the odds are stacked against them. There is no strategic plan – it is all haphazard and disjointed.”

80. At present, in many localities, too few service providers can support people with moderate to severe challenging behaviour well. Many commissioners have typically purchased services on the basis of lowest cost in the short-term, without considering the

long-term effects when things go wrong. Instead they need to work with service providers who are committed to developing the capability to serve people well in spite of their challenging behaviour and who can provide services locally. This will entail long-term partnerships between commissioners and service providing organisations.

81. This will mean proper planning for individuals well ahead of them needing services. The Government has emphasised the importance of transition planning and has promoted a new project to help councils use person-centred planning in the transition process⁷³. Nowhere is this more important than in the service of people whose behaviour presents a challenge. It is inexcusable that councils, responsible for provision of services to both children and adults, should not have well coordinated transition planning arrangements.
82. Planning ahead is required for everyone. As a priority, councils should fund the independent advocacy and co-ordination required to ensure at least that every person whose behaviour presents serious challenges to services has a proper person-centred plan for the services they need now and in the coming years. Planning ahead also implies building in some capacity in the system to cope with demand as it emerges, rather than waiting until crises occur.
83. Person-centred plans need to be translated into action. Councils should therefore strengthen their commissioning to combine expertise about challenging behaviour with the ability to actually develop the services needed. This is required at both strategic and operational levels. At strategic level, Councils should
 - ◆ *Garner resources*: work with other relevant agencies to identify all current expenditure on learning disability, including resources accessed in emergency or crisis, and obtain agreements to pool these resources and to work together to improve outcomes for people whose behaviour presents a challenge.
 - ◆ *Audit provision*: find out which services are good at supporting people whose behaviour presents a challenge and which are not, and why.
 - ◆ *Assess need*: find out how many people have behaviour which presents a challenge, including
 - Young people approaching transition from school
 - People placed in the area funded by other authorities
 - People living at home not receiving services
 - People placed out-of-area
 - ◆ *Develop partnerships*: work with provider organisations who are committed to developing good services to support people whose behaviour presents a challenge to agree commissioning and funding arrangements that will achieve value for money while sustaining investment and development in local services.
 - ◆ *Plan services*: forecast the amount of new housing, day opportunities and support that will be required in the years ahead; map the staffing and staff training implications of this; and plan how this will be financed.
84. At operational level, councils should
 - ◆ *Create service development resource*: identify people who know about challenging behaviour and services, to work with people to implement their person-centred plans. Such a team should combine aspects of commissioning and care management and work alongside professionals providing specialist support.

- ◆ *Identify people as a first priority*: these should be people whose behaviour presents a serious challenge to services, focusing on those people where problems are serious enough that intervention could make an important difference but where the context is supportive enough to allow the greatest impact.
 - ◆ *Develop services*: support the person-centred planning process for these people and deploy resources to implement the plans developed.
 - ◆ *Provide back-up*: notice when problems being to emerge (before they reach crisis-point) and intervene to provide moral and material support to sustain arrangements through difficult periods.
 - ◆ *Extend development to more people*: as successful arrangements become established, take on the support of additional people.
85. Recognising the fragmented nature of service provision, it is important that commissioners encourage provider cooperation and mutual support. For example, if a particular service enters a difficult period in which several staff are injured it is important that they can call on other staff of comparable levels of skill to help get through the difficulties. At present, services tend to work in isolation and even if staff could be borrowed from other local providers, they would be unlikely to have the knowledge and skill required in the more specialised service. Small-scale services have to work together if they are to be sustainable.
86. The role of the National Health Service is to support this process of service development. This means that health bodies should
- ◆ Keep contributing the financial resources needed to sustain the transfer of specialist learning disability services to Councils.
 - ◆ Not undermine the strategy set out in this report by commissioning poor-quality services, especially out of area, themselves.
 - ◆ Continue to provide sufficient levels of the professional support required to sustain good practice in community based services.
 - ◆ Provide specialist psychiatric assessment and treatment on a short-term basis, but only as part of an integrated pathway of care for the individual that gets them back into the community.
 - ◆ Enable fair access to generic health (including mental health) services for people with learning disabilities whose behaviour presents a challenge to services.

Staff training

87. A key contribution to local capability is that staff working with people whose behaviour presents a challenge have adequate training. Many services at present attempt to deal with the challenge they face by adding more and more staff at greater and greater cost. Instead, commissioners should fund higher levels of skill through training. All services will need staff who have enough understanding of the causes of challenging behaviour to prevent it arising or getting worse. This means that they are trained in person-centred approaches, including
- ◆ *Person-centred active support*⁷⁴
 - ◆ *Positive behaviour support*⁷⁵
 - ◆ *Total communication approaches*⁷⁶
 - ◆ *Recognising and responding to mental health problems*⁷⁷
 - ◆ *Person-centred planning*⁶¹

88. There has been a substantial growth in training in ‘reactive management’ (see paragraph 61) through training in physical intervention⁷⁸. The risk of training staff in physical intervention without training in the preventative approaches listed above is that staff will use them when prevention was possible, with consequent damage to the person’s quality of life. Training in physical intervention should always be based on training in person-centred approaches.
89. A consistent message from service-providing organisations is that the present emphasis in National Minimum Standards on achieving targets for numbers of staff trained at National Vocational Qualification level 2 is not helpful. NVQs are seen as too general, and too heavily influenced by assumptions relevant to services for older people, to be as useful as they should be for staff supporting people with learning disabilities whose behaviour presents a challenge. The Learning Disability Awards Framework is not sufficiently flexible to allow priority to the needs of this group of service users. Using almost all the available funding to train staff at the most basic level makes it harder to meet the needs of people whose behaviour presents a challenge now.
90. New proposals, being developed by the Valuing People Support Team and Skills for Care, for Learning Disability Qualifications to replace the Learning Disability Awards Framework and development of the content of NVQs will provide a more flexible route for front-line staff. Greater emphasis ought to be possible in this new approach on the skills needed to work with people whose behaviour presents a challenge.
91. Good models already exist to pool local resources to provide training at this level for staff from all agencies involved in serving people with learning disabilities. For example, in Cambridgeshire, staff from any organisation working with people whose behaviour presents a challenge can take part in training provided locally to help them improve their practice.
92. There is also a need for training at a more advanced level, particularly for first-line managers and for members of special challenging behaviour support teams. Examples of this are degree and postgraduate level courses provided at, for example, the Universities of Kent, Manchester and London. These are typically multi-disciplinary courses which aim to integrate person-centred approaches with specialist knowledge of challenging behaviour and mental health needs. The Sector Skills Councils should support service development by recognising more specialised and advanced courses in challenging behaviour and specialised training at a more advanced level than NVQ2 should be a requirement where people present challenging behaviour.

Support for local agencies

93. The Commission for Social Care Inspection and the Healthcare Commission have responsibilities for regulating and improving the quality of services received by people with learning disabilities whose behaviour presents a challenge and for the quality of commissioning. These Commissions plan joint work in learning disabilities which will include a focus on the issues raised in this report. The Department of Health also provides support through the Valuing People Support Team (part of the Care Services Improvement Partnership) to assist local authorities and health bodies to improve

services. The Valuing People Support Team plans a programme of work to support implementation of the recommendations of this report.

94. The Department of Health has also provided guidance on commissioning for health and wellbeing⁷⁹. This identifies eight steps towards effective commissioning, viz.
- ◆ Putting people at the centre of commissioning
 - ◆ Understanding the needs of populations and individuals
 - ◆ Sharing and using information more effectively
 - ◆ Assuring high quality providers for all services
 - ◆ Recognising the interdependence between work, health and well-being
 - ◆ Developing incentives for commissioning for health and well-being
 - ◆ Ensuring local accountability
 - ◆ Building capability and leadership.

The proposals made in this report are consistent with these steps and provide a more detailed statement of what is required to achieve effective commissioning of services for people with learning disabilities whose behaviour presents a challenge.

Conclusion

95. In the first version of this report, it was argued that challenging behaviour was an acid test of the policy of community care. Whether community services continue to get better depends in part on how they respond to challenging behaviour, not just in the small number of people who present exceptional problems at any one time, but throughout their service. If they develop the capacity to work with people who present challenges in small, local services they will keep the size of the problem to a minimum and they will provide a good service to individuals in both their mainstream and specialised services. Developing good local services will not be cheaper, overall, than institutional care but it will be more efficient because it will achieve more. If local services are not developed then a trickle of expensive out-of-area placements will become a rush as more people are excluded from mainstream community services by being defined as unmanageable in the community. Large amounts of money will be tied up in buying less good services. The policy of community care will be said to have failed.
96. Although the overall policy of replacing institutional care with better services in the community has worked, people with learning disabilities whose behaviour challenges are among those most at risk of services breaking down. More needs to be done to improve the capacity of learning disability services to support people who present challenges. Service models are available to do this and there are new and exciting opportunities provided by self-directed services and individual budgets. The critical factor now is to change the nature of commissioning to build and sustain the capacity to meet the needs of people in each area.

Appendices

Appendix 1

Illustrative examples of individual situations and service responses*

Michael Langley is 21. He had been behaving in an odd and antisocial fashion since puberty, and was diagnosed at age 17 as having a mental illness in addition to a learning disability. When his behaviour became too severe to be managed at home he was sent to a distant mental handicap hospital despite his and his parents distress. He remains there whilst his parents try desperately to get their large city to provide a local service.

June Pearson, age 25, had often been sent home from school because she harmed herself, including running through windows and attempting to throw herself downstairs. Individual work from a local specialist challenging behaviour team revealed that she had been sexually abused and needed psychological treatment. Because she disliked large groups of people she behaved better in a small alternative day service. Four years later none of the original behaviour occurs and no new challenges have emerged. Treatment still continues whilst she leads her new life.

Samina Hirag presented severe behavioural difficulties at age 11, and was sent to a long stay hospital at 14, where she spent 19 years, often in a locked ward. An attempt at resettlement resulted in behaviour such as urinating in other people's beds, smearing faeces and minor criminal offences. Staff from a specialist assessment and treatment unit were able to diagnose and stabilise a long standing mental illness and reduce the behavioural difficulties. This work is being successfully continued under a Guardianship Order in a community setting.

Victoria Macconi, who cannot speak, unpicks clothing, curtains and carpets when she is in a situation she dislikes. Despite good evidence that the behaviour disappears in a preferred setting, managers are still searching fruitlessly for a way to modify her behaviour in the unsuitable setting, owing to the difficulty of funding an alternative.

Adam Brown, who has a severe learning disability, had to leave home at the age of 12 because his mother could no longer handle his aggressive outbursts after his father left them. 10 years later he is living in a staffed house nearby and has supported work in a canteen. Constructive individual work has enabled a new relationship with his mother to begin. Now they are helped to spend time together at weekends and are planning occasional overnight stays.

Staff in a small house have tried for 3 years, with some success to modify the eye poking behaviour of Winston Attwell. Without support from their manager however, including access to specialist behavioural treatment and meaningful day activity, they are becoming disillusioned and Winston's behaviour is deteriorating.

George Benson is 19 and had attended a special school because of his learning disability. He set two fires in his group home. He was held on remand in prison whilst alternatives to custody were sought. During this period he was bullied and sexually assaulted and now suffers from severe post traumatic stress disorder. The Court is exasperated by the failure of local services to respond, yet do not wish to release him in the absence of support or without the possibility of specific treatment for his fire-setting. After 8 months on remand the health authority agreed to fund his transfer to a specialist assessment service. He was transferred under Section 35 of the Mental Health Act (1983).

* These are not the individuals' real names.

Appendix 2

A Charter for people with learning disabilities who have challenging behaviour or mental health needs

1. Standards and charters applying to other people shall also apply to people with learning disabilities and challenging behaviour or mental health needs.
2. Services will ensure that each person is treated as a full and valued member of their community, with the same rights as everyone else and with respect for their culture, ethnic origin and religion.
3. Services will be individually-tailored, flexible and responsive to changes in individual circumstances and delivered in the most appropriate local situation.
4. Services will strive to enable people to live in ordinary homes, and enjoy access to services and facilities provided for the general community.
5. Services will be provided by appropriately trained, qualified and experienced staff who will help the people they serve to develop fully in all aspects of their lives.
6. Services will be delivered in the least restrictive manner capable of responding to individual needs.
7. Services will strive to continually improve, using the latest research to provide the best treatment, care and support.

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