

People with learning disability and mental health, behavioural or forensic problems: the role of in-patient services

Faculty Report FR/ID/03
July 2013



Royal College of Psychiatrists'
Faculty of Psychiatry of Intellectual Disability

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Foreword

The Faculty of Psychiatry of Intellectual Disability at the Royal College of Psychiatrists commissioned this report as a result of the abuse scandal at Winterbourne View Hospital. In that hospital there was an appalling standard of care that no one would condone. Since that time, there has been much debate about the place of specialist in-patient care for people with intellectual (learning) disabilities.

This report sets out the different types of specialist in-patient services that are currently provided, and describes the sort of difficult and challenging circumstances in which such services can be an appropriate intervention for a person with intellectual disability. These are always serious and challenging problems, where there are major risks to the person themselves and other people, so serious that compulsory treatment under the Mental Health Act is often required. As such, in-patient services can form an essential component of an overall integrated care pathway.

Some people refer to all specialist in-patient services for people with learning disabilities as 'assessment and treatment units' but this report explains why this is a flawed approach and does a disservice to the people who use the service.

Much has been said about the enhancement of community services that is required to reduce the use of specialist in-patient services, and we wholeheartedly support the development of better community services, particularly for those with challenging behaviour and other major mental health needs. However, as this report says, even if such improvements do deliver a reduction in the need for beds, a range of specialist in-patient services will still be required. Of course these must be of the highest quality, and fortunately there are assessment tools already in use (some developed by the College) that are very helpful in assessing quality. The universal adoption of such tools will go a long way to help prevent the abuse that happened at Winterbourne View from happening again.

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Executive summary and recommendations

The BBC Panorama programme 'Undercover Care: the Abuse Exposed' aired in May 2011, followed by the Serious Case Review from the South Gloucestershire Adult Safeguarding Board in July 2012, and the interim and final reports from the Department of Health in June and December 2012, have focused attention on the in-patient care of people with learning disability and mental health or behavioural problems. Describing 'assessment and treatment units' as a new form of institutional care which has no place in the 21st century, the reports set out national actions to deliver five goals, namely: more people with learning disability being supported to live at home; fewer people developing behaviour that challenged and those that did being kept safe in their communities; far fewer being sent away to hospitals; and proper planning, keeping such hospital stays as short as possible. On these goals, there can be little disagreement. By striving to deliver effective treatment in the least restrictive setting while paying due diligence to minimising risks, psychiatrists and other professionals working within the field of mental health in learning disability strive to achieve precisely these goals. However, in-patient services are a crucial part of the effort to achieve those goals. Although the majority of people with learning disability, mental health, behavioural and forensic difficulties will be supported within well-resourced community services, specialist hospital settings should remain available whenever there is good evidence that hospital is the best setting to enable their necessary assessment, treatment and care. This document describes the categories of in-patient care available, their purpose and how we monitor in-patient services to ensure safe and effective care.

MENTAL HEALTH, BEHAVIOURAL AND OTHER NEEDS OF PEOPLE WITH A LEARNING DISABILITY

People with a learning disability who come into contact with specialist learning disability mental health services often have a complex mix of learning disability, other developmental disorders, mental illnesses, personality disorders, substance misuse, and physical disorders including epilepsy. Some of these conditions present with challenging behaviours, others do not.

Challenging behaviour is a socially constructed, descriptive concept that has no diagnostic significance. It can range from pica, smearing and self-injury in a person with a profound learning disability, to unlawful killing in someone with a mild learning disability and forensic issues. It may be

unrelated to psychiatric disorder, but can also be a primary or secondary manifestation of it. Treatment for challenging behaviour emphasises the use of the least restrictive community resource wherever possible. In-patient admissions are required if the risk posed by the behaviour is of such a degree that it cannot safely be managed in the community. Alternatively, for some people an early admission may be required for diagnostic clarification and initiation of appropriate treatment. Some people with learning disability have multiple physical problems, and in some who present with challenging behaviour it can be difficult to tease out whether the presentation is because of an underlying organic (physical) condition. In many of these complex presentations, continuous nursing observation, investigations, medical and psychiatric input may be needed within an in-patient setting for an accurate diagnosis and effective treatment. Appreciating this complexity is important in determining the role that in-patient units play in diagnosis and treatment. Good in-patient care can only be delivered by multidisciplinary teams working very closely with Social Services to ensure person-centred planning and plans for appropriate provision to move on from hospital care. It is important that people have the right care and support packages to meet their individual needs with agreed outcomes for moving on through the pathways of care.

THE RANGE OF IN-PATIENT SERVICE PROVISION

Describing all types of specialist in-patient services for people with learning disability as 'assessment and treatment units for challenging behaviour' does not capture the spectrum of in-patient services and their different functions in meeting the needs of those with complex presentations. When this approach is used by governments, regulatory authorities and some service providers, it results in mixing up categories of beds that serve completely different functions. As a consequence, targets that aim solely on cutting the numbers of 'assessment and treatment units for challenging behaviour' will result in significant gaps in service provision that will disadvantage the very patients it is meant to help.

This report sets out, with representative case examples, six categories of in-patient beds and their close relationship with each other. Although all these categories do involve some assessment and treatment, they serve different functions. They can be best understood within the context of the tiered model, where tier 4 constitutes the in-patient part of a specialist learning disability service provision:

- category 1: high, medium and low secure forensic beds
- category 2: acute admission beds within specialised learning disability units
- category 3: acute admission beds within generic mental health settings
- category 4: forensic rehabilitation beds
- category 5: complex continuing care and rehabilitation beds
- category 6: other beds including those for specialist neuropsychiatric conditions.

From a patient care perspective, the narrative should be that of in-patient services complementing community teams to achieve good treatment outcomes and being part of the pathway of care for those who present with

complex needs. Indeed, depending on patient needs, an admission to an in-patient bed can sometimes be appropriate and beneficial early on in the care pathway, to undertake a multidisciplinary assessment and provide early interventions to prevent rapid deterioration.

HIGH, MEDIUM AND LOW SECURE FORENSIC BEDS (CATEGORY 1)

Category 1 refers to beds within forensic hospitals in conditions of high, medium or low security. The decision whether a person becomes a 'forensic patient' or not often depends on both clinical judgements about risks and the attitudes of professionals working in the criminal justice system. Both of these are inevitably shaped by the availability of services, and if less restrictive in-patient facilities are unavailable, more patients can end up in these restrictive settings.

ACUTE ADMISSION BEDS WITHIN SPECIALISED LEARNING DISABILITY UNITS (CATEGORY 2) AND ACUTE ADMISSION BEDS WITHIN GENERIC MENTAL HEALTH SETTINGS (CATEGORY 3)

Category 2 and 3 beds are acute admission beds intended for the assessment and treatment of severe mental health and/or behavioural problems, of an intensity which poses a risk that cannot be safely managed in a community setting, but which does not meet the risk threshold to be considered for a forensic bed. Category 2 serves this function within a specialised learning disability unit, whereas category 3 does it within a generic or mainstream mental health ward setting. There is a considerable body of published literature about the comparison between category 2 and 3 beds, but there is no evidence to suggest that any one model is superior. The two models serve different types of patients and generic psychiatric care may be unpopular, especially with carers and families.

Category 2 beds in specialist learning disability units are needed because although the equity of access that a policy of mainstreaming brings is very pleasing, it is meaningless if not accompanied by equity of outcome. Being treated by specialists in the mental health of people with learning disability, within settings that are particularly suitable for those with learning or developmental disadvantage, is a reasonable adjustment that allows people with learning disability and mental health or behavioural difficulties to achieve the same equity of outcome as people without learning disability with the same mental disorders. These beds, therefore, are not a reminder of inequality through segregation but a guarantor of equity through specialisation.

That is not to say that category 3 beds cannot deliver good outcomes for people with mild learning disability and mental illness. The College report *Enabling People with Mild Intellectual Disability and Mental Health Problems to Access Healthcare Services* (Royal College of Psychiatrists, 2012) explains how this can be effective, if there is substantial specialist support available to facilitate this from community learning disability teams.

FORENSIC REHABILITATION BEDS (CATEGORY 4)

Category 4 is for people who have stepped down from forensic units with enduring issues of risky behaviours. Their legal status and current risk assessments still emphasise the need for ongoing therapeutic input and

robust external supervision for the protection of the public. The availability of these hospital beds, often in locked or open community units, allows them to receive treatment in a less restrictive setting than a category 1 bed.

COMPLEX CONTINUING CARE AND REHABILITATION BEDS (CATEGORY 5)

Category 5 is for people who have undergone the initial acute assessment and treatment process. For a variety of reasons, including enduring mental illnesses or severe behavioural problems that have not responded adequately to treatment, ongoing risks arising from neglect or vulnerability or persisting risks to the safety of others, a safe transition into the community has not been possible. The availability of these beds allows a process of rehabilitation and re-skilling in a safe, structured and therapeutic environment at a pace that patients can tolerate, and minimises the risk of 'revolving-door' patterns of hospital admissions to category 2 or 3 beds.

Category 4 and 5 beds are not unique to people with learning disability. They closely mirror the definition of the 'longer-term complex/continuing care units' contained in the recently published document *Defining Mental Health Services – Promoting Effective Commissioning and Supporting QIPP* (NHS Confederation, 2012). The definitions in that document have been endorsed by a range of organisations, including the Department of Health, the Care Quality Commission, the Audit Commission, the Association of Directors of Adult Social Services (ADASS), the NHS Information Centre, the Mental Health Network – NHS Confederation, the Royal College of General Practitioners, the Royal College of Psychiatrists, the Royal College of Nursing and mental health leads of the strategic health authorities.

OTHER BEDS INCLUDING THOSE FOR SPECIALIST NEUROPSYCHIATRIC CONDITIONS (CATEGORY 6)

This includes specialist beds for some neuropsychiatric conditions such as epilepsy and movement disorders. At present, this service provision is limited to a few, very specialised national units.

BED OCCUPANCY IN LEARNING DISABILITY IN-PATIENT SERVICES

Using data obtained from the Faculty of Psychiatry of Intellectual Disability's regional representatives, we found that at present there are around 3954 beds within the 10 strategic health authority regions of England. This is made up of approximately 2393 category 1, 814 category 2, 622 categories 4/5 and 125 category 6 beds (no specific data available for category 3 beds). This includes some, although not all, beds in specialist units designated for autism spectrum disorders. These figures include all National Health Service (NHS) and independent sector provision for forensic and non-forensic services and represent an almost 90% reduction from a high of over 33000 NHS beds in 1987–1988.

If, in the absence of significantly improved community services, the less restrictive in-patient facilities (categories 2–5) are further reduced because they are all uniformly described as assessment and treatment beds, then many more people will have unmet needs that compromise their mental health and safety. The result of this could be even more people ending up in far more restrictive forensic beds (category 1).

STEPPING DOWN FROM IN-PATIENT SERVICES

Currently, 70% of forensic (category 1) beds are in conditions of low security. Since the provision of relational and procedural security is often more important than physical security for people with learning disability, many patients currently in these beds could potentially move to the less restrictive rehabilitation beds (category 4 or 5). At present, this is problematic because the commissioning streams for secure beds (category 1) are different to those for all the other categories of hospital beds and the possibility of patients 'stepping down' creates financial pressures for clinical commissioning groups. In addition, there is significant geographic variation in the current distribution of in-patient beds. Although economies of scale may hamper the efforts to provide all categories of beds in every district, the emphasis should be on in-patient service provision as close to the person's place of residence as possible. It is therefore important to consider all in-patient beds, whether 'forensic' or 'non-forensic', as a whole while planning for future provision.

Although the aim is for all patients to move through to the community, it has to be recognised that not all will move at a predetermined pace all the way through the care pathway. For patients who stay in hospital for long periods, there should be demonstrable evidence of ongoing therapeutic input. This will include psychiatric input, nursing care, availability of psychological therapy, occupational therapy, rehabilitation activities that include educational and vocational opportunities, and supervised or independent access to the community. Even though the patient may choose sometimes not to engage in these activities, these therapeutic activities should nevertheless be available.

IN-PATIENT SERVICES' ACCREDITATION

Accreditation tools focus on process variables within in-patient units and ensure that clinical practice will be in keeping with standards that are accepted by peers. There are a range of such tools including the Royal College of Psychiatrists' Accreditation for Inpatient Mental Health Services in Learning Disability (AIMS-LD) and the peer review accreditation process (Quality Network for Forensic Mental Health Services). The measurement of these process variables will have to be supplemented with information about whether treatment provided in these settings works. A minimum data-set of outcome variables that cover measures of clinical effectiveness, patient safety and patient experience proposed in this report will help in benchmarking services nationally.

RECOMMENDATIONS

We make the following recommendations.

- 1 Lack of awareness about the six different categories of in-patient beds results in all of them being described incorrectly as 'assessment and treatment units'. When undertaking reviews of in-patient placements, service providers, commissioners and policy makers should be aware of these different categories and monitor their function against these categories. Inspection reports by regulatory authorities should specify these different bed categories.
Action: Care Quality Commission or equivalent, service providers and commissioners
- 2 A choice of both generic mental health and specialist learning disability mental health beds should be available for people with learning disability and mental health or behavioural problems who require acute in-patient treatment. This choice should be determined by clinical need, patient and carer preference and evidence-based practice.
Action: service providers, commissioners, service users, families and carers
- 3 Regional commissioning strategies should focus care pathways on well-developed community services and a spectrum of in-patient care as described by the six categories in this report.
Action: service providers, commissioners, service user and carer groups
- 4 Since there are local variations in the number of beds needed within each individual category, there should be discussion between patients, carers, professionals, providers and commissioners in each area about local need as part of a joint strategy in developing pathways of care for people with learning disability.
Action: service providers, commissioners, service users, families and carers
- 5 There should be an ongoing dialogue at a local level between learning disability health providers, mental health providers and local authorities to ensure that responsive local authorities and mental health services can help reduce the need for admission and shorten the length of stay in hospital. Commissioners and providers should plan from day one of admission to in-patient services for the person with learning disability to move back to community services.
Action: service providers, commissioners, local authorities and mental health services
- 6 Availability of multidisciplinary therapeutic input distinguishes good in-patient facilities from those that are no more than settings of containment. There should be regular monitoring of this availability through the care programme approach and other reviews.
Action: service users, parents, carers, service providers, commissioners, Care Quality Commission or equivalent
- 7 All in-patient units should be able to show evidence of having gone through an external accreditation process such as the Royal College of

Psychiatrists' peer review accreditation for forensic beds, the AIMS-LD project or any other equivalent.

Action: service providers, commissioners, Care Quality Commission or equivalent

- 8 All in-patient units should be able to show evidence of a minimum data-set of treatment outcomes that includes baseline descriptions of quality of care, measures for effective treatments, appropriate use of medication, patient safety, compliance with Mental Capacity Act, and patient experience.

Action: service providers, commissioners, Care Quality Commission or equivalent

- 9 A number of patients in category 4 and 5 beds (forensic rehabilitation and rehabilitation and continuing care) stay for very long periods in hospital because apart from therapeutic input, they also need continuous supervision for the protection of the public. If this type of continuous supervision was legally enforceable in the community, without it amounting to the legal standard for deprivation of liberty, then they could very well be managed outside hospitals. We recommend further scrutiny of this issue.

Action: government legislation or guidance

Introduction

Over the past 30 years, there has been a gradual reduction of hospital beds across all medical and surgical specialties in the NHS in England. This fall has been most dramatic in mental health and learning disability. Mental illness bed numbers have fallen from 67 421 in 1987–1988 to 22 403 in 2011–2012 (66.8% reduction) as compared to a reduction of learning disability beds from 33 421 to 1 800 in same time frame (95% reduction). Table 1 presents these numbers in more detail.

Government policy, the process of deinstitutionalisation and the development of a range of community services resulted in the closure of long-stay hospitals for people with a learning disability (Kingdon, 2005). As a result of this process, the number of in-patients in hospitals fell from a high of around 64 000 in 1970, to well under 10 000 by 2001 (Braddock *et al*, 2001; Department of Health, 2001). The latter included placements in residential accommodation within the NHS and with the campus closure programme (Department of Health, 2006), bed numbers fell further. The last remaining patients in NHS accommodation were moved out successfully to a range of community settings, such as nursing homes, residential group homes, supported living accommodation, family homes or independent living (Bhaumik *et al*, 2011). The closure of long-stay hospitals was accompanied by an increasing focus on community learning disability teams providing a range of services, including those for mental health and behavioural difficulties (Lindsey, 2000). Within this model, the purpose of in-patient beds changed from one that provided long-term residential accommodation, to one that was accessed for assessment and treatment of severe mental health and/or behavioural difficulties.

Table 1 Average daily number of available beds, England, 1987–1988 to 2012–2013 (NHS England, 2013)^a

Year	All specialties	Mental illness	Learning disability
1987–1988	297 364	67 122	33 421
1988–1989	282 918	63 012	30 048
1989–1990	270 301	59 288	26 406
1994–1995	211 812	41 827	13 211
2000–2001	186 091	34 214	6 316
2005–2006	175 436	29 802	3 927
2009–2010	158 461	25 503	2 809
2010–2011	142 470	23 159	2 191
2011–2012	138 574	23 200	1 800
2012–2013	138 574	22 403	1 859

a. No data available for years 1995–2000, 2001–2005 and 2006–2009.

The Department of Health's interim report (2012a) in the aftermath of the abuse scandal at Winterbourne View Hospital (BBC One Panorama, 2011) stated that there were 1252 occupied beds in in-patient services designated as assessment and treatment units dealing with challenging behaviour; 500 of those had lengths of stay of more than 6 months (Care Quality Commission, 2011). Concluding that there were too many people staying for too long within these units, the report suggested that only 300–400 assessment and treatment beds, the equivalent of 2 to 3 per local authority area, were needed across England. (That figure does not appear to be correct, since with 326 districts there are far more local authorities in England than the report assumes. We now understand that the report was referring not to all local authorities, but only the upper tier ones that number around 120.)

In a strongly worded foreword to the interim report (Department of Health, 2012a), the then Minister of State for Care Services described assessment and treatment units as a new form of institutional care. It was a theme that continued in the conclusions of the report where these units were described as a model of care that has no place in the 21st century. Quoting extensively from the Mansell report (Department of Health, 2007) and the *Valuing People* policy documents (Department of Health, 2001, 2009), this report recommended 14 national actions and gave a list of 5 goals that would be achieved were these actions to be taken. These were that more people with learning disability would be supported to live at home; fewer people would develop behaviour that challenged; those who did would be kept safe in their communities; far fewer would be sent away to hospitals; and when that happened, proper planning would mean that their stay would be as short as possible. The final report (Department of Health, 2012b) stated that many people who should be supported in communities were in hospital for too long. There was a widespread failure to design, commission and provide services locally and a failure to assess the quality and outcomes being delivered in hospitals. It broadly endorsed the goals set out in the interim report and established a programme of action and a concordat towards achieving that.

On the goals that are thus set out, there can be little disagreement. Indeed, psychiatrists and other professionals working within the field of mental health in learning disability strive to achieve precisely these goals, namely deliver effective treatment in the least restrictive setting, while paying due diligence to minimising and managing the risks that pose a danger either to the patients themselves or to others. We suggest, however, that in-patient units are a crucial part of the effort to achieve these goals. Far from being institutions that have no place in the 21st century, they are vital to ensure that people with learning disability and mental health or behavioural difficulties get the treatment they require. The response to abuse in any such unit should be renewed efforts to stamp out poor practice, enhance governance structures and punish criminal activity, rather than seeking to shut down a crucial part of patient care altogether. In this, we suggest that the response should be exactly similar to how abuse scandals have been dealt with elsewhere in the health system within general hospitals.

Although the majority of people with learning disability, mental health, behavioural and forensic difficulties will be supported within well-resourced community services, specialist hospital settings should remain available whenever there is good evidence that hospital is the best setting to enable their necessary assessment, treatment and care.

Coming as they did in the aftermath of the Winterbourne scandal, the Department of Health reports, perhaps understandably, focused on issues around 'challenging behaviour' and 'assessment and treatment units'. We suggest that this is too narrow a focus. Effective planning requires a fuller examination of the whole issue of in-patient service provision rather than a particular subtype. It would be useful to examine this within the tiered model of service provision that describes the patient journey between hospital and community settings (Royal College of Psychiatrists, 2011a). Such an exercise can delineate why in-patient services are needed, the types of those services, the different models of that service provision and the ways of measuring and monitoring them. In the absence of such a fuller examination, targets that focus solely on the number of 'assessment and treatment beds for challenging behaviour' will result in service cuts that far from delivering equality to a marginalised population will only serve to further disadvantage them.

This report is prepared on behalf of the Faculty of Psychiatry of Intellectual Disability of the Royal College of Psychiatrists and focuses on adults with a learning disability. It is primarily based on statistics from England, but wherever available, in-patient information from Wales, Scotland and Northern Ireland is given. The models of healthcare that are described would apply equally to all jurisdictions. The report examines the following points:

- 1 learning disability, mental health morbidity and challenging behaviour
- 2 in-patient service provision for people with learning disability, mental health and behavioural problems: categories of beds and service models
- 3 monitoring of standards and outcomes.

Learning disability, mental health morbidity and challenging behaviour

LEARNING DISABILITY

The UK government uses the term learning disability, yet the international classificatory systems, DSM-IV (American Psychiatric Association, 1994) and ICD-10 (World Health Organization, 2008), currently use the term mental retardation. The Royal College of Psychiatrists recently decided to use the term intellectual disability. Since governmental organisations and commissioning bodies in the UK are still using the term learning disability, this report uses that terminology throughout.

Learning disability is a condition characterised by significant impairments of both intellectual and adaptive functioning and an onset before the age of 18 (World Health Organization, 2008). About 1–2% of the general population will have a learning disability (Emerson *et al*, 2011). In England, the Learning Disabilities Public Health Observatory estimated that in 2011 just below 1 million adults aged 18 or above had that condition (Emerson *et al*, 2011). The degree of learning disability can be mild, moderate, severe or profound, with over 90% of those affected falling within the mild range (Department of Health, 2001). Since their functional abilities are very close to the lower end of normality, those with a mild learning disability often may not come to the attention of specialist learning disability health services at all.

MENTAL HEALTH MORBIDITY

People with a learning disability have high rates of mental health comorbidity (Deb *et al*, 2001). Epidemiological studies have suggested a prevalence rate of 31–41% (Cooper *et al*, 2007; Morgan *et al*, 2008). For those in contact with specialist learning disability health services, a recent study (Kiani *et al*, 2013) offers a good demonstration of this point. The counties of Leicestershire and Rutland (including the city of Leicester) have a total population of just under 1 million and one would expect around 10000–20000 people with a learning disability there. The long-established Leicestershire Learning Disability Register (McGrother *et al*, 1993) has only 3062 people on it and of these 2713 receive help from the specialist learning disability services of the local NHS trust (Kiani *et al*, 2013). Of this 2713,

between 33 and 35% (about 920 people) have a diagnosable mental disorder based on ICD-10 criteria.

For those who are treated within hospital settings, figures from 9 specialist in-patient unit studies (Hurst *et al*, 1994; Singh *et al*, 1994; Trower *et al*, 1998; Raitassuo, 1999; Alexander *et al*, 2001; Tajuddin *et al*, 2004; Xeniditis *et al*, 2004; Hall *et al*, 2006a) show rates of major mental illness comorbidity ranging from 50 to 84%. This is in addition to other comorbid conditions such as autism spectrum disorders, attention-deficit hyperactivity disorder, personality disorders and substance misuse. For individuals treated within or referred to forensic (i.e. secure) hospital services for those with learning disability, similarly high figures are reported. Up to half have a personality disorder, up to a third have an autism spectrum disorder, about a third to half have a major mental illness, about a third to half have substance misuse/dependence and about a fifth have epilepsy (Alexander *et al*, 2002, 2006; Plant *et al*, 2011). It is thus clear that of those people with a learning disability who come into contact with psychiatrists, whether they are in the community or in specialist hospitals, it is not learning disability alone that is the focus of treatment. Their clinical presentations are often a complex mix of learning disability, mental illnesses, other developmental disorders, personality disorders, substance misuse, and physical disorders including epilepsy. Some of these conditions present with challenging behaviours, whereas others do not. Appreciating this complexity is important in determining the role that in-patient units play in diagnosis and treatment. Good in-patient care can only be delivered by multidisciplinary teams working very closely with Social Services to ensure person-centred planning and plans for appropriate provision to move on from hospital care. It is important that people have the right care and support packages to meet their individual needs with agreed outcomes for moving on through the pathways of care.

CHALLENGING BEHAVIOUR

Behaviour can be described as challenging when it is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion (Royal College of Psychiatrists *et al*, 2007). Challenging behaviour is a socially constructed, descriptive concept that has no diagnostic significance, and makes no inferences about the aetiology of the behaviour. It covers a heterogeneous group of behavioural phenomena across different groups of people; for example, oppositional behaviour in children, faecal smearing in those with a severe learning disability, and self-harm in adult mental illness. Challenging behaviour may be unrelated to psychiatric disorder, but can also be a primary or secondary manifestation of it (Xeniditis *et al*, 2001). For people with learning disability who come into contact with health services, it can range from stereotypes and self-injury in a person with a profound learning disability, to unlawful killing in someone with a mild learning disability and forensic issues. A meta-analysis of risk markers for challenging behaviour that looked at 86 studies described four types of challenging behaviours: self-injury, aggression, stereotyped behaviours and destruction of property (McClintock *et al*, 2003). Suggesting that male gender, severe learning disability and autism were possible risk markers, this comprehensive paper commented

about the lack of data on the incidence, prevalence and chronicity of challenging behaviours in this population. The recent report from the Department of Health (2012a) states that there are a total of 15000 people in England with learning disability or autism and behaviour that challenges. Data provided by the Leicestershire Learning Disability Register studies would suggest that the numbers may be higher (Tyrer *et al*, 2006; Kiani *et al*, 2013). In an area with a population of around 1 million, there are 540 people with some form of problem behaviour, including 443 with physical aggression of more than 3 episodes per week and/or severe intensity. Extrapolating from this, it appears that between 22000 and 26000 people with a learning disability in England are likely to have some form of behaviour that challenges.

Treatment for 'challenging behaviour' does not necessarily require an in-patient setting. Indeed, the therapeutic approach to it has been well described and emphasises the use of the least restrictive community resource wherever possible (Royal College of Psychiatrists *et al*, 2007). In-patient admissions are required only if the risk posed by the behaviour is of such a degree that it cannot safely be managed in the community. Persistent challenging behaviour, which poses a level of risk that is unmanageable in a community setting, may be the manifestation of some other underlying mental health difficulty that requires careful assessment and treatment in the safe setting of an in-patient resource. Equally, there may be many people with a learning disability who require an in-patient admission for further assessment, diagnosis and treatment of mental disorders that do not necessarily present with challenging behaviour. Indeed, admission to a specialist unit can sometimes be appropriate and beneficial early on in the care pathway, rather than as a last resort. Suffice to say that the purpose of admitting a person with a learning disability to a specialist in-patient setting is not merely because that person has 'challenging behaviour'.

In-patient service provision for people with learning disability and mental health or behavioural problems

WHY ARE IN-PATIENT BEDS NEEDED?

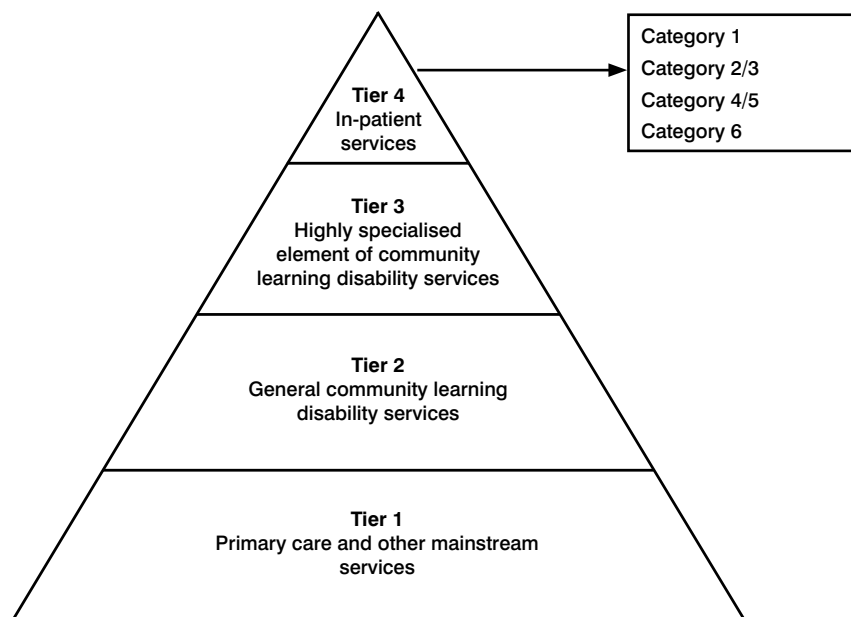
The assumption that all behaviours were a consequence of institutional lifestyles, which would diminish once community care was introduced, may be flawed (Holland *et al*, 2002). There are several reasons why people with a learning disability and mental health/behavioural difficulties need access to specialist in-patient provision.

- 1 Behaviours previously hidden or tolerated within institutions become more visible in the community and lead to adverse consequences (Moss *et al*, 2002).
- 2 An increased societal aversion to risk (Carroll *et al*, 2004) makes this dynamic more potent. Behaviour, whether it is aggression or self-injury, can pose a level of risk that is deemed unacceptable in a community setting. In this situation, in-patient settings of varying degrees of security are needed for varying periods of time. The guiding principle is to go for the least restrictive within those options.
- 3 Any patient who is seen as 'liable to be detained' under the Mental Health Act will by law require a hospital bed (*R v Hallstrom ex p W* [1986]).
- 4 Just as in the general population, people with learning disability also develop mental ill health. As discussed in detail in the previous chapter (p. 19), they have in fact higher rates of psychiatric and developmental morbidity. For those who come into contact with specialist or generic mental health services, this is not just because they have a learning disability. Their clinical presentations are usually a complex mix of learning disability, mental illnesses and other developmental disorders. The natural course of these mental disorders suggests that there may be both crisis situations and situations where symptoms or behavioural disturbance persist in spite of adequate treatment. During those times, they need a safe setting with professionally qualified staff who can treat them.
- 5 People with learning disability and mental health problems also have an extraordinary range of physical disorders including epilepsy (Emerson

& Baines, 2012) that makes their presentation even more complex. For some people who present with challenging behaviour, physical and mental health issues are intricately linked with each other and often it can be difficult to tease out whether the presentation is because of an underlying organic (physical) condition. In many of these complex presentations, continuous nursing observation, physical investigations, medical and psychiatric expertise may be needed within an in-patient setting for an accurate diagnosis and effective treatment.

WHAT ARE THE TYPES OF IN-PATIENT BEDS?

A number of authors have described or summarised different categories of in-patient beds (Dickinson & Singh, 1991; Alexander *et al*, 2001; Chaplin, 2004, 2009, 2012; Hall *et al*, 2006a,b). All in-patient services for this group of patients can be best understood within the context of the tiered model of service provision, with tier 4 constituting the in-patient part of a specialist learning disability service provision (Fig. 1).



Tier 1 encompasses primary care and other mainstream services. It is the tier of service provision that serves the general health, social care and educational needs of people with learning disability and their families. The community learning disabilities team and the psychiatrist have limited direct clinical contact in this tier. Nevertheless, they are involved in activities which may influence patients' care and interacting with this tier is essential to the training of learning disability psychiatrists.

Tier 2 is general community learning disability services. At this level the person with learning disability starts to use specialist learning disability services. Most specialist services are provided jointly between health and social services or are moving towards such a model.

Tier 3 is a highly specialised element of community learning disability service. This includes areas of specialised needs such as epilepsy, dementia, challenging behaviour, pervasive developmental disorders and out-patient forensic services.

Tier 4 is specialist in-patient services. It includes all specialist in-patient services for people with learning disabilities, ranging from local assessment and treatment services to high secure forensic services.

Fig. 1 Tiered/stepped model of care for learning disability services (adapted from Royal College of Psychiatrists, 2011a).

Based on discussions with stakeholders (service users, family members, carers, general practitioners, psychiatrists in various subspecialties, nurses, psychologists, speech therapists, social workers, occupational therapists, physiotherapists and service commissioners) we describe six categories of in-patient beds for people with learning disability and mental health and behavioural difficulties (Box 1).

Inspection reports on so called 'assessment and treatment units' (Care Quality Commission, 2012) tend to group bed categories 2, 3, 4 and 5 together. Consequently, it is not surprising that there is a very wide range in the length of stay mentioned in these reports. This in turn leads to stringent criticism about the inappropriate use of assessment and treatment beds (Scottish Executive Joint Improvement Team, 2006; Department of Health, 2012a,b). It is absolutely imperative to tease out these differing categories of beds using the typology we describe, to inform appropriate commissioning.

CATEGORY 1 (HIGH, MEDIUM AND LOW SECURE FORENSIC BEDS)

At the most restrictive end, there are the forensic beds. These are for patients who pose a level of risk assessed as requiring the physical, relational and procedural security of a high, medium or low secure unit (Box 2). The general characteristics of these units have been described elsewhere (Kennedy, 2002; Royal College of Psychiatrists, 2007a,b; R. Alexander & H. Boer, personal communication, 2013). Although all patients accessing these beds tend to be detained under the Mental Health Act 1983 (amended 2007), not all may have gone through the criminal justice system and hence may not be detained under Part 3 of the Mental Health Act (in practice, therefore, these patients may be detained on sections ranging from Section 3 to Section 37 or Section 41).

There is a tendency among those responsible for health planning and indeed some clinicians to see these forensic beds as somehow completely different from the other in-patient provision. Admittedly, this approach may be problematic in all areas of mental health, but it is particularly so in learning disability. This is because the way the criminal justice system manages law-breaking behaviour by people with learning disability is variable (R. Alexander & H. Boer, personal communication, 2013). A person with a more severe learning disability is unlikely to ever come before the courts unless the criminal act is very serious. Even for those with a milder degree

Box 1 CATEGORIES OF IN-PATIENT BEDS WITHIN TIER 4 FOR PEOPLE WITH LEARNING DISABILITY AND MENTAL HEALTH AND/OR SEVERE BEHAVIOURAL PROBLEMS

- Category 1: high, medium and low secure forensic beds
- Category 2: acute admission beds within specialised learning disability units
- Category 3: acute admission beds within generic mental health settings
- Category 4: forensic rehabilitation beds
- Category 5: complex continuing care and rehabilitation beds
- Category 6: other beds including those for specialist neuropsychiatric conditions and short breaks

Box 2 CASE VIGNETTE: CATEGORY 1 TYPICAL PATIENT STORY

Kylie is a 30-year-old woman with a mild learning disability who has had a childhood history of being sexually abused. She was in and out of local authority care, left school without any qualifications, never had any productive employment and was never in any stable relationship. By early adulthood, she was misusing alcohol and illicit drugs, and had a range of difficulties. The most problematic were impulsive behaviour, a tendency to become aggressive when these impulsive acts were thwarted in any way, a persistent pattern of self-harm (overdosing, slashing herself and inserting objects into her body), marked instability of mood, and uncontrolled bursts of anger resulting in aggression targeted towards acquaintances, professionals and members of the public. The aggression often resulted in her being evicted from various placements. In her late 20s, she also appeared to develop an episodic depressive illness associated with psychotic features. These episodes would last for 3–4 months at a time. Her index offence was one of assaulting a fellow resident at an emergency placement with a knife. Arrested by the police, she was assessed and initially admitted to the local psychiatric ward under Section 3. In hospital, her psychotic features improved with medication, but there was little engagement in any other therapy. The police and Crown Prosecution Service decided to drop charges because they felt that she was already receiving treatment in hospital and the victim was not considered a reliable witness. As discussions were going on about discharging her, she got into another argument and repeatedly stabbed a fellow patient with a dinner knife causing serious injury. This time, she was charged with grievous bodily harm, the case went through the courts and she was placed under Section 37 in a specialist medium secure unit for people with learning disability. Her clinical diagnosis on admission was one of mild learning disability with significant impairment of behaviour (ICD-10 code F70.1), emotionally unstable personality disorder (ICD-10 code F60.3), recurrent depressive disorder, currently in remission (ICD-10 code F33.4) and harmful use of alcohol (ICD-10 code F10.1). Her treatment plan included diagnostic clarification, appropriate psychotropic medication, a psychological formulation and dialectical behaviour therapy adapted for people with learning disability, an occupational therapy-led life skills and education programme, nursing care, supervised community access and a graded transition into a supported living setting within the community through gradually reducing level of therapeutic security.

of learning disability only a small minority end up being formally charged, prosecuted or convicted. This means that the decision whether a person becomes a 'forensic patient' or not often depends on clinical judgements about risks and the attitudes of professionals working in the criminal justice system. These attitudes and decisions are inevitably shaped by the availability of resources. If less restrictive in-patient facilities are unavailable, either because they were shut down or not commissioned, these patients end up in far more restrictive forensic beds (R. Alexander & H. Boer, personal communication, 2013). There could hardly be a better demonstration of the law of unintended consequences. Similarly, an absence of appropriate step-down facilities including forensic rehabilitation beds, rehabilitation and continuing care beds and appropriate community placements can also result in patients remaining for longer periods than necessary in medium or low secure settings. It is therefore important to consider all in-patient beds, whether 'forensic' or 'non-forensic', as a whole while planning for future provision. Many patients in these beds have a mild learning disability and fall between the boundaries of 'mainstream' mental health and learning disability

services in the community – too disabled for one and too disordered for the other. Although admission to ‘mainstream’ forensic units may achieve the aim of equity of access, that achievement is meaningless in the absence of equity of outcome. A low IQ often excludes people from treatment programmes (Beech *et al*, 1998; Talbot, 2007). This happens not necessarily because these ‘mainstream’ forensic units are overcome by prejudice, but because for those with learning disability the treatment content needs to be delivered in a way that is appropriate for their developmental and intellectual level. Economies of scale, as well as availability of a critical mass of expertise may mean that these developmental-level specific treatment programmes are best delivered in specialised forensic learning disability units (Alexander *et al*, 2010).

CATEGORY 2: ACUTE ADMISSION BEDS IN SPECIALIST LEARNING DISABILITY UNITS, AND CATEGORY 3: ACUTE ADMISSION BEDS PROVIDED WITHIN ACUTE MENTAL HEALTH WARDS OR SUCH WARDS WITH A SPECIALIST LEARNING DISABILITY FUNCTION

Both these categories of beds are intended for the assessment and treatment of severe mental health and/or behavioural problems, of an intensity which poses a risk that cannot be safely managed in a community setting, while not meeting the risk threshold to be considered for a forensic bed. Category 2 beds provide this function within the setting of a specialised learning disability unit (Box 3), whereas category 3 would do that within a generic or mainstream mental health ward setting (Box 4, p. 28).

The philosophy of normalisation that underpinned the move to community care emphasised that people with learning disability live their lives in a similar way to others in society (Bhaumik *et al*, 2011). In terms of in-patient care for mental health difficulties, the implication would be that they should access mainstream psychiatric services the same way as they would access generic services for physical health (Department of Health, 2001; Alexander *et al*, 2002; Chaplin, 2004, 2009; Cole & Gregory, 2004). The logical extension of that argument would be to say that there is no place for category 2 beds and anyone with a learning disability who needs in-patient treatment for mental health or behavioural difficulties should access category 3 beds in generic mental health wards. The clinical reality, informed not just by the views of clinicians, but also those of patients, their relatives and carers, is considerably different and much more nuanced.

There is a considerable amount of literature published over the past 20 years that has explored treatment outcomes from these two types of in-patient provision for assessment and treatment. The main studies are summarised in Appendix 1. This extensive evidence base has been well summarised in two elegant structured reviews (Chaplin, 2004, 2009); the first examined 24 studies and the second 28. The studies included were controlled trials or descriptive surveys drawn from the UK, the USA, Canada and Australia. The main conclusions can be summarised as:

- there is no conclusive evidence to favour either model (category 2 or category 3 beds)
- the two models serve different types of patients and this would partially explain the differences in length of stay

Box 3 CASE VIGNETTE: CATEGORY 2 TYPICAL PATIENT STORY

Mark is a 33-year-old man with mild to moderate learning disability secondary to tuberous sclerosis, childhood autism and generalised epilepsy (well controlled on multiple anti-epileptic medications). He has a history of minor self-injury (head banging) and various challenging behaviours (e.g. property destruction and smearing faeces). Over the past 3 weeks, since a well-liked staff member left, the team at his supported home struggled to manage his increasingly difficult and aggressive behaviour. On the day of admission he was constantly crying and banging his head. He seemed more disoriented and did not respond to well-known staff. He frequently visited the toilet and at one time may have collapsed. In the evening he assaulted three people and required police intervention. After a Mental Health Act assessment he was admitted under Section 2. Assessment included physical examination with prompt physical health screening (urine dip test and microbiology, ultrasound scan of renal tract, computed tomography of the head) and observations for an adjustment disorder. He was managed with nursing support and minimal use of as required medication while a formulation was agreed. He required treatment for a urinary tract infection and his acute behaviours settled gradually. His other tests showed little change from scans performed some years ago. A health action plan was agreed to include longer-term specialist renal and neurological review. The speech therapist revised his communication passport for him and the occupational therapist completed a sensory processing assessment. He agreed to stay informally after 3 weeks, to further assess and manage his minor behaviour problems, and his Section 2 order was rescinded. After a further 4 weeks with his home staff working with him on the unit, he started to go out on leave to his home. After a total of 8 weeks he was discharged with an enhanced care package, action plans for future risk management and ongoing review by a community nurse and psychiatrist (who also managed his epilepsy).

- people with severe learning disability were not well served by generic services (category 3 beds)
- there was a worse outcome for people with learning disability in generic settings, particularly in the older studies; this could change once a specialist learning disability component was introduced into that generic setting
- generic psychiatric care is unpopular, especially with carers; this could be improved by specialist input
- the provision of general psychiatric care without specialist learning disability input is not sufficient to meet the needs of people with learning disability.

Patient and carer experiences submitted to us strongly reflect some of these points (Appendix 2) and consistently favour category 2 beds as opposed to category 3 beds. This could be due to several factors, which include: lack of expertise of staff in the assessment and management of mental health problems in people with learning disability; lack of availability of therapeutic approaches which are accessible and appropriate; and inappropriateness of the physical environment and patient mix on wards. It is important to stress, however, that category 2 beds are needed not merely because mainstream mental health units do not care or are prejudiced, or are staffed by people with no training. If these were the only issues, they

Box 4 CASE VIGNETTE: CATEGORY 3 TYPICAL PATIENT STORY

Martha is a 34-year-old woman who lives at home with her mother and has mild learning disability and bipolar affective disorder. She is monitored by her care coordinator, who is employed by the learning disability services. However, she presented with symptoms of a manic relapse: irritability, elation, overspending, vulnerability and grandiose and persecutory delusions. Despite the support she was receiving, as well as treatment with lithium carbonate and olanzapine, her mental state deteriorated to the point that she needed admission for assessment under the Mental Health Act 1983. She was assessed by the psychiatrist from the learning disability team. A bed was found on the local acute general psychiatric admission unit where she was admitted following discussion with the general psychiatric consultant responsible for her sector. On admission, an assessment was made of her physical health needs in conjunction with her general practitioner, mother and care coordinator. Her communication and self-care needs were also assessed and staff from the community learning disability service gave advice to the in-patient staff on how to meet those needs. The general adult consultant assumed responsible clinician status during her in-patient stay but ward rounds were conducted jointly with her community learning disability consultant and care coordinator. Doses of her medication were optimised and she had periods of leave, initially accompanied by her care coordinator, as she started to recover. Prior to discharge she underwent assessment which involved her mother, care coordinator, learning disability psychiatrist, general adult psychiatrist, and in-patient nurse. She was discharged from section, returned home and was followed up by her care coordinator and the consultant psychiatrist in learning disability.

Adapted from Royal College of Psychiatrists, 2012.

could of course be put right by good governance and adequate training. Category 2 beds are needed because although the equity of access that a policy of mainstreaming brings is very pleasing, it is meaningless if not accompanied by equity of outcome. It has been suggested that 'equal' does not always mean 'the same' and that the 'reasonable adjustments' that are needed to make services equally accessible to people with learning disability are not particularly difficult to make (Department of Health, 2008). Being treated by specialists in the mental health of people with learning disability within settings that are particularly suitable for those with learning or developmental disadvantage is a reasonable adjustment that allows people with learning disability and mental health or behavioural difficulties to achieve the same equity of outcome as others with the same mental disorders. These beds therefore are not a reminder of inequality through segregation but a guarantor of equity through specialisation.

That is not to say that category 3 beds cannot deliver good outcomes for people with mild learning disability and mental illness. College report CR175 (Royal College of Psychiatrists, 2012) explains how this can be effective if there is substantial specialist support available from community learning disability teams to facilitate this.

Speaking in a different context, the comment has been made about how an insistence on treating everyone as equal when they are obviously unequal not only perpetuates inequality but also leads to injustice (BBC Radio 4, 2012). The same situation could happen for people with learning disability and mental health problems if they are all forced into mainstream mental health services regardless of their unique needs. There is the

lingering worry that the agenda of inclusion is merely being used as a means of disguising cuts to these specialist services which were crucial in delivering good and equitable outcomes for people with learning disability and mental health or behavioural difficulties in the first place (Cumella, 2010). We recommend that people with learning disability and mental health or behavioural problems and their families should have the choice to determine the most appropriate service for their needs.

CATEGORY 4: FORENSIC REHABILITATION AND CATEGORY 5: COMPLEX CONTINUING CARE AND REHABILITATION

These two categories refer to in-patient provision for a number of patients whose mental health problems and behavioural difficulties remain intractable in spite of optimum treatment. These patients continue to need the structure, security and care offered by a hospital setting for long periods of time.

Category 4 is mostly people who have stepped down from forensic units with enduring issues of risky behaviours towards others or self (Box 5 and 6). Many of these patients have committed serious offences in the past and may sometimes be under restrictions from the Ministry of Justice. Although they have gone through offence-specific and other

Box 5 CASE VIGNETTE: CATEGORY 4 TYPICAL PATIENT STORY (A)

John is 43 years old and has mild learning disability and a long history of behavioural difficulties, including physical and sexual aggression that started from late childhood and early adolescence. His victims included children of both genders as well as people with learning disability less able than him. After many incidents that did not result in prosecution he was, at the age of 30, convicted of a serious sexual offence against a child. He received a Section 37 order and spent 4 years in a high secure and 3 years in a medium secure hospital. He had one or two depressive episodes during this time but these were treated and he responded well.

After initial reluctance, he engaged in a range of therapies including the adapted sex offender treatment programme. Although his insight and behaviour within supervised settings improved, professionals involved in his care were unanimous that ongoing supervision was an integral part of his treatment plan, not least because his active sexual interest in children remained problematic. At the same time, it was felt that he could be in a less restrictive setting that guaranteed an adequate level of therapeutic input, albeit with less physical security. He was hence transferred from the medium secure unit to a locked rehabilitation setting. The treatment plan there included monitoring of his mental state, treatment of depression when relevant, nursing support, supportive therapy with a relapse prevention focus from psychology, regular supervised access to the community, an occupational therapy-led rehabilitation service and a voluntary work placement with staff supervision. Unescorted leave remains problematic; there were at least two incidents when he was the subject of complaints from members of the public, although it did not lead to prosecution. Psychology work continues to focus on these issues. He has been an in-patient in locked rehabilitation for 6 years and is still detained under the Mental Health Act.

Box 6 CASE VIGNETTE: CATEGORY 4 TYPICAL PATIENT STORY (B)

Robert is 21 years old and has a mild learning disability. He was charged with grievous bodily harm and was in prison on remand where he was vulnerable and suffered from low mood and suicidal ideation. Initially transferred to a low secure unit on remand, he later received a hospital order under Section 37. Robert engaged well with the therapy programmes in the low secure unit and after 18 months was transferred to a locked rehabilitation facility closer to his home.

During his stay in locked rehabilitation, Robert's mental and physical health was monitored and work on his offending behaviour continued with psychology and nursing involvement. He enrolled in an education course and started a work placement in the community. He soon started having unescorted leave and developed a good relationship with his family. After a period of 1 year, he was discharged to the community. He lives in a flat with a support package. He continues with his work placement and has developed a good network of friends.

programmes, their current risk assessments still emphasise the need for robust external supervision and ongoing therapeutic input. Within a structured therapeutic environment provided by a category 4 bed, they are able to stay out of trouble with the law. They tend to have long durations of stay often running into years, but it is the availability of these beds, often in locked or open community units, that allows them to receive treatment in a less restrictive setting than a secure unit. It does appear that the need for continuous supervision for the protection of the public is the primary reason for their long hospital stay. This degree of supervision where a capacious individual's right to access the community is rigidly controlled at all times by a supervising staff member would, under the current legislative framework, amount to a deprivation of liberty and hence be legally untenable. If there was a way of making this continuous supervision legally enforceable in the community without it amounting to the current standard for deprivation of liberty in capacious individuals, then they could very well be managed outside hospitals. We recommend further legal or legislative scrutiny of this issue.

Category 5 is mostly for people who have undergone the initial intensive treatment process. Their diagnostic and psychological formulations are available and they have had access to a range of biopsychosocial treatments (Box 7). There are some who argue that there is no place for this continuing care category and that all these patients should be treated in the community. However, we suggest that these beds are required for a small number of patients because of a variety of reasons. This can include enduring mental illnesses not responsive to treatment, severe behavioural challenges that have not responded adequately to treatment approaches, ongoing risks arising from neglect or vulnerability and persisting risks to the safety of others similar to that posed by people in category 4 beds. Because of this, a safe transition into the community has not been possible even with adequately resourced community provisions.

The provision of a stable, structured and predictable environment with qualified staff who can continue to offer physical and psychosocial treatments that incorporate positive risk-taking offers the best quality of life. It is thus

Box 7 CASE VIGNETTE: CATEGORY 5 TYPICAL PATIENT STORY

Linda is a 35-year-old woman with a moderate learning disability secondary to anoxic brain damage, limited speech, a recurrent depressive disorder and a range of challenging behaviours. During her school years, the challenging behaviours included pulling other students' hair, kicking, hitting out and scratching. This behaviour resulted in her being excluded several times. By her late teens, it appears that she developed an episodic depressive illness characterised by low mood, social withdrawal, weight loss and other somatic symptoms. Her parents, however, for whom she was an only daughter, appeared to manage her at home with minimal contact with health or social services.

By the time she was 23, Linda was having several of these episodes associated with aggressive acting-out behaviours. She was then referred to the learning disability psychiatry service. An additional stress factor at the time was her parents' decision to divorce. Her depressive disorder was treated with various psychotropic medications and she received input from the psychology team, but she remained unmanageable in the community and her mother with whom she stayed was increasingly unable to cope. Because of Linda's depression, agitation and periods of unpredictable, impulsive and severe aggression, she was admitted to the assessment and treatment unit (a category 2 bed). Assessments suggested that although some of her behaviour was related to the depression, a substantial part was an integral part of her communication style. She lacked the verbal ability to express her feelings and often relied on her behaviours to express them. In hospital, she had access to a range of psychological and behavioural interventions.

Several attempts were made to identify appropriate placements, however, service providers felt unable to cope with her challenging behaviours and she was promptly returned to the unit. Given the long-standing nature of her behaviours and the need for an environment which could provide ongoing treatment as well as re-skill her to live back in the community, she was transferred to the continuing care unit of the learning disability service (a category 5 bed). Within the stable environment of the facility it was possible to undertake a further review of her medication. She also received ongoing input from a speech and language therapist and occupational therapist, who were able to develop and contribute to behavioural management plans put forward by the psychologist.

On a combination of an antipsychotic, mood stabiliser and antidepressant medication along with the other interventions, there was a significant improvement in her mood and an overall reduction in her challenging behaviours. She began accessing the community with staff support and enjoyed going to clubs with other patients as a group accompanied by staff on an evening out. She benefitted from the stable and quieter environment of the unit where it was possible for her to engage with the multidisciplinary team, including art therapy and drama therapy. This period of stability meant that placements could be explored and providers were willing to offer suitable accommodation and staff support. The multidisciplinary team then worked with the staff from the residential home, ensuring that they were well equipped with the skills to manage both her vulnerability and behaviours. She was tried on an extended period of leave into the new placement and eventually discharged successfully.

a process of rehabilitation and re-skilling for a transition to community settings. This may, however, be at a pace these patients can cope with and therefore duration of stay tends to be long. If these beds were not available, the consequence could potentially be revolving-door patterns of hospital admissions to category 2 or 3 beds. Category 5 also includes a very small number of people with a significant learning disability, an autism spectrum disorder and a marked, violent sensitivity to the novel, unexpected or untoward. The management of this group requires a skilled, multidisciplinary staff group who are not only familiar with the person with autism spectrum disorder, but also have the training and skills to react non-intuitively in providing an unusually structured, predictable and consistent environment.

Category 4 and 5 beds are not unique to people with learning disability. The description of these beds closely mirrors the definition of the longer-term complex/continuing care units contained in *Defining Mental Health Services – Promoting Effective Commissioning and Supporting QIPP*, a recently published document from the NHS Confederation's Mental Health Network (NHS Confederation, 2012). The definitions in that document have been endorsed by a range of organisations including the Department of Health, Care Quality Commission, Audit Commission, ADASS, NHS Information Centre, Royal College of General Practitioners, Royal College of Psychiatrists, Royal College of Nursing and the mental health leads of strategic health authorities (NHS Confederation, 2012).

Arguably, the provision of relational and procedural security is more important than physical security for people with learning disability and hence many patients currently in forensic units, particularly in conditions of low security, could potentially move to the less restrictive rehabilitation beds (category 4 or 5). At present, this is problematic because the commissioning streams for forensic beds are different to those for all the other categories of hospital beds and the possibility of patients 'stepping down' creates financial pressures for local health commissioners. There is therefore a need for a wider regional commissioning of in-patient to community care pathways that will include all the six categories of in-patient beds. Service providers should be able to demonstrate clear evidence of ongoing therapeutic activity. This will include psychiatric input for monitoring of mental state and appropriate treatment, nursing care, availability of psychological support and therapy, an occupational therapy-led rehabilitation service, which may include educational and vocational opportunities, and supervised or independent access to the community on a regular basis. Although the patient may choose sometimes not to engage in these activities, these therapeutic activities should be available and accessible. It is this that will distinguish good in-patient facilities from those that are no more than 'settings of containment'. Relatives, carers, commissioners and regulating authorities should be able to monitor this through regular reviews.

There will have to be an acceptance, however, that not all patients move at a predetermined pace all the way through the care pathway. At all times, there should be demonstrable evidence that patients are in the least restrictive setting appropriate for their clinical state.

CATEGORY 6: OTHER TYPES OF BEDS

This includes specialist beds for some neuropsychiatric conditions such as epilepsy and movement disorders. At present, this service provision is limited to a few, very specialised national units.

NUMBERS OF BEDS AND OPTIMISING THEIR USE

A striking feature is the different figures that are available for bed numbers in this area. Figures given by various sources may be different because of the variations in counting forensic and non-forensic beds or NHS and independent sector beds. The Winterbourne interim report from the Department of Health (2012a) states that there are 1252 assessment and treatment beds. It is not clear whether this includes all the non-forensic beds (i.e. categories 2–6). A survey of forensic learning disability beds (i.e. category 1) estimated that there were 48 high, 414 medium and 1356 low secure beds for people with learning disability in 2009 within the 10 strategic health authority regions of England (Alexander *et al*, 2011). It showed a very uneven distribution of these beds, with some regions not having any medium or low secure unit within its borders. These data included both NHS and independent sector beds. A more up-to-date comprehensive survey was undertaken as part of this report in 2012/2013 by the Faculty of Psychiatry of Intellectual Disability of the Royal College of Psychiatrists, acquiring data from NHS trusts and independent sector hospitals across all categories in the ten strategic health authority regions in England. The survey showed that there were about 3954 beds in England: 2393 category 1, 814 category 2, 622 categories 4/5 and 125 category 6 beds. A further breakdown of beds by NHS or independent sector and by region is detailed in Table 2. This includes some beds in specialist units designated as those for people with autism spectrum disorders. A separate survey of these units may give a more accurate number and the proportion of these beds occupied by people without a learning disability whose needs and presentations may be different. This figure includes all NHS and independent sector provision for forensic and non-forensic services and represents an over 90% reduction from a high of more than 33000 NHS beds in 1987–1988.

The occupancy figure of the currently available beds, though difficult to elicit precisely, is estimated to be about 80%. This figure is in keeping with the best practice guidelines for bed occupancy within in-patient mental health settings (Royal College of Psychiatrists, 2011b). Thirteen years ago, research suggested that the total bed requirement (in all the 1–6 categories) was 14–29 per 100000 population (Bailey & Cooper, 1997). Based on our survey and consultation, we would now estimate that the total bed requirement taking all six categories of in-patient beds together is only about 6 to 7 per 100000. We must stress, however, that this figure is only intended as a broad guideline and may vary significantly based on local realities. In any case, this number represents a substantial reduction from before and has been possible because of significant improvements in community learning disability services and better working arrangements with generic mental health teams.

The total number of in-patient beds currently available across the six categories therefore represents an appropriate number. This is with due regard to clinical needs, government policies on risk management and current legislation. If the less restrictive in-patient facilities (categories 2–5) are cut down further, many more patients could end up in far more restrictive forensic beds (category 1).

There is scope for some people currently in category 1, 2 or 3 beds to move to less restrictive options within categories 4 and 5. The precise number of beds in each category therefore can vary depending on local factors and this should be a subject of discussion between patients, carers,

Table 2 Royal College of Psychiatrists, Faculty of Psychiatry of Intellectual Disability survey of in-patient beds (2012–2013)

Regions	Category 1				Category 2				Categories 4 & 5				Category 6	
	High secure		Medium secure		Low secure		Acute admission beds		Forensic rehabilitation		Continuing care		Other	
	NHS	Non-NHS	NHS	Non-NHS	NHS	Non-NHS	NHS	Non-NHS	NHS	Non-NHS	NHS	Non-NHS	NHS	Non-NHS
North East	0	0	42	0	155	8	97	59	139	19	0	0	18	0
North West	0	0	52	13	127	28	64	0	85	0	0	0	14	76
Yorkshire and Humber	0	0	32	88	44	142	73	0	15	0	19	0	0	0
East Midlands	48	0	0	150	16	189	46	0	0	0	19	0	48	0
West Midlands	0	0	15	0	71	123	69	60	16	0	25	0	53	0
Eastern	0	0	52	67	25	465	64	0	5	17	9	0	0	0
London	0	0	67	0	25	127	146	108	0	0	10	78	0	0
South East Coast	0	0	0	16	57	10	10	0	0	0	0	0	0	0
South Central	0	0	10	0	28	71	52	0	9	0	14	0	6	0
South West	0	0	0	0	28	12	25	0	0	0	13	0	0	0
Total NHS/independent sector	48	0	270	334	519	1222	646	168	174	171	104	173	125	0
Total	48		604		1741		814		345		277		125	
Total in each category			2393				814		622				125	
Total in-patient beds in England	3954													

NHS, National Health Service.

professionals, providers and commissioners in each area. However, not all patients may move at a predetermined pace all the way through the care pathway. The emphasis at all times has to be on the least restrictive setting that is clinically indicated at that point, with evidence of ongoing therapeutic input. This would be a better approach than the introduction of arbitrary time scales.

In-patient service provision should be as close to the person's place of residence as possible to facilitate the link with local community learning disability teams. Although arguments regarding economies of scale and the availability of a critical mass of professional expertise, particularly for category 1 beds, may hamper efforts to provide all categories of beds in every district, the emphasis should be on in-patient service provision as close to the person's place of residence as possible. We recommend that commissioning for in-patient services should therefore include all six categories of beds, be focused on care pathways from hospital to the community and may have to be regional (covering neighbouring health districts).

For a community learning disability team to function optimally, it is important to have the backup of these categories of in-patient provision. Whereas further development of community services in the form of intensive outreach services may reduce the use of in-patient beds, the numbers of such beds have now been reduced to a very low level. There is little evidence that in this situation any further reduction of bed usage can be achieved in a good service. The UK 700 study carried out in adult mental health services had suggested that those with borderline learning disability may require less in-patient provision if combined with intensive case management (Hassiotis *et al*, 1999, 2001). In the only randomised controlled trial of service provision that compared standard and assertive styles of community team functioning in learning disability (the latter characterised by more intensive professional input) (Oliver *et al*, 2005), there was little difference between the number of days of in-patient stay for patients in the two groups. Service planners need to consider the factors that affect the number of in-patient beds needed in a region. These include eligibility criteria for admissions to these units, types of intervention provided in these units, the role of community learning disability teams in the prevention of admissions and in facilitating discharges, and availability of specialised providers of community placements (with pro-active commissioning from health and Social Service commissioners).

Close monitoring and review of 'out-of-area' and indeed 'within-area' placements by health and local authorities is required, not just as a guarantee for preserving standards but also to tackle any issues around delayed discharges that may compromise the optimal use of in-patient beds. Discharge planning should start at the beginning of the admission with identification of a community care coordinator within the care programme approach framework. Health commissioners have an active role to play in liaising with their local authority counterparts to expedite this process.

The figures provided in Table 2 are best estimates submitted by the College's regional representatives. Some bed categories may have changed or may be incomplete. In many cases, it includes beds designated as those for specialist autism services.

This survey also showed that in Scotland there were an estimated 50 beds in category 1, 158 in categories 2 and 3, 44 in category 4 and 58 in category 5. In Northern Ireland there were 19 in category 1, 67 in categories 2 and 3, and 84 in category 5.

Monitoring standards and outcomes

In measuring service delivery, there are two key questions (Brugha & Lindsay, 1996). First, is the treatment carried out to an adequate standard as defined by current clinical practice? Second, does such treatment actually work?

STANDARDS

Standard is defined as a level of quality or attainment. There are several standards available through various professional organisations, some of which are mentioned below. The evaluation of whether a service achieves a level of standard can be done through the process of audit.

For category 1 beds, the peer review accreditation process for forensic beds from the Royal College of Psychiatrists (2007*a,b*; Tucker *et al*, 2012) offers a set of standards that can be rated through peer review.

For category 2 and 3 beds, the Royal College of Psychiatrists published the second edition of AIMS-LD in November 2010 (Cresswell *et al*, 2010). That manual of standards was written primarily for non-forensic assessment and treatment beds for adults of working age with a learning disability, where the person is admitted for a short to medium term and is then discharged. These standards were drawn from a range of key documents from the National Institute for Health and Care Excellence and the Care Quality Commission, and were finalised after extensive discussions with a range of stakeholders including psychologists, psychiatrists, nurses, academics, regulators, commissioners, service users, carers, service managers, charities and interested individuals. The AIMS-LD has standards that cover five broad areas: general standards; timely and purposeful admission; safety; environment and facilities; and therapies and activities. To support the accreditation process, each standard has been categorised:

- type 1: failure to meet these standards would result in a significant threat to patient safety, rights or dignity and/or would breach the law
- type 2: standards that an accredited ward would be expected to meet
- type 3: standards that an excellent ward should meet.

This accreditation process is widely regarded as a gold standard and wards that are compliant with these standards could not conceivably be the settings of containment rather than personalised care that some fear assessment and treatment units may become.

For beds under category 4 the forensic peer review standards could apply and for those in category 5 and 6, the AIMS-LD standards could apply.

These accreditation standards cover the process variables within in-patient units and ensure that clinical practice will be in keeping with standards accepted by peers as appropriate.

OUTCOMES

Outcome is defined as an end result or consequence. In health services, it is a measure of what happens to the health of the patient as a result of the treatment and care they receive. Outcome measures need to relate to the three domains of quality: effectiveness, patient safety and patient experience (Department of Health, 2008). For category 1 or forensic beds, there were a total of two outcome studies from low (Day, 1988; Reed *et al*, 2004), four from medium (Halstead *et al*, 2001; Alexander *et al*, 2006, 2011; Gray *et al*, 2007) and two from high secure hospitals (Butwell *et al*, 2000; Morrissey *et al*, 2007). There have not been any from category 4 forensic rehabilitation beds, although some of the low and medium secure unit studies listed do talk about care pathways to rehabilitation. The most common outcome variable described was duration of stay. Others included direction of care pathway, institutional aggression, reoffending, reconviction and readmission to hospital. None of the outcome studies have looked at the cost of placements and this means that discourse about costs in this area is often based on anecdote and opinion rather than objective evidence. Based on this evidence, for categories 1 and 4, a minimum data-set of outcome measures that cover baseline measures and the domains of clinical effectiveness, patient safety and patient experience is set out in Table 3.

For bed categories 2, 3 and 5, there have been over 30 published studies that describe outcomes and some of them are listed in Appendix 1. In addition, the Royal College of Psychiatrists (2011a,b) has recommended the use of patient-identified goals, Health of the Nation Outcome Scales (HoNOS), physical health measures (e.g. blood pressure, body mass index), social outcomes (e.g. employment, accommodation, community engagement), symptom-specific scales, benchmarking incident reporting, suicide and self-harm rates, harm caused to others, in-patient safety measures and validated measures drawn up using patient and carer expertise. Based on this evidence, a minimum data-set of outcome measures that cover the domains of clinical effectiveness, patient safety and patient experience is set out in Table 4.

Table 3 Minimum data-set of outcome variables for in-patient beds in categories 1 and 4

Measures at baseline	
Essential	<ul style="list-style-type: none"> ▪ Diagnoses on ICD-10 criteria or equivalent: include degree of learning disability, pervasive developmental and other developmental disorders, personality disorders, mental illnesses, substance misuse or dependence and physical disorders (Gray <i>et al</i>, 2007; Alexander <i>et al</i>, 2011) ▪ IQ score on WAIS-IV or equivalent (Wechsler, 2008) ▪ Coded forensic history: index offence, nature of detention, past convictions for offences of violence, sex, arson and other offences, history of aggression towards other people, property and self (Alexander <i>et al</i>, 2006, 2011; Gray <i>et al</i>, 2007) ▪ HoNOS secure score (Dickens <i>et al</i>, 2007)
Desirable	<ul style="list-style-type: none"> ▪ PCL:SV score (Hart <i>et al</i>, 1995; Morrissey, 2003, 2007, 2011; Gray <i>et al</i>, 2007; Fitzgerald <i>et al</i>, 2011) ▪ HCR-20 (Webster <i>et al</i>, 1995; Gray <i>et al</i>, 2007; Fitzgerald <i>et al</i>, 2011) ▪ VRAG score (Gray <i>et al</i>, 2007; Quinsey <i>et al</i>, 2006; Fitzgerald <i>et al</i>, 2011) ▪ START score (Webster <i>et al</i>, 2004)
Measures of effectiveness	
Essential	<ul style="list-style-type: none"> ▪ Global measures or measures of symptom severity: HoNOS secure, yearly and at discharge (Dickens <i>et al</i>, 2007) ▪ Progress measures: community leave status (no leave/escorted leave/unescorted leave) ▪ Progress measures: length of stay ▪ Progress measures: direction of care pathway (whether moved to a less restrictive setting)
Desirable	<ul style="list-style-type: none"> ▪ Symptom-specific assessment scales (e.g. measures of anger, depression/anxiety, other psychopathology) ▪ HCR-20: yearly and at discharge ▪ START score: regular intervals (e.g. 2-monthly and at discharge) ▪ Clinical Global Impression (CGI) scale (Guy, 1976)
Measures of patient safety	
Essential	<ul style="list-style-type: none"> ▪ Proxy measures of aggression: index of the number of restraints and seclusions (total number divided by length of stay) (Alexander <i>et al</i>, 2010) ▪ Proxy measures of self-injury/self-harm: index of the number of incidents (total number divided by length of stay) ▪ Number of alerts regarding patient safety ▪ Any 'never' incidents: escapes, suicide
Measures of patient experience	
Essential	<ul style="list-style-type: none"> ▪ Evidence of patient participation in treatment planning: My Shared pathway (NHS Networks; Esan <i>et al</i>, 2012) ▪ Patient satisfaction surveys ▪ Evidence of carer/family participation in treatment
Desirable	<ul style="list-style-type: none"> ▪ Measures of social climate: Essen Climate Evaluation Schema or equivalent (Schalast <i>et al</i>, 2008) ▪ Quality of Life measure: EQ-5D-3L or equivalent, yearly and at discharge (EuroQol Group, 1990)

Table 4 Minimum data-set of outcome variables for in-patient beds in categories 2, 3 and 5

Measures at baseline	
Essential	<ul style="list-style-type: none"> ▪ Comorbid diagnoses on ICD-10 criteria or equivalent: include degree of learning disability, pervasive developmental and other developmental disorders, personality disorders, mental illnesses, substance misuse or dependence and physical disorders ▪ IQ score on WAIS-IV or equivalent (Wechsler, 2008) ▪ HoNOS learning disability score
Desirable	<ul style="list-style-type: none"> ▪ Measure of symptom severity using TAG (Slade <i>et al</i>, 2000), Reiss Screen Test (Reiss, 1988), PIMRA (Matson, 1988), PASADD checklist (Moss <i>et al</i>, 1998), MOAS (Oliver <i>et al</i>, 2007) and symptom-specific assessment scales (e.g. measures of anger, depression/anxiety, other psychopathology)
Measures of effectiveness	
Essential	<ul style="list-style-type: none"> ▪ Global measures or measures of symptom severity: HoNOS learning disability, on admission, discharge and at regular intervals ▪ Progress measures: community leave status (no leave/escorted leave/unescorted leave) ▪ Progress measures: length of stay ▪ Progress measures: direction of care pathway (whether moved to a less restrictive setting)
Desirable	<ul style="list-style-type: none"> ▪ Measure of symptom severity using TAG, Reiss Screen Test, PIMRA, PASADD checklist, MOAS and symptom-specific assessment scales (e.g. measures of anger, depression/anxiety, other psychopathology). ▪ CGI scale
Measures of patient safety	
Essential	<ul style="list-style-type: none"> ▪ Proxy measures of aggression: index of the number of restraints and seclusions (number divided by length of stay) ▪ Proxy measures of self-injury/self-harm: index of the number of incidents (number divided by length of stay) ▪ Number of alerts regarding patient safety ▪ Any 'never incident' (e.g. suicide)
Measures of patient experience	
Essential	<ul style="list-style-type: none"> ▪ Evidence of patient participation in treatment planning ▪ Evidence of community participation: education, work experience and leisure ▪ Patient satisfaction surveys ▪ Evidence of carer/family participation in treatment
Desirable	<ul style="list-style-type: none"> ▪ Measures of social climate: Essen Climate Evaluation Schema or equivalent (Schalast <i>et al</i>, 2008) ▪ Quality of Life measure: EQ-5D-3L or equivalent, yearly and at discharge (EuroQol Group, 1990)

Appendix 1. Studies describing acute admission units (category 2 and 3 beds)

Study	Sample	Measures used	Comments
Hurst <i>et al</i> , 1994	<ul style="list-style-type: none"> ■ 157 patients (97 male, 60 female) ■ Age on admission: range 15–63 years, mean 30 	<ul style="list-style-type: none"> ■ Level of disability according to DSM criteria ■ Primary psychiatric diagnosis ■ Length of stay ■ Whether the patient was readmitted 	<ul style="list-style-type: none"> ■ Category 2 beds ■ Case-note review, testing treatment effectiveness for the dually diagnosed ■ Outcomes are more unfavourable in patients with borderline learning disability as they resent this type of placement or those with pervasive developmental disorder ■ Median length of stay 68 days (94% returned to the community, with the remainder returning to the psychiatric hospital which had originally referred them; 37% were readmitted, of whom 62% had one readmission and the remainder had multiple readmissions) ■ Patients with learning disability respond well to treatment in an environment which is attuned to their level of communication skill
Singh <i>et al</i> , 1994	<ul style="list-style-type: none"> ■ 11 patients (5 male, 6 female) ■ Average age 38 years 	<ul style="list-style-type: none"> ■ Demographic data ■ Length of stay ■ Reason for admission ■ Past psychiatric care ■ Level of handicap ■ DSM diagnosis and treatment ■ Other social factors deemed important to note at admission 	<ul style="list-style-type: none"> ■ Category 3 beds ■ A description of the first 18 months of the Hillingdon district service where admission facilities for people with dual diagnosis were made available on a general psychiatric ward ■ Case-note analysis ■ Average length of stay was 8 weeks; longer admissions which are appropriate for this client group are less likely to be tolerated on a general psychiatric ward ■ There was a trend in individuals with major psychiatric illness for the illness to become more chronic ■ Learning disability admissions to a general psychiatric ward are problematic for a number of reasons. Lack of staff training and experience. Occupational therapy may not be developmentally appropriate for this client group ■ It is doubtful whether this model of treatment can work
Raitasuo <i>et al</i> , 1999	<ul style="list-style-type: none"> ■ 40 in-patients staying in a specialist psychiatric unit in Finland 	<ul style="list-style-type: none"> ■ Brief Psychiatric Rating Scale (BPRS) ■ Diagnostic Assessment for the Severely Handicapped (DASH) scale ■ Visual Analogue Scale (VAS) – patients and their primary carers were asked to independently estimate the patient's psychiatric state ■ Living place at discharge evaluated in order of most supportive to least supportive 	<ul style="list-style-type: none"> ■ Category 2 beds ■ Study describes the psychiatric in-patient treatment ('need-adapted treatment' – individually tailored treatment plans) of those with dual diagnosis in a specialist psychiatric unit ■ Patients' psychotic symptoms improved greatly on the BPRS during their in-patient stay, but not during aftercare ■ 4 patients' psychiatric symptoms were recorded on the DASH scale, 1 of the patients' symptoms were significantly reduced and 3 patients' symptoms remained the same ■ Patients and their primary carers considered their condition to have improved significantly during their in-patient stay ■ Living place at discharge: 33 patients' living arrangements were the same at admission and at discharge, 3 needed a less supportive placement and 4 a more supportive placement ■ The mean treatment time in the unit was 2.91 months (range 0.16–12.3, s.d.=3.35)

Alexander <i>et al</i> , 2001	<ul style="list-style-type: none"> ■ 56 in-patient admissions to Hillingdon and Westminster over 3 years (63% v. 59% male respectively) ■ Mean age, years: Hillingdon 24, Westminster 32 	<ul style="list-style-type: none"> ■ Length of stay ■ ICD-10 diagnostic categories were used throughout ■ Level of learning disability ■ Demographic data 	<ul style="list-style-type: none"> ■ Comparison of category 2 and category 3 beds in two London districts ■ Retrospective case notes-based survey – a descriptive comparison of the sociodemographic and clinical variables of 3 years of in-patient admissions in Hillingdon and Westminster ■ Mean length of stay was 369 days in the specialist learning disability unit and 79 days in the general psychiatry ward ■ The only significant predictor variable for the duration of stay was residential status at the time of admission (those from residential homes tend to stay longer) ■ Difficulty in discharging back to the same place as that at time of admission would predict 'new long-stay'
Tajuddin <i>et al</i> , 2004	<ul style="list-style-type: none"> ■ 72 individuals (49 male, 23 female) ■ Age: range 18–63 years, mean 34 	<ul style="list-style-type: none"> ■ Demographic information ■ Diagnoses/severity of learning disability ■ Length of stay ■ Readmission ■ Residence before and after admission ■ Reiss Screen for Maladaptive Behaviour before and after admission ■ Individual clinical outcomes 	<ul style="list-style-type: none"> ■ Category 2 beds ■ Aimed to evaluate the use of the acute specialist in-patient unit for adults with dual diagnosis: retrospective case-note review of all admissions over 2 years ■ Mean length of stay was 70.8 days (range 2–215) ■ Long-stay patients were more likely to be males with mild learning disability and a primary diagnosis of schizophrenia, behaviour disorder or personality disorder ■ 22% of the individuals were admitted on more than one occasion (69% of this group had a behaviour disorder or a personality disorder) ■ Significant reduction on the Reiss score suggests an improvement in overall patient presentation ■ 76% of patients were successfully treated and discharged to their original residence; on 22 occasions patients had to be discharged elsewhere as their initial placements were unwilling to accept them back
Xentidis <i>et al</i> , 2004	<ul style="list-style-type: none"> ■ 84 admissions recorded in time period studied (36 male, 48 female): 39 in specialist unit, 45 in generic settings ■ Age: mean 34.55 years 	<ul style="list-style-type: none"> ■ Key variables of gender, age, ethnic group, presence of autism, epilepsy ■ Primary psychiatric diagnosis ■ Length of stay ■ Readmissions ■ Level of learning disability ■ Psychiatric Assessment Schedules for Adults with Developmental Disabilities (PAS-ADD) checklist ■ Global Assessment of Functioning (GAF) Scales ■ Disability Assessment Scale (behavioural functioning) ■ Threshold Assessment Grid (TAG) 	<ul style="list-style-type: none"> ■ Comparison of category 2 and category 3 beds ■ The study aimed to describe the patient characteristics and treatment outcomes of patients admitted to the specialist unit using standardised measures; admissions to the specialised unit are also compared with admissions to generic psychiatric wards ■ No significant differences in key variables between the admissions ■ Readmission rates were similar in both groups: 5 patients in the specialist group were readmitted twice, in the generic group 3 patients were admitted twice, 1 patient had 3 admissions and 1 patient was readmitted 4 times ■ Highly significant difference in that length of stay was much longer for patients in the specialist unit (mean 23.2 weeks, s.d.=14.1; in the generic group mean 11.1 weeks, s.d.=13.6) ■ Statistical differences were yielded on all four measures of treatment outcomes: TAG score halved; significant reduction in severity of mental health problems; GAF score almost doubled, indicating an increase in overall level of functioning; PAS-ADD symptoms were reduced by almost half ■ Significant improvements were demonstrated within the specialist unit cohort; specialist units are an effective care option for this patient group

Hall <i>et al</i> , 2006	<ul style="list-style-type: none"> ■ Assessment of psychiatric symptoms <ul style="list-style-type: none"> ■ Risk ■ Needs ■ Level of functioning 	<ul style="list-style-type: none"> ■ Category 2 beds and community patients ■ Community and in-patient groups were compared across three time points using a range of clinical outcome measures that assessed psychiatric symptoms, risk, needs and level of functioning ■ In-patients and community groups had similar mental health problems, however, patients living in an in-patient setting had higher unmet needs, lower functioning and were also higher risk ■ There were significant improvements across the range of outcome measures in both groups ■ Effective mental healthcare for people with learning disability is provided when learning disability, social care and mental health services work collaboratively
Seager <i>et al</i> , 2000	<ul style="list-style-type: none"> ■ 154 people with learning disability 	<ul style="list-style-type: none"> ■ Category 2 beds ■ People with learning disability who were discharged from hospital to community care were studied (using information from care staff and case notes) with a view to establishing the number of readmissions and exploring the reasons for these ■ A readmission rate of 8.4% was found, which was broadly in line with previous studies in this area ■ Severe problem behaviour was a prominent reason for hospital readmission, with physical aggression to staff and peers a factor in each of these cases ■ Relapsing mental illness was thought to be a factor in a number of the admissions precipitated by physical aggression ■ Physical deterioration featured highly as a cause of readmission to the learning disability hospitals, demonstrating their continuing role in providing physical healthcare for a group of patients who were not being provided for by generic services
Kent & Bird, 1994	<ul style="list-style-type: none"> ■ 20 young people with learning disability (14 male, 6 female) ■ Age: mean 23.50 years, range 17–34 ■ Level of intellectual functioning as assessed by the WAIS-R or WISC-R ■ Adaptive Behaviour Scale (ABS) ■ Length of stay ■ Severity of challenging behaviour ■ 3 questionnaires designed specifically for this project measuring characteristics (Q1), characteristics of follow-up placement (Q2) and patient and carer feelings towards the placement (Q3, more qualitative) 	<ul style="list-style-type: none"> ■ A pilot follow-up study of a behavioural programme for 20 young people with learning disability and challenging behaviour; the study was designed to identify behavioural problems which can most successfully be addressed in this type of unit, and to provide outcome measures ■ Between admission and discharge 18 out of 20 participants had increased their adaptive points by a mean of 40; of these, 9 had continued to improve at follow-up, 1 showed no change and 6 had decreased slightly; 2 participants' scores had decreased by 37 and 40 points, taking their adaptive scores to lower than before admission ■ Between admission and discharge 18 out of 20 participants had made good progress with regard to their challenging behaviour; 7 of the 13 who displayed self-injurious behaviour had improved significantly ■ Participants were divided into two groups: the good-outcome group and the poor-outcome group; those in the good-outcome group were: younger on admission, scored lower on adaptive skills and higher on challenging behaviours; they had remained on the treatment programme for 12–18 months and had been discharged from the unit for longer

Kent & Bird, 1994 cont.	<ul style="list-style-type: none"> ■ The overall level of independent living had increased from pre-admission and the majority of patients were living in a less restrictive placement ■ Length of stay on the treatment programme was 3–66 months (mean 20.30); 10 young people moved to the rehabilitation unit for 3–28 months (mean 14.30) ■ Minimum of 5 months' follow-up
Trower et al, 1998	<ul style="list-style-type: none"> ■ Demographic data <ul style="list-style-type: none"> ■ Level of learning disability ■ Duration of admission ■ Section/informal admission ■ Seclusion episodes ■ Residency before and after discharge ■ ICD-10 psychiatric or behavioural disorder was also ascertained with the clinically responsible consultant ■ Presence of active epilepsy also recorded ■ 113 new admissions into a specialist in-patient unit over a 2-year period, accounted for by 80 individuals (52 male, 28 female) <ul style="list-style-type: none"> ■ Age: mean 33.5 years, range 18–66 ■ Category 2 beds ■ Case-note analysis evaluating the use of an acute admission unit over a 2-year period ■ Generic mental health services are mostly accessed by patients with mild learning disability ■ Mean duration of stay was 46.6 days (range 2–194); 4 had been in-patients for more than 1 year and could be described as 'new long-stay' – this study's findings suggest that such an outcome is not inevitable ■ Most individuals were discharged back to the residence they were from, only a minority had to be found alternative accommodation, for a variety of reasons ■ Findings suggest that a specialised in-patient unit is able to meet the needs of those adults with a learning disability and a psychiatric problem who need short-term in-patient assessment and treatment; the authors argue that the expertise of the multidisciplinary care team makes the specialist unit the treatment of choice for learning disability patients
Clare & Murphy, 1993	<ul style="list-style-type: none"> ■ American Association for Mental Deficiency (AAMD) Adaptive Behaviour Scale (ABS) ■ Vineland Social Maturity Scale ■ Client's quality of care prior to entering the service established via staff interviews ■ Client's quality of life during receipt of the service established using the Residents' Opinions Schedule ■ Category 2 beds ■ Between entering and leaving, all 6 patients had made gains in their level of skills and social functioning; 5 had also reduced their challenging behaviours for which referral had been sought ■ All were living in less restrictive residential facilities than when they had entered
Chaplin, 2004	<ul style="list-style-type: none"> ■ Literature review using a variety of electronic sources plus hand-searching to identify all studies which evaluate the outcomes of people with learning disability and mental illness using general psychiatric services ■ Although 27 studies were located, only 2 were of randomised controlled trials; the evidence is poor quality and therefore further service evaluation is necessary to provide more robust evidence as to which services are preferred ■ Results referred to: general v. specialised services, novel intervention v. standard treatments, home-based treatments, people with learning disability v. people without learning disability and other methodologies ■ No conclusive evidence to favour the use of general or specialist psychiatric services

Chaplin, 2009	<ul style="list-style-type: none"> ■ Review article ■ Literature review aiming to establish differences in treatment outcomes for patients with learning disability and mental disorders treated in general or specialised learning disability mental health services ■ Conducted using electronic databases and websites of learning disability and mental healthcare 	<ul style="list-style-type: none"> ■ People with learning disability, particularly severe, have reduced access to general psychiatric services ■ Generic services are unpopular, particularly with carers, however, services can be improved by providing trained staff and in-reach from community teams ■ Hall <i>et al</i> (2006a,b) describe a service in which people with learning disability were admitted to beds on a general psychiatric ward with a specialised learning disability function and cared for by nurses who have received learning disability training ■ General psychiatric services without help are not sufficient to meet the needs of people with learning disability
Bouras & Holt, 2004	<ul style="list-style-type: none"> ■ Review article 	<ul style="list-style-type: none"> ■ The specialisation of mental health services for people with learning disability, provided by mainstream mental health services at a tertiary care level, offers a way forward
Burge <i>et al</i> , 2002	<ul style="list-style-type: none"> ■ 62 individuals with developmental disabilities 	<ul style="list-style-type: none"> ■ Category 3 beds ■ A retrospective chart review on all individuals with developmental disabilities who were psychiatric in-patients at a Canadian general psychiatric hospital over a 4-year period (1994–1998); a comparison sample of admissions of patients without learning disability was chosen ■ When individuals with learning disability are psychiatric in-patients, their length of stay is affected by some factors that have been identified in previous studies not specific to learning disability (e.g. referral source and diagnosis) ■ Male patients with learning disability have longer lengths of stay than do female patients in the same sample
Gustafsson, 1997	<ul style="list-style-type: none"> ■ The study sampled adult people with learning disability receiving special services and admitted to in-patient psychiatric care in one Swedish county 	<ul style="list-style-type: none"> ■ Category 2 and 3 beds ■ The results show a low frequency of psychiatric care utilisation among people with learning disability and coexisting psychiatric disorders in comparison with the proportion of psychiatric care utilisation among people with psychiatric disorders in the general population ■ The results are discussed in terms of how the level of learning disability might influence referral or diagnosis, the length of admissions, and the support provided within the special services to people with learning disability and psychiatric disorders
Hall <i>et al</i> , 2006a	<ul style="list-style-type: none"> ■ 37 participants 	<ul style="list-style-type: none"> ■ Category 3 beds ■ In-patients and community groups had similar mental health problems, but in-patients had higher unmet needs and lower functioning, and were at greater risk ■ There were significant improvements across the range of outcome measures in both groups

<p>Hall <i>et al</i>, 2006a cont.</p>	<ul style="list-style-type: none"> ▪ Working with mainstream mental health services and across health and social service boundaries delivers effective mental healthcare for people with learning disability. A specialised learning disability input into the ward was necessary
<ul style="list-style-type: none"> ▪ Threshold Assessment Grid (TAG) ▪ Health of the Nation Outcome Scales for people with Learning Disabilities (HoNOS-LD) ▪ Camberwell Assessment of Need for Adults with Developmental and Intellectual Disabilities short version (CANDID-s) 	<ul style="list-style-type: none"> ▪ Category 2 beds ▪ Out of 348 admission episodes, 59 were accounted for by 40 patients who were previously resident in the long-stay institution; most admissions were for new patients from the community ▪ Over time, admissions to the specialist unit decreased when occupancy reached and persisted at 100%, coinciding with a significant rise in admissions of adults with learning disability to general adult psychiatric wards ▪ Resettlement after closure of long-stay learning disability institutions has not been accompanied by a high readmission rate for former residents, but neither has there been a decreasing need for psychiatric beds for those with learning disability and severe psychiatric disturbance ▪ Most of these admissions are for people with learning disability who are relatively new to the service ▪ There has been a persistent problem with full occupancy of these beds, which reflects delayed discharges indicating a lack of community resources and an increasing demand for admission
<p>Lyall & Kelly, 2007</p>	<ul style="list-style-type: none"> ▪ 348 admission episodes
<ul style="list-style-type: none"> ▪ To examine the use of specialist psychiatric beds for people with learning disability, created following the closure of a long-stay institution ▪ Admission and discharge data were examined, including history of previous institutional admission, diagnosis at discharge and number of subsequent readmissions 	<ul style="list-style-type: none"> ▪ A questionnaire was sent to all NHS trusts that had learning disability in-patient beds, and all private or voluntary healthcare establishments providing services for people with mental health problems or learning disability; it asked for information about the unit, its residents and the views of the unit manager
<p>Mackenzie-Davies & Mansell, 2007</p>	<ul style="list-style-type: none"> ▪ 333 people from 38 units
	<ul style="list-style-type: none"> ▪ Questionnaire study that targeted category 2 beds ▪ 44 agencies confirmed that they provided assessment and treatment units, of which 38 returned questionnaires ▪ These units served 333 people of whom 75% had mild or moderate learning disability; a quarter had been in the units more than 2 years; 40% of residents had a discharge plan and 20% had this and the type of placement considered ideal for them in their home area ▪ The main strengths of the units were identified as the knowledge and experience of the staff and having sufficient staff; the main problems as inappropriate admissions, bed-blocking and the relationship with other services, difficulties with recruiting and retaining staff, the location and environment of the unit and the mix of residents ▪ There has been an increasing rate of provision of special units, which now predominantly serve people with moderate or mild learning disability; this model of service provision is becoming more widespread but the potential problems are still present ▪ Areas are identified for further research

Nawab & Findlay, 2008	<ul style="list-style-type: none"> ■ Cases were identified using the ward admission register and Patient Information Management System (PIMS) ■ Demographic data ■ Admission and discharge processes ■ Length of stay ■ Diagnosis (recorded in case notes) 	<ul style="list-style-type: none"> ■ Category 2 beds ■ There is a need for a small number of specialist assessment and treatment beds for those with a learning disability; it is up to services (healthcare, social care, justice and carer organisations) to coordinate their expertise to ensure that individuals' needs are appropriately met and that they do not remain in-patients after their need for this level of care has diminished ■ Joint protocols, robust risk assessments and interagency working recommended
Ashaye <i>et al</i> , 1997	<ul style="list-style-type: none"> ■ 26 long-stay elderly patients in a psychogeriatric ward v. 23 long-stay patients with learning disability aged 65+ and 40 long-stay patients with learning disability aged 50-65 years 	<ul style="list-style-type: none"> ■ On the HoNOS, the elderly psychiatric patients scored significantly higher for problems with mood, relationships and occupation/activities. There were no significant differences for any of the scales rated between the 50- to 65-year-old and >65-year-old patients with learning disability ■ The similarities between the three groups of patients would suggest that for some patients the same services may be utilised; this could reduce the cost of the care in the community and entail more economical use of the facilities and staff ■ The HoNOS proved to be a concise and simple instrument, which could become a useful tool in monitoring the outcome of healthcare in long-stay patients
Chan <i>et al</i> , 2004	<ul style="list-style-type: none"> ■ 2 case studies 	<ul style="list-style-type: none"> ■ The case studies illustrate the difficulties in accessing mental health services for this 'invisible' group of individuals with learning disability, and demonstrate the gaps in service delivery and clinical practice ■ The paper argues that mental health concerns should be considered when challenging behaviours are present in persons with learning disability
Cowley <i>et al</i> , 2005	<ul style="list-style-type: none"> ■ 752 adults 	<ul style="list-style-type: none"> ■ Category 2 beds ■ Predictors of admission for a cohort of 752 adults living in community settings; 83 were admitted ■ Schizophrenia spectrum disorders and mild learning disability independently predicted admission for the total cohort ■ The presence of symptoms associated with psychosis and the presence of physical aggression predicted admission in the subsamples
Driessen <i>et al</i> , 1997	<ul style="list-style-type: none"> ■ Determinants of (1) referral to psychiatric services and (2) the amount of mental healthcare consumed were analysed in a population of individuals with learning disability, using data from a cumulative mental health case register in a defined geographical area 	<ul style="list-style-type: none"> ■ Category 2 and 3 beds ■ Associations between level of disability, gender, age and social environment on the one hand, and psychiatric referral and service consumption on the other were expressed as odds ratios (ORs) ■ Being older (OR=1.9, 95% CI 1.5-2.5), having milder learning disability (OR=1.4, 95% CI 0.9-2.3) and living alone (OR=5.8, 95% CI 2.8-11.9) predicted a higher probability of receiving psychiatric treatment ■ Living alone (OR=15.3, 95% CI 1.7-136.1) was also associated with higher level of mental health service consumption

<p>Gustafsson, & Sonnander, 2004</p>	<ul style="list-style-type: none"> ■ Samples from two Swedish counties ■ The Reiss Screen for Maladaptive Behaviour ■ Psychopathology Inventory for Mentally Retarded Adults 	<ul style="list-style-type: none"> ■ The overall occurrence of mental health problems in adults with learning disability ranged from 34 to 64% ■ The most common mental health problems were aggressive, self-injurious behaviours, signs of depression, anxiety or adjustment problems ■ The occurrence of adults with learning disability among patients receiving out- or in-patient psychiatric care was approximately 1%; between 70 and 90% of these persons had a mild level of learning disability ■ The overall occurrence of mental health problems was similar to reported overall figures in comparable studies conducted in the USA, the UK and Denmark. The number of adults with learning disability registered for out- or in-patient psychiatric care was low compared with the occurrence of mental health problems based on the screening results
<p>Holden & Neff, 2000</p>	<ul style="list-style-type: none"> ■ 28 adults with mental retardation and severe psychiatric disorder 	<ul style="list-style-type: none"> ■ Category 3 beds ■ The impact of intensive out-patient mental health interventions (in a dual-diagnosis clinic) on the hospitalisation rate and length of stay was examined for 28 adults with mental retardation and severe psychiatric disorder; they were selected on the basis of frequent use of mental, medical and social services ■ Charts were reviewed for the 12-month periods before and after referral to the programme to compare service utilisation; a single group pre- and post-test design with no control group was employed ■ Correlated <i>t</i>-tests comparing the pre- and post-program number of hospitalisations and lengths of stay indicated significant decreases in both hospitalisations and lengths of stay after programme entry, which may result in significant reductions in hospital costs
<p>Lohrer <i>et al</i>, 2002</p>	<ul style="list-style-type: none"> ■ 64 people with dual diagnosis 	<ul style="list-style-type: none"> ■ Category 3 beds ■ Anecdotal reports suggest that persons with a dual diagnosis (mental retardation and psychiatric illness) admitted to acute psychiatric hospitals stay longer and require more services than individuals without mental retardation. To test these hypotheses, a questionnaire was completed for 64 people with dual diagnosis admitted to 10 psychiatric hospitals over 3 months ■ Multivariate analysis revealed that a diagnosis of mental retardation was not a predictor of length of stay. Use of 1:1 staffing was more likely, whereas arrangement of different community placement at discharge was less likely for persons with than without dual diagnosis. Additionally, age, diagnosis, symptomatology, living arrangements, insurance status and service use distinguished the patient groups. Implications are discussed in the context of a need for further examination and training focused towards this population

Metcalfe <i>et al</i> , 2005	<ul style="list-style-type: none"> ▪ Patients with severe psychosis were randomly allocated to intensive case management (ICM) or standard case management. For each patient group with complex needs the effect of ICM is compared with that in the rest of the cohort 	<ul style="list-style-type: none"> ▪ The UK700 trial failed to demonstrate an overall benefit of ICM in patients with severe psychotic illness. This does not discount a benefit for particular subgroups, and evidence of a benefit of ICM for patients of borderline intelligence (NART error score of 40 or above) has been presented. The aim of this study is to investigate whether this effect is part of a general benefit for patients with severe psychosis complicated by additional needs. Outcome measures are days spent in psychiatric hospital and the admission and discharge rates ▪ ICM may be of benefit to patients with severe psychosis complicated by borderline intelligence or depression, but may cause patients using illicit drugs to spend more time in hospital. There was no convincing evidence of an effect of ICM in a further seven patient groups. ICM is not of general benefit to patients with severe psychosis complicated by additional needs. The benefit of ICM for patients with borderline intelligence is an isolated effect which should be interpreted cautiously until further data are available
Patterson <i>et al</i> , 1995	<ul style="list-style-type: none"> ▪ Patients with learning disability and mental illness who were admitted to a state hospital. Exact numbers not available 	<ul style="list-style-type: none"> ▪ Category 3 beds ▪ Clients with developmental disability and a concomitant mental illness are often underserved or inappropriately treated because of interorganisational barriers, leading to unnecessary hospitalisation and lengthy delays in community placement. To overcome these barriers, agencies responsible for developmental disabilities and mental health services in Spokane County in Washington State developed a collaborative system of care in 1989. An interagency consortium was established to promote coordination of services between the community mental health centre, the state hospital, the county human services agency, the state's regional developmental disability service agency, the state institution for the people with developmental disability, and several community agencies serving this group of patients ▪ Between 1990 and 1992, admissions of persons with developmental disability to the state hospital were more likely to be appropriate admissions of persons with a mental illness, patients were discharged more efficiently, and crisis respite services were used in place of hospitalisation. In addition, anecdotal reports indicated a reduction of interagency tensions
Lunsky <i>et al</i> , 2006	<ul style="list-style-type: none"> ▪ Secondary analysis of data from the 1999–2003 Colorado Client Assessment Record (CCAR), and all tertiary and all tertiary psychiatric hospitals in Ontario, Canada 	<ul style="list-style-type: none"> ▪ Category 3 beds ▪ Patients with both mental retardation and a psychiatric diagnosis differed from those who did not have mental retardation in terms of demographic characteristics, diagnostic and symptom profile, resources and recommended level of care. More specifically, patients with both mental retardation and a psychiatric diagnosis had significantly worse ratings across nearly all CCAR functional domains and were assessed as requiring more than the recommended levels of care compared with other patients

<p>Lunsky <i>et al</i>, 2006 cont.</p>	<ul style="list-style-type: none"> ▪ Random sample of 3927 cases, representing 12470 patients receiving psychiatric services 	<ul style="list-style-type: none"> ▪ Patients who have both mental retardation and a psychiatric diagnosis constitute a sizeable subgroup of an already underserved psychiatric hospital population. Greater attention is required to meet the unique clinical and service needs of this challenging group
<p>Saeed <i>et al</i>, 2003</p>	<ul style="list-style-type: none"> ▪ All psychiatric admissions of people with developmental disabilities over a 5-year period were selected ($n=294$), and were compared using survival analysis to a random sample of admissions from the general psychiatric population ($n=287$) 	<ul style="list-style-type: none"> ▪ Category 3 beds ▪ This study investigated associations between the presence of developmental disabilities and length of in-patient stay for mental healthcare ▪ Overall, people with developmental disabilities stayed in hospital longer than those without developmental disabilities, and this extra stay was partially attributed to case-mix differences between the cohorts. Sub-analysis in both cohorts showed that those going back to their usual living arrangement stayed a shorter period than those who were discharged elsewhere, and that people with developmental disabilities were less likely to be discharged to their usual living arrangement than were people without the disability ▪ This study highlighted the importance of specialised residential and personal supports for people with developmental disabilities and a coexisting mental disorder
<p>Lunsky <i>et al</i>, 2011</p>	<ul style="list-style-type: none"> ▪ 246 out-patients identified as having learning disability, from both specialised and general programmes 	<ul style="list-style-type: none"> ▪ Category 2 and 3 beds ▪ Individuals with learning disability in specialised programmes differed from patients with learning disability in general programmes with regard to demographics, diagnostic profile, symptom presentation and recommended level of care. Further research is required to determine why individuals access some services over others

Appendix 2. Service user and carer testimonies

MRS J, PARENT OF A SON WITH LEARNING DISABILITY AND MENTAL HEALTH PROBLEMS:

'I am a carer for my son who has learning disability and mental health problems. I strongly support the need for specialised in-patient services for people with learning disability and mental health problems.

My experience of specialist in-patient learning disability services has been positive. Staff are available when needed and they understand people with learning disabilities. The environment is also structured for the needs for people with learning disability. I felt confident that learning disability staff could care for my son and they were able to respond to his individual needs. I was able to speak to my son at any time over the phone and the staff always actioned anything they said they were going to do.

My son, himself, has never had any complaints about the services he received. Therapy staff were always available and my son looked forward to seeing other people and enjoyed the social side of things.

I have also had experience of my son accessing adult mental health services and accident and emergency department where my experience was not good. I felt that staff in generic services did not understand my son's needs and it was frightening for me and my son and the general public present in these places. It was an experience that I hope that I never have to go through again.'

MRS P, CARER:

'I am a paid carer for people with learning disability and mental health problems.

I have had several of my residents who have accessed specialist learning disability in-patient services over the years. I feel that staff working in learning disability services have specialist expertise to meet the needs of people with learning disabilities and mental health problems. The staff are welcoming and person-centred.

The admission process is good and the paperwork is always in place and there is a named nurse who is contactable. There is always a calm

feeling about the learning disability in-patient unit even if it is noisy. It has a good layout, and there are visitor rooms and there is excellent communication between staff and carers.

One of the strong points is the availability of therapy staff who engage very well with the patients. The in-patient and community teams liaise with each other for a smooth discharge from the in-patient unit. Staff and doctors have a very good rapport with patients and I would prefer the learning disability in-patient unit to the adult mental health unit for my residents.

I have also had experience of my residents being admitted to generic services where the environment is very busy and chaotic. There are no rooms available to discuss the patient's problems in private. I feel that generic staff do not have an understanding with people with learning disability and their needs. There was no therapy available in generic service, and there was poor communication between the staff and carers with regard to the patient's admission and discharge process. I have also had experience of patients being sent on home leave before it was checked whether it was safe to do so. I personally feel that generic services could learn a lot from learning disability in-patient services.'

FS, SERVICE USER:

'My name is FS. I have learning disabilities and mental health problems. I have received support and help from the learning disability service for many years and I have been admitted to the learning disability in-patient unit and also to adult mental health units in the past. I feel that learning disability in-patient units are better suited to me when I am unwell and need to be admitted to hospital.

I get admitted to get better. This is because I find it difficult to cope at home sometimes. When I am in the learning disability in-patient unit I have people to talk to and I feel safe. When I have been admitted to other mental health units in the past I have felt vulnerable from other patients who pick on me.

Staff on other mental health units do not spend much time with me and the environment is also noisy and very busy. The chairs and beds are nailed to the floor and there are no wardrobes or cupboards in the room. I feel even if staff do spend more time with me and even if the environment is much better, other patients will still pick on me on mental health wards. This is why I prefer to be admitted to a learning disability in-patient unit if I become unwell.'

MRS CAROL TILLEY, CARER:

'My son has now been an in-patient at the learning disability assessment and treatment unit for 15 weeks and I would like to tell you how very different this experience has been for both my son and myself compared with his previous experience as an in-patient in an assessment ward in a psychiatric hospital.

My son is 37 years of age. He was born with a learning disability and Asperger syndrome and over the years has experienced depression,

anxiety, psychotic depression, catatonia, and more recently been diagnosed with bipolar disorder. In October 2010, he was admitted to our local psychiatric hospital for assessment following the onset of catatonia and psychotic depression. At this time he was an extremely unwell, vulnerable person and his family were very concerned that the assessment ward in a general mixed psychiatric centre would be the wrong environment for him. Our fears were justified when it became clear that although staff did their best to support him, they were having difficulties because they had very little knowledge of, or training in, learning disability. This lack of knowledge and experience extended to the consultant psychiatrist and the ward manager. They were all in difficulty.

The family tried very hard to locate somewhere more suitable for him and although we did identify a specialist centre, we were unable to get the local authority to agree to work with us to improve his hospital placement. After a very difficult period, he was discharged to my care. By March 2011, he was able to take up his normal life again and we hoped that all would be well. However, we remained very concerned that if his mental health was to break down again, there would not be any suitable provision available to help him as a person with learning disability and mental health problems.

Towards the end of 2011 my son's mental health was causing concern and by mid-January 2012 he needed hospitalisation. This time it was suggested by his psychiatrist that a specialist learning disability assessment and treatment unit would be more appropriate for his care and treatment and I visited the centre to learn more about it. I was reassured straight away by meeting the manager, who spent time with me outlining how the unit works and informing me that, with agreement from our local commissioners with regard to cost, they had a bed available and would be able to admit my son. Within 48 hours he was admitted and I felt entirely different this time about his safety and the ability of staff in understanding his needs.

I have long been concerned about the use of psychiatric medication for those with learning disabilities, and am pleased to see that a holistic and health-centred approach is taken alongside the use of medication. During my son's time in the unit he has had a complete check of his physical health, plus visits to the dentist and optician. He has had regular meetings with the psychologist and psychiatrist. Other appropriate activities are organised, available and offered to him. I am also reassured that the medication, and its effect on him, is closely monitored.

The outstanding difference about this unit is that it is specifically to help those with a learning disability who also have mental health problems, and it is this difference that makes it so important that units like this should continue to be available for these most vulnerable members of our society when they are needed.

I do find myself wondering already what will happen when and if my son needs in-patient service again, what will happen to him if the specialist learning disability assessment and treatment unit is unable to provide a bed? There is clearly a shortage of specialist mental health services for those with a learning disability and this worries me greatly.

I hope that you will have the opportunity to bring this to the attention of the commissioners or providers of services and as a professional working in this field stress the need for these services to continue to be provided, and for these services to be more widely available.

Mental illness is common in people with learning disability, although not always recognised, and improved support for some of the most vulnerable members of our society is an area that still needs more work.'

COMMENTS FROM SERVICE USER MENTAL HEALTH ADVOCACY GROUP SUPPORTED BY THE ESTIA CENTRE, LONDON

MR PETER CRONIN, SERVICE USER, PEER REVIEWER AND WARD VISITOR TO REPORT ON QUALITY:

'Staff were polite and friendly (on the learning disability ward). The learning disability ward was more understanding. Some people were aggressive [on the acute mental health ward]. It was unsettling. On the [acute mental health ward] communication isn't so good. The learning disability ward had lots of leaflets, some on medication. They were good at communication. I did an audit on the learning disability ward. They were doing lots of activities. Some patients were playing cricket with the staff, some were doing cooking with the [occupational therapist].'

YOLANDA ZIMOCK, SERVICE USER, ON THE IN-PATIENT EXPERIENCE ON A LEARNING DISABILITY WARD:

'There are lots of things to do, like gym, relaxation class, cooking. The staff really helped me. Sometimes it's too noisy.'

QUOTES FROM SERVICE USERS WHO DO NOT WISH TO BE NAMED:

'The nurses listen to me (learning disability ward). They help me with my worries. They made a book for me, it's with worries. It has pictures in it, it's easy to read.'

'People understand me here. They are good at working with people with learning disabilities. They take time to tell you about things. There are lots of things to do. I feel safe, there is no bullying. It's better to be on a ward for people with learning disabilities.'

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