

# Future role of psychiatrists working with people with learning disability

Faculty Report FR/LD/1



Faculty of the Psychiatry of Learning Disability  
Royal College of Psychiatrists

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of the Royal College of Psychiatrists

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Faculty of the Psychiatry of Learning Disability  
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# Working group

This report was written by members of the Future Roles Working Group, Royal College of Psychiatrists, Faculty of the Psychiatry of Learning Disability

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The draft versions of the report were consulted on with the Faculty Executive and other members of the Faculty.

# Executive summary and recommendations

This document has been produced by the Faculty of the Psychiatry of Learning Disability at the Royal College of Psychiatrists as part of the College's professionalism work stream. It describes how we think psychiatrists should work with people who have learning disabilities. We acknowledge that it is important for people with learning disabilities to access mainstream services, with support from specialist services where necessary, and that many people also need to access specialist services to optimise their mental health. The roles here described are crucial for setting the appropriate competency-based curriculum for future trainees in the psychiatry of learning disability.

There is considerable variation in the organisation and provision of services for people with learning disability and this can lead to variation in the role of the psychiatrist within such services. We propose that a tiered care model best describes the different types of services and interventions that psychiatrists working with people with learning disabilities can offer, and puts them in the context of the different settings in which they work.

## TIER 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 1 roles:

- health promotion, facilitation, screening and prevention – working closely with users, carers, general practitioners, dentists, etc.
- user/carer partnerships – facilitating joint learning, designing guidance and outcomes, developing skills
- liaison – with organisations and other professionals, for example giving advice on mental capacity
- training and education – direct or through supervision of staff members (e.g. training on changing attitudes to people with learning disability)

- management and leadership – for example working with the partnership board to improve access to mainstream services
- research – focusing on access to services, epidemiology.

## TIER 2

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 2 roles:

- referrals are directed through a single point of access
- assessment work is focused on those with mental health needs who specifically need psychiatric skills, with consultation on other assessments as required
- treatment and other interventions are generally short-term, arising out of assessments
- consultation and clinical advocacy – ensuring standards in assessments, making appropriate recommendations and giving advice regarding management
- training – e.g. professionals working in primary care and educating the trainers within the service
- management and leadership – clinical governance (e.g. ensuring that clinical guidelines are implemented), supervising and managing medical staff, service planning and development
- research – aimed at service evaluation, epidemiology and common mental health problems.

## TIER 3

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

Tier 3 clinical roles:

- joint working with other specialists such as neurologists, those in mental healthcare for older people and those in challenging behaviour teams
- direct clinical responsibility for individuals with complex needs who require sustained multiprofessional involvement
- ensuring accessibility – providing care that is as local as possible and within the least restrictive option
- ensuring multidisciplinary working – within the service and across the services via direct care as well as through advice, training, redesign, etc.

## TIER 4

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

Tier 4 clinical roles:

- assessments for possible admission
- assessment, treatment and relapse prevention for people admitted
- responsible clinician role for detained individuals
- working closely with the multidisciplinary team
- maintaining overview of out-of-area placements and planning for the person's return if appropriate.

## NON-CLINICAL ROLES IN TIERS 3 AND 4

There are considerable overlaps in the non-clinical roles in tiers 3 and 4 and they are considered together.

Tier 3 and 4 non-clinical roles:

- training, education and workforce development, with a particular focus on specialist clinical areas
- developing capabilities of teams at all tiers so they may be able to support people with more complex needs
- leadership and management, for example making sure that services meet national standards as demonstrated by external inspections, working with commissioners to develop a more strategic view of service development, establishing care pathways and clinical networks
- research, for example participating in interventional research including clinical trials for specific conditions and specialist service evaluations.

Working in partnership with users and carers is a vital part of the role of the psychiatrist at all tiers, as is good liaison with primary care services. In the appendices we discuss additional roles and responsibilities taken on by consultants in forensic learning disability psychiatry (Appendix 1, pp. 31–32) and in child and adolescent learning disability psychiatry (Appendix 2, pp. 33–35).

## RECOMMENDATIONS

- 1 A tiered approach based on a stepped care model with care pathways is the most efficient way of commissioning specialist health services for people with learning disability. We recommend that health commissioners and providers adopt such a tiered approach suitably modified to take into account the local circumstances. The implementation of such a model should enable the psychiatrists who work with people with learning disability to deliver the services in an effective way which provides the best value to service users.
- 2 We recommend this report to all psychiatrists working in the field as it provides a clear vision of their role within a stepped care model.



# Introduction

In this report, we describe the multifaceted role of a psychiatrist working with people with intellectual disabilities which encompasses their role as clinical leader and specialist doctor. We aim to stay true to the principles of good clinical care embodied in *Good Psychiatric Practice* (Royal College of Psychiatrists, 2009). However, we must also respond to the rapidly changing environment in which health and social services operate, which has made the need to clarify the future role of psychiatrists working with people with learning disability essential. We therefore uphold the public policy principles of social inclusion, rights, independence and choice for people with learning disability. We acknowledge that it is important for people with learning disability to access mainstream services with support from specialist services where necessary, but also that many people with learning disability need to access specialist services to optimise their mental health.

This report should be read alongside other key documents produced by the Royal College of Psychiatrists, including the *Role of the Consultant Psychiatrist: Leadership and Excellence in Mental Health Services* (2010a), *Good Psychiatric Practice* (2009) and *A Competency-Based Curriculum for Specialist Training in Psychiatry* (2010b).

In producing this report, our objectives are to aspire to excellence in practice and to enable a clear understanding of what part the psychiatrist plays in meeting the needs of people with learning disability. The psychiatrist working with this group of service users must have the skills to work effectively in modern health and social care settings and be driven by the primary purpose of delivering high-quality care for people with learning disability who have mental health problems.

We propose a guide for the role of the psychiatrist working in learning disability services and define the values and competencies that will enable them to deliver mental healthcare for this group of service users. The aim is to provide care which is clinically effective, safe and person-centred. A psychiatrist's role should of course complement the roles of other multidisciplinary healthcare team members and should be adapted to the local population need and the skills available in a capable workforce. We hope that by articulating a clear vision of the role of psychiatrists we will be able to minimise any ambiguity, overlaps or confusion in relation to multidisciplinary team working.

This report should also pave the way for setting the appropriate competency-based curriculum for the future trainees in learning disability so that they are well prepared for the role of a consultant psychiatrist after completion of their training. In the original *CanMEDS* work (Royal College of Physicians and Surgeons of Canada, 2005), the roles of a doctor have been summarised as being a medical expert, good communicator, collaborator, manager, health advocate, scholar and professional. However, particularly

relevant to our role as psychiatrists working with people with learning disability are clinical leadership, responsibility, accountability and the ability to manage highly complex clinical problems. This Faculty Report therefore supplements both the College's Occasional Paper OP74 (Royal College of Psychiatrists, 2010a) and the *CanMEDS* (Royal College of Physicians and Surgeons of Canada, 2005), as well as highlighting the competencies required along with suggesting areas for continuing skills development in this specialist role.

We have adopted a tiered approach to care in order to describe the different types of work that psychiatrists do. This approach should lead to the most effective use of resources for people with learning disability.

## BACKGROUND

Specialist healthcare for people with learning disability is provided within a wider system of health and social care and involves many stakeholders. This report underlines the importance of clarifying the roles and responsibilities of consultant psychiatrists working with people with learning disability in this context.

Providers of specialist healthcare do not determine the whole system of care for people with learning disability, but are able to define how they interact with that system. We propose that this is best conceptualised as a stepped or tiered care model (East Midlands Strategic Health Authority, 2008). This is in line with developments in mental health, long-term conditions and also child and adolescent mental health services.

### *PRINCIPLES THAT SHOULD UNDERPIN THE SPECIALIST SERVICES PROVISION*

Specialist services should:

- adopt a person-centred approach in supporting people with learning disability
- use evidence-based approaches where possible
- develop collaborative care pathways that enable the most effective use of resources, working in a multidisciplinary way where this is in the person's best interests
- focus on a recovery model to maximise independence and social inclusion and minimise the likelihood of institutionalised responses
- be provided as close to home (including in the home) as possible, under conditions of no greater security than is justified on clinical or welfare grounds
- collaborate with mainstream services to secure effective mental and physical healthcare
- promote the safety of service users, carers and the public, and have clear policies for safeguarding children and vulnerable adults
- fulfil all legal requirements including those arising from the legislation on mental health, mental capacity, disability discrimination and human rights
- use an explicit ethical framework to inform decision-making.

Specialist healthcare for people with learning disability meets a wide range of needs as varied as: communication, speech and eating difficulties; severe mobility or postural difficulties; physical disabilities; psychological and psychiatric difficulties; neurological problems; and challenging behaviour. Services need to be accessible and provided as close to home as possible. Specialist assessment and treatment, crisis, intensive outreach and forensic care services are needed to support this vision for community-based care. Specialist services must provide person-centred coordination to help those with the most complex needs and their carers navigate their way through the health system, securing the care and treatment they need.

## TIERED CARE MODEL

There is considerable variation in the organisation and provision of services for people with learning disability and this can lead to variation in the role of the psychiatrist within such services. We propose that a tiered care model best describes the different types of services and interventions that psychiatrists working with people with learning disabilities can offer and puts them in the context of the different settings in which they work. This model is summarised in Fig. 1.

Such a tiered care model will be helpful only if changing needs, crises and circumstances allow for easy moving 'up' or 'down' the tiers.

In the end, it is the care that is delivered at the appropriate tier that matters. Key to the safe and effective implementation of such a model are specialist crisis, outreach, assessment and treatment services (including in-patient care), as well as cross-sector, multi-agency care pathways. Given the very wide range of needs that people with learning disabilities have, a number of needs or condition-based care pathways need to be put in place.

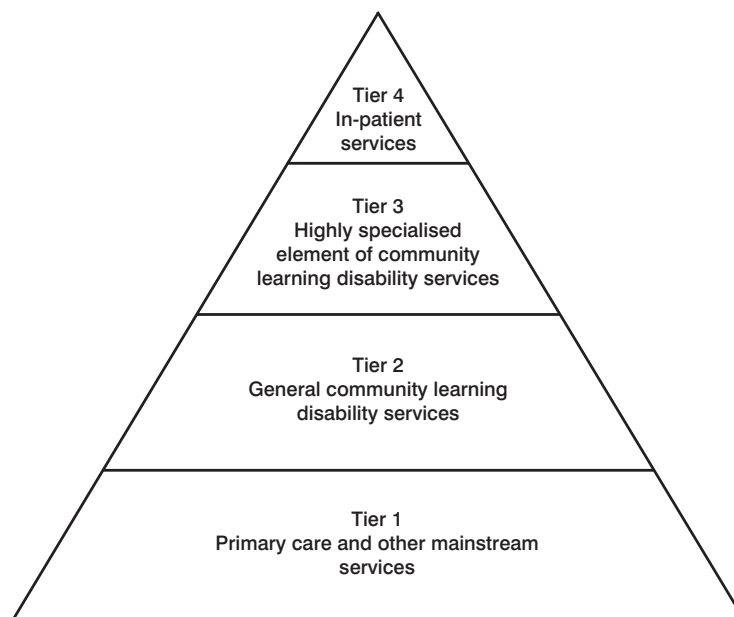


Fig. 1 Tiered care model for services for people with learning disability

The tiered care model strives to enable the right care to be delivered by the right people and at the right time and place. Such a model recognises a range of levels of need – from people with less severe needs, who are able to manage and thrive with the support of their family, friends and ordinary health and community services, through to people whose difficulties require intensive specialist support.

## CARE PATHWAYS

Key needs- or condition-based care pathways can be developed that will incorporate this approach and that will be in line with tariff-based systems of funding healthcare, such as payment by results. Health needs in populations of people with learning disability can be classified into three broad categories of need (Fig. 2).

Psychological (or mental health) needs include common mental illnesses such as depression and anxiety, as well as severe mental illnesses such as schizophrenia and bipolar affective disorder. They also include behaviour problems, personality disorder and offending behaviour, developmental disorders such as autism, dementia and other degenerative conditions, and mental ill health associated with physical disability. These needs are met in tiers 2, 3 or 4 depending on their nature and severity and whether more intense and specialised services are required.

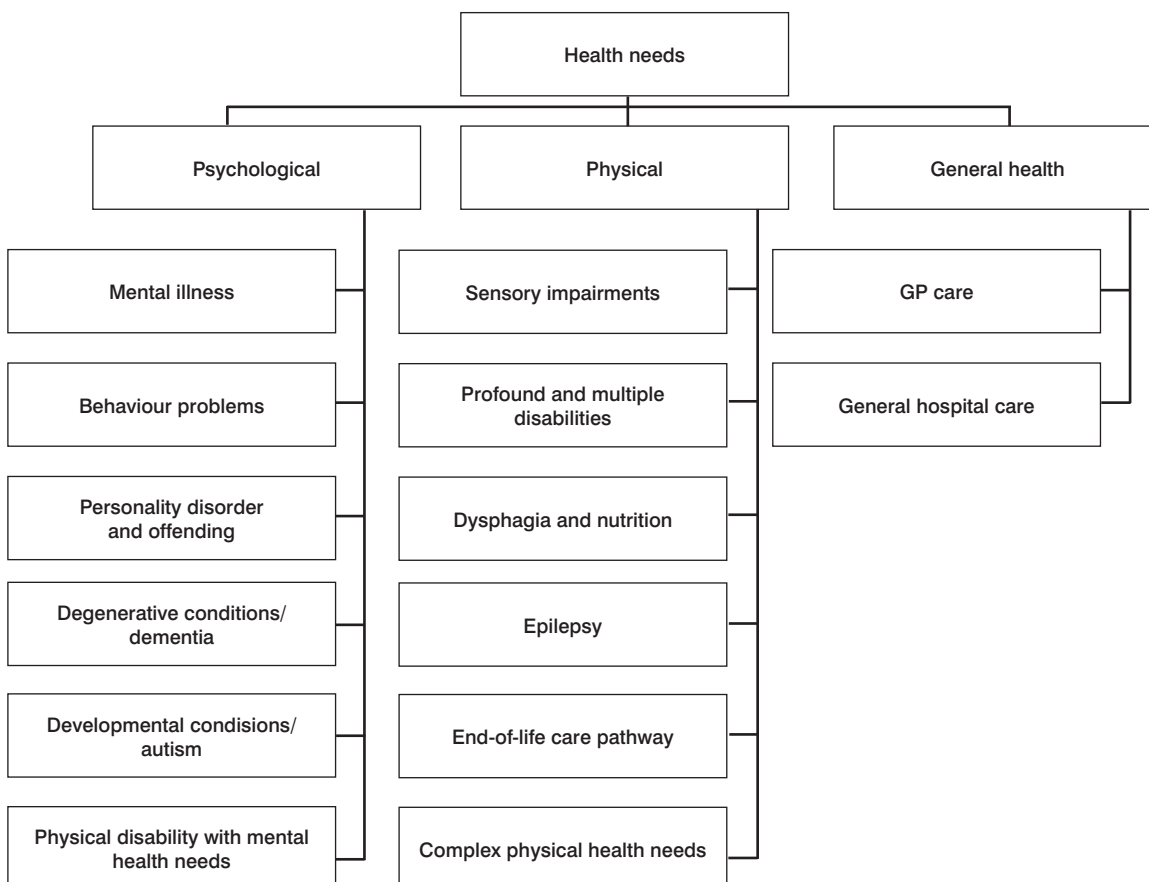


Fig. 2 Health needs in people with a learning disability

Physical needs include epilepsy, sensory impairments, dysphagia and nutritional problems, end-of-life conditions, profound multiple learning disability and complex physical disabilities such as sensory and communication problems. These needs are usually met by multiprofessional teams in tiers 2 and 3.

Finally, general health needs are those that arise from the health conditions often encountered in general practice and in acute hospital settings, where services for people with learning disability provide a supportive and facilitative role. These needs are usually provided by general health services and are met in tier 1.

The care pathways based on these needs should:

- set out the arrangements for the assessment of need
- clarify the range and choice of evidence-based care appropriate to the need
- clarify and guarantee the roles and responsibilities of staff across all relevant agencies in delivering such care
- have built-in both health and social outcomes
- take into consideration the roles and needs of carers and advocates.

# Tier 1: Primary care and other mainstream services

Tier 1 is the level of service provision that serves the general health, social care and educational needs of the population of people with learning disability and their families. Services provided in this tier are primary care, voluntary service provisions, education and Social Services. The community learning disabilities team and the psychiatrist have limited direct clinical contact in this tier, but they are involved in activities which may influence patients' care. Interacting with this tier is essential to the training of learning disability psychiatrists.

## CLINICAL ROLE

### *HEALTH PROMOTION, FACILITATION, AND SCREENING AND ILLNESS PREVENTION*

A core function of the community learning disability team is to enable and promote access for people with learning disabilities to primary and secondary care services. The learning disability psychiatrist has expert knowledge of the physical health problems associated with learning disability. He or she makes an important contribution in supporting the work of the team and promoting and enabling access to generic services in primary care.

The psychiatrist and community learning disability team work closely with individual service users, carers, GPs and dentists in the team's catchment area. Health promotion and prevention is part of the patient-centred process. The psychiatrist for people with learning disabilities provides advice and support to the team in dealing with other aspects of patient's health: advice regarding lifestyle screening and support to the community learning disability team to help reluctant patients to access GP health check. They may design literature, carry out teaching and set up specific initiatives to improve the health of people with learning disabilities. They will work closely with other doctors in their catchment to improve the care and treatment of adults with learning disability who have physical health problems. They may work towards the development of specialist local services for people with learning disabilities, for example, audiology screening programmes or specialist audiology clinics for adults with Down syndrome or introducing learning disability liaison nurses in general hospitals.

The psychiatrist working with people with learning disabilities may use his or her expertise to support local commissioning through partnership boards. They can hold local acute care and mental health providers to account if the latter do not make reasonable adjustments to enable service

access for people with learning disabilities. Psychiatrists may also take on a more national role working with commissioners and national organisations such as the Valuing People Support Team in England, the Royal College of General Practitioners, the Department of Health and voluntary sector organisations.

#### CASE STUDY 1

A GP calls a psychiatrist in the community learning disability team because a patient with moderate learning disability previously known to the psychiatrist needs a blood test. The psychiatrist works with a nurse in the team to provide the GP with pictorial information to explain the process to the patient and offer advice on timing the appointment when the surgery is quiet so that the patient does not have to wait and allowing extra time for the appointment so that the patient is not rushed.

#### CASE STUDY 2

Screening programmes designed for the general population may have thresholds for referral that are incorrect for people with learning disability. For example, a 25dB hearing loss is the threshold for referral for audiology assessment but people with learning disability need referral at lower thresholds.

Learning disability psychiatrists advise the Department of Health to develop health checks for people with learning disability which are then incorporated into the routine work of GPs (Wales).

#### CASE STUDY 3

The psychiatrist also has a role in tier 1 in promoting the detection of mental health problems and neurodevelopmental disorders in people with learning disabilities, for example, through training staff in screening for mental health problems using the screening instruments such as the PAS-ADD checklist ([www.passadd.co.uk/Checklist.htm](http://www.passadd.co.uk/Checklist.htm)).

## *USER-CARER PARTNERSHIPS*

The psychiatrist is in a privileged position with regard to users and family carer partnerships through the nature of their training and daily practice. They use relationships here to facilitate joint learning, design guidance, facilitate outcomes and develop skills (in other psychiatrists and in carers). They are able to provide support through life stages and life events such as bereavement. The psychiatrist has an opportunity to build relationships over time with users and family carers and is able to provide continuity of care.

## *LIAISON*

Liaison work cuts across all the tiers and in some clinical situations it will involve face-to-face contact, assessment and treatment advice. Psychiatrists working with people with learning disability are likely to provide liaison support to a number of different organisations and professionals. Liaison may be provided to primary care, acute hospitals, mental health services, social care providers, third-sector organisations and directly to users and carers.

Psychiatrists may be called on to provide advice on capacity or deprivation of liberty for users in this tier. For more complex cases, a direct face-to-face assessment may be required (this would be provided in tier 2).

#### CASE STUDY 4

A GP contacts the psychiatrist about a patient with severe learning disability who has been previously under the care of the learning disability team and has shown a re-emergence of severely challenging behaviour. The psychiatrist reads the patient's notes and informs the GP that the patient's genetic disorder is associated with severe acid reflux and that previously the challenging behaviour responded to medication for this. The GP prescribes appropriate medication for acid reflux and the patient improves.

#### CASE STUDY 5

A doctor in an accident and emergency unit calls the psychiatrist in the learning disability team about a patient with moderate learning disability and autism who has presented in casualty screaming, punching furniture and assaulting staff. Care staff report a 2-week history of constipation. The patient has been previously known to the psychiatrist and has a history of recurrent constipation secondary to a restricted and stereotyped diet and restricted fluid intake. When constipated, the patient's behaviour becomes challenging. The psychiatrist faxes the patient's previous care plan to emergency department and advises the doctor on management.

## TRAINING AND EDUCATION

Training and education may be provided directly by the psychiatrist or by the psychiatrist supervising other team members. It may be provided to a very wide range of people (Table 1) in a considerable range of settings and can be delivered face-to-face or through training materials appropriate for tier 1. It is good practice to provide training jointly with users and family carers.

**Table 1 Training in tier 1**

Groups for whom training may be provided	Some topics for training
Partnership boards	Mental and physical health needs of people with learning disability
Other doctors	Physical health needs of people with learning disability
Other health professionals	Adjusting services for people with learning disability
Commissioners	Service provision and needs
Medical students	What is a learning disability
Education	Managing challenging behaviour
Voluntary sector workers	Communication strategies
Social Services	What is autism
Users	Roles and relationships
Carers	Understanding mental illness and psychotropic medication



#### CASE STUDY 6

As part of their psychiatry attachment, medical students visit adults with learning disability at home and at their GP surgery. They take a history and perform a physical examination. The results of the examination are fed back to the GP and the students present their visit to their peers.

## MANAGEMENT AND LEADERSHIP

The psychiatrist working with people with learning disabilities has a special expertise in the needs of this patient group, which enables him or her to perform management and leadership roles, including in the clinical role described earlier. The psychiatrist works closely with other health and social services as well as voluntary and independent services, and can use their knowledge of this network of resources to improve services for people with learning disabilities. Services in tier 1 may benefit from support in making reasonable adjustments for people with disabilities and in being responsive to patients' needs. The psychiatrist may offer direct advice or, for example, put a GP practice manager in touch with a voluntary sector agency who has a training package or helpful literature in this area. The psychiatrist may also offer advice to the learning disability partnership board about how to promote the access of people with learning disability to mainstream services.

The psychiatrist may provide input in tier 1 at local, regional and national levels, and may develop literature, provide training, contribute to audit or research or use their knowledge to act as expert advisors. They will keep up to date with advances in the medical (mental and physical) knowledge relevant to their patient population and have a responsibility to disseminate this knowledge both locally and nationally (through liaison with appropriate national bodies) to improve services for people with learning disabilities.

An important role for the psychiatrist in tier 1 is to help workers achieve an attitudinal shift towards people with learning disabilities. This is partly through training and education, partly through providing them with useful material, partly through utilising links with voluntary organisations and partly through working to support them with individual users so they are more confident in working with them.

The psychiatrist uses all of these approaches to raise awareness of mental and physical ill health experienced by people with learning disabilities.

## RESEARCH

At tier 1 research is likely to focus on access, epidemiology and aetiology, with methods likely to be qualitative and participatory. Research may involve the multidisciplinary team as well as users and family carers (participatory research).

#### CASE STUDY 7

Some general hospitals employ learning disability liaison nurses. They are alerted if a person with learning disability attends the hospital. They liaise with the person and their support networks and ensure the hospital is ready to meet the person's needs. This includes making appointments at the start of a clinic so there is no waiting time, allowing the person with learning disability to visit the hospital or see any equipment for procedures before their appointment and having visual materials available to aid communication. The liaison nurse also ensures health professionals are 'disability aware' and understand the importance of looking at and talking to the person.

#### CASE STUDY 8

Many learning disability psychiatrists provide specialist clinics in educational facilities or day centres attended by people with learning disability. This has the combined benefit of improving access to services and educating staff about mental illness and its management in people with learning disability. In one area with a high prevalence of learning disability in a minority ethnic group but low uptake of services, the psychiatrist worked with local community and voluntary agencies to set up a regular health promotion and awareness group in a local community centre. This improved communication and trust between the ethnic group and local mental health services.

#### CASE STUDY 9

Psychiatrists working with people with learning disability advise the government health department about developing health checks for people with learning disability which are then incorporated into GPs' routine work.

# Tier 2: 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.

## CLINICAL ROLE

### *REFERRAL*

Many services have developed or are moving towards a single point of access that all referrals go to, including self-referrals, referrals from carers, GP referrals, referrals from mental health teams, referrals from children's services and so on. Most services have abandoned the requirement for referrals to come through primary care as this created a barrier to access. Referrals are usually considered on a weekly basis by the community learning disability team, although emergency referrals will usually be considered on the day of receipt. All referrals to consultant psychiatrists would go through this process.

### *ASSESSMENT*

Many services have developed a joint assessment process between health and social services. This is sometimes called a 'single assessment process' and it is generally the preferred way of working to meet service user need. Risk assessment should be a core part of this process.

There is usually no requirement that psychiatrists be involved in all initial assessments, as many will be for social care needs or will address physical health needs such as access to primary care. Many service users presenting with mental health needs will not necessarily need a psychiatrist to conduct the initial assessment, although this would be advisable in some circumstances, for example:

- if it appears that urgent psychiatric treatment will be required (e.g. if there is active suicidal intent or another high-risk situation)
- if the mental health needs appear highly complex or there is substantial diagnostic uncertainty.

Psychiatrists should be available to consult on all mental health assessments where required, although it will be a professional decision by the assessors whether to consult the psychiatrist about individual cases.

## TREATMENT AND OTHER INTERVENTIONS

Complex mental health interventions will be provided in tier 3. Tier 2 interventions will be relatively short-term and will most likely arise out of assessment work. They are unlikely to require management systems such as the care programme approach or care coordination.

### CASE STUDY 10

The psychiatrist makes a diagnosis of autism-spectrum disorder following a referral for challenging behaviour in a person with severe learning disability. In conjunction with a fellow team member, the psychiatrist recommends the provision of day opportunities by a specialist provider. A follow-up visit to the provider is made to educate them about the person's needs and make further suggestions about meeting them.

### CASE STUDY 11

During the initial assessment process, which involves the psychiatrist and a social worker, a person with mild learning disability is diagnosed with an adjustment disorder following bereavement. They recommend the person to be supported to access a bereavement counselling service in the voluntary sector, which the social worker arranges.

### CASE STUDY 12

Following a diagnosis of moderately severe depression in a person with moderate learning disability made during the single assessment process, recommendations are made for extra social support and treatment with an antidepressant is initiated. The psychiatrist sees the person for follow-up at 2, 6 and 12 weeks, and because the depression has responded to treatment, the person is referred back to the GP for follow-up. The discharge letter gives clear advice on how long to continue the medication and specifies the indications for re-referral if problems should recur.

## CONSULTATION AND CLINICAL ADVOCACY

At tier 2 much of the psychiatrists' clinical work will be indirect. They are likely to be involved in ensuring that single assessments are of an appropriate standard and in making appropriate recommendations. They are also likely to provide advice about the management of individual cases to other health and social care professionals in the team.

### CASE STUDY 13

A speech and language therapist and a social worker assess a young man with tuberous sclerosis who has developed challenging behaviour in the context of some changes to his care package. They ask whether medication might help the situation. After discussing the case in detail with the assessors, the psychiatrist recommends referral to the GP to rule out physical illness as there are signs of a possible ear infection. She agrees that work on communication with the new support workers is likely to help and suggests this as a more appropriate initial intervention than psychotropic medication.

#### CASE STUDY 14

A community nurse is involved in supporting a woman with moderate learning disability through her pregnancy. The obstetrician suggests that that he perform a tubal ligation during the elective Caesarean section. The psychiatrist is involved in consulting with the community nurse about the detail of the woman's capacity assessment and strategies to ensure that a decision is made in her best interests if she lacks capacity.

#### CASE STUDY 15

The team counsellor is seeing a man with mild learning disabilities about emotional problems secondary to sexual abuse he experienced from his stepfather. The man has engaged in self-harm and sometimes talks about 'ending it all'. The counsellor discusses with the psychiatrist about how to assess the risk of harm and how to manage it appropriately.

## TRAINING AND EDUCATION

Training at tier 2 might include educating primary care workers about working with people with learning disability and about when to refer them to specialist services. Training to other team members and service providers might include issues such as supporting people with learning disability who have additional mental health problems and challenging behaviour, and managing risk. The role will also involve consulting to other team members to support them to deliver appropriate training.

In terms of medical training, the activity at tier 2 is relevant to core psychiatric trainees, specialty trainees in psychiatry of learning disability and medical students.

## MANAGEMENT AND LEADERSHIP

The psychiatrist can have an important management role at tier 2. This might include:

- clinical governance work – ensuring there are systems in place to:
  - adhere to clinical guidelines such as those provided by the National Institute for Health and Clinical Excellence (NICE)
  - ensure clinical effectiveness
  - manage risk and ensure patient safety
  - prioritise according to clinical need
  - meet quality standards in service delivery, for example Care Quality Commission standards
  - ensure staff are appropriately trained to create a capable workforce
  - ensure optimum patient/user experience of mental healthcare
  - demonstrate that improvements have been made and standards are being met through a programme of clinical audit

- supervising and managing medical staff
- service planning and development
- developing care pathways and clinical networks (e.g. for the management of dementia in people with learning disabilities).

## RESEARCH

At tier 2, research activity, where present, will be focused on:

- service evaluation and service development needs
- epidemiology of common mental health conditions in people with learning disabilities
- management of common mental health conditions.

# Tier 3: highly specialised element of community learning disability service and tier 4: specialist in-patient services

The clinical role of the psychiatrist can usefully be considered separately in two distinct tiers, but there are considerable overlaps in the non-clinical roles of the psychiatrist in tier 3 and tier 4 and they are considered together.

## CLINICAL ROLE

### *TIER 3: HIGHLY SPECIALISED ELEMENT OF COMMUNITY LEARNING DISABILITY SERVICE*

This tier consists of the more specialised part of the community-based service for people with learning disabilities. Examples include areas of specialised needs such as epilepsy, dementia, challenging behaviour and forensic services (Fig. 2, p. 11). In some services, particularly those serving larger catchment areas, separate specialist teams may exist, for example challenging behaviour teams. In others, the tier 3 services may exist as specialist functions of a larger team. Psychiatrists have a prominent role in these services.

Some work in tier 3 will be joint work with other specialist services for an agreed period of time, where there are complex needs requiring input of both services.

#### CASE STUDY 16

A woman with a moderate learning disability has developed dementia accompanied by major behavioural problems. The dementia has failed to respond to first-line treatment with anti-dementia medication. The psychiatrist from the learning disability team takes overall responsibility for the management of the case. However, the mental healthcare of older people team agree to provide advice and support to the learning disability team especially with regard to alternative pharmacological strategies and exploring social care options that will be able to meet her changing needs.

### CASE STUDY 17

A young man has a severe learning disability and epilepsy that is refractory to treatment. He also has challenging behaviour, which may in part be related to the treatment for the epilepsy. He lives with his family and his adherence to antiepileptic medication is variable. He attends a nurse-led epilepsy clinic run jointly by the neurology and learning disability nurses. Specialist advice on the management of the epilepsy is provided by the consultant neurologist and the consultant psychiatrist working with people with learning disability. The psychiatrist meets with the family together with the community nurse to explore the reasons behind the young man's problems with adherence. He also liaises with the neurologist about the possible effects of the antiepileptic medication on the man's behaviour and mental state.

For other people using tier 3 services who present a high risk to self and others and who need sustained multiprofessional specialist input, the psychiatrist could take primary clinical responsibility for a period of time. This would include people who have major mental illness and require input from more than one mental health professional and whose care and treatment is managed under the care programme approach. People with severe and dangerous offending behaviour should also be managed at this level. A core part of working in tier 3 is the use of highly specialist clinical skills, including making complex diagnostic assessments and formulating and delivering complex clinical management plans.

Once people achieve a stable clinical state a period of joint working could be embarked upon before transfer to tier 2 or to a mainstream service.

### CASE STUDY 18

A young man with mild learning disability and autism and a history of aggression is brought before the court and found responsible for an arson attack. He is given a suspended sentence and ordered to attend a fire-setters' therapeutic group. This treatment is provided by a specialist forensic team for people with learning disability (tier 3). After treatment, the forensic team assesses the man to be of sufficiently low risk to be handed over to the community team (tier 2). The community nurse maintains links with the programme tutor to ensure that the service user maintains his diary and other carers are on the alert for early warning signs of increasing risk.

The core clinical role of the psychiatrist may be across tier 3 as a whole or relate to a particular clinical service area that the psychiatrist is a part of. Figure 2 (p. 11) shows the range of mental health and psychological needs where psychiatrists are likely to have a major role in assessment, treatment and relapse prevention. All treatment should be provided as locally as possible and in the least restrictive setting possible. The role involves close working with the multiprofessional teams based in the community in learning disability services and mental health services as well as a range of in-patient teams. It also requires developing links with a range of clinical networks in the local area.



## **TIER 4: SPECIALIST IN-PATIENT SERVICES**

Tier 4 is appropriate for supporting people with learning disability when the level of risk they present cannot be met in community resources despite the highest level of support possible. This tier includes all specialist in-patient services for people with learning disabilities, ranging from local assessment and treatment services to high secure forensic services. Many in-patient services are now run by private and voluntary providers. The clinical role at tier 4 includes:

- assessment of referrals to in-patient services; this may involve liaison with community teams and other referrers to safeguard appropriateness of admission, ensuring that it is in the least restrictive setting that will meet the person's needs; where short-term admission is proposed, it is crucial to consider discharge plans at the time of admission
- assessment, treatment and relapse prevention of all people admitted to specialist in-patient care for people with learning disability
- taking a lead responsibility for the management of patients detained under the mental health legislation, including fulfilling the role of responsible clinician under the Mental Health Act
- close working with the in-patient multiprofessional team to develop and manage a patient pathway through the service that ensures that all their needs are met and minimises duplication and delay; this means close working across all tiers of the service
- maintaining strong links with in-patients who are in out-of-area placements, to ensure they are regularly reviewed and to enable them to access more local treatment where possible and appropriate.

### **CASE STUDY 19**

A young man with a moderate learning disability, autism and history of challenging behaviour was referred to the psychiatrist in the community team. He had become extremely aggressive, smashing up furniture in the residential home where he lived; the staff were too frightened to work with him, as one of them had been punched in the nose.

He was admitted to a local assessment and treatment unit for people with learning disability, because it did not prove possible to assess his challenging behaviour further in the community setting and the powers of the Mental Health Act were required to safely manage his behaviour. Short-term use of medication was required for emergency management. During the assessment, it was apparent that poor dental health and communication difficulties between the man and staff in the residential home were factors maintaining the behaviour and both of these factors were addressed. The speech and language therapist devised a communication strategy in the in-patient unit. As part of the discharge planning under the care programme approach, arrangements were made for this to be adapted for use in the residential setting. An educational programme about autism was delivered jointly to the residential home staff by members of the multidisciplinary team.

## TRAINING AND EDUCATION

Training and education in tiers 3 and 4 focuses mainly on:

- training and development of psychiatric trainees and career-grade doctors at all levels through appraisal, job planning and supervision, with a particular focus on skills relating to in-patient services and specialist clinical areas
- training and development of all professionals and care staff who have a role in meeting psychological and other behavioural needs of people with a learning disability (their range of needs is summarised in Fig. 2, p. 11)
- developing the capacity and capability of all multiprofessional teams in all tiers to increase the complexity and numbers of patients they treat routinely so that the service is increasingly delivered in the least restrictive and most accessible environment
- providing targeted training to maintain a person with learning disability in a mainstream service, for example training psychiatric intensive care unit staff in appropriate approaches to addressing challenging behaviour in people with learning disability.

## LEADERSHIP AND MANAGEMENT

At tiers 3 and 4, leadership and management roles include:

- providing medical leadership in developing a strategic vision both for the service as a whole and for individual specialist clinical areas
- participating in clinical governance, to:
  - ensure the development of clinical information systems that aid clinicians in recording clinical information
  - ensure the development of workforce plans for the service to improve quality and cost-effectiveness
  - work with other professionals to develop and implement quality outcome measures for the service
  - provide clinical leadership that enables the setting of quality standards for the service and ensuring that standards are maintained to the satisfaction of regulatory bodies such as the Care Quality Commission
  - develop systems for recording clinical effectiveness, safety and positive user experience and ensure they are used in routine clinical practice
  - ensure that audit focuses on national, organisational and professional priorities and that it is used systematically to improve services
- developing links with a wide range of mainstream services and working with them to set a strategic direction for interface working; this should include links with mental health (using appropriate standards, such as those set in the *Green Light Toolkit* (Foundation for People with

Learning Disabilities, 2004), forensic services, epilepsy services and child and adolescent mental health services

- ensuring that psychiatrists and other clinicians play a well-defined role in facilitating service redesign to improve quality by developing and delivering evidence-based, patient-centred pathways of care
- developing the expertise of commissioners to take a more strategic view; this would mean:
  - developing a shared perspective on severe and complex health needs of the population
  - developing service models with care pathways that make services more local and cost-effective as well less restrictive
  - agreeing quality standards to evaluate services
  - ensuring a holistic approach to commissioning which allows for all domains of the individual's life to be considered and fulfilled using a person-centred approach.

## RESEARCH

At tier 3 and tier 4, the role of the psychiatrist working with people with learning disability includes:

- ensuring that research activity is strongly supported and that there is a minimum delay in implementing evidence-based practice as well as improving compliance with best practice guidelines including those from NICE
- focusing research on specialist areas of need, including in-patient services
- ensuring that all initiatives in the area of audit, research and service evaluation are carried out in partnership with users and carers, who should be involved in agreeing priorities, carrying out the projects and then in implementing change
- participating in clinical trials or other interventional research and in the development of improved outcome measures for people with learning disabilities.

## WORKING WITH SERVICE USERS AND CARERS

A partnership with service users and carers is a crucial aspect of the psychiatrist's work at this level as in all tiers. Psychiatrists may interact with users and carers directly at events such as partnership boards, where service delivery is discussed. They may provide training to users and carers to develop relevant literature or information. The psychiatrist is likely to work closely with voluntary organisations or charities that have a strong user/carer presence or lead and they may also interact with users and carers to carry out research projects.

## CASE STUDY 20

Learning disability psychiatrists work with a national learning disability charity to establish a user group to advise the Faculty of the Psychiatry of Learning Disability at the Royal College of Psychiatrists. The user group takes part in a faculty meeting and runs a workshop. The workshop is turned into a play which is presented by a theatre company of adults with learning disability at an international psychiatric meeting.

# Overarching aspects

Some aspects of work that learning disability psychiatrists undertake span all four tiers, whereas other roles are not explicitly linked to the tiered model for clinical services.

## RELATIONSHIP WITH PRIMARY CARE

Developing and maintaining excellent relationships with primary care is crucial at all tiers. On the clinical front, barriers to the referral process between services can be minimised by direct communication between the psychiatrist and the GP. Establishing mutual agreement through a shared care protocol can help address issues of physical health monitoring, medication prescribing and enabling people with learning disability to access the services of other health professionals, such as phlebotomists and district nurses. It can also facilitate the discharge of service users back to primary care once their mental health has stabilised after a period of treatment under tiers 2–4. An excellent relationship with primary care also helps to address the issues of clinical risk by ensuring that therapeutic interventions are implemented swiftly through appropriate care pathways.

Training is a key aspect for the success of partnership with primary care. Enhancing the skills of GPs in identifying learning disability, as well as health and social care needs of this vulnerable population and signposting them to appropriate agencies is vital. Similarly, psychiatrists working with people with learning disability can improve their own knowledge and skills to ensure that the physical health needs of people with learning disability who have mental health problems are properly met.

An excellent relationship with primary care will facilitate appropriate commissioning of services for people with learning disability who have mental health needs, particularly with the enhanced role of GPs as healthcare commissioners.

## MENTORING

Mentoring is especially important in small specialties such as psychiatry of learning disability, where there may be only one or two consultant posts in each local area and there may be some degree of professional isolation. The consultant in the psychiatry of learning disability should have a mentor, at least at the beginning, to help their own personal development. They themselves should also act as mentors for junior consultants, specialist registrars who are preparing to become consultants, consultants in other

specialties, senior nursing colleagues who are in managerial positions as well as other non-medical members within the organisation.

## 'CATEGORY 2' AND MEDICO-LEGAL WORK

Psychiatrists for people with learning disability are involved in several other roles that are outwith the core services provided by National Health Service (NHS) organisations and Social Services. Sometimes these attract separate fees. Examples of this are:

- making assessments under mental health legislation such as the Mental Health Act 1983 (amended 2007) in England and Wales
- making assessments as a medical assessor under mental capacity legislation, for example in relation to Deprivation of Liberty Safeguards
- writing court reports, for example:
  - reports for people with learning disability accused of criminal offences
  - for the court of protection to provide evidence of lack of capacity
  - to give an opinion for the court of protection about the best interests of a person who lacks capacity.

## OTHER LOCAL AND REGIONAL ROLES

Often there are only a small number of learning disability psychiatrists in an organisation, which means that an individual may have to take on a number of wider roles. Although management is relevant to all four tiers, some management roles in the organisation, such as clinical director, medical director or clinical governance lead, span all tiers and may go beyond learning disability services altogether. The same is true of training roles such as specialist training programme director or lead for undergraduate medical education.

An awareness of issues such as ethics and the need for safeguarding both children and vulnerable adults are obvious skills required at all tiers and consultants may take on leadership roles in these areas for their organisations.

## NATIONAL ROLES

The Royal College of Psychiatrists has a crucial role in supporting clinicians in their role, as well as taking a national lead on training for junior doctors and continuing professional development for consultants working in all four tiers. It is also at the forefront of defining the future role not only in services for people with learning disability, as in this report, but also in the wider neurodevelopmental field.

# Conclusions

Psychiatrists working with people with learning disability have the primary aim of improving the mental health of this patient group. To do this effectively, they need to work within the current policy framework and embrace ideas such as person-centred planning and supporting people to access mainstream services where this is in their best interests. Psychiatrists also need to ensure that specialist health resources (including their own time) are used in the most effective way to deliver the best value to people with learning disability. The roles of the consultant in the different tiers are summarised in Table 2.

Many services around the country already adopt elements of this tiered approach to service provision. We hope that in this report we have clarified and reinforced the role of psychiatrists working with people with learning disability.

**Table 2 Roles of the consultant psychiatrist working with people with learning disabilities (crosses denote proportion of time devoted to each role)**

Tiers/roles	Clinical/ advisor	Direct clinical	Training and education	Leadership and management	Audit and research
4	+	+++	++	++	+++
3	++	+++	++	++	+++
2	++	+++	++	++	+++
1	+++		+++	++	+

# Appendix 1 Consultants in forensic learning disability psychiatry: additional roles and responsibilities

The roles and responsibilities of the consultant in forensic learning disability psychiatry overlap considerably with those of the psychiatrist working at tier 3 and tier 4 (pp. 22–27). However, there are some aspects that are specific to working in forensic settings, as set out below.

## CLINICAL ROLE

The clinical role of the forensic learning disability psychiatrist includes assessment, making a diagnosis (where applicable), management and rehabilitation of offenders with learning disability. This may be in high secure, medium secure, low secure, open ward in-patient and community settings. Important elements are multidisciplinary gate-keeping assessments for suitability for admission to forensic services and ongoing risk assessment and management as part of a multidisciplinary process (including, for example, seclusion reviews and assessment for eligibility for leave).

Preparing psychiatric reports for solicitors and the Crown Prosecution Service, and liaison work with prisons and probation services are core parts of the clinical role of the forensic learning disability psychiatrist. Working closely with these services will ensure that people with learning disability do not remain vulnerable in these settings and that they receive psychiatric help at the right time.

A substantial part of the consultant's work may be in relation to the Mental Health Act in the form of reports for managers' hearings and mental health review tribunals. For individuals subject to restriction orders, close collaboration with the Ministry of Justice is required.

At tier 3, the clinical role includes supporting forensic and non-forensic community learning disability teams as part of the habilitation and rehabilitation of service users into the community and step down from secure units. Some regions have specialist forensic learning disability community services where learning disability psychiatrists with a special interest in forensic learning disability develop their skills to provide a quality service.

Other aspects of the clinical role specific to forensic settings include:

- having an understanding of psychotherapy as it relates to offenders with a learning disability; this includes both individual and group therapy, and cognitive-behavioural therapy (CBT), which forms



the framework for sex offender treatment programmes (SOTP), is especially relevant

- measuring outcomes for clinical interventions by using the appropriate outcome measures for this population (e.g. Health of the Nation Outcome Scales (HoNOS)-secure)
- liaison work with stakeholders through relevant clinical networks and managed clinical networks, such as those for violence and aggression
- assessing risk, particularly that of harm to others (note that the assessment of risk is a core part of the clinical skills of all psychiatrists)
- maintaining a specialised knowledge of law where it relates to psychiatry
- having a clear understanding of the importance of ensuring public safety and balancing this with the medical practitioners' general duty of care to the patients; this is particularly relevant when liaising with the multi-agency protection panel and other criminal justice organisations.

## TRAINING AND EDUCATION

Specific roles in relation to forensic aspects include:

- training of other mental health staff and other professionals, including psychiatrists in specialties other than learning disability psychiatry, police, prison staff, lawyers, social workers and probation officers, on screening for, recognising and generally being aware of learning disability in their settings
- training on being an expert witness (e.g. writing medical reports for mental health tribunals, writing reports for court or attending court as an expert witness)
- enhancing the understanding of the Mental Health Act and the criminal justice system.

## LEADERSHIP AND MANAGEMENT

Additional roles specific to working with offenders with learning disability include:

- close working with management about issues in relation to the forensic service, which are often high-profile services within the organisation
- actively influencing the commissioning process and working closely with commissioners: this is likely to involve liaison with secure commissioning teams, as commissioning may be on a regional basis, in contrast to the commissioning of other specialist learning disability services
- ensuring that generic policies reflect issues in forensic services
- ensuring that there are clear links with other specialist in-patient services for people with learning disability to ascertain there are no gaps in provision.

# Appendix 2 Consultants in child and adolescent learning disability psychiatry: additional roles and responsibilities

Consultant psychiatrists who work with children and adolescents with a learning disability may work in tiers 2–4. Much of their roles and responsibilities are similar to those of consultants working with adults. Aspects of the role specific to working with children and adolescents are discussed below.

## CLINICAL ROLE

The clinical role of the consultant working with children and adolescents with a learning disability includes the assessment, diagnosis and management of children and adolescents with a learning disability who have additional behavioural, emotional or psychiatric problems. Children are seen in a variety of settings such as school clinics, hospital out-patient units, their homes, residential schools, residential children's homes and paediatric or psychiatric in-patient units. Many of these children have additional comorbidities such as autism, attention-deficit hyperactivity disorder (ADHD) and epilepsy, which may not have been recognised and which are contributing in large part to their current problems. The psychiatrist will be involved in the diagnosis and management of autism-spectrum disorders and ADHD, particularly when the diagnosis is not straightforward.

## ASSESSMENT

Specific skills include:

- the diagnosis of autism-spectrum disorders in young children and the management of significant associated problems such as aggression, self-injury, sleep disorders and severe dietary restrictions
- the assessment and treatment of ADHD in children with a learning disability (ADHD may be comorbid with autism-spectrum disorders)
- assessment of the parenting and family situation as it affects the young person

- assessment of contributing problems such as sensory disabilities, physical problems and behavioural phenotypes associated with specific genetic syndromes
- recognition of other contributing factors such as educational or environmental problems (e.g. housing difficulties and the need for social support).

## TREATMENT AND CLINICAL MANAGEMENT

Crucial to the clinical role of the consultant working with children and adolescents with a learning disability is the development of an understanding of the roles of other members of the multidisciplinary team and selecting who will be the most appropriate person/people to work with the child. These are likely to include community nurses, clinical psychologists, speech and language therapists, dieticians and occupational therapists (especially those trained in sensory integration). Many children will be seen by the team outside the traditional clinic setting in schools, respite units or in their homes.

Roles specific to working with children and adolescents include:

- close working with generic child and adolescent mental health services (CAMHS) who in some models of service will see most of the children who have a mild learning disability
- educating parents, carers and teachers about the child's specific needs
- close working with Social Services
- liaison with special education departments and special schools
- effective work with colleagues in adult learning disability psychiatry on the transition to adult services
- measuring outcomes and using assessment tools appropriate to children and adolescents with learning disability
- preparing reports including court reports in specialist areas (e.g. family court proceedings and safeguarding children); knowledge of the relevant procedures and legislation – the Children Acts and mental health legislation as it applies to children – is crucial
- making judgements about the possible need for in-patient treatment and whether this should be in a mainstream child and adolescent mental health in-patient unit or one of the few specialist in-patient units for adolescents with a learning disability
- liaising with colleagues in community paediatrics.

## TRAINING AND EDUCATION

Training may be delivered to other child psychiatrists and paediatricians, as well as other health disciplines working with children with learning disabilities, teachers, social workers and parents.

## LEADERSHIP AND MANAGEMENT ROLES

Leadership and management roles for psychiatrists in child and adolescent learning disability psychiatry are:

- liaising with commissioners for children's services and those responsible for adults with a learning disability
- working closely with trust management on service development which will most likely currently be with the mainstream CAMHS
- influencing national policy-making including work within the Royal College of Psychiatrists and the Royal College of Paediatrics and Child Health.

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