

FR/ID/06

Community-based services for people with intellectual disability and mental health problems

Literature review and survey
results

Faculty of Psychiatry of Intellectual Disability

FACULTY REPORT

Faculty Report ID/06

May 2015

© 2015 The Royal College of Psychiatrists

The Royal College of Psychiatrists is a charity registered in England and Wales (228636) and in Scotland (SC038369).

Authors and acknowledgements

Authors

Professor Angela Hassiotis, Professor of Psychiatry of Intellectual Disability, University College London

Mr Ashley Guinn, Data Officer, Hertfordshire Partnership NHS Foundation Trust

Dr Margherita Tanzarella, Consultant Psychiatrist, East London NHS Foundation Trust

Dr Jane McCarthy, Consultant Psychiatrist in Intellectual Disability, East London NHS Foundation Trust

Dr Ashok Roy, Chair, Faculty of Psychiatry of Intellectual Disability, Royal College of Psychiatrists

Acknowledgements

The authors thank John Devapriam, Sujeet Jaydeokar, Brian Fitzgerald, Kiran Purandare, Tom Berney, Sherva Cooray, Susan Johnston, Rohit Shankar, Shoumi Deb, Nick Bouras, Fabian Haut, Jennifer Dolman and Regi Alexander.

| Contents

Executive summary	5
Introduction	8
Literature review: community-based mental health services	11
Survey: community-based services	24
Appendix 1. Literature review tables	30
Appendix 2. Survey questions	34
References	37

Executive summary

This report summarises the current evidence on existing community service models for adults with intellectual disability and mental health, behaviour or forensic problems and reports the findings of a survey of community-based psychiatrists.

This complements the Royal College of Psychiatrists' (2013) Faculty of Psychiatry of Intellectual Disability's report on in-patient services, *People with Learning Disability and Mental Health, Behavioural or Forensic Problems: The Role of In-Patient Services*. Community services for people with intellectual disability have frequently been poorly planned in the UK and internationally. Despite the strong comorbidity of intellectual disability with other mental and physical health conditions, along with the increased recognition of the needs of this group, there is significant variation in the commissioning of services to target those needs and in how services interpret policy guidance. There is now a recommendation for a national mandatory commissioning framework.

Service models can be categorised as either specialist, stand-alone services or services integrated with mainstream mental health services. People with intellectual disability are diverse in terms of their presenting problems, from individuals with severe intellectual disability presenting with behaviours that pose a significant risk to themselves, to mild intellectual disability who have committed serious offences.

The literature review showed there are diverse models in place; however, there is insufficient evidence to determine which model provides the most effective care. Key findings were as follows.

- Services work better when delivered around individual need in a person-centred approach.
- People with severe mental illness and borderline intellectual functioning benefit from intensive community-based care in terms of reduced length of time in hospital.
- Positive behavioural support works well in community-based settings.
- A multi-agency approach reduces at-risk behaviours.
- There is little evidence of routine collection of outcome data by community services.

All papers included in the review recommended further investigation of the service models and the interventions offered in order to clarify whether it was the whole service model or the individual interventions offered that proved effective.

There was evidence that staff in generic mental health services and community forensic teams lack the knowledge and skills to support patients with intellectual disability. In addition, those working in the specialist community intellectual disability teams might not have the skills to assess and manage individuals presenting with offending behaviour in the community or being discharged from a secure hospital.

A small number of psychiatrists working in community intellectual disability services across England were surveyed. Several important messages emerged. There is geographical variation in the integration of health and social services: London is more integrated and other parts of the country are less integrated. Challenging behaviour teams are the most common specialist type of community service. Psychological therapies (e.g. cognitive-behavioural therapy) and specialist memory assessments are now a feature of the range of services provided by community intellectual disability teams. The most commonly reported care pathways are those for the care of people with dementia and people with challenging behaviour. Outcome measures are not used routinely, but the Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD) tool was by far the most commonly completed. The single most common development reported is the closure of National Health Service (NHS) in-patient units.

Recommendations

- 1 There is no one-size-fits-all model, but community-based intellectual disability services must take a person-centred approach in delivering care and treatment. Professionals across mainstream and specialist community teams must possess the skills and expertise to provide care for people with intellectual disability who have additional mental health, behavioural and forensic problems.
- 2 A strategic approach to the local development of pathways between specialist, adult mental health and other services, such as social care, is required to ensure positive health outcomes and a reduction in inappropriate admissions.
- 3 Community intellectual disability services are key in supporting people in their homes and local communities. However, they need to be more outcomes-focused and commissioning should encourage this approach.
- 4 More research is needed into the effective components of community intellectual disability service models.
- 5 Community services need to be supported by local in-patient facilities for the assessment and treatment of people with intellectual disability and mental health problems and offending behaviour that present an unacceptably high risk to the individual or the community.

- 6 A comprehensive survey of community services is required to provide information on the existing configuration of services and community teams to develop an effective network of community services, which can further reduce the need for in-patient care.
- 7 There needs to be a strategic approach to the development of the workforce, building on existing training initiatives to ensure that services are personalised, effective and fit for purpose, supported by a national Workforce Academy.

Introduction

In response to the Winterbourne View Report (Department of Health, 2012a), a programme of action was agreed upon (Department of Health, 2012b), to be followed by health and care commissioners with regard to in-patients with intellectual disability or autism spectrum disorder. It was planned that 'health and care commissioners will review all current hospital placements and support everyone inappropriately placed in hospital to move to community-based support as quickly as possible and no later than June 2014' (Department of Health, 2012b). Each region would put in place a locally agreed plan for high-quality care and support services for people with challenging behaviour that accords with the model of good care, to ensure that new patients do not take the place of current in-patients. Health Education England would provide appropriate staff training in supporting people with challenging behaviour. Skills for Care would improve patients' skills and qualifications so that patients can find employment. The Local Government Association would support commissioners to develop comprehensive local services and help community intellectual disability teams provide more integrated services. The Department of Health would review the prescription of antidepressants and antipsychotic medication for people with challenging behaviour and carry out an audit on challenging behaviour services to identify out-of-area placements and average length of stay in hospital.

The Bubb (2014) report revealed that progress towards achieving these objectives has been slow and highlighted the key role of community services for people with intellectual disability and mental health, behaviour and forensic problems in reducing or preventing inappropriate hospital placements.

This report summarises the current evidence on community services, including a description of current models. It aims to complement previous reports on in-patient services and people with intellectual disability in contact with the criminal justice system (Royal College of Psychiatrists, 2013, 2014a).

This document addresses the needs of adults with intellectual disability. Services for children with intellectual disability are usually provided by child and adolescent mental health services. However, many of the issues dealt with here are equally relevant to children, and we hope that our colleagues in children's services will find this document useful. Many of the behaviours and mental health problems seen in adults arose during childhood and it is vitally important that good community services are available to all young people to tackle issues

as they arise. Left unmanaged, these problems lead to additional handicaps and are harder to treat in adulthood. Transition between children and adult services is another important topic that is not discussed in this paper. There needs to be continuity of care between adolescent and adult services, with robust care pathways in place. The needs of adults with autism spectrum disorder are covered in College Report 191 (Royal College of Psychiatrists, 2014b).

There is a critical need for improvement in community mental health services offered to people with intellectual disability (Chaplin *et al*, 2009). These patients often present with comorbidities and significant mental health needs (Deb *et al*, 2001; Cooper *et al*, 2007; Morgan *et al*, 2008); the estimated prevalence of a comorbid mental health condition in this population is 30–50% (Smiley, 2005). However, people with intellectual disability and a comorbid mental health condition can have difficulty accessing the services they require. People with intellectual disability are placed into in-patient care that is usually away from their local area because of the lack of suitable community-based resources within their local services (Chaplin *et al*, 2010a).

The white paper *Valuing People* (Department of Health, 2001) advocated that more people with intellectual disability and a mental health condition should be treated within mainstream services. However, a mental health condition can be experienced differently by those with intellectual disability in terms of subjective experience and expression of the disorder (Lunsky *et al*, 2008). Additionally, when treated by mainstream mental health services, such patients can experience problems due to factors such as mental health professionals lacking knowledge and experience in dealing with patients with intellectual disability (Spiller *et al*, 2004) or challenging behaviour being attributed to the intellectual disability rather than a mental health condition (diagnostic overshadowing).

Community service models

There are a number of community service models for the treatment and care of people with intellectual disability and a mental health condition. Some of the most common models are described below.

Community intellectual disability teams/services

These multidisciplinary teams might include psychiatrists, psychologists, psychiatric/intellectual disability nurses, social workers, speech and language therapists, occupational therapists and physiotherapists. They can be run as a partnership between primary care services, social care services and specialist mental health teams. They intend to provide comprehensive support for all physical, social and mental health needs. Mental health needs can be obscured by the emphasis on social care (Chaplin *et al*, 2010b).

Generic community mental health services/ mainstream services

These multidisciplinary teams take on people with a variety of mental health conditions. The UK government's agenda is to improve access to these services for people with intellectual disability (Department of Health, 2001). However, it is often the case that staff in these services lack the skills and experience required to provide effective care for patients with intellectual disability (Werner & Stawski, 2012).

Specialist mental health in intellectual disability teams

These are often single-profession teams (e.g. nursing or psychiatry) or multidisciplinary teams with nursing, psychiatry and psychology components, whose focus is the treatment of mental health problems in people with intellectual disability. They can provide specialist assessment and treatment, along with support in accessing generic services (Sheehan & Paschos, 2013). In contrast to generic services, they usually offer a very specific range of treatments, have a fixed capacity and the staff have very well-defined roles and specific training (Bouras *et al*, 2003). Patients are often referred from primary care or generic mental health services. However, there is currently not enough of these services available and patients can have difficulty accessing them (Chaplin *et al*, 2010a).

Virtual teams

These multidisciplinary teams are composed of staff from different services/agencies who meet regularly (often via teleconference or video conference) to review people in the community whose intellectual disability is compounded by a mental health condition (Hall *et al*, 2006a). The team aims to implement person-centred care and have both preventive and treatment functions. Some might also provide inreach to in-patient services to facilitate discharge and improve contact with mainstream services. This model has been found to lead to improved functioning and reduced risk of self-neglect and harm to self or others in in-patients (Hall *et al*, 2006b).

Single point of entry

Fear *et al* (2012) described another service model offering integrated healthcare to all with a single entry point to mental health services. Following assessment, patients with or without intellectual disability are assigned to the most appropriate care pathway. This allows patients with intellectual disability to access a full range of services based on their needs rather than diagnosis. Interdisciplinary teams are supported by specialist intellectual disability services when required. This model emphasises adapting the service around the person's individual needs and engagement of the person's family in the care planning where possible.

Literature review: community-based mental health services

We followed a rapid review method and carried out searches using databases including Ovid, the Cochrane Library and Google Scholar. Search terms included 'community mental health services', 'community care models', 'mental health service models', 'challenging behaviour', 'services', 'outcomes', 'autism', 'ADHD', 'neurodevelopmental', 'intellectual disability' and 'learning disability'. Other literature included the Royal College of Psychiatrists' policy documents and national guidelines. We also consulted with co-authors and the members of the Faculty's Executive Committee about information on additional papers and local reports or service developments.

Community mental health services

In the UK, mental health services for people with intellectual disability have long been based on normalisation (Wolfensberger, 1991): encouraging people with intellectual disability to use mainstream mental health services. Community mental health services started to gain prominence in the 1970s following deinstitutionalisation, and policy initiatives increased patient numbers in the community over long-stay hospitals (Bouras *et al*, 1995). These early services were often poorly planned and few in number because the effects of mental health conditions on intellectual disability populations were underestimated (Hemmings *et al*, 2013).

In the early 1990s, there was a growing recognition of the lack of adequate care and treatment for people with intellectual disability and a coexisting mental health condition (Day, 1995). It became clear that mainstream mental health services were finding it difficult to provide adequate care for those patients and there was poor communication between intellectual disability and mainstream mental health services (Bouras, 1999). Therefore, strong working relationships and effective communication between these services was, and still is, crucial to improving the quality of care.

Despite frequent publications of reports on how to improve services (e.g. Department of Health, 1993; Royal College of Psychiatrists, 1996) many patients with intellectual disability and a mental health condition still do not receive adequate support. For example, one longitudinal

study on people with intellectual disability receiving community care found that many of these people had become excluded from mainstream care and that some services had become fragmented or diluted and unable to provide adequate support (Cambridge *et al*, 2005). The study suggested moving away from generic and diluted models to more intensive, integrated models and person-centred planning so that the patient is at the centre of the decision-making.

Community intellectual disability teams

Person-centred models have been gathering more attention. Fear *et al* (2012) implemented such a model in Gloucestershire, in which specialist mental health services were integrated to provide a single access point and care was delivered based on a person's needs rather than circumstances. They also devised 'locality hubs' composed of interdisciplinary teams (replacing community mental health teams) of 150 staff. These hubs are made up of smaller teams across different specialties working together to focus on particular patient clusters (as defined in the payment by results system; Department of Health, 2012c). This model has not been evaluated to date but it is hoped that it might allow a better response to patients across the range of intellectual disability.

There is evidence to suggest that community intellectual disability teams cannot meet the mental health needs of their patients because of barriers such as lack of teamwork, excessive caseloads, poor eligibility criteria leading to patients falling in between services, lack of staff and inadequate training of staff (Slevin *et al*, 2008). Chaplin *et al* (2009) identified a lack of strategic direction in commissioning community intellectual disability services, which leads to inadequate service provision.

The current evidence base for the organisation and delivery of mental healthcare for people with intellectual disability is inconclusive and inconsistent. It relies largely on retrospective reports and uncontrolled studies with small numbers of participants (Chaplin, 2004). A review by Slevin *et al* (2008) on the effectiveness of community intellectual disability teams found most publications were based on opinion rather than evidence. This lack of an evidence base has led to huge inconsistency in the service models implemented across the UK (Chaplin *et al*, 2009). Hemmings *et al* (2014) advocate that future research needs to focus on service components such as responses to crisis rather than whole-service models, and suggest that the way forward is to develop new ways of working with professionals in mainstream mental health and forensic services.

A survey by Moore & Thurley (2011) brought further insight into the inefficiency of community intellectual disability teams. It found that a large amount of time was spent on administration and inputting data

into IT systems and therefore less time could be spent on care management and face-to-face contact with patients. There were regional variations in time spent on patient contact and it was also found that while integrated teams did not differ from non-integrated teams in terms of time spent on patient contact and care management, more time was spent on administrative tasks. It was proposed from this survey that community intellectual disability teams could be more effective by implementing consistent IT systems across services, reducing administrative tasks and increasing time spent in contact with patients.

Moore & Thurley (2011) proposed the following roles/priorities for community intellectual disability teams:

- delivering specialist interventions and advice
- reducing health inequalities
- supporting health professionals in general and mental health services
- reducing out-of-area placements
- supporting personalisation
- improving safeguarding in services
- supporting patient transition between teams (e.g. child to adolescent)
- developing strong working ties with criminal justice system.

Generic mental health teams

Coelho *et al* (1993) looked at a mainstream community mental health team that randomly assigned patients to an active treatment model of increased contact with professionals or a standard case model. They found that in comparison with the standard model, the active model led to increased functional behaviours and reduced challenging behaviours. The researchers reasoned that this was because the more intensive active model allowed improved observation of mild symptoms and so it was easier to prevent the patients from reaching crisis. To this end, it was also observed that while patients treated by the active model used acute in-patient services more, fewer required long-term hospitalisation compared with those receiving standard care.

Specialist mental health in intellectual disability teams

Chaplin *et al* (2008) and Hemmings *et al* (2013) describe a team known as Mental Health in Learning Disability (MHiLD), which delivers care to targeted patient groups, offers a specific range of treatments, has a fixed capacity and has clear roles and responsibilities of staff

members (reducing role blurring and conflict). The MHiLD team is led by a consultant psychiatrist and also includes trainee psychiatrists and community mental health nurses with expertise in intellectual disability. The service is flexible and offers assessment, review and intervention via out-patient clinics, outreach work, day centres, home visits and telephone. The team is often involved in multidisciplinary reviews as well as providing advice to other services by expert consultation. The service also works with child and adolescent services to provide help for patients approaching 18 years of age and about to transition into adult services.

Intensive community-based services

Minnen *et al* (1997) compared 25 patients treated in a hospital with 25 patients who received outreach treatment from a community intellectual disability team. They found that outreach treatment was equally effective at reducing psychiatric symptoms and was also more cost-effective. In addition, Hassiotis *et al* (2000) found that, in people with psychosis and borderline intellectual functioning, intensive community care led to significantly less time spent in hospital in comparison with standard care.

Views of professionals

Hemmings *et al* (2009) used the Delphi method to gather a consensus opinion from mental health professionals on what should be provided by community services for patients with intellectual disability and psychosis. The highest-rated components were 'a focused approach to the presenting problem' (e.g. monitoring of mental state, medication and access to a crisis plan and out-of-hours support) and 'a need to work within a wider context' (e.g. improving patient access to social, leisure and occupational activities and accommodation, and support and advice for family/carers on mental health issues).

Another study collated data from semi-structured interviews with professionals from specialist intellectual disability services on the important components of community intellectual disability services (Hemmings & Al-Sheikh, 2013). Themes identified were clarity of purpose, training in assessment of dual diagnosis, providing a person-centred service, flexible delivery and care that is holistic, multidisciplinary and evidence based. It also identified a need for clear, local care pathways and improved joint working between mainstream mental health services and specialist intellectual disability services. See Appendix 1 for a summary of studies found in the literature for models of community mental health services.

Challenging behaviour services

'Challenging behaviour' is a term that covers many different forms of socially unacceptable behaviour, from self-harm and inappropriate verbal habits to physical violence (Naylor & Clifton, 1993). Challenging behaviour is fairly common, occurring in around 10–15% of people with intellectual disability (Royal College of Psychiatrists *et al*, 2011). Most importantly, people with intellectual disability and challenging behaviour need the most contact and resources from community services (Slevin & Sines, 2005). However, this group finds it harder to obtain help from these services (Emerson *et al*, 2000). The publication of the Mansell Report (Department of Health, 1993) led to the development of specialist, community-based, challenging behaviour services that could offer support to mainstream services. It was also suggested that the development of community support teams, residential services and occupational/employment schemes would be important in supporting the behavioural programmes.

There is currently a mismatch between the needs of patients with intellectual disability displaying challenging behaviour and the services available (Royal College of Psychiatrists *et al*, 2011). A government report made recommendations about the core principles that should guide services for challenging behaviour (Local Government Association, 2014). Specialist local services should have a clear positive behavioural support (PBS) pathway and local policies should reflect this. PBS is a multi-component framework that is known to work well in community-based settings and can lead to reductions in challenging behaviour and medication use and to improved quality of life for some patients (Carr *et al*, 1999; McClean *et al*, 2007). The report recommends that specialist services should also support generic services in using PBS alongside person-centred care, ensuring that patients are provided with meaningful activities and routines.

Challenging behaviour services can be either integrated into or separated from community intellectual disability services (Queensland Centre for Intellectual and Developmental Disability, 2002). An example of such a service is the intensive support service (ISS), which is located in Glamorgan, Wales. This is a small team of clinicians, with a ring-fenced budget, access to a six-bed admission unit and a peripatetic support team. This model has been found to significantly reduce challenging behaviour and mental health problems as well as improve patients' quality of life and adaptive behaviours (Lowe *et al*, 1996). Allen (1999) compared groups of patients who received treatment from this service and were either successfully (maintained group) or unsuccessfully (breakdown group) maintained in the community. They found few behavioural or psychiatric differences between the groups, but only 50% of the breakdown group received ISS input at the time they experienced placement breakdown, whereas 100% of the maintained group received ISS input. Overall, 93% of the breakdown group had previously received ISS input, suggesting that longer-term support

for these patients was needed. Additionally, the breakdown group were more likely to come from services that were poorly organised and had suboptimal resource utilisation. Therefore, while specialist services can lead to positive outcomes for patients with challenging behaviour, if managed inadequately they can result in no improvement or worse outcomes.

McGill *et al* (2010) identified 46 peripatetic services of teams with two or more members of staff focused on addressing the behavioural needs of the individual and identified as additional service provision to the person (therefore, not part of the services that support them on a day-to-day basis). The teams were given the opportunity to complete an online questionnaire regarding how their team operated on a daily basis; 20 services responded to the survey. The results suggested services are similar throughout the country and that they perceived success in the services they offered. Further research is needed to ascertain if it is the individual peripatetic service that is effective or the interventions that it offers. Studies examining behavioural interventions across services would help identify which factors influence the effectiveness of the peripatetic teams.

Out-patient approach

Many factors can hinder the local treatment of patients presenting challenging behaviour, leading to a lack of integration into the community (Andrea Barron *et al*, 2011). Lehrer & Ott (2009) followed patients with persistent challenging behaviour who were referred to a university-affiliated, interdisciplinary out-patient hospital clinic. It was found that this approach allowed more consultations, more evaluation of professionals providing care and a more comprehensive treatment plan, leading to significantly reduced levels of challenging behaviour. Patients' family members also reported improved patient quality of life and more involvement in the community.

McKenzie (2011) noted that many staff working in community settings report that they lack knowledge of and training in dealing with challenging behaviour. Methods such as applied behaviour analysis were difficult to apply outside a structured environment. McKenzie *et al* (2009) implemented a community-based project for four individuals with challenging behaviour. Psychology graduates, supervised by a clinical psychologist, supported the patients in their own homes. The project, which ran for a year, showed a decrease in challenging behaviour; a positive experience was reported by both staff and patients. While these results are promising, the project needs to be evaluated on a larger scale.

Assertive community treatment

Originally developed as an alternative to in-patient hospital treatment (Stein & Test, 1980), assertive community treatment (ACT) teams act

as a support system for patients to help them increase autonomy and improve coping skills and community integration. These specialist teams form intensive, long-term relationships with patients who have had difficulty working with services. They offer a range of supports such as psychological therapy, medication management, help with daily living and supporting the patient's family. Meisler *et al* (2000) was the first to apply the ACT model to patients with intellectual disability and a mental health condition. This model is described as an interdisciplinary team with blurred roles and shared responsibilities. Treatment, rehabilitation and support services are fully integrated to provide high continuity of care. Assertive outreach can be carried out either by a select group of professionals within a community intellectual disability team or by a single independent team of specialists led by a consultant psychiatrist or psychologist (Hassiotis *et al*, 2003).

Two randomised, controlled trials have evaluated ACT in people with intellectual disability who present with both a mental health condition and challenging behaviour. Oliver *et al* (2005) found no significant differences in global function and burden/quality of life outcomes between ACT and standard care. Martin *et al* (2005) found a trend towards better outcomes (unmet needs, carer burden, functioning and quality of life) with standard care over ACT, but these differences were not statistically significant. Furthermore, the group receiving ACT showed more behavioural problems, as measured by the Aberrant Behavioural Checklist (Aman *et al*, 1985). Standard care and ACT in these studies seemed to differ mostly by intensity of the treatment, with ACT being more intensive. In both studies, the treatment received by the two groups was similar and both could be considered assertive (Oliver *et al*, 2005). Future studies must make sure to evaluate aspects of ACT that could actually benefit patients, rather than just the intensity of the treatment.

The ACT models used in these studies differed from each other and the original model (Hemmings *et al*, 2008). When Hemmings and colleagues interviewed professionals delivering ACT, these professionals felt their services should be more similar to the original model devised by Stein & Test (1980); for example, holding weekly team meetings and having a shared case-load, a practising team leader and good continuity of staff. The professionals also felt it was unrealistic and unnecessary to work too intensively with patients, such as providing 24 h coverage, having a low intake rate and having a no drop-out policy. It was concluded that, since the ACT model can be difficult to define and implement for this patient group, it might be more useful to evaluate broader models of specialist, community-based services.

Ayres & Roy (2009) described the benefits of a multi-agency approach and the development of a supported-living outreach team to enable people with complex and severe psychiatric and behavioural problems to be assessed, treated and given longer-term support in the local community. The amount of support offered varies depending on the patient's needs, but has the goal of developing independent living skills so that patients can function well within the community.

Ayres & Roy found that this approach provided value for money by significantly reducing patient risk/challenging behaviour and therefore reducing the need for high levels of support for patients with severe challenging behaviour.

Specialist forensic community services for adults with intellectual disability

Although the literature on challenging behaviour in people with intellectual disability is very extensive, the dividing line between challenging and offending behaviour can be imprecise (Royal College of Psychiatrists, 2013, 2014a). The assumption that all such behaviours are a consequence of institutional lifestyles, and would subsequently diminish once community care is introduced, might be flawed (Holland *et al*, 2002).

Although it is theoretically possible to provide services for those with intellectual disability in generic mental health settings, a lack of specialist skills in the diagnosis and treatment of mental disorders in people with intellectual disability within such teams is a sizeable obstacle (Cumella, 2009) and the relatively small numbers of cases give the staff little opportunity to gain the necessary skills (Moss *et al*, 1997). Similarly, staff within specialist community intellectual disability teams might not have the specialist skills to deal with the assessment and management of offending behaviour and forensic issues (Devapriam & Alexander, 2012). In-patient intellectual disability forensic services provide an environment that emphasises care and treatment rather than punishment (Hollins, 2000; Kingdon, 2005) and should really only be for the small number of patients who present risks above the threshold for safe management in the community. In light of the scrutiny of in-patient facilities for people with intellectual disability following the Winterbourne scandal and the national response to it (Department of Health, 2012a,b), it is imperative for clinicians to decide on the appropriateness and requirement of in-patient treatment.

Setting up community forensic services for those with intellectual disability can help modify some of these drivers and reduce the number of patients who end up in in-patient forensic services. Equally, these services can also facilitate the care pathway of those discharged from secure in-patient facilities to less restrictive settings and improve long-term outcomes. This is particularly important because people who are discharged from these facilities have problems and risks that continue well after discharge, with a small number remaining disturbed and challenging after many years (Alexander *et al*, 2006, 2011). In-patient forensic services that wish to provide good treatment outcomes for their patients should therefore see it as being in their own interest to have skilled community teams who can provide appropriate support to these patients long after discharge (Devapriam & Alexander, 2012).

Three community forensic intellectual disability teams have been described in the literature. Benton & Roy (2008) described the first 3 years of a community forensic service for people with intellectual disability in Birmingham. Dinani *et al* (2010) reported on the first 8 years of a tertiary community forensic team for people with intellectual disability in Avon. Devapriam & Alexander (2012) described a tiered model of community forensic provision established in collaboration between the NHS and the independent sector. These kinds of services are best understood within the framework of a tiered model of service and the categories of in-patient beds described by the Royal College of Psychiatrists (2011, 2013) and could greatly help to minimise the risk of inappropriate hospitalisation.

International literature

Ireland

Ireland's National Disability Authority (2003) found inequality in the mental health treatment provided for people with intellectual disability. It recommended the development of community intellectual disability teams: specialist teams for people with intellectual disability and a mental health condition that would receive referrals from and work closely with generic intellectual disability teams. These multidisciplinary teams would be integrated into the generic community mental health team and provide coordinated care for the individual, including assessment, treatment and reviews. They would also help the individual access the services required for treatment. Eight of these teams, each serving a population of around 450 000, was estimated to be sufficient to meet the mental health needs of people with intellectual disability in Ireland. These teams would offer liaison and education to other service providers. However, there have been no further publications on the implementation or progress of these teams.

USA

As in the UK, patients with intellectual disability in the USA have found it difficult to access mental health services because of a long-standing division between mental health and intellectual disability services (Hackerman *et al*, 2006). An early study by Torrey (1993) recognised that integration of mental health and intellectual disability community services is important in providing adequate care. Administrative distinctions left some people with intellectual disability and a mental health condition trapped in the gap between mental health and intellectual disability services. In 1999, the Developmental Disability Assistance and Bill of Rights Act led to the development of university centres for the treatment of people with intellectual disability and a mental health condition.

Mental health services for people with intellectual disability are usually offered by consultants, university-affiliated programmes and out-patient clinic services. The Rochester model, in which a

specialist out-patient team provides mental health support as part of a generic mental health team or a developmental disability service, is also implemented in some areas (Queensland Centre for Intellectual and Developmental Disability, 2002). After becoming involved in a class action lawsuit, the state of North Carolina devised an integrated and coordinated care system across services for those with a dual diagnosis of intellectual disability and mental illness.

Polgar *et al* (2000) surveyed 100 programme leaders and found that the networking of mental health and disability services allowed good coordination of facilities such as health, housing, social and occupational services. Good cooperation between programme leaders allowed increased service variety and interorganisation linkage, leading to better access to care for patients. Key areas of good practice included a single point of entry and special linkages of disability services to other services.

Australia

Overall, mental health services for adults with an intellectual disability in Australia are regarded as unsatisfactory (Molony, 1993; Trollor, 2014). This is due to problems with limited psychiatric input, negative attitudes and a lack of education among professionals around the mental health needs of patients with intellectual disability (Einfeld *et al*, 2006). Mental health conditions in those with intellectual disability often go undetected because of a number of barriers, such as general practitioners being unaware of the mental health needs of this group and carers/family being unable to relay psychiatric symptoms to professionals.

Service development across Australia has been poorly coordinated and varies widely between states (Queensland Centre for Intellectual and Developmental Disability, 2002). In Victoria, the Gippsland Dual Disability Evolution Project was implemented to conceptualise and analyse a model of service delivery for adults with dual diagnosis (Chesters *et al*, 1999). Victoria also has a state-wide psychiatric service specifically for those with a dual diagnosis. In some states, such as New South Wales, there are research centres for intellectual disability that also provide general health clinics for patients. Yet several states, for example Tasmania and Western Australia, do not have any specialist services specifically for those with a dual diagnosis.

Overall, it seems there needs to be improved networking and sharing of resources between states to provide consistent service and reach as many people as possible. A report has identified that, to improve how intellectual disability services deal with patients with mental health problems, there needs to be better access to mainstream services and specialist services available when this is not possible (Bennett, 2014). A national roundtable (NSW Council for Intellectual Disability, 2013) suggested several key areas for action: making reasonable adjustments; effective communication; interagency working; and more policy developments specifically addressing the needs of people with intellectual disability.

Europe

The BIOMED MEROPE project compared mental health services for those with intellectual disability across five European countries: Austria, England, Greece, Ireland and Spain (Holt *et al*, 2000). This comparison was carried out via a literature search as well as collecting questionnaires from and interviewing service providers in each participating country. It was found that normalisation was taking effect across all five countries, with deinstitutionalisation and integration into communities becoming more common. However, although the mental health needs of people with intellectual disability were being recognised, there was often a failure to implement recommended guidelines because of unclear policies and a lack of planning.

Mansell (2006) examined the effect of deinstitutionalisation and the quality of community services across different countries in Europe, North America and Australasia. The main finding was that community-based models led to superior outcomes for patients in comparison with institutional care. However, Mansell also identified some problems with deinstitutionalisation: for example, he was critical of a market-based approach to managing health needs, which leads to internal competition between providers and an emphasis on quantity of places available over service quality.

See Appendix 1 for a summary of international studies related to models of community mental health services.

Commissioning for the future

The Learning Disability Professional Senate, which represents the views of professional bodies, commissioners and families of people with intellectual disability in the UK, summarises the core functions of community intellectual disability health teams and recommends that these are specified while commissioning community services as follows (National Learning Disability Professional Senate, 2014).

- Improving access by providing a positive link with mainstream health services through health promotion, facilitation and liaison.
- Providing direct, specialist, therapeutic input for people with mental and behavioural needs through assessment, formulation, treatment, training, advice and coordination of care and support.
- Supporting other services to deliver person-centred care through clinical advice, signposting, training, workforce and service development.
- Crisis response role through crisis prevention, crisis management and planning in partnership with other providers and with commissioners.
- Strategic service development and quality assurance function alongside commissioners.

The Joint Commissioning Panel for Mental Health (2013), in its guidance for commissioning community services for people with intellectual disability and mental health problems, highlights several needs.

- Working alongside local primary care and acute services to ensure good access and timely support for dealing with physical health problems.
- Working alongside local mental health services to ensure good access and effective treatment and support from mainstream mental health services.
- Providing specialist therapeutic input for the assessment and management of mental illnesses, behaviour problems, autism and developmental disorders as well as offending behaviour.

After the unsuccessful attempts to reduce reliance on in-patient care as recommended by the Bubb report on Winterbourne View (Bubb, 2014), it is even more important to enhance the role of specialist community services, including the systematic development of skills regarding effective management of challenging behaviour. This report highlights the role of community-based providers and the need to systematically develop the skills of the community workforce through the creation of a national Workforce Academy.

Commissioners must accept more responsibility for their commissioning decisions, decommission inappropriate services and encourage, rather than stifle, person-centred, innovative systems of care. Personalised services need not be more expensive, but standards must be actively improved. The Bubb report (Bubb, 2014) calls for a national mandatory commissioning framework for services for people with intellectual disability.

Conclusions

Community-based services for people with intellectual disability vary widely, both regionally and internationally. Research into the effectiveness of such models is limited and the evidence base is not strong enough to determine which model provides the most effective care. Some randomised, controlled trials have provided evidence that intensive care is superior to standard care.

Studies collating the opinions of mental health professionals emphasise that care should be patient-centred, holistic, multidisciplinary and evidence based. Other research evidence suggests that there is a need for improved staff training in the assessment of those with a dual diagnosis of intellectual disability and mental illness within mainstream mental health services and also improved expertise within forensic community teams for the care of offenders with intellectual disability. It is suggested that this, coupled with strong interagency working, will ensure patients are receiving appropriate care.

Further research is required and should focus on evaluating services by results and outcomes, not by their intentions. The structure of services should be respectful of the population served, skill mix and structures of staff available (with plans to enhance and develop skills) and be determined by local needs and the geography in which the service is delivered. The requirements of a dense city population differ vastly from those of a geographically dispersed rural population.

Survey: community-based services

Method

The Faculty of Psychiatry of Intellectual Disability at the Royal College of Psychiatrists carried out a survey of members about current community intellectual disability service models in England. Data for the survey were collected over 1 month. The survey was emailed to 310 members of the Faculty who are consultant psychiatrists with the psychiatry of intellectual disability as their main specialism. There were 65 respondents and 53 complete responses: the response rate was therefore 20%.

Results

There was a good geographical dispersion of respondents from across England, with the top four areas by number of respondents being the South East, Yorkshire, West Midlands and North Central/North East London (Table 1). For the purposes of this report, the areas are referred to as the South, North, Midlands and London.

Table 1 Location of survey respondents

Region	Respondents
South East (Kent, Surrey, Sussex)	14%
West Midlands	14%
Yorkshire	12%
London (North Central and North East)	12%
North West	6%
South West	6%
Trent	6%
Eastern	6%
London (South West)	4.5%
North East	4.5%
London (North West)	3%
South East (Oxford, Buckinghamshire, Berkshire)	3%
South West (Wessex)	3%
London (South East)	1.5%
North West (Mersey)	1.5%
East Midlands	1.5%

The most common model for community intellectual disability teams was the generic community intellectual disability team (84%; Fig. 1). Next were specialist challenging behaviour services (21.5%), stand-alone mental health intellectual disability teams (16%) and neurodevelopmental disorders services (16%). The 'other' category (11%) included two intensive support teams, two integrated teams, a child and adolescent mental health team and a specialist epilepsy service. These findings suggest that mainstreaming has become a regular feature of ordinary practice. It also suggests that the majority of teams (70%) categorise themselves under one particular model. Seventeen teams had multiple functions.

The majority of services (71%) were not integrated with social care. Service integration with social care had an effect on other variables within the survey. For example, integration differed markedly by area (Table 2), with London being the only area where teams integrated with social care (69%) outnumbered those who are not (31%). This is

Integration with social care	London	South	North	Midlands
Integrated	69%	20%	8%	20%
Not integrated	31%	80%	92%	80%

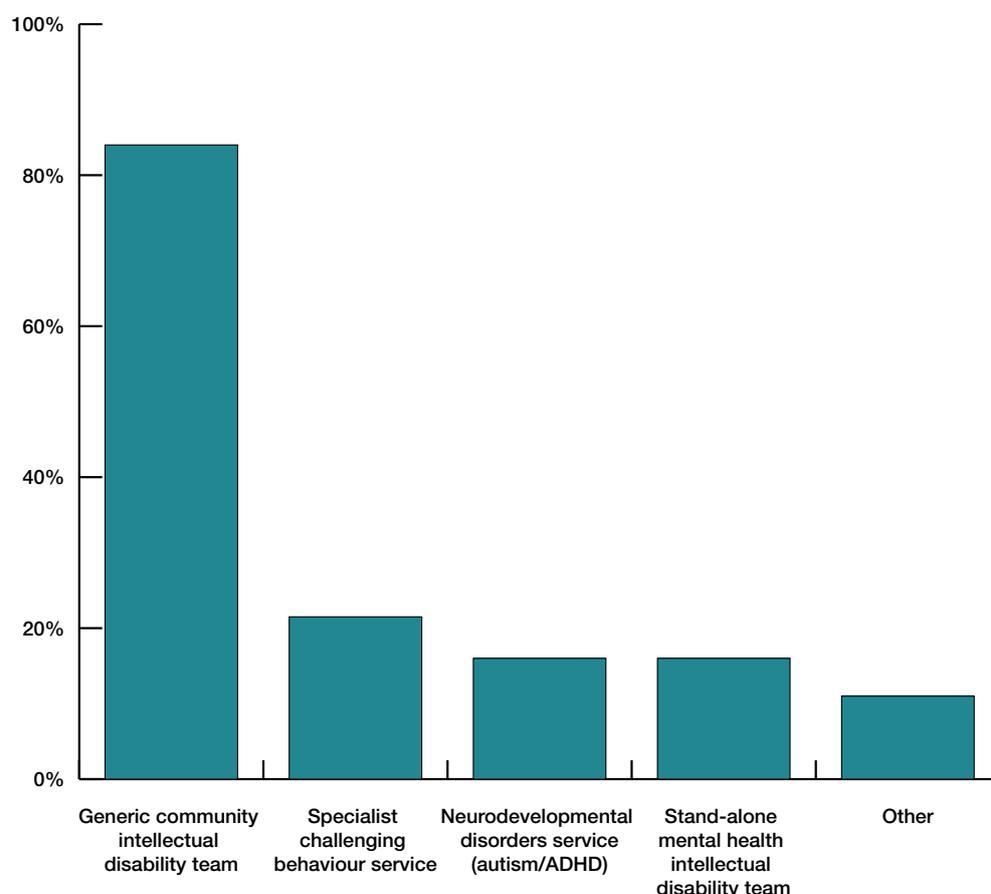


Fig. 1 Models of community intellectual disability services that respondents identified their teams as operating under (more than one answer could be selected). ADHD, attention-deficit hyperactivity disorder.

in contrast to the North, where only 8% of teams were integrated with social care. Likewise, only 20% of teams in the South and Midlands areas were integrated.

The most common intervention offered by the respondent's own team was psychological therapy (85%; Fig. 2). Acute in-patient services were also frequently part of community teams (54%). Some teams offered memory clinics (37%) and crisis intervention (31%), but assertive outreach (23%), rehabilitation (21%) and early intervention (12%) services were less frequently offered. Overall, 75% of community intellectual disability teams offered more than one type of intervention. Community intellectual disability teams integrated with social care offered a wider variety of services.

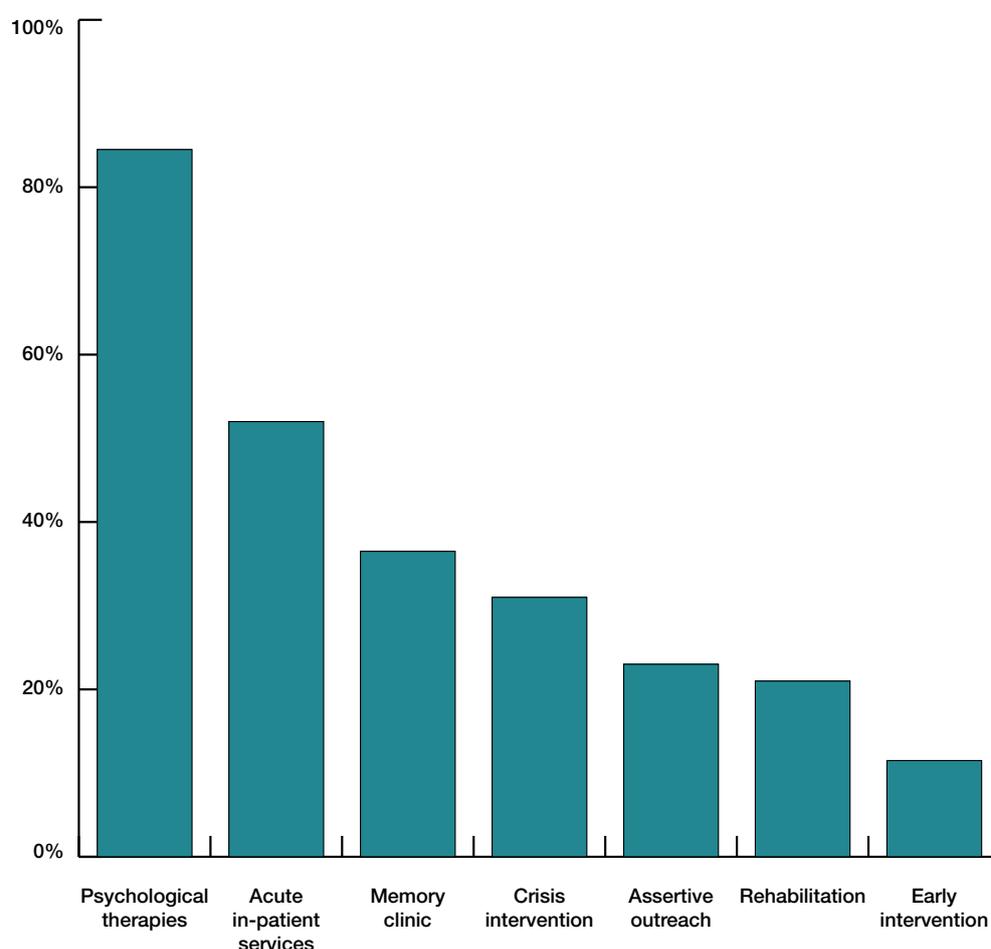


Fig. 2 Additional interventions offered by the respondent's service (more than one answer could be selected).

Mental health liaison status	London	South	North	Midlands
Offers a mental health liaison	85%	73%	69%	40%
Does not offer a mental health liaison	15%	27%	31%	60%

The majority of services offered liaison with mainstream mental health services (61%; Table 3). This was true of all regions except the Midlands, where the majority of services did not offer mental health liaison.

The most common types of external psychiatric services that respondents referred patients to (Fig. 3) were crisis and acute in-patient services (both 82%), followed by early intervention services (39%) and Improving Access to Psychological Therapies (34%). Respondents did not frequently refer patients to assertive outreach programmes (21.5%), assessment services (21.5%), memory clinics (19.5%) or rehabilitation services (16%).

The majority of respondents were aware of local care pathways related to mental health services for adults with intellectual disability (58%). In total, 26 respondents specified which local care pathways they were aware of: 8 respondents mentioned pathways related to joint working of mental health and intellectual disability teams; 7 respondents mentioned dementia/memory assessment pathways; 5 mentioned challenging behaviour pathways; and 1 respondent was aware of an autism pathway (Fig. 4).

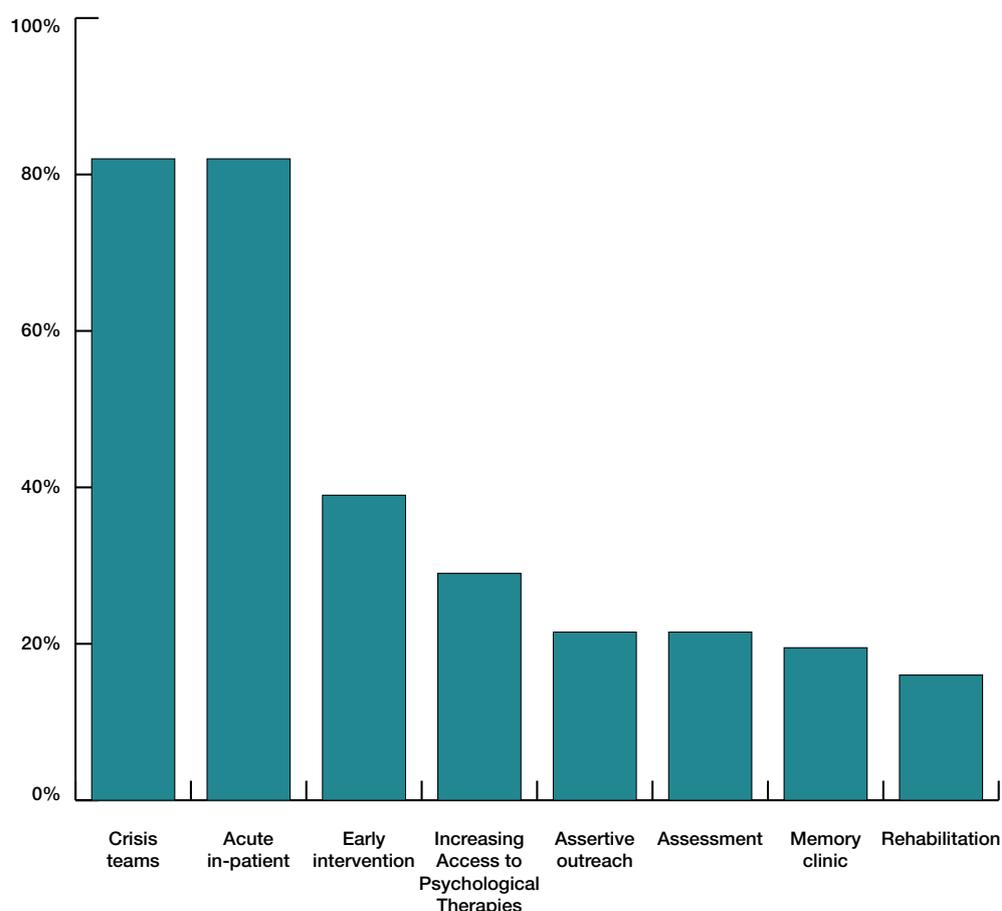


Fig. 3 External psychiatric services used (more than one answer could be selected).

The majority of community intellectual disability teams implemented outcome measures in routine practice (66%). The most commonly used tools were:

- HoNOS-LD (Roy *et al*, 2002) – 78%
- Aberrant Behaviour Checklist (Aman *et al*, 1985) – 27%
- Psychiatric Assessment Schedule for Adults with Developmental Disabilities (Moss *et al*, 1996) – 16%
- Early Detection of Dementia in Adults with Learning Disabilities (Eurlings *et al*, 2006) – 5%
- Assessments of Motor and Processing Skills (www.innovativeotsolutions.com/content/amps) – 3%.

The majority of respondents were not aware of any plans for commissioning or decommissioning services in their local area (76%). For those who were aware of such plans, they most frequently reported the closure of in-patient beds/services (56%). This was often reported to be coupled with the commissioning of intensive, community support services in compensation. Setting up accommodation/housing for people with intellectual disability was also mentioned.

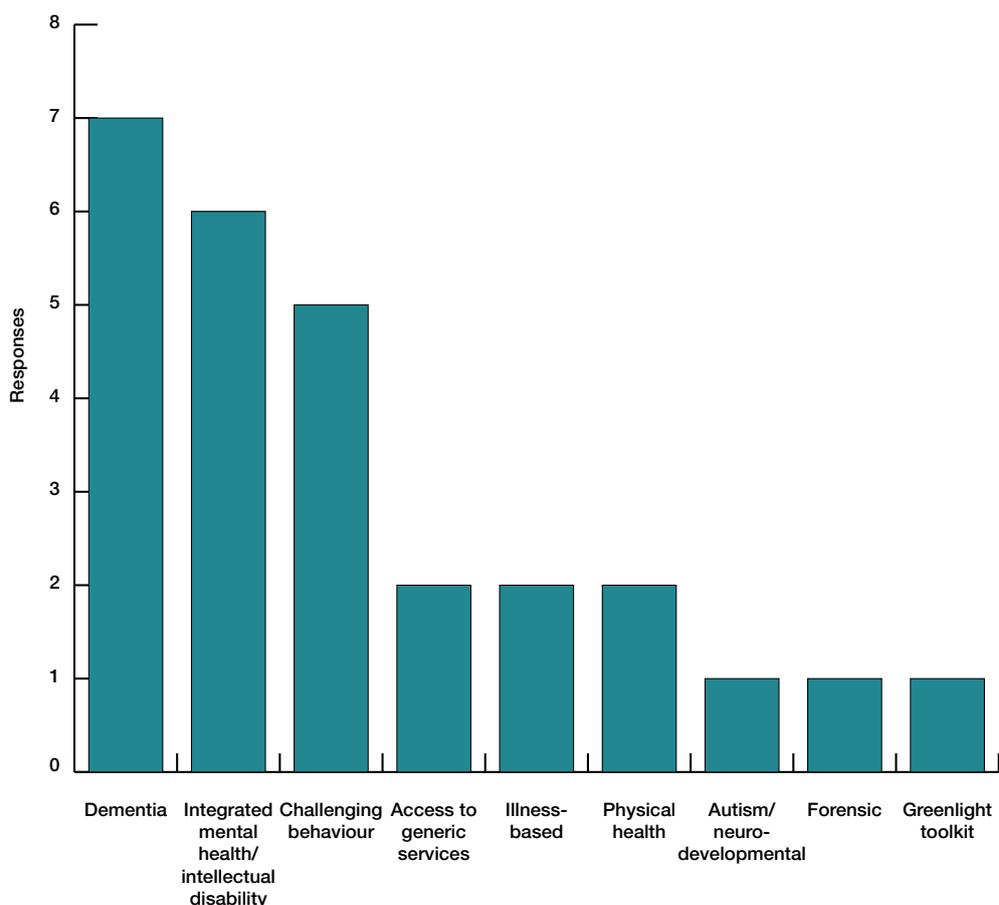


Fig. 4 Local care pathways that respondents worked within or were aware of.

A variety of opinions were offered in this survey regarding the service developments respondents felt would be important for their local area:

- increasing numbers of intensive support teams and greater integration
- increased access to mainstream mental health services and growing awareness of intellectual disability within these services
- developing more robust community services and assertive outreach services to meet the needs arising from decommissioning of in-patient services.

Discussion

This survey was limited because of a low response rate and its limited geographic coverage, making the findings difficult to generalise. It did not take into account services where more than one consultant worked in a community team. This could be overcome by a more systematic trust-by-trust survey, which would provide a more accurate picture of community services.

There was considerable variation in the level of mental health liaison provided by intellectual disability services. Similarly, there were differing levels of integration with the local authority Social Services depending on the geographic region. There was evidence of the use of care pathways, especially in the area of dementia, mental illness and challenging behaviour. Acute in-patient services and crisis teams were frequently used by community teams in the sample. The in-patient services were frequently provided by intellectual disability services rather than mainstream mental health services.

Community intellectual disability services are key in supporting people with intellectual disability in their homes and local communities. However, they need to be more outcomes-focused and commissioning should encourage this approach. Commissioners and providers need to work in partnership to create local community-based services that are personalised, effective and safe. More research is needed into the effective components of community intellectual disability service models and care pathways for adults with mental health, behavioural and forensic problems in reducing the use of in-patient services.

Appendix 1.

Literature review

Table A1 International studies of models of mental health services for people with intellectual disability

Study	Population (area)	What they did	What they found
Torrey (1993)	6 case studies of people with an ID and mental health condition	Discusses how to treat people with an ID and a mental health condition in the community	Professionals should focus on the clinical needs of patients and try to reduce administrative barriers.
Holt <i>et al</i> (2000)	Service providers across 5 countries (Austria, England, Greece, Ireland and Spain)	Carried out a literature review as well as collected data from questionnaires and interviews with service providers	Mental health needs of those with ID were not addressed on a national level, except in England and Ireland. However, there were still gaps in these countries' services. Normalisation has taken effect across all the countries. Policy tends to separate disability and mental health, rendering the full service needs of this group invisible.
Polgar <i>et al</i> (2000)	100 program leaders of the Thomas S class service (North Carolina, USA)	Conducted a survey about a coordinated care system for those with a dual diagnosis	Single entry point improved accessibility. Linkages of mental health and disability services allowed better coordination of health, housing, social and occupational services offered. Cooperation of program leaders led to increased service variety and interorganisation linkage.
Hackerman <i>et al</i> (2006)	210 patients at special needs clinic that provides comprehensive treatment for people with intellectual disability and a psychiatric illness (Baltimore, USA)	Reports on the clinical characteristic and service utilisation of patients using the clinic	Factors supporting a good service include professionals having expertise with patient's condition, good relationship with other disability and mental health services, and good understanding of targeted behaviours.
Mansell (2006)		Identifies problems of deinstitutionalisation and current community service models for people with intellectual disability	Changes required: improving quality of life of patients and allowing staff to provide more facilitative support, especially for patients with more complex needs.

Table A2 UK studies of models of mental health services for people with intellectual disability

Study	Population (area)	What they did	What they found
Cambridge <i>et al</i> (2005)	275 people with intellectual disability and 125 people with a mental health condition (Kent)	12-year, longitudinal study looking at the community care of patients who had previously been admitted to hospital	Found many services became fragmented. Supports community care modes of integrative services and a person-centred approach.
Hall <i>et al</i> (2006b)	37 participants: 19 in in-patient care, 18 in community care (London)	Assessment of an integrative mental health service model; participants were assessed across three time-points for outcomes such as symptoms, risk, needs met and level of functioning	Significant improvements in outcome measures were seen for participants. Supports mainstream services working across health and Social Service boundaries.
Chaplin <i>et al</i> (2008)		Description of Mental Health in Learning Disabilities (MHILD) services in four South London boroughs	MHILD provides specialist mental health care for 600–800 people with intellectual disability in the London area. MHILD works across several interfaces including adult mental health services, community intellectual disability teams, the independent sector, Social Services and local authorities to provide optimal care.
Slevin <i>et al</i> (2008)		Literature review of community intellectual disability teams	Lack of evidence-based literature. The teams are not efficient enough to meet the mental health needs of patients.
Chaplin <i>et al</i> (2009)		Evaluates care given to people with intellectual disability and a mental health condition	Mainstream mental health services are not good enough for people with intellectual disability. Commissioners must work with staff/professionals to improve services.
Hemmings <i>et al</i> (2009)	49 multidisciplinary professionals: 29 psychiatrists, 12 nurses, 5 psychologists, 1 operational manager, 1 social worker, 1 occupational therapist (UK)	Used the Delphi method (a series of questionnaires), which allowed consensus on important components for community services for adults with psychosis and intellectual disability	Most important service provisions were a need for focused approach to the patient and their illness (e.g. monitoring mental state, monitoring medication, access to crisis plan, out-of-hours support, care coordinators, risk assessment/management, care programme approach) and the need to work within the wider context of the patient (make sure they are engaged with recreational activities, have appropriate housing, adequate advice/support for patient and carers/families).
Fear <i>et al</i> (2012)	Interviews of patients, carers, commissioners and politicians (Gloucester)	Described a person-centred and non-discriminatory model of mental health service that allows services to be accessed via a single access point and for patients to be treated based on their needs rather than circumstances	No results but hope that model will lead to an improved service for those with intellectual disability.

Table A2 <i>cont'd</i>			
Study	Population (area)	What they did	What they found
Hemmings & Al-Sheikh (2013)	14 professionals: 4 psychiatrists, 4 nurses, 3 psychologists, 2 social workers and 1 occupational therapist (UK)	Semi-structured interviews about important service components of community services for adults with intellectual disability and a mental health condition	Important components identified included clarity of purpose, training in assessment of dual diagnosis, person-centred services, holistic, multidisciplinary and evidence-based service and flexible delivery. Also, clearer care pathways and improved joint working with mainstream services. Interviewees also expressed a desire for increased resources for services but admitted that this might not be financially viable.
Bouras & Holt (2004)		Review of evidence base of mental health care for people with intellectual disability	Evidence base is inconsistent and inconclusive. Supports tertiary services as the way forward.

Table A3 Models of specialist services for aggression/challenging behaviour			
Study	Population	What they did	What they found
Naylor & Clifton (1993)	-	Literature review of challenging behaviour in people with intellectual disability. Aims: <ul style="list-style-type: none"> ● define challenging behaviour ● identify therapeutic intervention ● identify models of service ● identify implications of developing a skilled workforce to deal with challenging behaviour 	Definitions of challenging behaviour vary. People with a dual diagnosis are at risk of losing provisions from both intellectual disability and mental health services. Professional tension regarding therapeutic response and service models must be resolved in order to provide appropriate service.
Lowe <i>et al</i> (1996)	30 individuals with challenging behaviour and referred to a specialist service; 21 individuals with challenging behaviour but not referred to a specialist service	Compared outcomes for patients treated at two different specialist community services for people with intellectual disability and challenging behaviour over a 3-year period	Patients treated in service A had significantly reduced behavioural problems, improved mental health, gained adaptive behaviours and enhanced quality of life in comparison to service B. Service A differed in that the staff had more prior experience of working with ID. The team members had clear delineated roles and there was a single referral point. Service B was underfunded while service A had a ring-fenced budget.
Martin <i>et al</i> (2005)	27 patients with mild-moderate intellectual disability and a mental health condition	Randomised, controlled trial comparing assertive outreach treatment with standard community care	No significant differences between unmet needs, carer burden, functioning and quality of life. Borderline difference for quality of life favouring standard treatment.

Table A3 *cont'd*

Study	Population	What they did	What they found
McClellan <i>et al</i> (2007)	5 individuals with mild to severe intellectual disability and long-standing challenging behaviour	Monitored five outcomes (behaviour, medication, quality of life, psychiatric symptoms and costs) for the individuals receiving positive behavioural support in their community over 2 years	Significant reductions in challenging behaviour and improved outcomes were seen in all patients over 2-year period. Challenging behaviour reduced to near zero levels, use of medication dropped by 66% and there was a significant improvement in quality of life for 3 in 5 patients.
Hemmings <i>et al</i> (2008)	21 staff who provide assertive community treatment (ACT) to patients with intellectual disability	Conducted in-depth structured interviews on staff agreement on statements made about ACT	Agreement that service should be delivered in the community and involve the patient's support network. Patients and carers should have involvement in service development, support roles and feedback.
Lehrer & Ott (2009)	38 patients referred to specialty clinic after challenging behaviour could not be resolved in community	Measured challenging behaviour by the Aberrant Behaviour Checklist at initial assessment and then at 6-month follow-up	Interdisciplinary evaluation and treatment resulted in reduction in challenging behaviour. Families also said the patients' quality of life improved and they became more involved in community.
Oliver <i>et al</i> (2005)	30 patients recruited over 25 months; inclusion criteria: moderate–mild intellectual disability, a serious mental health condition and challenging behaviour	Randomised, controlled trial comparing assertive outreach treatment to standard community care	No significant differences on outcomes such as functioning, carer burden and quality of life. In practice, there was a blurring of standard and assertive practice.
McKenzie <i>et al</i> (2009)	4 individuals with an intellectual disability and challenging behaviour	1-year community-based project in which psychology graduates supported patients with challenging behaviour in their own homes	On average challenging behaviour decreased over time and it was a positive experience for staff and patients. But the sample size was very small, so further research is needed.
Allen (1999)	14 patients who had experienced placement breakdown and admitted to hospital or institutional care and 33 patients who had been successfully maintained in the community. All patients were being treated by intensive support services.	Natural observational study over 6-year period monitoring personal characteristics, support service characteristics and type of specialist support received	No behavioural or psychiatric differences between groups. The group who experienced breakdown were less likely to receive intensive support services input and were more likely to come from services with a lack of internal organisation and optimal resource utilisation.

Appendix 2.

Survey questions

- 1 Please indicate within which region your service is located.
 - London North Central and North East
 - London North West
 - London South East
 - London South West
 - North East
 - Yorkshire
 - North West
 - North West (Mersey)
 - South East (Kent, Surrey, Sussex)
 - South East (Oxford, Buckinghamshire, Berkshire)
 - South West
 - South West (Wessex)
 - Trent
 - Eastern
 - West Midlands
 - Other (please specify)

- 2 What model of community intellectual disability service do you offer? (Please tick all that apply.)
 - Generic community intellectual disability team
 - Neurodevelopmental disorders service (autism/ADHD)
 - Stand-alone health intellectual disability team
 - Specialist challenging behaviour service
 - Other (please specify)

- 3 Is your service integrated with social care?
 - Yes
 - No

- 4 Please tick any other psychiatric services that you use. (Please tick all that apply.)
 - Crisis teams
 - Assertive outreach
 - Acute in-patient services

- Rehabilitation services
 - Early intervention
 - Assessment service
 - Increasing Access to Psychological Therapies (IAPT)
 - Memory clinic
- 5 Please indicate which of these (if any) are also provided by your intellectual disability service (tick all that apply)
- Crisis teams
 - Assertive outreach
 - Acute in-patient services
 - Rehabilitation services
 - Early intervention
 - Assessment service
 - Improving Access to Psychological Therapies (IAPT)
 - Memory clinic
- 6 Does your service offer a mental health liaison (that is support to generic mental health services) in cases of patients treated by such services?
- Yes
 - No
- 7 In your area, do you work under or are you aware of any local care pathways for adults with an intellectual disability and mental health disorder?
- Yes
 - No
- 8 If yes, please describe the pathway (or you can send reports or documents to IDproject@rcpsych.ac.uk)
- 9 Do you regularly implement any outcome measures in your daily practice?
- Yes
 - No
- 10 If yes, what are they? (tick all that apply)
- ABC
 - HoNOS-LD
 - SF-36
 - GAF
 - PAS-ADD
 - TAG
 - CANDID
 - Other (please specify)

- 11 Are you aware of any plans for commissioning new services for adults with an intellectual disability and mental health disorder in your local area?
- Yes
 - No
- 12 Are you aware of any plans for decommissioning services for adults with an intellectual disability and mental health disorder in your area?
- Yes
 - No
- 13 If yes, please give details (or you can send reports or documents to IDproject@rcpsych.ac.uk)
- 14 Who is the lead commissioner of intellectual disability in your area?
- CCG
 - Local authority
 - Joint commissioning
 - NHS England
 - Other
- 15 Which outcomes and/or service developments do you think are important for community mental health services for adults with an intellectual disability in your area?
- 16 We are interested in any research projects and service evaluations that are being carried out on models of care for mental health services for those with an intellectual disability. Have you carried out or been involved in any such research or evaluation? If yes, any reports or documents can be sent to IDproject@rcpsych.ac.uk and would be greatly appreciated.

References

- Alexander RT, Crouch K, Halstead S, *et al* (2006) Long-term outcome from a medium secure service for people with intellectual disability. *Journal of Intellectual Disability Research*, **50**: 305–15.
- Alexander RT, Hiremath A, Chester V, *et al* (2011) Evaluation of treatment outcomes from a medium secure unit for people with intellectual disability. *Advances in Mental Health and Intellectual Disabilities*, **5**: 22–32.
- Allen D (1999) Success and failure in community placements for people with learning disabilities and challenging behaviour: An analysis of key variables. *Journal of Mental Health*, **8**: 307–20.
- Aman MG, Singh N, Stewart AW, *et al* (1985) The Aberrant Behaviour Checklist: a behaviour rating scale for assessment of treatment effects. *American Journal of Mental Deficiency*, **89**: 485–91.
- Andrea Barron DA, Hassiotis A, Paschos D (2011) Out of area provision for adults with intellectual disabilities and challenging behaviour in England: policy perspectives and clinical reality. *Journal of Intellectual Disability Research*, **55**: 832–43.
- Ayres M, Roy A (2009) Supporting people with complex mental health needs to get a life: The role of the Supported Living Outreach Team. *Tizard Learning Disability Review*, **14**: 29–39.
- Bennett C (2014) Understanding systemic problems in providing mental health services to people with an intellectual disability and co-morbid mental disorders in Victoria. *Australasian Psychiatry*, **22**: 48–51.
- Benton C, Roy A (2008) The first three years of a community forensic service for people with a learning disability. *British Journal of Forensic Practice*, **10**: 4–12.
- Bouras N, Holt G, Gravestock S (1995) Community care for people with learning disabilities: deficits and future plans. *Psychiatric Bulletin*, **19**: 134–7.
- Bouras N (1999) Editorial. *Tizard Learning Disability Review*, **4**: 3–5.
- Bouras N, Cowley A, Holt G, *et al* (2003) Referral trends of people with intellectual disabilities and psychiatric disorders. *Journal of Intellectual Disability Research*, **47**: 439–46.
- Bouras N, Holt G (2004) Mental health services for adults with learning disabilities. *British Journal of Psychiatry*, **184**: 291–2.
- Bubb S (2014) *Winterbourne View – Time for Change: Transforming the Commissioning of Services for People with Learning Disabilities and/or Autism*. NHS England.
- Cambridge P, Carpenter J, Forrester-Jones R, *et al* (2005) The state of care management in learning disability and mental health services 12 years into community care. *British Journal of Social Work*, **35**: 1039–62.
- Carr EG, Horner RH, Turnbull AP, *et al* (1999) *Positive Behavior Support for People with Developmental Disabilities: A Research Synthesis*. American Association on Mental Retardation.
- Chaplin R (2004) General psychiatric services for adults with intellectual disability and mental illness. *Journal of Intellectual Disability Research*, **48**: 1–10.
- Chaplin E, O'Hara J, Holt G, *et al* (2008) MHILD: A model of specialist mental health services for people with learning disabilities. *Advances in Mental Health and Learning Disabilities*, **2**(4): 46–50.
- Chaplin E, O'Hara J, Holt G, *et al* (2009) Mental health services for people with intellectual disability: Challenges to care delivery. *British Journal of Learning Disabilities*, **37**: 157–64.

- Chaplin E, Kelesidi K, Emery H, *et al* (2010a) People with learning disabilities placed out of area: the South London experience. *Journal of Learning Disabilities and Offending Behaviours*, **1**: 5–14.
- Chaplin E, Paschos D, O'Hara J (2010b) The specialist mental health model and other services in a changing environment. In *Mental Health Services for Adults with Intellectual Disability* (eds N Bouras, G Holt). Psychology Press.
- Chesters J, O'Neal P, O'Toole R (1999) *The Report of the Gippsland Dual Disability Evolution Project: Developing a Service System for People with an Intellectual Disability and Mental Illness*. Department of Human Services.
- Coelho RJ, Kelley PS, Deatsman-Kelley C (1993) An experimental investigation of an innovative community treatment model for persons with a dual diagnosis (DD/MI). *Journal of Rehabilitation – Washington*, **59**(2): 37–44.
- Cooper SA, Smiley E, Morrison J, *et al* (2007) An epidemiological investigation of affective disorders with a population-based cohort of 1023 adults with intellectual disabilities. *Psychological Medicine*, **37**: 873–82.
- Cumella S (2009) Mental health services for people with a learning disability. *Advances in Mental Health and Learning Disabilities*, **3**: 8–14.
- Day K (1995) Psychiatric services in mental retardation: generic or specialised provision? In *Mental Health in Mental Retardation: Recent Advances and Practices* (ed. N Bouras). Cambridge University Press.
- Deb S, Thomas M, Bright C (2001) Mental disorder in adults with intellectual disability: prevalence of functional psychiatric illness among a community based population aged between 16 and 64 years. *Journal of Intellectual Disability Research*, **45**: 495–505.
- Department of Health (1993) *Challenging Behaviours and/or Mental Health Needs of People with Learning Disabilities (The Mansell Report)*. The Stationery Office.
- Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. The Stationery Office.
- Department of Health (2012a) *Transforming Care: A National Response to Winterbourne View Hospital: Department of Health Review Final Report*. Department of Health.
- Department of Health (2012b) *Winterbourne View Review: Concordat: A Programme of Action*. Department of Health.
- Department of Health (2012c) *A Simple Guide to Payment by Results*. Department of Health.
- Devapriam J, Alexander RT (2012) Tiered model of learning disability forensic service provision. *Journal of Intellectual Disabilities and Offending Behaviour*, **3**: 175–85.
- Dinani S, Goodman W, Swift C, *et al* (2010) Providing forensic community services for people with learning disabilities. *Journal of Learning Disabilities and Offending Behaviour*, **1**: 71–6.
- Einfeld SL, Piccinin AM, Mackinnon A, *et al* (2006) Psychopathology in young people with intellectual disability. *JAMA*, **296**: 1981–9.
- Emerson E, Robertson J, Gregory N, *et al* (2000) Treatment and management of challenging behaviours in residential settings. *Journal of Applied Research in Intellectual Disabilities*, **13**: 197–215.
- Eurlings HA, Evenhuis HM, Kengen MMF (2006) *Early Detection of Dementia in Adults with Learning Disabilities*. Harcourt.
- Fear C, Scheepers M, Ansell M, *et al* (2012) 'Fair horizons': a person-centred, non-discriminatory model of mental healthcare delivery. *The Psychiatrist*, **36**: 25–30.
- Hackerman F, Schmidt CW, Dyson CD, *et al* (2006) Developing a model of psychiatric program for patients with intellectual disability in a community mental health center. *Community Mental Health Journal*, **42**: 13–24.

- Hall I, Higgins A, Parkes C, *et al* (2006a) The development of a new integrated mental health service for people with learning disabilities. *British Journal of Learning Disabilities*, **34**: 82–7.
- Hall I, Parkes C, Samuels S, *et al* (2006b) Working across boundaries: clinical outcomes for an integrated mental health service for people with intellectual disabilities. *Journal of Intellectual Disability Research*, **50**: 598–607.
- Hassiotis A, Ukoumunne O, Byford S, *et al* (2000) Outcome of patients with severe mental illness and borderline intellectual functioning. *European Psychiatry*, **15** (Suppl 2): 291S.
- Hassiotis A, Tyrer P, Oliver P (2003) Psychiatric assertive outreach and learning disability services. *Advances in Psychiatric Treatment*, **9**: 368–73.
- Hemmings C, Underwood LA, Bouras N (2008) ACT for people with intellectual disabilities and mental health problems. *Psychiatric Services*, **59**: 956–7.
- Hemmings CP, Underwood LA, Bouras N (2009) Services in the community for adults with psychosis and intellectual disabilities: a Delphi consultation of professionals' views. *Journal of Intellectual Disability Research*, **53**: 677–84.
- Hemmings C, Al-Sheikh A (2013) Expert opinions on community services for people with intellectual disabilities and mental health problems. *Advances in Mental Health and Intellectual Disabilities*, **7**: 169–74.
- Hemmings C, Deb S, Chaplin E, *et al* (2013) Review of research for people with ID and mental health problems: a view from the United Kingdom. *Journal of Mental Health Research in Intellectual Disabilities*, **6**: 127–58.
- Hemmings C, Bouras N, Craig T (2014) How should community mental health of intellectual disability services evolve? *International Journal of Environmental Research and Public Health*, **11**: 8624–31.
- Holland T, Clare ICH, Mukhopadhyay T (2002) Prevalence of 'criminal offending' by men and women with intellectual disability and the characteristics of 'offenders': implications for research and service development. *Journal of Intellectual Disability Research*, **46**: 6–20.
- Hollins S (2000) Developmental psychiatry – insights from learning disability. *British Journal of Psychiatry*, **177**: 201–6.
- Holt G, Costello H, Bouras N, *et al* (2000) BIOMED MEROPE* project: service provision for adults with intellectual disability: a European comparison. *Journal of Intellectual Disability Research*, **44**: 685–96.
- Joint Commissioning Panel for Mental Health (2013) *Guidance for Commissioners of Mental Health Services for People with Learning Disabilities*. JCP-MH.
- Kingdon A (2005) Resettlement from secure learning disability services. In *The Handbook of Forensic Learning Disabilities* (eds T Riding, C Swann, B Swann). Radcliffe Publishing.
- Lehrer D, Ott D (2009) Treatment outcomes for individuals with developmental disabilities and challenging behaviour and psychiatric hospitalization referred to an interdisciplinary clinic. *Mental Health Aspects of Developmental Disabilities*, **12**: 23–8.
- Local Government Association (2014) *Ensuring Quality Services: Core Principles for the Commissioning of Services for Children, Young People, Adults and Older People with Learning Disabilities and/or Autism who Display or are at Risk of Displaying Behaviour that Challenges*. Local Government Association.
- Lowe K, Felce D, Blackman D (1996) Challenging behaviour: the effectiveness of specialist support teams. *Journal of Intellectual Disability Research*, **40**: 336–47.
- Lunsky Y, Bradley E, Durbin J, *et al* (2008) A comparison of patients with intellectual disability receiving specialised and general services in Ontario's psychiatric hospitals. *Journal of Intellectual Disability Research*, **52**: 1003–12.

- Mansell J (2006) Deinstitutionalisation and community living: progress, problems and priorities. *Journal of Intellectual and Developmental Disability*, **31**: 65–76.
- Martin G, Costello H, Leese M, *et al* (2005) An exploratory study of assertive community treatment for people with intellectual disability and psychiatric disorders: conceptual, clinical and service issues. *Journal of Intellectual Disability Research*, **49**: 516–24.
- McClellan B, Grey IM, McCracken M (2007) An evaluation of positive behavioural support for people with very severe challenging behaviours in community-based settings. *Journal of Intellectual Disabilities*, **11**: 281–301.
- McGill P, Cooper V, Honeyman G (2010) *Developing Better Commissioning for Individuals with Behaviour that Challenges Services – A Scoping Exercise*. Tizard Centre and Challenging Behaviour Foundation.
- McKenzie K, Broad R, McLean H, *et al* (2009) Evaluating a community-based project for supporting clients with challenging behaviour. *Learning Disability Practice*, **12**: 27–32.
- McKenzie K (2011) Providing services in the United Kingdom to people with an intellectual disability who present behaviour which challenges: A review of the literature. *Research in Developmental Disabilities*, **32**: 395–403.
- Meisler N, McKay CD, Gold PB, *et al* (2000) Using principles of ACT to integrate community care for people with mental retardation and mental illness. *Journal of Psychiatric Practice*, **6**: 77–83.
- Minnen AV, Hoogduin CAL, Broekman TG (1997) Hospital vs outreach treatment of patients with mental retardation and psychiatric disorders: a controlled study. *Acta Psychiatrica Scandinavica*, **95**: 515–22.
- Molony H (1993) Mental health services for people with intellectual disability: Current developments. *Australia and New Zealand Journal of Developmental Disabilities*, **8**: 169–76.
- Moore D, Thurley J (2011) *The Role of Specialist Health Services in Supporting the Health Needs of People with Learning Disability – Community Learning Disability Teams*. Debra Moore Associates.
- Morgan VA, Leonard H, Bourke J, *et al* (2008) Intellectual disability co-occurring with schizophrenia and other psychiatric illness: population-based study. *British Journal of Psychiatry*, **193**: 364–72.
- Moss SC, Goldberg DP, Patel P, *et al* (1996) *The Psychiatric Assessment Schedule for Adults with Developmental Disability (PAS ADD 10)*. Hester Adrian Research Centre and the Institute of Psychiatry.
- Moss S, Emerson E, Bouras N, *et al* (1997) Mental disorders and problematic behaviours in people with intellectual disability: future directions for research. *Journal of Intellectual Disability Research*, **41**: 440–7.
- National Disability Authority (2003) *Review of Access to Mental Health Services for People with Intellectual Disabilities*. NDA.
- National Learning Disability Professional Senate (2014) *Delivering Effective Specialist Community Learning Disabilities Health Team Support to People with Learning Disabilities and their Families or Carers*. National Learning Disability Professional Senate.
- Naylor V, Clifton M (1993) People with learning disabilities – meeting complex needs. *Health and Social Care in the Community*, **1**: 343–53.
- NSW Council for Intellectual Disability (2013) *Communiqué. National Roundtable on the Mental Health of People with Intellectual Disability*. NSW Council for Intellectual Disability.
- Oliver PC, Piachaud J, Tyrer P, *et al* (2005) Randomised controlled trial of assertive community treatment in intellectual disability: the TACTILD study. *Journal of Intellectual Disability Research*, **49**: 507–15.
- Polgar MF, Johnsen MC, Starrett BE, *et al* (2000) New patterns of community care: coordinated services for dually diagnosed adults in North Carolina. *Journal of Health and Human Services Administration*, **23**: 50–64.

- Queensland Centre for Intellectual and Developmental Disability (2002) *Sand in Society's Machine: Models of Service Provision to Adults with an Intellectual Disability with Coexisting Mental Illness (Dual Diagnosis)*. University of Queensland.
- Roy A, Matthews H, Clifford P, *et al* (2002) Health of the Nation Outcome Scales for people with Learning Disabilities (HoNOS-LD). *British Journal of Psychiatry*, **180**: 61–6.
- Royal College of Psychiatrists (1996) *Meeting the Mental Health Needs of Adults with Mild Learning Disabilities* (Council Report 115). Royal College of Psychiatrists.
- Royal College of Psychiatrists (2011) *Future Role of Psychiatrists Working with People with Learning Disabilities* (FR/LD/1). Royal College of Psychiatrists.
- Royal College of Psychiatrist (2013) *People with Learning Disability and Mental Health, Behavioural or Forensic Problems: The Role of In-Patient Services* (FR/ID/03). Royal College of Psychiatrists.
- Royal College of Psychiatrists (2014a) *Forensic Care Pathways for Adults with Intellectual Disability Involved in the Criminal Justice System* (FR/ID/04). Royal College of Psychiatrists.
- Royal College of Psychiatrists (2014b) *Good Practice in the Management of Autism (Including Asperger Syndrome) in Adults* (CR191). Royal College of Psychiatrists.
- Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists (2007) *Challenging Behaviour: A Unified Approach* (CR144). Royal College of Psychiatrists.
- Sheehan R, Paschos D (2013) A comparison of different models to meet the mental health needs of adults with intellectual disabilities. *Advances in Mental Health and Intellectual Disabilities*, **7**: 161–8.
- Slevin E, Sines D (2005) The role of community nurses for people with learning disabilities: working with people who challenge. *International Journal of Nursing Studies*, **42**: 415–27.
- Slevin E, Truesdale-Kennedy M, McConkey R (2008) Community learning disability teams: developments, composition and good practice. A review of the literature. *Journal of Intellectual Disabilities*, **12**: 59–79.
- Smiley E (2005) Epidemiology of mental health problems in adults with learning disability: an update. *Advances in Psychiatric Treatment*, **11**: 214–22.
- Spiller M, Holt G, Bouras N, *et al* (2004) *A Qualitative Contextual and Strategic Study of the Operational Interface Between the Specialist Mental Health in Learning Disabilities Team and Generic Acute Adult Mental Health Wards using the Framework Methodology*. Estia Centre.
- Stein LI, Test MA (1980) An alternative model to mental hospital treatment: I. conceptual model, treatment program, and clinical evaluation. *Archives of General Psychiatry*, **37**: 392–7.
- Torrey WC (1993) Psychiatric care of adults with developmental disabilities and mental illness in the community. *Community Mental Health Journal*, **29**: 461–76.
- Trollor J (2014) Making mental health services accessible to people with an intellectual disability. *Australian and New Zealand Journal of Psychiatry*, **48**: 395–8.
- Werner S, Stawski M (2012) Mental health: knowledge, attitudes and training of professionals on dual diagnosis of intellectual disability and psychiatric disorder. *Journal of Intellectual Disability Research*, **56**: 291–304.
- Wolfensberger W (1991) Reflections on a lifetime in human services and mental retardation. *Mental Retardation*, **29**: 1–15.