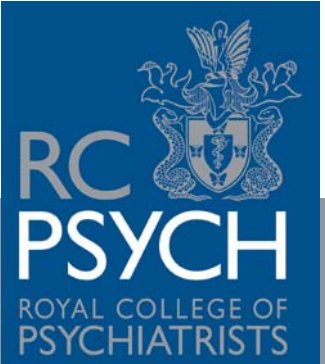


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Enabling people with mild intellectual disability and mental health problems to access healthcare services

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Enabling people with mild intellectual disability and mental health problems to access healthcare services

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Draft versions of the document were consulted on with both Faculty Executives.

Executive summary and recommendations

This report has been jointly revised by the Faculty of Psychiatry of Intellectual Disability and the General and Community Psychiatry Faculty, Royal College of Psychiatrists, and replaces Council Report CR115 (Royal College of Psychiatrists, 2003).

The intended target audience is front-line professionals (e.g. psychiatrists, nurses, psychologists), who refer, assess and manage adults with intellectual disability in the community. It provides a framework within which to facilitate collaboration between adult mental health and community intellectual disability services in order to meet the mental health needs of people with intellectual disability. It is also relevant to those individuals who may have significant psychosocial difficulties as a result of comorbid neuropsychiatric problems such as autism spectrum disorder.

The significant variation in the organisation and provision of services for people with intellectual disability and mental illness will inevitably have an impact on the recommendations we have made and this report cannot guard against future changes. However, at the core of good practice lies the joint working arrangements between general adult mental health services and community intellectual disability services. This collaboration can ensure that care pathways for people who may need support for mental ill health are clearly delineated and that high-quality care, including reasonable adjustments where necessary, is delivered promptly. Self-assessment processes in mental health organisations and new commissioning requirements may also help to bring about further improvements in clinical practice and training.

The focus of the present guidance is necessarily narrow in addressing mainly the mental health needs of adults with mild intellectual disability. These service users form the majority of the population of people with intellectual disability and are more likely to present with identifiable mental disorders, but nevertheless may have difficulty accessing services such as in-patient wards and home treatment teams, particularly at times of crisis. Often, adult mental health professionals maintain that they lack the specialist skills needed in order to treat these individuals. However, in our view, community intellectual disability services have a crucial role with this group in the diagnosis and treatment of mental health ill health, and, in particular, supporting and facilitating access to mainstream mental health services where extra support is required.

We acknowledge that there is a significant proportion of adults with more severe intellectual disability including limited communication who when acutely distressed may present with challenging behaviour such as aggression or agitation. It is frequently difficult to establish a diagnosis of

mental disorder without a period of assessment and observation. These individuals are unlikely to fit within the existing adult mental health facilities as currently configured. In these cases, where extra care is required, a specialist in-patient service for people with learning disability may provide a tailor-made treatment plan. Added support may also be given by dedicated community challenging behaviour teams where those are available. However, further discussion of this topic is not in the remit of the present document.

RECOMMENDATIONS

- 1 Each organisation providing intellectual disability and mental health services should have protocols or practices in place to meet the mental health needs of adults with mild intellectual disability, jointly agreed between services for people with intellectual disability, adult mental health services and Local Authorities. Clinical and non-clinical managers of intellectual disability services should ensure that the needs of this group are on the agenda of the local bodies responsible for the development of mental health services.
- 2 Such protocols should facilitate patient care pathways through adult mental health services that include a wide range of expertise and skills such as recovery centres, crisis management, psychological therapies, rehabilitation, assertive outreach and home treatment teams. They should describe how community intellectual disability services will facilitate access for people with mild intellectual disability and the expectations from each part of the system.
- 3 Regular interface meetings between the two services can steer the strategic direction of service developments and resolve problems as they arise as well as disseminate examples of good practice and shared care. There should be promotion of joint working where there is a need to treat complex cases, such as individuals with forensic histories, significant risk or personality disorder.
- 4 Key information about people with mild intellectual disability and mental illness should be available to professionals in mental health services within and outside working hours. This means working towards information-sharing with partner organisations.
- 5 Core training placements in the psychiatry of intellectual disability should continue to be offered within training schemes. Year 4–6 specialty trainees (ST4–6) in general adult psychiatry should be encouraged to do special interest sessions within local community intellectual disability services.
- 6 Input to local educational programmes by professionals from community intellectual disability teams may help to highlight practice issues relevant to adults with mild intellectual disability and mental disorder, increase awareness of the problems faced by these individuals and promote reflective practice.

Introduction

DEFINITION

Current classification systems (ICD-10 (World Health Organization, 1992) and DSM-IV (American Psychiatric Association, 1994)) define intellectual disability (known as 'mental retardation' in both systems¹) as a combination of significantly limited adaptive ability, an impairment of global intelligence (as indicated by an IQ of below 70 on an appropriately administered test), and presentation during the developmental period. There are estimated to be approximately >1 million people with intellectual disability in the UK, although only about a quarter of those are known to specialist intellectual disability services, that is, are currently in receipt of care (Emerson *et al*, 2010).

In this report we focus on adults with mild intellectual disability who make up the majority of people with intellectual disability, approximately 2% of the population. Many are able to live either independently or in supported accommodation, may have families, and a small proportion may be in employment.

People with intellectual disability have high rates of all psychiatric disorders, with prevalence reaching approximately 40% (Cooper *et al*, 2007a). Certain mental disorders such as psychosis and severe affective disorders are not only more common in this group but research suggests a shared pathway with intellectual disability, although this is far from being fully delineated (Owen, 2012). Increasingly, and where possible, people with mild intellectual disability and mental illness access mainstream mental health services, and community intellectual disability services have an important role in supporting them to do so.

COMMUNITY INTELLECTUAL DISABILITY SERVICES

In the UK, intellectual disability services are delivered by community-based teams that serve defined geographical areas. In the majority, the lead organisation in these services is the Local Authority, but other service configurations also exist such as stand-alone intellectual disability services or

1. The WHO ICD Working Group on the Classification of Intellectual Disabilities has proposed that mental retardation should be replaced by intellectual developmental disorder in ICD-11 (for further information see www.ncbi.nlm.nih.gov/pmc/articles/PMC3188762/).

partnerships with (mental health) foundation trusts. Community teams are increasingly integrated with co-located professionals from health and social care and include psychiatrists, psychologists, nurses, occupational therapists, physiotherapists, and speech and language therapists. Professionals provide the core service that manages a full range of mental health problems, advocates on behalf of service users and takes part in undergraduate and postgraduate specialist training.

Adults with mild intellectual disability and mental illness are mostly treated by the community intellectual disability teams in their local communities. Where indicated, adult mental health provision such as early intervention, home treatment, assertive outreach, substance misuse and other services where available may be additional treatment options. On occasion, though, overly stringent eligibility criteria imposed by either service may have a detrimental effect on the service user's well-being, especially if associated with protracted assessments and lack of a management plan.

Policy context

There have been many changes in policy and organisation of services since the previous report CR115 was written (Royal College of Psychiatrists, 2003). These include the completion of the intellectual disability campus closure programme (Improving Health and Lives, 2012) and the publication of important guidance documents on how to deliver high-quality care for those with dementia or challenging behaviour, or who have severe and multiple disabilities (Royal College of Psychiatrists *et al*, 2007; Royal College of Psychiatrists & British Psychological Society, 2009; Mansell, 2010).

Other relevant government guidance that has shaped service delivery in adult mental health and intellectual disability services across the UK is listed below. An important tenet of the guidance is the interface between general adult psychiatry services and intellectual disability services and the adoption of an inclusive approach, emphasising that people with mild intellectual disability and mental illness should be able to access treatment within mainstream mental health services where this is appropriate to their needs and with prompt input from professionals from within community intellectual disability teams.

ENGLAND

VALUING PEOPLE NOW (DEPARTMENT OF HEALTH, 2009)

Valuing People Now follows on from *Valuing People* (Department of Health, 2001) and is a high-level strategic document that aims to set out what people with intellectual disability can expect from statutory agencies. Key messages relevant to the present document are that all people with intellectual disability and their families will:

- have greater choice and control over their lives and have support to develop person-centred plans; and
- get the healthcare they need and the support they need to live healthy lives.

For services, there are requirements that:

- appropriate commissioning, leadership, delivery and partnership structures are put in place; and
- workforces across services are given the appropriate support and training to equip them with the values, skills and knowledge to deliver the *Valuing People Now* priorities for all people with intellectual disability.

GREEN LIGHT FOR MENTAL HEALTH (COLE & GREGORY, 2004)

The Green Light for Mental Health toolkit was developed by the Foundation for People with Intellectual Disabilities in order to assist mental health providers and commissioners to assess the standards of provision to people with intellectual disability and mental illness. It contains a framework for an integrated comprehensive mental health service and a self-assessment toolkit to help organisations identify areas of good practice and areas that must be improved.

It includes several domains with standards to be met in planning and commissioning processes, local partnerships, pooling of resources, access to service and treatment pathways, transition protocols, joint working, key services, care programme approach, other provision, workforce planning and a number of other priorities (e.g. mental health and mental capacity legislation). The self-assessment tool uses a traffic lights system of red, amber and green to rate whether a service meets a requirement or not. Mental health services must report their self-assessments annually to the regulator the Care Quality Commission (www.cqc.org.uk).

WALES

STATEMENT ON POLICY & PRACTICE FOR ADULTS WITH A LEARNING DISABILITY (WELSH ASSEMBLY GOVERNMENT, 2011)

The Welsh Assembly has now published its document on the modernisation of services for people with intellectual disability in Wales. The document, written with input from All Wales People First, clearly recommends the use of primary, secondary and specialist care of people with intellectual disability and their complex needs to be met in the context of an 'ordinary life'. It does not offer specific guidance regarding mental health issues.

SCOTLAND

OUR NATIONAL HEALTH (SCOTTISH EXECUTIVE HEALTH DEPARTMENT, 2000) & THE SAME AS YOU? (SCOTTISH EXECUTIVE, 2000)

With input from both service users and carers, these documents reflect government policies of social inclusion, equality and fairness, and opportunities to improve the lives of people with intellectual disability and mental illness. They uphold seven key principles that ensure that people with intellectual disability are valued, have the same rights as the rest of the population and should be able to use mainstream services wherever possible. Working well together also creates an obligation to train staff in both mental health and intellectual disability to manage service users with mental ill health. Both documents acknowledge the need for specialist services but not instead of general services. Overall, there has been little mention of mental health in both documents and the level of collaborative relationships between mental health and intellectual disability services remains variable.

Values and principles

There are limits on how far government policy will affect the quality of services offered to individuals and the values and principles adopted by staff working within these services. Psychiatrists involved in the care of adults with mild intellectual disability and mental health needs should ensure that the core National Health Service values of compassion, respect and dignity of patients, commitment to quality of care, to improving lives, and working together with patients, form the cornerstone on which care is offered. Finally, the underlying principle is that all people with intellectual disability and a mental disorder or offending behaviour should have access to high-quality care for physical health problems.

People with intellectual disability find it difficult to navigate through services and to negotiate the care they need. Therefore, it is essential that providers of services do not present barriers to their gaining access because of intellectual disability.

The usefulness of the present report is in guiding good practice and helping adult mental health and intellectual disability services to develop the partnerships that are necessary in order to help this vulnerable group of people. We consider some crucial issues that need to be addressed in clinical practice and suggest minimum requirements of clear service-level agreements and care pathways that are essential in order to support people with mild intellectual disability and mental illness.

The guidance will help front-line clinicians and managers to establish collaborative working arrangements to bring about improvements in local practice. There have been incidents in the past where both general adult and intellectual disability services have stood on either side of a rigid divide and patient care has suffered as a result due to a combination of inflexible arrangements and lack of resources, skills and expertise to manage this group of service users.

Mental health services for people with intellectual disability

Epidemiological studies suggest a prevalence of any type of psychiatric disorder including problem behaviours of 40% (Cooper *et al*, 2007a; Smiley *et al*, 2007). Psychotic disorders are up to five times higher (Morgan *et al*, 2008) and dementia three times higher (Strydom *et al*, 2007) than in the general population. Anxiety and affective disorders, including self-harm, are frequent (Cooper *et al*, 2007b) and, increasingly, people with mild intellectual disability become exposed to substance misuse (Barrett & Paschos, 2006), stigma and exploitation (Scior, 2011).

People with autism spectrum disorder or attention-deficit hyperactivity disorder may have (comorbid) low intelligence or social deficits of such degree that require specialist support delivered by professionals in community intellectual disability teams (Adamou *et al*, 2011). These arrangements, however, are variable across England at least and often it is unclear who will be supporting the service user or which service will deliver which aspects of care; for example, an adult with Asperger syndrome may require psychiatric care from adult mental health services or access psychological therapies but their social care may be enhanced or guided by the intellectual disability service.

Community intellectual disability services can facilitate and support the management of people with mild intellectual disability and mental disorder through diagnostic assessment, provision of treatment packages, interagency work, building of partnerships and local treatment pathways in order to provide personalised care. Since the publication of *Valuing People Now* (Department of Health, 2009), adult mental health services are required to become more responsive to people with intellectual disability in England.² In practice, this may take the form of a variety of mental health treatment options, for example home treatment teams, in-patient units, psychiatric intensive care units or crisis houses being made available to service users with mild intellectual disability in addition to traditional management by the community intellectual disability team. Although research evidence on interventions for mental ill health in people with intellectual disability is limited to evaluations of in-patient care (Chaplin, 2004, 2009), there may be benefits from using adult mental health in-patient services such as improvement in risk indices and decrease in number of unmet needs (Hall *et al*, 2006). A review of Health of the Nation Outcome Scales-measured clinical outcomes of consecutive admissions to an integrated in-patient unit over 18 months revealed that service users improved in several domains of functioning (Hillier *et al*, 2010).

2. Similar legislation may be relevant in other countries such as Wales and Scotland.

It is encouraging that anecdotal information indicates that several areas have developed local protocols to facilitate service users with mild intellectual disability either accessing adult mental health services at a time of mental health crisis or facilitating early discharge or rehabilitation. Examples of good practice based on shared care arrangements have been reported in cases of service users with borderline personality disorder, early-onset psychosis or substance misuse problems.

Case studies 1 and 2 present examples of shared care in both in-patient and community settings. These case studies illustrate practice in England, so although the casework may be similar in other countries, mental health legislation will differ.

SERVICE USERS' AND CARERS' VIEWS

A few UK-based studies have examined the experiences of service users with intellectual disability who have been admitted to adult psychiatric wards and those of their carers. Reports based on qualitative research indicate that service users found the generic psychiatric wards noisy, uncomfortable and complained that staff were not available to help them (Longo & Scior, 2004; Parkes *et al*, 2007; Vos *et al*, 2007). However, this was balanced by service users who stated that adult mental health in-patient wards provided the potential for social interaction with other patients, with the benefit that each could learn from the other (Case study 3). Carers were critical of the lack of coordinated discharge planning and of being ignored in general psychiatric wards.

CASE STUDY 1 SHARED CARE: IN-PATIENT

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

CASE STUDY 2 SHARED CARE: COMMUNITY

Abdul was a 23-year-old man living with his mother and two brothers in the community. He had missed a lot of schooling because of behavioural problems and living abroad, but overall had been assessed as having a mild intellectual disability. He had had one previous episode of schizophreniform psychosis. His mother asked for an urgent assessment because she was unable to manage his aggressive behaviour. The psychiatrist and community nurse from the community intellectual disability service visited the family at home, together with an interpreter for the mother. Abdul was found to be acutely psychotic and his mother reported that he had been smoking a lot of cannabis, partly because he had been hanging around with a local gang. His concordance with his antipsychotic medication had been very patchy. He was referred to the home treatment team by the community nurse. A joint management plan was developed that included the intellectual disability nurse taking part in the home treatment initial assessment; the home treatment team would visit daily including at weekends to supervise medication and provide ongoing advice about cannabis and behaviour management. The intellectual disability nurse would join the home treatment team twice a week to facilitate specialist aspects such as communication. The intellectual disability service agreed to fund 9 extra hours of a support worker per week to help develop constructive community activities. The consultant psychiatrist in intellectual disability agreed to continue to take the medical lead for the case in partnership with the specialty doctor in the home treatment team. The relapse resolved over 3 weeks and the home treatment team discharged Abdul. The intellectual disability team is now the main provider of care to Abdul and his family.

CASE STUDY 3 TESTIMONIAL OF A SERVICE USER WITH MILD INTELLECTUAL DISABILITY

'They should accept that people with learning difficulty and mental health, and with people with just mental health...they should mix, mix people in together, so that people with the mental health can understand people with learning difficulties. They can make friends and understand each other and their problems, and all that you know.

They shouldn't be really separated from people like us, you know; people with a learning difficulty and with a mental health problem shouldn't really be separated. They should really all be mixed in together.'

The guiding principle should be to ensure that service users with mild intellectual disability are supported at all times to manage the admission process. In general, accessible information about the process of the ward round, the Mental Health Act 1983 and mental capacity legislation should be available, and many such resources can be found on the internet. Where possible, service users should continue to be supported to attend ward-or community-based activities while still an in-patient. However, if there are appropriate options for treatment and management in the community, including reduction of risk of self-harm or harm to others, then the need for admission to hospital should be reconsidered.

Suggested care pathway

Several of the ongoing difficulties in implementing the government guidelines on the treatment of mental disorders in adults with mild intellectual disability should be set in the historical background of adult mental health professionals claiming to lack training and expertise to manage a heterogeneous group of service users and the limited financial and operational agreements to provide adequate care options in the community. Additional problems arise from conflicts that exist within different care perspectives.

When a person known to adult mental health services is later diagnosed as also having intellectual disability, it may be clinically appropriate to continue their treatment in their existing team, although social care may be provided by the community intellectual disability service. This model is not prescriptive and at all times handover arrangements should take place to avoid duplication, and the service user must be at the centre of all decision-making.

In Fig. 1 overleaf, we present a process map of an integrated service that harnesses the skills of staff in both mental health and intellectual disability services. It allows a flexible and personalised response, including joint working of all local services.

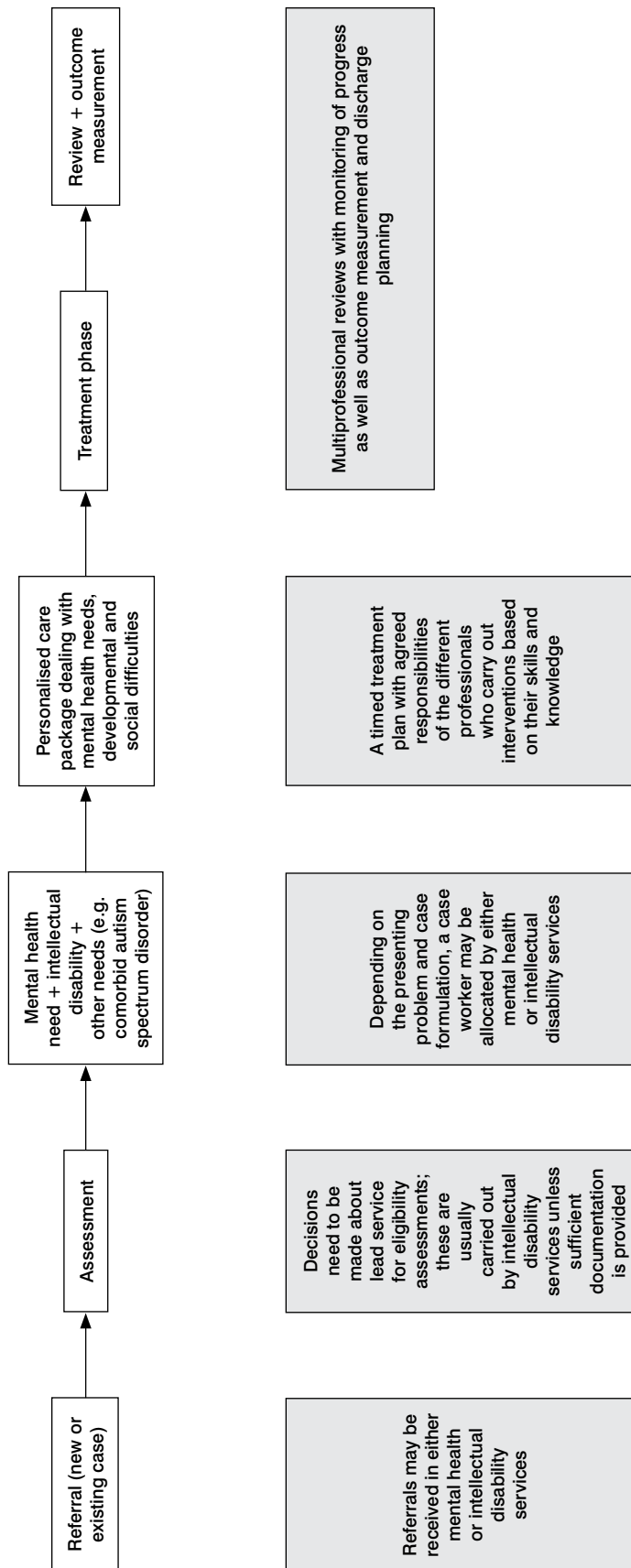


Fig. 1 Integrated pathway of care for people with mild intellectual disability and mental health needs.

Service interface

Clinicians and managers should follow a common sense approach and work within existing frameworks – such as the Green Light for Mental Health toolkit (Cole & Gregory, 2004) – in building joint service protocols to ensure that the care of people with mild intellectual disability and mental health problems is not compromised by service configurations and boundaries. Services will need to develop a locally agreed response to the autism strategy (Department of Health, 2010) and the National Institute for Health and Clinical Excellence (2008) guidance for the management of adult attention-deficit hyperactivity disorder. Key issues for discussion are shown in Box 1.

Disputes about service boundaries should not be to the detriment of the service user's health. Where intellectual disability and adult mental health services cannot agree responsibilities for provision of a care package, it is expected that the relevant stakeholders should meet with the aim of resolving the matter, involving senior management where necessary (Case study 4).

The development of mental healthcare clusters (payment by results; Department of Health, 2011) may have unexpected consequences for the provision of integrated care to people with mild intellectual disability. Community intellectual disability services are developing a similar approach to describe and define an episode of care for this population group. Planning a 'patient journey' will have to take account of the new service lines.

Therefore, the commissioning role is paramount in ensuring that effective and high-quality care is offered to people with intellectual disability. It should be based on evidence, provide value for money, and reflect local needs and resources. In such a framework the interface of adult mental health and community intellectual disability services is pivotal. Additional

Box 1 KEY ISSUES TO BE ADDRESSED LOCALLY

- Eligibility assessment process (which service does what)
- Place for specialist admissions for adults with intellectual disability
- How to manage shared care
- Assessment process of adults with intellectual disability and mental ill health
- Documentation and information access
- Referral process for people with neurodevelopmental disorder

CASE STUDY 4 LOCAL INTERFACE³

A mental health and intellectual disability interface liaison group may be a way for services to conduct an ongoing dialogue about how general mental health services respond to the supports needed around intellectual disability and mental health. The group should have a membership from both organisations and be multiprofessional. Difficulties in facilitating service access, high-level advocacy, development of responses to guidance documents, and representation of the intellectual disability mental health issues at trust management level may be some of the functions of such a group.

information about commissioning guidance can be found in the document *Improving the Health and Wellbeing of People with Intellectual Disabilities* (Improving Health and Lives & Royal College of General Practitioners, 2011) and via the National Mental Health Commissioning Programme (www.nmhdu.org.uk/news/mental-health-commissioning-programme).

3. This example is taken from the Camden and Islington Foundation Trust, Camden Learning Disability Service and Islington Learning Disability Partnership. It meets six times a year and has a role in steering strategic developments and resolving practice issues.

Information systems

It is essential that a minimum data-set regarding a person with mild to moderate intellectual disability and mental ill health is accessible by all mental health professionals at all times. This may be particularly difficult given the variety of electronic care records software in use by different National Health Service and social care organisations. However, local information-sharing protocols can provide a way forward that takes into account professional codes of practice. Examples may include:

- hard copies of care plans relating to adults with mild intellectual disability and mental disorder to be deposited at designated places (e.g. in-patient wards or liaison psychiatry teams); or
- electronic copies of care plans being up-loaded on the case record system of the mental health provider.

Clinical competencies and training

In order to become competent in managing the mental health needs of people with intellectual disability, clinical placements in the specialty are available for core trainees in psychiatric rotations across the UK. It is accepted that not all trainees will complete a 6-month placement in the psychiatry of intellectual disability. Trainees should be encouraged to complete formal workplace-based assessments in the psychiatry of intellectual disability that can provide further educational opportunities. Higher trainees who do not specialise in intellectual disability should be encouraged to consider obtaining additional experience in special interest sessions in the specialty. Induction at 6-monthly intervals for core trainees and annually for ST4–6 are additional opportunities to discuss the presentation of mental disorder in people with mild to moderate intellectual disability in accident and emergency departments or general psychiatric wards. Models of on-call rotas may include trainees and consultants from adult mental health and psychiatry of intellectual disability or be separate for each specialty. We would recommend joint on-call rotas, as they promote better integration between services.

Nursing (Hardy *et al*, 2010) and other professionals from community intellectual disability teams can provide training to their colleagues in adult mental health services. Topics may include case discussions or more structured module teaching as part of continuing professional development programmes. Box 2 shows suggested learning points that can be of help to staff in adult mental health services. By the same token, staff in community intellectual disability services would also need skills in recognising symptoms of mental or neurodevelopmental disorders, atypical presentations and simple management approaches to substance misuse or self-harm.

Box 2 TOPICS THAT MAY BE OF RELEVANCE TO STAFF IN ADULT MENTAL HEALTH SERVICES

- Improved communication skills
- Presentation of mental illness/atypical presentation
- The person with mild to moderate intellectual disability in the accident and emergency department
- Modifying treatment approaches
- Working with the wider support network

Conclusions

People with mild intellectual disability as well as those with neurodevelopmental disorders and other behavioural and social difficulties present with significant mental ill health and complex needs. They are disadvantaged and frequently have limited ability to manage their mental health needs. However, they have a right to have their mental and physical needs met in the way most appropriate to them, including the use of general services where this is indicated, and to be fully supported by community intellectual disability services.

It falls to all clinicians, managers and commissioners to ensure that skills and services in both intellectual disability and mental health are available and have a common purpose in working together to meet the challenge of not excluding people from services on account of their level of functioning.

Partnership working should be supported by joint ownership of care pathways and measurement of outcomes underpinned by joint training across all professional groups involved in meeting mental health needs, where appropriate.

According to the International Classification of Functioning, Disability and Health (www.who.int/classifications/icf/en), disability is a condition faced by those with mental ill health regardless of intellectual ability and therefore 'disability is a universal human experience'. Adults with intellectual disability and mental health needs arising from psychiatric, developmental and behavioural disorders should have access to services comprising mainstream and specialist skills in order to promote recovery and inclusion.

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