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ARTICLE

Interface between community intellectual disability and general adult psychiatry services

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SUMMARY

People with intellectual disability can have a range of common mental health difficulties that sit at the interface of two psychiatry subspecialties: intellectual disability and general adult psychiatry. Clinical presentations, comorbidities and complexities can affect the setting of boundaries between the two disciplines. This article touches on current concepts, drives for inclusion of people with intellectual disability in mainstream psychiatry services and some of the difficulties at the interface. It focuses on potential solutions for managing this interface between the two subspecialties.

LEARNING OBJECTIVES

After reading this article you will be able to:

- understand the concept of intellectual disability psychiatry and the role of intellectual disability psychiatrists compared with general adult psychiatrists
- identify important issues at the interface between general adult and intellectual disability psychiatry
- understand how to manage the interface.

KEYWORDS

Intellectual disability; community mental health teams; comorbidity.

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The Royal College of Psychiatrists describes the psychiatry of intellectual disability as a subspecialty involved in working with people with intellectual disability (often known as learning disability in UK health services) who have mental disorders and treating severe mental illness and conditions such as autism spectrum disorders in this population. Intellectual disability psychiatrists are expected to have deeper understanding of relevant legislation and complex biological, psychological and social factors contributing to mental disorders in intellectual disability. General adult psychiatrists, however, have special expertise in the diagnosis and treatment of a wide range of mental disorders, including organic brain disorders, psychosis, depressive illness and personality disorders in the working-age population (Royal College of Psychiatrists 2018).

Assessment and treatment of common mental disorders, which have a higher prevalence in people with intellectual disability (Cooper 2007), is a common factor overlapping the interface between the two disciplines. This creates a common role for the two disciplines. Increased progress towards inclusion and facilitating access for people with intellectual disability to mainstream services is often challenged by factors such as variable depth of training and expertise, variable access to services at certain stages of the patient journey, boundary disputes and referral criteria.

Challenges at the interface in the past have led to patients suffering discontinuity of care and falling through gaps between the two services (Royal College of Psychiatrists 2020). Furthermore, tensions and dissatisfaction might arise between the two multidisciplinary teams.

In England and Wales, people with intellectual disability and mental health difficulties are currently supported at various levels of healthcare: primary, generic mental health and specialist intellectual disability services. In practice, however, the most common form of psychiatric care so far is provided within community intellectual disability services (Bouras 2004). This, especially in those with moderate, severe and profound intellectual disability, is usually due to the interplay of other complicating factors, such as challenging behaviour, communication difficulties, autism spectrum disorder, sensory impairment, offending, and mobility and swallowing difficulties.

Currently, in my experience, interface problems mainly arise with comorbid mental illnesses in people with a mild intellectual disability. In the county of Gloucestershire in the UK, Fear et al (2012) developed a model based on integration of specialist mental health services, with a single point of access and person-centred mapping of mental healthcare delivery for people with intellectual disability (Fear 2012). The authors recommended a similar model nationwide. Thus far, however, there is no agreed national model of

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integration of community intellectual disability and general adult psychiatry services. Therefore, there are currently inconsistencies at the level of integration and partnership at the interface between the two services.

Concepts of intellectual disability and referrals to mainstream services

The British Psychological Society defines intellectual disability as a condition in which there is significant impairment of intellectual functioning, significant impairment of adaptive behaviour and the onset of both impairments is before adulthood (British Psychological Society 2015: p. 3). Box 1 lists the impairments in these domains, as defined by the British Psychological Society.

Mental health services encounter people with various severities of intellectual disability and IQ ranges: mild (IQ = 50–69), moderate (IQ = 35–49), severe (IQ = 20–34) and profound (IQ < 20). A low IQ (<70)is a requirement to diagnose intellectual disability recommended in ICD-10 (World Health Organization 1993) and the British Psychological Society (British Psychological Society 2015).

Community intellectual disability teams usually set criteria for accepting referrals. These criteria typically include the presence of intellectual disability and of identified healthcare needs (in integrated health–social care teams, health and social care needs are specified). Furthermore, owing to the increasing shift towards inclusion of people with intellectual disability in mainstream services, many teams will also explore whether the needs could be met by mainstream services by providing reasonable adjustment. Typical problems and healthcare needs that prompt referral are set out in Box 2.

There is a scarcity of research comparing the quality of care people with intellectual disability receive within mainstream psychiatric services compared with specialist intellectual disability services. A 25-year-old inner-city survey in London, UK (Gravestock 1995) reported greater availability and accessibility of services in specialist intellectual disability services than in generic mental health services. Bouras & Holt (2004) reported two studies from much the same era showing inconclusive and inconsistent outcomes: the Van Minnen et al (1997) study showed reduced hospital admissions when people with intellectual disability received care from a community intellectual disability team. In contrast, the Coelho et al (1993) study reported better adaptive function when people with intellectual disability had intensive case management by a mainstream community mental health team.

BOX 1 Areas of intellectual and adaptive behaviour impairment as specified by the British Psychological Society

Intellectual functioning

- Reasoning
- Planning
- Problem-solving
- Abstract thinking
- Comprehension
- Learning from experience
- Speed of learning

Adaptive behaviour

- Conceptual skills: language, reading and writing, and money, time and number concepts
- Social skills: communication, social responsibility and social problem-solving
- Practical skills: activities of daily living such as personal care, occupational skills, use of money, use of healthcare and transportation, understanding safety, and use of the telephone

(British Psychological Society 2015: pp. 12–14)

Mental health at the interface

The influence of normalisation

Normalisation is a concept that involves recognition of full and equal rights for people with intellectual disability (Simpson 2018). Early models of normalisation were developed in Scandinavia in the 1960s by Niels Bank-Mikkelson and Bengt Nirje. In 1970s, the concept was expanded in the USA by Wolf Wolfensberger, with emphasis on social integration and abandonment of institutional segregation of people with intellectual disability (Culham 2003).

Following the process of 'normalisation', people with intellectual disability were moved from institutional care back into community care. Introduction of community intellectual disability teams about 50 years ago resulted in better management in the community, greater recognition of human rights, higher standards of care and increased life expectancy for people with intellectual disability and mental health difficulties (Chaplin 2009). However, this is associated with unprecedented demands facing specialist intellectual disability mental health services.

The presentation of mental disorders in intellectual disability

People with intellectual disability experience the full range of mental disorders (Hall 2006) and have high rates of psychiatric disorders (32.2%) compared with the general population (11.2%) (Kerr 2004).

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BOX 2 Typical reasons for referral of people with intellectual disability from mainstream to intellectual disability services

- Significant change in behaviour
- Mental health problems
- Autism (comorbid with intellectual disability)
- Communication difficulties
- Swallowing difficulties and dietary needs
- Sensory problems
- Postural, respiratory and mobility difficulties, falls
- Cognitive deterioration
- Medical conditions such as epilepsy
- Counselling and psychological therapy
- Specialist advice and reasonable adjustment needs

The presence of intellectual disability can affect the way that mental illnesses are manifested, detected, diagnosed and managed. Patients with intellectual disability may have difficulties in expressing subjective experiences that can be synthesised into symptoms of particular mental disorders such as depression or schizophrenia. In depression, for example, the patient might be unable to express symptoms of low mood; however, biological changes in bowel habits, appetite, weight and sleep might be more readily detected. Generally, people with intellectual disability present with changes in behaviour and functioning (Gravestock 1995). In schizophrenia someone with intellectual disability might present with significant change of behaviour rather than verbal expression of delusional beliefs and hallucinations. Diagnostic overshadowing, where symptoms of mental disorders are attributed to the patient's underlying intellectual disability, is common (Hall 2006; Jones 2008).

About 5–15% of people with intellectual disability display behavioural difficulties that could be described as challenging. Challenging behaviours could complicate the clinical picture and might create additional difficulties for mainstream services.

Training and competencies for specialist and mainstream services

Assessment and management of mental disorders in the intellectual disability population require competencies in understanding of genetic, developmental, neurological and psychosocial predispositions (Lindsey 2002).

Intellectual disability psychiatrists receive additional training in diagnosing and managing physical and psychiatric comorbidities in people with intellectual disability, but many general adult psychiatrists have had little or no formal training in intellectual disability (Chaplin 2009). These psychiatrists might find the complex interplay of intellectual disability and mental illness challenging. Communication difficulties, for example, might set a challenge to services not adequately trained and staffed to manage them.

IQ score as a blunt identifier

Currently, many referrals to community intellectual disability teams are based only on the presence of intellectual disability or even on the single criterion of a low IQ. The presence of intellectual disability, however, need not be a rigid criterion determining the service that the patient should fall into. The National Institute for Health and Care Excellence (NICE 2016) recommends that all mainstream mental health and psychological treatment services should have the competencies to treat people with intellectual disability, calling on specialist support if needed. Furthermore, there is an obligation under the UK's Equality Act 2010 that requires reasonable adjustments are made in order that people with disabilities are appropriately supported in mainstream services. This is sometimes forgotten when there is a readily available intellectual disability service.

Low IQ does not provide definitive diagnosis of intellectual disability. In chronic schizophrenia, for example, performance IQ might fall as much as 15% below verbal IQ (Chaplin 2009). National Instutute for Health and Care Excellence also suggests that IQ score does not provide information about a person's social, medical, educational and personal needs, nor the nature of support they might need (NICE 2016). Therefore, an IQ in the 50–69 range is not necessarily associated with health needs exclusively to be met by either mainstream or specialist intellectual disability services alone. The patient might still have complex health needs requiring collaboration of more than one service.

For more than two decades the concept of mainstreaming has been giving the concept of normalisation a new impetus (Hall 2006). Enhancing access to mainstream psychiatric services may reduce stigma and negative attitudes among healthcare professionals (Joint Commissioning Panel for Mental Health 2013).

Drivers of normalisation: Valuing People, the Equality Act and the Green Light Toolkit

The government has a long-standing policy, Valuing People, that encourages mainstream services to undertake psychiatric care of people with intellectual disability (Department of Health 2001).

The Equality Act 2010 imposes a duty on public service providers to make reasonable adjustment for people with disabilities: a disabled person must not be disadvantaged in comparison with a person who is not disabled. Any failure to comply with this duty and any discrimination in provision of services on the grounds of intellectual disability are therefore unlawful. Healthcare services must therefore make reasonable adjustments to accommodate and respond to the needs of people with intellectual disability.

The Green Light Toolkit is a framework published by the National Development Team for Inclusion (2017). It focuses on enabling people with intellectual disability to access mainstream and specialist mental health services, providing tools for self-assessment/audit and guiding services through integration. However, there are challenges in using the Toolkit, such as unresolved questions about coordinating its use, ownership of leading and commissioning (Chaplin 2009) and lack of scrutiny. In spite of this, there are innovative examples of implementing the Toolkit. Norfolk and Suffolk NHS Foundation Trust, for instance, reports positive outcomes such as improved partnership working and enhanced professional relationships across services (Bridges 2019).

How best can we improve the interface?

Applying stringent exclusion criteria for either service, for example using the presence of intellectual disability to exclude someone from general adult psychiatry, or an IQ score in the 'mild intellectual disability' range to exclude people from community intellectual disability services, or comorbid mental disorder to exclude from either service, might create unhealthy boundaries. As already mentioned, symptoms of common mental illnesses occur in people with mild intellectual disability as they do in the rest of the population. Furthermore, communication difficulties vary among people with intellectual disability. Generally, people with mild intellectual disability are usually able to engage in conversation, including diagnostic and therapeutic psychiatric interviews. They are also mostly independent in terms of self-care, daily living and domestic skills (Bennett 2013).

Furthermore, National Institute for Health and Care Excellence suggests that the rate of challenging behaviour is not the same for all people with intellectual disability (NICE 2015). Individuals with mild intellectual disability have lower rates of challenging behaviour than those with severe to profound intellectual disability.

Effective communication, collaboration and arrangements must be in place to manage the interface while enabling people with intellectual disability to access mainstream adult mental health services. The knowledge, skills and expertise of both disciplines need to be utilised to respond to the healthcare needs of this population at the interface. In the remainder of this section I will explore a number of recommendations (Box 3) for managing the interface between intellectual disability and adult mental health services made by the Royal College of Psychiatrists (2020) and various professionals.

BOX 3 Possible arrangements to the manage interface between intellectual disability and adult mental health services

- Referrals from adult services for advice on intellectual disability-related problems
- Joint-working protocols
- Joint multidisciplinary interface meetings
- Developing a needs-based model
- Setting up virtual cross-service teams
- Training and education in intellectual disability for mainstream staff

(Hall 2006; Royal College of Psychiatrists 2020)

Referrals

Khosla et al (2014) point to referrals made by general adult to forensic psychiatrists for advice on risk and management as a model of cooperation to resolve interface difficulties between general adult and forensic psychiatry. This model could also be applied at the interface between general adult and intellectual disability psychiatry. Patients could be referred for advice about intellectual disability-related behavioural, communication, mental health and sensory problems.

Joint-working protocols

In certain areas the two disciplines have developed protocols for joint working to address issues of transition between the two services, timescales, best approaches to joint care and the process of escalation in case of disagreement between the two clinical teams.

Support with the care programme approach (CPA) and allocation of a care coordinator might be helpful in coordination of joint working, establishing an appropriate and systematic approach to needs assessment, care-planning and monitoring.

The RCPsych specifically recommends that various services agree on joint-working protocols as good practice to prevent patients falling into the gaps between different services and to deliver more

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holistic care (Royal College of Psychiatrists 2020). The aim of such protocols is to manage transition between services, for example the service receiving the referral should complete the initial assessment, arrange cognitive assessment and hold case management responsibility during transition. Another aim is to facilitate access for people with intellectual disability to a wide range of services, such as community-based intensive mental health support services, early intervention in psychosis, personality disorder, rehabilitation, eating disorder and forensic services and recovery centres.

Joint multidisciplinary meetings

These meetings could include members of the two involved services as well as wider stakeholders such as commissioners and Social Services. The purpose of the meetings is to enhance mutual understanding of each service's structure, care pathways, staffing, commissioning requirements and other organisational matters. They also create the opportunity to discuss clinical and eligibility issues arising at the interface and to disseminate areas of good practice (Royal College of Psychiatrists 2020). These forums could potentially discuss and set up pathways, protocols and joint out-patient clinics.

Developing a needs-based model

A needs-based approach has been used for many years in education and healthcare in countries such as Canada. The basic philosophy of this approach is a focus on needs rather than the diagnosis of disability. The Royal College of Psychiatrists suggests that it is a good practice to enable access of people with intellectual disability to services best meeting their needs regardless of their intellectual functioning (Royal College of Psychiatrists 2020).

General adult psychiatry services are more resourceful in terms of the ability to respond to patients' needs patient at different stages of the patient journey. For example, they have early intervention services (EIS) for psychosis, and assertive outreach (AO) and crisis resolution and home treatment (CRHT) services, which are absent or less developed within intellectual disability community teams. In addition, patients with intellectual disability might benefit from mainstream psychological services such as the improving access to psychological therapies (IAPT) programme.

Equally, intellectual disability services possess unique skills when patients with any severity of intellectual disability present with additional difficulties – and needs – due to communication, physical health problems such as epilepsy, and challenging behaviour. The needs-based approach could offer a different and flexible care model. This model needs interdisciplinary collaboration and utilisation of the knowledge, skills and expertise of both disciplines in order to prioritise the areas of intervention and to respond to health needs.

Virtual teams

Collaborative working within community 'virtual teams' demonstrates some success towards integrated models of care between community intellectual disability and mainstream general adult psychiatry services (Hall 2006). These teams could be effective when various professionals work in different locations, organisations or specialties. Staff from different teams can regularly meet virtually to discuss individuals with intellectual disability and comorbid mental disorders. The virtual team could also include staff from other community services, such as substance misuse and out-of-hours crisis teams, to promote access of people with intellectual disability to these services. Another example of virtual team work is the 'Fair Horizons' model, with single-point entry and assessment by experienced front-line staff in order to assign the patient to the most appropriate pathway (Fear 2012).

Training and education

In most countries of the world, including many high-income ones, there is currently no separate specialist psychiatry postgraduate training for intellectual disability. In these countries, people with intellectual disability use mainstream services. However, there are many schemes and courses, ranging from a few days to many months, to educate mainstream psychiatry doctors about intellectual disability and to provide focused training. In Germany, for example, a short course, comprising 40 h of theory and another 50 h of hospital placement, is regularly offered via the charity Ärzte für Menschen mit geistiger oder mehrfacher Behinderung (Doctors for People with Learning or Multiple Disabilities). This course is directed at, among others, psychiatry specialists interested in developing their knowledge and skills in intellectual disability (Jungnickel 2008).

In the UK, development of skills in the assessment and management of patients with intellectual disability should be encouraged during postgraduate training in general adult psychiatry. This can be developed through interdisciplinary teaching and training events. The RCPsych regards completion of a recognised intellectual disability post during psychiatry core training and developing special interest in intellectual disability by general adult psychiatry trainees as desirable in skills building (Royal College of Psychiatrists 2020).

MCQ answers
1 e 2 d 3 a 4 b 5 e

Conclusions

Psychiatry of intellectual disability and community intellectual disability teams have an important role to play in enhancing access to mainstream psychiatry services by people with intellectual disability who have mental disorders. Currently there are neither prescriptive or agreed models of care to set out a framework for this purpose nor wider acknowledgement of the challenges facing mainstream services in dealing with the complexities of mental health difficulties in people with intellectual disability. Management of the interface can be guided by the Equality Act 2010, initiatives and frameworks such as Valuing People and the Green Light Toolkit, and guidelines published by the National Institute for Health and Care Excellence. At local levels, the interface can be improved through coordination of care and collaboration between community intellectual disability and general adult psychiatry teams through joint shared-care protocols, consultation referrals, joint interface meetings, a needs-based approach, virtual teams and training of mainstream staff.

As there is currently a dearth of data about outcomes of mainstreaming in the community, further research is needed to discern the impact of accessing mainstream services on the care standards and life of people with intellectual disability.

Declaration of interest

None.

An ICMJE form is in the supplementary material, available online at https://doi.org/10.1192/bja.2020.31.

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MCQs

Select the single best option for each question stem

1 The British Psychological Society's definition of intellectual disability:
- a does not recommend low Intelligent Quotient (IQ) as a requirement to diagnose intellectual disability
- b rejects reduced practical skills such as use of money and healthcare as impaired adaptive behavious
- c does not recognise speed of learning as a component of intellectual functioning
- d relies on IQ test scores more than the overall clinical judgment
- e involves demonstration of significant impairment of intellectual functioning and adaptive behaviours which started before adulthood.

2 The process of 'normalisation':
- a involves treating people with intellectual disability in hospitals
- b started about 10 years ago
- c means that people with intellectual disability cannot be treated by mainstream mental health services
- d has led to a better recognition of human rights of people with intellectual disability
- e has reduced the standard of care for people with intellectual disability.

3 In intellectual disability:
- a common mental disorders occur at a higher rate than in the general population
- b the rate of schizophrenia is the same as in the general population
- c mental illnesses can be easily diagnosed when they develop
- d individuals cannot express their symptoms when they are ill
- e challenging behaviour, if present, is always related to the intellectual disability.

4 As regards the 'reasonable adjustments' required by the Equality Act 2010:
- a they are needed only when people are cared for within the specialist intellectual disability services
- b all UK public health services have a duty to make reasonable adjustments for people with intellectual disability
- c they do not apply to general hospitals
- d they do not include providing easy-read information
- e they exclude people with severe intellectual disability.

5 To improve the interface between intellectual disability and general adult psychiatry:
- a everyone with intellectual disability should be exclusively eligible to receive specialist intellectual disability services
- b patients' choice is usually not so important
- c setting a stringent criteria based on IQ rather than needs would identify the best service for the patient
- d involving social care support is not helpful
- e developing joint-working protocols could be useful.