Abstract

Objectives

The objectives of this mixed methods study are to 1) investigate the knowledge and skills of mainstream psychiatrists in managing patients with Intellectual Disability (ID) and comorbid mental health disorders 2) assess their perception of the quality and accessibility of services for this population and 3) establish the local implementation of the Green Light Toolkit.

Method

We surveyed mainstream psychiatrists in the Thames Valley region working in general adult, forensic and older adult services, to ascertain their opinions about their knowledge and skills in managing patients with ID and comorbid mental disorder, as well as quality and accessibility of services.   We compared our findings with previous UK and international research.

Results

Respondents mirrored views expressed in earlier studies that inpatient care should be provided in dedicated units for people with ID, rather than general adult inpatient wards. Limited resources, training and competence, and lack of collaborative working were highlighted as key barriers to provision of effective care.

Conclusion

Psychiatrists broadly support a specialist service model for people with ID. In the UK, specialist psychiatric services for people with ID have been delivered through inpatient and community services, but there is a current shift towards integrating ID with mainstream service models. Participants expressed concern that mainstream services fail to meet the

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mental health needs of this patient group, and lead to increased patient vulnerability. Green Light Toolkit was not well known or used within services. A number of ways of improving collaborative care between services are suggested.

Background

People with Intellectual Disability (ID) are at increased risk of developing mental illness (Cooper *et al.* 2007) and when in need of acute psychiatric care are may be admitted to general inpatient facilities alongside patients without intellectual disability (Chaplin 2011). Psychiatrists who do not specialise in working with people with an ID may not have adequate training to assess and manage mental illness in this patient group (see Chaplin 2011 for a review of this literature).

During the 1970's the principles of de-institutionalisation and normalisation gained popularity in the UK. This resulted in the closure of long stay hospitals, which had housed large numbers of people with ID, and people with ID moving to live in community settings. Such changes in government policy were mirrored within UK health services, and the 2001 Department of Health white paper 'Valuing People' stated that the 'NHS is to ensure that all mainstream services are accessible to people with Intellectual Disability (Department of Health 2001).

Internationally there are a variety of service provision models for psychiatric and mental health provision for people with an ID (Chaplin 2009), including generic or mainstream services, whereby people with Intellectual Disability receive psychiatric care from mainstream community and inpatient services. Historically the UK has largely retained specialist ID services, which are now based within the community. However a range of different service models exist across the UK. An earlier review concluded that there was no clear evidence to support any specific model (Chaplin 2004). Currently NHS England's policy appears to be shifting towards the mainstream service model (Improving Health and Lives and Royal College of General Practitioners 2012) although recent guidance from the

National Institute for Health and Care Excellence (NICE) appears to contradict this, stating that those with Intellectual Disability who need a mental health assessment are referred to a professional with expertise in this area (NICE 2017).

Research into the outcomes of and experiences of people with ID and comorbid mental illness using mainstream psychiatric services has generally been fragmented and inconclusive. For example, an English survey comparing both specialist and generic inpatient units concluded that the former had greater staff expertise, but longer lengths of stay (Mackenzie-Davies *et al.* 2007). A similar study (Hemmings *et al*. 2009) conducted in London concluded that generally people with ID were able to access mainstream services, although those with complex needs could not have these needs met in mainstream units. Specialist ID units had more planned admissions and general units were most likely to admit patients with affective disorders.

The Royal College of Psychiatrists (RCPsych) published a report following the national investigation into the inappropriate care of patients with ID admitted to Winterbourne View Hospital (RCPsych 2013). This highlighted the need for inpatient services for people with ID who present with challenging behaviour and are a risk to themselves and others, whilst simultaneously recognising the need to improve community services. It suggests that specialist ID inpatient beds allow for equitable outcomes to patients with the same mental health problems but without ID. It also suggests that treatment within mainstream mental health inpatient units can provide good outcomes for patients with ID if there is adequate support from community ID teams. Hall *et al* (2006) report on the complexity of developing inpatient and community services for people with ID which are able to provide specialist

support for those with complex needs, but which allow for integration with mainstream services, and develop the skills of those working in mainstream services.

The UK is one of the few countries who offer a specialist training curriculum in psychiatry of ID. The UK offers core psychiatric training posts in ID and a three-year dedicated higher training programme in ID. Jess *et al.* (2008) compared psychiatric training in the UK (which includes specialist ID training) with Australia (where no specialist ID training is included). UK psychiatrists expressed greater confidence than Australian respondents in their own training and knowledge of patients with ID and comorbid mental illness. UK respondents reported more skills and exposure to working with people with ID, and thus a greater level of experience and expertise. Australian respondents expressed lower levels of confidence owing to less experience and training. The authors conclude that the specialist ID model of service provision and training has advantages over the generic mental health model.

The Royal College of Psychiatrists acknowledges the range of models for providing psychiatric care for people with ID and provides recommendations for ensuring good quality provision. This includes protocols for joint working between mainstream and specialist teams, regular interface meetings between the two services, models of shared care, information sharing, and educational and training opportunities within all training grades of psychiatry, to ensure adequate exposure to ID services (RCPsych 2012).

Recent key guidance for commissioners (Joint Commissioning Panel for Mental Health 2013) refers to the Green Light Toolkit. The Green Light Toolkit was developed by the National Development Team for Inclusion (NDTi), and originally published by the Department of Health in 2004 (revised in 2017). It provides a self-audit tool kit to enable services to ensure

that they are making reasonable adjustments to mental health services to ensure that people with autism and/or an intellectual disability are not being discriminated against. It provides standards for collaborative shared care between general adult mental health services and specialist ID services to ensure the provision of accessible and high quality services for people with ID (Cole *et al.* 2004).

Aims

The aims of this study are to 1) gather information about the levels of knowledge and skills amongst mainstream psychiatrists in managing patients with ID and comorbid mental health disorders, 2) assess their perception of the quality and accessibility of psychiatric services for people with ID and 3) establish the local implementation of the Green Light Toolkit.

Method

Participants were psychiatrists from two mental health trusts working in general adult, forensic and older adult services within the Thames Valley region. They were asked to complete a questionnaire (based on one developed by Chaplin *et al.* 1996).

The questionnaire consisted of 20 statements (see Table 2) and participants were asked to rate their endorsement of each statement using a 6 point Likert scale format ranging from 1 = strongly disagree to 6 = strongly agree. There were also three forced choice questions (Have you been involved in the assessment/treatment of a patient with LD in the past one year? ; During any stage of your training did you gain any experience/training in assessment and management of patients with LD?; Have you heard of the Greenlight Toolkit?) and two free text questions: 'What do you perceive to be the barriers to collaborative care?' and 'How might these barriers be overcome?'

The questionnaire was concerned with five overarching domains; a) mainstream inpatient facilities (5 questions), b) training/attitudes/knowledge (12 questions), c) Greenlight toolkit (2 questions), d) access to collaborative working with specialist ID services (3 questions), e) perceived barriers to collaborative working (2 questions). Response statements for each question are given in Table 2. The questionnaire was piloted on 20 psychiatrists and one item was modified following this pilot.

The project was registered with the Research and Development Departments in the two participating NHS Trusts. The questionnaire was distributed to all consultant psychiatrists, higher trainees and non-training grades working in general adult, forensic and older adult psychiatry. Psychiatrists working in child and adolescent, and ID services were excluded. The questionnaire was distributed in three ways:

1. Electronically using the Trust email system.
2. Hard copies via the Trust internal postal service.
3. Hard copies distributed at academic meetings.

In Trust 1 the questionnaire was distributed by internal post, and a stamped addressed return envelope was provided. In Trust 2, half of the questionnaires were distributed personally at academic meetings, while the rest were sent by email. Owing to time constraints only one month was allowed for responses from Trust 2, whereas the response time allowed for responses from Trust 1 was 3 months.

Results

Data analysis

The results from the Thames Valley sample were analysed using descriptive statistics. Mean and standard deviation scores for Likert scale responses are provided in Table 2. Thematic analysis was conducted on the free text responses derived from the questionnaire.

Main findings

The overall response rate was 62.5% (107/171). The response rate for Trust 1 was 81.8% (72 responses) and for Trust 2 was 42 % (35 responses).   61% (65/107) of participants had been involved in the assessment or treatment of a person with an ID in the past year. The commonest condition encountered in patients with ID was challenging behaviour, followed by schizophrenia and autistic spectrum disorder (Table 1).

Table 1: Single most common condition encountered in patients with ID & comorbid mental illness

	Trust 1 Responses	Trust 2 Responses
Challenging behaviour	22	26
Schizophrenia	17	8
Autistic spectrum disorder	16	4
Anxiety disorder	5	7
Personality disorder	9	2
Organic	8	3
Depression	6	4
Bipolar affective disorder	4	2

Across the Thames Valley, there was firm support for 2 out of 5 statements covering the domain of inpatient facilities. Similarly, for the domain knowledge/skills and attitudes, participants largely agreed with 7 out of 12 statements. For those statements covering the domain of shared working, only 1 out of 3 was clearly endorsed (Table 2).

Table 2: Mean Likert scores from 107 respondents (from 1 = strongly disagree to 6 = strongly agree)

Response Statements	Mean Likert Score (standard deviation)
Psychiatric inpatient facilities	
Inpatient psychiatric care should be provided in dedicated units for adults with Intellectual disability	4.62 (1.07)
Adults with intellectual disability are vulnerable to exploitation from other patients using general adult mental health services.	4.89 (1.06)
Inpatient facilities in general adult psychiatric services are adequately suited to adults with a mild intellectual disability and mental health problems.	2.67 (1.15)
Adults with intellectual disability commonly stay too long as inpatients when they are admitted for assessment/treatment.	4.14 (1.15)
People with an intellectual disability receive a relatively poor standard of psychiatric care	3.87 (1.28)
Knowledge/skills/attitudes	
Psychiatrists in general adult services receive sufficient training/experience to manage patients with intellectual disabilities and mental health problems	2.40 (0.97)
There is no role for the psychiatrist in assessing and managing challenging behaviour in people with intellectual disabilities	1.96 (1.12)
Psychiatrists in general adult services should be offered a dual training in intellectual disabilities option as part of their higher training.	4.23 (1.43)
Personally, you would not prefer to treat people with an intellectual disability.	3.08 (1.14)
Personally, you would be confident conducting an assessment of a person with an intellectual disability presenting with a mental health problem.	3.58 (1.08)
Antipsychotics are overused in people with intellectual disability and challenging behaviours.	4.08 (1.07)
Mental health problems are rare in adults with intellectual disabilities.	1.53 (0.83)
It is important for psychiatrists to have knowledge of behavioural phenotypes.	4.85 (1.12)

An individual with severe intellectual disability may present with challenging behaviour as a manifestation of a mental illness.	5.30 (0.84)
There is no real need to investigate psychiatric symptoms in those with severe intellectual disabilities.	1.46 (1.06)
Adults with intellectual disabilities who have offended do not require a psychiatric assessment.	1.54 (0.92)
Psychiatric treatment of adults with intellectual disabilities is mainly symptomatic rather than based on diagnostic classification.	3.06 (1.44)
Shared working	
Protocols exist which clearly specify roles and responsibilities of inpatient and community teams in both general adult mental health and intellectual disability services.	2.48 (1.30)
When a person has both mental health and intellectual disability, there is joint care planning and a written care plan which specifies what support each service can expect from the other.	2.85 (0.98)
There are protocols with clearly specified consultant responsibility for transfer or shared care between intellectual disability and general adult mental health services.	2.70 (1.02)

From the whole sample, only 2 respondents (both from Trust 2) had heard of the Green Light Toolkit.

Thematic analysis

A higher number of free text responses were received from the respondents in Trust 1, reflecting the larger number of respondents from that Trust. Qualitative data was provided in response to two questions: 'What do you perceive to be the barriers to collaborative care?' and 'How might these barriers be overcome?' Data was analysed using Thematic Analysis (Braun *et al.* 2006). Thematic analysis is a method for identifying, analysing and reporting patterns or themes within data. Four themes were identified around barriers to collaborative care.

Perceived Barriers

The theme of 'Difficulties with collaborative working' between mainstream and ID services was discussed by a number of participants. This was illustrated with several quotes which

reflected a sense of frustration, such as "*teams love to have barriers to avoid work*".

Collaboration was being hindered by the fragmented or "*arbitrary division between services*".

Respondents from mainstream services described difficulties in engaging specialist ID

services in joint working: "*It is difficult to have constructive dialogue with the LD team about*

patient care as they seem extremely reluctant to be involved when patients with a learning

disability also have a psychiatric illness"

The second theme was that of 'Communication'. Participants from both groups identified

concrete examples of barriers to communication such as "*Different electronic info system*"

which resulted in "*No access to patient background information*" as an obvious barrier to

good communication between services. However a more subtle area of communication

difficulty was identified, which was concerned with difference in understanding around the

roles and criteria of the different services. Examples of this included "*Disagree[ing]*

regarding patients' primary needs" and a perceived "*tendency for mild LD [learning*

disability] patients to be pushed into GA [general adult] services". Worryingly participants

identified "*a gap in both services for patients with mild degree of disability*", indicating that

these people may be at risk of falling in a gap between services.

Within the theme 'Limited Resources', participants acknowledged the lack of resources

(primarily in terms of time and staffing levels) in both services : "*Both services being*

overwhelmed and very busy", "*Burden of work and lack of time/resources in both teams*"

Participants reflected on the impact this has on patient care: "*Everyone is cutting the*

corners". This theme also encompassed wider resources such as a lack of training, and few

opportunities to develop competence and skills at an individual and service level: "*Lack of*

proper training about intellectual disability services in psychiatry" and "*Lack of LD training opportunities for core/higher trainees in general adult posts*". Participants went on to consider how this may impact on patient care, and the experience of people accessing services "*results in lack of awareness and understanding of the needs of LD patients*".

Within the fourth theme of 'Organisation issues', participants from Trust 1 particularly commented on the separate services being run by different organisation and the "*organisational boundaries*" this posed in terms of access to information from colleagues: "*no opportunity to see relevant notes of colleagues easily*"

Some respondents commented on the perceived differences in cultures between services with learning disability services being seen as having a "*culture of non-medicalisation*" and "*Better and more holistic family services for those with LD so disadvantage to GA services*"

There was some confusion about the local agreement for agreed protocols "*No clear protocols to guide management of patients with mental illness and LD*" with participants wanting "*Clear protocols to define what we should do*".

Overcoming perceived barriers

Three themes were identified in participants' suggestions of ways to overcome the barriers to collaborative care.

'Developing joint ways of working' was identified as an important theme. Several participants suggested that "*Proper protocols to be developed whereby shared working goals and care pathways are developed*" would be helpful. Several different models were proposed such as "*direct liaison units between general psychiatry and LD services*" and "*Joint assessment should be the norm for patients referred to CMHT [Community Mental Health Team]*." The role of communication was seen as important with suggestions for improvement

such as "*Meet the LD team to discuss role/responsibilities and the possibilities of joint working*" and having "*More shared meetings, grand rounds*". As well as these more formal arrangements, an informal, collaborative attitude was also suggested. "*More integrated working*" was also identified as a possible way forward to promote "*a kinder and more collaborative working ethos*".

A second theme of 'Additional resources' included concrete resources such as "*More bed space in specialist intellectual disability services at this hospital*" and increased staff time and expertise, with ideas including "*IQ testing becoming more available*" being seen as helpful. Improved training at different levels such as "*Robust clinical experience and training for all psychiatrists*", "*Core training-mandatory in basic LD*" and "*Joint CPD [continuing professional development] /meetings to allow improvement of knowledge and skills and azlso set up a culture of shared learning*" were suggested.

A core theme was identified around 'Leadership'. Participants indicated that in order for collaborative care to become embedded in services, "*senior managerial influence*" would be required in order to have "*a clear policy defining the roles of the services*". Services that are "*Jointly commission[ed] "* within the "*Same organisation*" were recommended.

Discussion

Main Findings

Differences across the two Trusts

Trust 1 had a higher response rate than Trust 2. Three possible reasons are suggested for this difference. Firstly, different methods of distribution and response time were used in each Trust. In Trust 1 the questionnaire was distributed by internal post, and a stamped addressed

return envelope was provided. In Trust 2, half of the questionnaires were distributed personally, while the rest were sent by email. Secondly, owing to time constraints only one month was allowed for responses from Trust 2, whereas the response time allowed for responses from Trust 1 was 3 months. Finally, Trust 1 has specialist ID service provision commissioned through an external Trust. This could have encouraged more responses, as participants may have felt more at ease to comment on an external service provider, in comparison with Trust 2 where ID specialist service provision is provided from within the same mental health Trust. Overall, the response rate of 62.5% is relatively high for a questionnaire based study. However it may be that the attitudes, knowledge and skills of those who chose to participate may be different from those psychiatrists who did not respond to the study. Therefore the results should be interpreted with some caution.

Results demonstrate that people with ID and a range of additional psychiatric and behavioural difficulties are being seen within mainstream services, as well as specialist ID services. The most commonly encountered diagnoses were challenging behaviour and schizophrenia which is in keeping with previous studies and current NICE (2015) guidance. Other conditions included autistic spectrum disorder and organic diseases, which along with challenging behaviour, could be seen at higher rates within the ID population. Challenging behaviour is not an official diagnosis under ICD10 or DSM-V, but is a social construct. The problem behaviour may be unrelated to the psychiatric disorder, but can also be a primary or secondary manifestation of it (Emerson 2010). The concept of diagnostic overshadowing whereby "symptoms of physical or mental ill health are mistakenly attributed to a behavioural problem or as being inherent in the person's intellectual disabilities", can be an issue which may potentially contribute to the overuse of this diagnosis.

Inpatient facilities

There was strong agreement that inpatient psychiatric care should be provided in specialist ID units. This is in line with previous research (Jess *et al.* 2008) but contrasts with current government policy which aims to reduce specialist ID inpatient units and integrate them into mainstream services (NHS England 2015).

Participants were concerned that patients with ID who are admitted to mainstream inpatient units are vulnerable to exploitation from other patients, in line with Hall et al, (2006). UK studies found that treating patients with ID in mainstream psychiatric inpatient facilities is unpopular with carers and service users (Parkes *et al*. 2007). This can be improved to some extent by providing specialised trained staff and in reach services from community ID teams (Hall *et al* 2006; Chaplin 2011).

The theme that the generic model fails to meet the mental health needs of people with ID, and increases patient vulnerability, is of concern for the UK, if generic service models are to be increased alongside a reduction in specialist ID services in the future. However specialist inpatient units specifically for people with ID can have long length of admissions, and risk people becoming institutionalised (NHS England 2015). Alternative models such as providing specialist ID beds within mainstream units may allow for additional time and resources to be provided to meet the additional needs of people with ID, whilst mitigating against the disadvantages of exclusive specialist ID inpatient units (Hall *et al*. 2006; Xenitidis *et al.* 2004).

Training

Participants strongly felt that they receive insufficient training to treat patients with ID and comorbid mental health problems. This was reported within both quantitative and qualitative aspects of the study.

Currently, undertaking a specialist ID training post in core psychiatric training is not mandatory. Psychiatrists are only expected to have sufficient knowledge for the MRCPsych membership examinations. The curriculum states that not all trainees will have the opportunity to work in an ID training post, *"there will be a few trainees who have to gain these skills in other ways. The knowledge base will come from clinical experience coupled with lectures, seminars and private study including study for examinations. Those who do not get a post are strongly advised to negotiate a clinical attachment during another placement to best prepare them"* (Royal College of Psychiatrists 2016). The Faculty of Psychiatry of Learning Disabilities (FPLD) has raised concerns that consultants from other psychiatric specialties are being requested to work in psychiatry of ID without the desired or requisite training. They were receiving an increasing number of requests from such consultants about attaining the competence to work in psychiatry of ID (Jones *et al*. 2012). The FPLD continue to advocate strongly for retention of ID psychiatry Certificates of Completion of Training (CCT) despite a desire from both the Royal College of Psychiatrists and the General Medical Council to reduce the number of CCTs, heading towards two pathways of training in either General Psychiatry or Child and Adolescent Psychiatry.

Knowledge

It is encouraging that some respondents demonstrated areas of knowledge around mental illness in people with ID. This is demonstrated though endorsement of Likert statements relating to prevalence of mental illness in ID, knowledge of challenging behaviour, and

recognising the need for psychiatrists to be familiar with behavioural phenotypes presenting as a manifestation of mental illness. The respondents endorsed the need to investigate psychiatric symptoms in those with severe ID and psychiatric assessment of offenders with severe ID. Respondents clearly advocated the role of the psychiatrist in assessing and managing challenging behaviour in people with ID. However it should be noted that self-report may not be the most accurate way of measuring knowledge of an area and therefore results should be interpreted cautiously. In addition there was some evidence of poor attitudes towards people with ID with some respondent indicating a preference for not working with people with ID, which may reflect stigmatising attitudes, which are seen more widely within healthcare professionals (Mencap 2018).

Collaborative working

Respondents strongly agreed that there are a lack of protocols for joint care planning which clearly specify roles and responsibilities of inpatient and community teams within both mainstream and ID specialist services.   Difficulties with collaborative working between mainstream and ID services were identified in the qualitative data, and are in line with other studies in this area (e.g. Chaplin *et al.* 2007). The need for strong organisational leadership to develop collaborative working was emphasised.

It is of concern that this study identified that only 2 respondents had heard of the Green Light Toolkit. The Toolkit was designed to support efforts in improving access to mental health services for people with ID. Significant reorganisation of services has resulted in variable use of the toolkit. In 2012, National Development Team for Inclusion (NDTi) reviewed the

reasonable adjustments being made by mental health services towards equal access and collaborative care (National Development Team for Inclusion 2012). The report identified *pockets of imaginative and positive practice* where services had audited and redesigned their practice using the toolkit. The Department of Health (DoH) continue to promote the toolkit as part of an audit framework for all mental health services within and outside of the NHS, including an 'easy-read' version of the audit framework and toolkit so that people with ID can be full stakeholders in the process. The toolkit was revised in 2013 and 2017 (NDTi 2013, 2017).

Strengths and limitations

The survey had a good response rate for a questionnaire-based study, which may have been enhanced by using multiple methods of distribution. The inclusion of qualitative feedback was helpful in ascertaining respondents' perceptions from their personal experiences.   This could have been developed by conducting in-depth interviews with a subsection of respondents. As the sample was recruited regionally, it may be difficult to generalise the findings on a national scale. The study would have been strengthened by including the views and personal experiences of service users, their family and carers.

Conclusion

This study highlights ongoing issues around lack of training, collaborative working and shared care protocols with specialist ID services, as the main barriers to ensuring good quality care and services for those with an ID and mental illness. Government policy in the UK continues to advocate for the inclusion of ID services within mainstream services. In order for this to provide best quality care, this study suggests that additional training and

sharing or skills and knowledge across ID and mainstream services is needed, and that this requires strong and explicit leadership. Models which incorporate the best of specialist ID services, alongside the advantages of mainstream services are being developed. Further research should include the opinions of patients with ID and their carers in any future study (Parkes *et al*. 2007). Gathering information on how the Greenlight toolkit is being implemented nationally would help to promote the goals of collaborative working.

Declaration of Interest (on behalf of all Authors)   - None

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