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"Why can't they be in the community?" A policy and practice analysis of transforming care for offenders with intellectual disability

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Abstract

Purpose: This paper describes key policy and practice issues regarding a significant subgroup of people with intellectual disability - those with offending behaviour being treated in forensic hospitals.

Approach: The reasons why psychiatrists continue to be involved in the treatment of people with intellectual disability and mental health or behavioural problems and the factors that may lead to patients needing hospital admission are examined. Using two illustrative examples, three key questions- containment versus treatment, hospital care versus conditional discharge and hospital treatment versus using Deprivation of Liberty safeguards (DOLS) usage in the community are explored.

Findings: Patients with intellectual disability, mental health problems and offending behaviours who are treated within forensic inpatient units tend to have long lengths of stay. The key variable that mediates this length of stay is the risk that they pose to themselves or others. Clinicians work within the framework of mental health law and have to be mindful that pragmatic solutions to hasten discharge into the community may not fall within the law.

Originality/value: The article makes practical suggestions for the future on how to best integrate hospital and community care for people with intellectual disability, mental health and offending behaviours.

Keywords:
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Introduction

Following the broadcast of BBC's Panorama programme 'Undercover care: the abuse exposed' in May 2011 (BBC, 2011), specialist intellectual disability hospitals came under scrutiny. Describing such treatment as an outdated model of institutional care, the government published The Concordat to work with other stakeholders and meet 63 Transforming Care commitments, with one central commitment of moving into the community, anyone with an intellectual disability and challenging behaviour that does not need to be in a hospital setting (Department of Health 2012a; 2012b). The dramatic reduction in hospital placements that was expected did not happen (Health and Social Care Information Centre, 2013). It is now acknowledged that the complexity and scale of the challenge was underestimated and the scope and quality of data on inpatients with intellectual disability was poor (National Audit Office, 2015).

This paper focuses on the policy and practice issues regarding a significant subgroup of people with intellectual disability - those with offending behaviour being treated in forensic hospitals. Some of the issues discussed however, may be equally applicable to patients treated in other bed categories.

Intellectual disability, Psychiatrists and Psychiatric Hospitals

The community care movement led to the closure of the long-stay institutions that used to accommodate large numbers of people with intellectual disability (Kingdon, 2005). Deinstitutionalisation involved moving people out of large Victorian campuses into community settings, such as nursing homes, group residential homes, supported living accommodations, family homes or independent living (Bhaumik, Tyrer, & Gangadharan, 2011). Currently in England, the vast majority of people with intellectual disability live fairly

independent lives in the community. Of the 900,000 adults with the condition, 191,000 (21%) have any contact with specialist intellectual disability services (Emerson et al., 2012) and 3,035 (0.3%) receive treatment in psychiatric inpatient settings, including specialist intellectual disability hospitals (Health and Social Care Information Centre, 2013; Devapriam et al., 2015).

There is an argument, sometimes explicit but often implicit, that since intellectual disability is not a mental illness, psychiatrists and psychiatric hospitals should have no role in the care of these patients. It is this argument that leads to the position that admitting someone with intellectual disability to a psychiatric hospital is a throwback to institutionalisation. This position is wrong and will ultimately lead to people with intellectual disability and mental health or severe behavioural problems being denied the equity of treatment outcomes that they deserve (Devapriam et al., 2015). This issue is addressed in some detail in the Royal College of Psychiatrists' Faculty of Psychiatry of Intellectual Disability report (2013) on inpatient care for people with intellectual disability and mental health, behavioural or forensic problems. While being wholly supportive of the aim of avoiding *inappropriate* hospital stays, the report emphasised that it was a fundamental mistake to label all inpatient services as "*assessment and treatment units for challenging behaviour*", and outlined the most common reasons for admission and treatment within inpatient services.

Firstly, people with intellectual disability have significantly higher rates of comorbid mental health problems than the general population and this increases their vulnerability to mental health crises. The majority of those who come into contact with specialist intellectual disability inpatient services have complex comorbidities including mental illnesses, personality disorders, substance misuse, physical disorders and behavioural problems (Xentidis et al., 2004; Alexander et al., 2011). This belies the simple dichotomy of "is it intellectual disability" or "is it mental health". It is often both and more. Hence the description

of people being in hospital only because of “intellectual disability and challenging behaviour” (Department of Health, 2012b) may well be a gross over simplification.

Secondly, under the current Mental Health Act in England and Wales, mental illnesses are not the only mental disorders that warrant treatment in hospital. Other conditions like personality disorders, disorders of sexual preference or disorders of development can also be mental disorders. The Act specifically sees “intellectual disability associated with abnormally aggressive and seriously responsible behaviour” as a mental disorder. This means that people with intellectual disability can satisfy the statutory criteria for detention to be admitted and treated in hospital in the absence of any mental illness, a point reinforced by recent case law (Regina v Alan Fletcher, 2012).

Thirdly, challenging behaviour is a socially constructed, descriptive concept that has no diagnostic significance and which makes no inferences about aetiology. It may be unrelated to psychiatric disorder, but can also be a primary or secondary manifestation of it (Xeniditis *et al.*, 2001). It would be wrong to consider it as some sort of unitary entity. For people with intellectual disability who come into contact with health services, it can range from stereotypies, pica, faecal smearing or mild self-injury at one end to serious sexual assaults or unlawful killing at the other. The dividing line between challenging behaviour and offending behaviour is often blurred, but more serious examples of the latter would be seen by most professionals, not to speak of members of the public, as requiring treatment within a safe hospital setting.

Fourthly, intellectual disability covers a wide range- from those with mild degrees of disability whose adaptive functioning would only be slightly lower than the general population, to those with severe and profound disabilities who need help from others in most aspects of adaptive function. The public face of intellectual disability tends to be the latter, while the majority of

people who end up in psychiatric inpatient and forensic hospital settings tend to be in the former category. This has not been sufficiently explained in the media or elsewhere.

Finally, all inpatient beds are not the same. Royal College of Psychiatrists' Faculty of Psychiatry of Intellectual Disability (2013) proposed a classification of six different bed categories that serve entirely different functions. This classification has now been adopted in the National Intellectual disability Census (Health and Social Care Information Centre, 2015). Category 1 is made up of beds within forensic hospitals in conditions of either high, medium or low security. Categories 2 and 3 are acute admission beds, located within specialist intellectual disability units or generic mental health settings. Category 4 are forensic rehabilitation beds for people who continue to have enduring risk issues, but have stepped down from a Category 1 bed. Category 5 is for those with a similar profile, who have stepped down from a Category 2 or 3 bed. Category 6 is for the short term assessment of some neuropsychiatric conditions such as epilepsy and movement disorders. It is worth noting that these bed categories are not unique to those with intellectual disability and similar bed provision exists in other areas of mental health (NHS Confederation, 2012). These bed categories are best understood within the context of a tiered care model of service provision with Tiers One (liaison working with other agencies) to Three (intensive case management in the community) constituting community intellectual disability services, and Tier Four constituting an inpatient element of care (Royal College of Psychiatrists' Faculty of Psychiatry of Intellectual Disability, 2011).

Why do patients come into contact with forensic services?

Admissions to forensic inpatient beds (Category 1 or 4) happen after incidents of offending behaviour or in the words of the Mental Health Act, abnormally aggressive or seriously irresponsible behaviour. The majority are admitted under Part 3 of the Mental Health Act, which means they are subject to a court order with or without restrictions from the Ministry of Justice. However, not all patients in these forensic beds take this route, and this can be

either due to the police, the crown prosecution service or other criminal justice agencies not taking the case through the courts, or dropping proceedings once they see that the person they are pursuing is already in hospital even if that is under Part 2 ("civil" sections). Furthermore, carers of those with intellectual disability can be less likely to involve the police when an offence is committed (Lyall et al., 1995; Clare & Murphy, 1998). These situations usually result in an "upwards referral" where patients are referred to services of increasing security, without going through the criminal justice system. Of the 3,230 patients included in the 2014 Learning Disability Census, 2,585 patients (80%) were subject to the Mental Health Act (MHA) of which 1,460 patients (45%) were detained under Part II, 425 patients (13%) were detained under Part III without a restriction order, and 635 patients (20%) were detained under Part III and subject to Ministry of Justice restriction order (Health and Social Care Information Centre, 2015).

Almost all patients admitted to forensic beds (Category 1 or 4) have been treated in community settings beforehand. The factors that mediate their admission to or contact with forensic services have been examined (Devapriam, & Alexander, 2012) and are summarised below:

1. For some people, psychiatric co-morbidity and behavioural problems remain persistent in spite of adequate treatment. The assumption that all behaviours were a consequence of institutional lifestyles, which would diminish once community care was introduced, may be flawed (Holland et al., 2002).
2. Behaviours that were previously hidden or indeed tolerated within institutions become more visible in the community and lead to adverse consequences (Moss et al., 2002).
3. There is an increased societal aversion to any degree of risk that makes the first two drivers more potent (Carroll, Lyall, & Forrester, 2004; Denney, 2009).

4. The assumption that these problems could be adequately catered for within generic mental health services is impeded by a lack of specialist skills in the diagnosis and treatment of mental disorders in people with intellectual disabilities (Cumella, 2010).
5. Staff working within Community Intellectual Disability Teams (CIDTs) may not have the specialist skills to deal with the assessment and management of offending behaviour and forensic issues (Devapriam, & Alexander, 2012).
6. Community intellectual disability services are limited still further both by a shortage of beds for short-term admissions and difficulties in moving people through these beds into appropriate long-term accommodation (Jaydeokar, & Piachaud, 2004).
7. Inpatient intellectual disability forensic services provide an environment that emphasises care and treatment rather than punishment (Hollins, 2000) and should really only be for a small number of patients who present risks above threshold for safe management in the community. However some of the above drivers can sometimes result in an inappropriate "forensicisation" of challenging behaviour (Douds, & Bantwal, 2011).

By giving two illustrative examples, we highlight the complex interface between clinical and legal issues that exists for patients placed in Category 1 or 4 forensic beds. These examples are not of real patients, but are representative of the sort of the clinical presentations that one sees in this area. The legal framework referred to in these examples is the Mental Health Act 1983 (amended 2007) for England and Wales.

Case Example 1:

Mr A is 43 years old, with mild intellectual disability and "challenging behaviour" including physical and sexual aggression that started from late childhood and early adolescence. His victims included children of both genders as well as people with intellectual disability less able than him. After many incidents that did not result in prosecution, he was convicted at the age of 30, of a serious sexual offence against a child. He received a Section 37/41 order

and spent four years in a high secure and three years in a medium secure hospital (i.e., Category 1 beds). While in secure care, the treatment plan followed the principles of the 10 point treatment plan described by Alexander et al. (2011) and included:

1. A multi-axial diagnostic assessment that covered the degree of intellectual disability, cause of intellectual disability, pervasive developmental disorders, other developmental disabilities, mental illnesses, substance misuse or dependence, personality disorders, physical disorders, psychosocial disadvantage and types of behavioural problems
2. A collaboratively developed psychological formulation
3. Risk assessments
4. A Management of Aggression Care Plan
5. Pharmacotherapy, targeting both co-morbid mental illnesses and physical conditions
6. Individual and group psychotherapy, guided by the psychological formulation
7. Offence-specific therapies, particularly targeting violent and sexual offending
8. Education, skills acquisition and occupational / vocational rehabilitation
9. Community participation through a system of graded leave periods
10. Preparation for transition

His primary clinical diagnosis was mild intellectual disability associated with significant impairment of behaviour requiring attention or treatment (ICD-10 code F70.1). In addition he was considered to have a recurrent depressive disorder (ICD-10 code: F33) and a disorder of sexual preference (ICD-10 code: F65). After initial reluctance, he engaged in a range of therapies including the Adapted Sex Offender Treatment programme. Although his behaviour within supervised settings improved, professionals were unanimous that on-going supervision was an integral part of his treatment plan. At the same time, it was felt that he could be in a less restrictive setting that guaranteed an adequate level of therapeutic input, albeit with less physical security. He was hence transferred from the medium secure unit to a

locked rehabilitation setting (a Category 4 bed). Within this setting, the same treatment plan continues. It includes monitoring of his mental state, treatment of depression when relevant, nursing support, psychological therapy with a relapse prevention focus, regular supervised access to the community, an occupational therapy-led rehabilitation service and a voluntary work placement with staff supervision. Unescorted leave remains problematic; there were two incidents when he was the subject of complaints from members of the public, although it did not lead to prosecution. Psychology work continues to focus on these issues. He has been in this setting for six years and is still detained under the Mental Health Act. He has not offended during this time, but behavioural observations indicate the sexual interest in children remains in spite of treatment.

Case Example 2:

Mr B has a similar clinical history as Mr A, except that he is detained under a Section 3 rather than Section 37/41. This is because while his behavioural and psychiatric presentation was exactly the same as Mr A, the Crown Prosecution Service (CPS) decided not to prosecute him because they felt he was already receiving treatment in a hospital under Section 3 and there was little public interest in pursuing him through the courts.

There are three key questions that practising clinicians have to consider in these patients' care.

1. *Are Mr A and B having treatment or are they being contained in hospital?*

In hospital, Mr A and B have a structured programme of daily activities coordinated by occupational therapy and nursing departments. The psychiatrist monitors their mental state, particularly for any depressive symptoms, and treats it accordingly. At present, neither are on any medication. They have progressed through the Adapted Sex Offender Treatment Programme and the current psychology and nursing input focuses on relapse prevention.

They are encouraged to maintain diaries that are monitored regularly. This includes Section 17 leave preparation and debriefing. These debriefs are then discussed within the psychology support sessions. The Code of Practice suggests that treatment consisting only of nursing and specialist day-to-day care under the clinical supervision of an approved clinician, in a safe and secure therapeutic environment with a structured regime may constitute appropriate medical treatment. Mr A and Mr B have more than that. Their participation in psychology led interventions, the monitoring of their psychiatric state, nursing observations, the use of appropriate medication when needed and the occupational therapy led rehabilitation activities are over and beyond the minimum standard proposed by the Code of Practice, or "milieu therapy" that is sometimes referred to in similar cases (MD v Nottinghamshire Healthcare NHS Trust, 2010).

Saying that there is no treatment or that treatment has not been effective would be accurate only if one assumed that the only measure of success is being unsupervised in the community. That is not and should not be the case. Mr A and B have made progress during these treatments, particularly around sexual knowledge and awareness of social rules and behaviour. The uncontained, aggressive and indiscriminate sexual behaviour that characterised them for many years is no longer there and it is now possible to have supervised community leaves to a range of settings without incident, thus increasing their degree of community participation. However, unsupervised access to the community is not considered appropriate because of the considerable risk of sexually aggressive behaviour towards children. Under the Mental Health Act, there is no requirement that appropriate treatment reduce the risk posed by an individual *(*MD v Nottinghamshire Healthcare NHS Trust, 2010*)*. It is sufficient if the treatment prevents a deterioration of the symptoms or manifestations of the disorder and this has indeed happened in their cases.

2. *Why can't Mr A be conditionally discharged from the Section 37/41 or why can't Mr B be on a Community Treatment Order from his Section 3?*

At present, both Mr A and B satisfy statutory criteria for detention under the Mental Health Act. The clinical diagnosis is one of mild intellectual disability, a recurrent depressive disorder and a disorder of sexual preference. While they have not offended, diaries and behavioural observations evidence an enduring sexual interest in children. Within the meaning of the Mental Health Act 1983, Mr A and Mr B have a mental disorder that is of a nature and degree that makes it appropriate for them to receive treatment in hospital. The mental disorder includes intellectual disability that is associated with abnormally aggressive and seriously irresponsible behaviour including the sexual targeting of children. Treatment in hospital is necessary for their health, safety and the protection of others. Appropriate treatment remains available for them in the hospital setting.

A conditional discharge (for Mr A) or a discharge under a Community Treatment Order (CTO) (for Mr B) was considered carefully. However the level of risk is such that, wherever they are placed, they cannot be allowed to go anywhere at all without supervision from a member of staff. This supervision is for the protection of others, particularly children. If placed in a residential setting with more vulnerable peers, they will need staff supervision within the residence. While they may not need supervision within a residence with less vulnerable peers, it will have to be ensured that there are no opportunities whatsoever for them to leave the residence without staff knowledge; which means the residence will have to be locked. These conditions are so restrictive and absolute that they effectively deprive them of their freedom and amount to de facto detention.

There is the pragmatic view that being in a residential home (albeit de facto detained) would perhaps be better than being in a hospital. This was examined, particularly if Mr A and B were to voluntarily agree to accept these terms. However, whether driven by conceptions of patient's best interest or indeed costs for commissioning bodies, this option is effectively detention in an institution other than a hospital (e.g.: a residential home). What is more, it

could potentially be detention other than for the purpose of treatment (i.e., pure containment). These considerations would make this option untenable (Secretary of State for Justice v RB and Lancashire Care NHS Foundation Trust, 2011).

3. *Why can't they be on a Deprivation of Liberty Safeguards (DOLS) order and managed in the community?*

Although Mr A and B have a mental disorder that includes intellectual disability, they have the capacity to decide where and how they want to live. They understand that approaching children for sex, or indeed having sex with them is wrong and against the law. Since they have this capacity, the issue of DOLS shouldn't arise at all. The severe restrictions suggested are not because they lack capacity, but because they have a mental disorder and pose a risk to the safety of others.

Secondly, even if one were to stretch legal imagination and assume that because of their difficulties in areas of sexual behaviour, they lack the capacity to decide where they should live, they would still be individuals who meet statutory criteria for detention under the Mental Health Act. That being the case, decision makers will have to recognise the primacy of the Mental Health Act and take all practical steps to ensure that this primacy is recognised and given effect to, rather than attempting to pick and choose between the two statutory regimes as they think fit. In other words, the Mental Health Act trumps the Mental Capacity Act (GJ V Foundation Trust, 2009). Within the framework of the Mental Health Act, it is important that they are in the least restrictive setting possible, and that is what the Category 4 bed provides.

Suggestions for the future

Patients treated within forensic inpatient units tend to have long lengths of stay. Quite often the variable that mediates this length of stay is the risk that they pose to themselves or

others. Clinicians work within a legislative framework in all Western democracies. So while it may be tempting to blame clinical decisions or inertia for people remaining in hospitals (Roy, 2015), those decisions are taken within the framework of the law. As indicated in the illustrative examples above, what appears to be a common sense or pragmatic solution may not necessarily be within the law.

1. Improving training of community intellectual disability teams on issues of risk assessment and management and enabling them to manage safely people with intellectual disability and offending behaviours can reduce hospital admissions. It can also facilitate the discharge of people from units into the community. Practical ways of training teams for this purpose have been summarised elsewhere (Devapriam, & Alexander, 2012; Royal College of Psychiatrists' Faculty of Psychiatry of Intellectual Disability, 2014).

2. However, even with the best trained community teams, it would be a mistake to assume that one can manage without any inpatient beds whatsoever. There is a tendency among those responsible for health planning and indeed some clinicians to see forensic beds as somehow completely different from the other inpatient provision. This is wrong because the way the criminal justice system manages law-breaking behaviour by people with intellectual disability is variable. A person with a more severe intellectual disability is unlikely to ever come before the courts unless the criminal act is very serious. Even for those with a milder degree of intellectual disability, only some end up being formally charged, prosecuted or convicted. This means that the decision whether a person becomes a 'forensic patient' or not often depends on clinical judgements about risks and the attitudes of professionals working in the criminal justice system. These attitudes and decisions are inevitably shaped by the availability of resources. If less restrictive inpatient facilities are unavailable, either because they were shut down or not commissioned, these patients end up in

far more restrictive forensic beds, a fair demonstration of the law of unintended consequences. Similarly, an absence of appropriate step-down facilities including less restrictive inpatient provision can also result in patients remaining for longer periods than necessary in medium or low secure settings. It is therefore important to consider and commission all inpatient beds, whether 'forensic' or 'non-forensic', as a whole while planning for future provision (Royal College of Psychiatrists' Faculty of Psychiatry of Intellectual Disability, 2013; 2014).

3. Many patients in these beds have a mild intellectual disability and fall between the boundaries of 'mainstream' mental health and specialist intellectual disability services- too disabled for one and too disordered for the other. Although admission to 'mainstream' units may achieve the aim of equity of access, that achievement is meaningless in the absence of equity of outcome. A low IQ often excludes people from treatment programmes. This happens not necessarily because these 'mainstream' units are overcome by prejudice, but because for those with intellectual disability the treatment content needs to be delivered in a way that is appropriate for their developmental and intellectual level. Economies of scale, as well as availability of a critical mass of expertise may mean that these developmental-level specific treatment programmes are best delivered in specialised intellectual disability units (Royal College of Psychiatrists, 2013 2014).

4. Service cultures can be faulted both for a lack of positive risk taking (Morgan, 2004; 2010) and for adverse events when positive risk taking goes wrong (Ellicott, 2011; Nottingham Post, 2012). Because of this, there is a need for greater clarity on how governments perceive risk and risk management for people with intellectual disability who are detained under the Mental Health Act. Is it that if the type of mental disorder is intellectual disability, statutory criteria should include one on patient rights and this should trump those for the protection of others. That would be a significant change

that amounts to seeing intellectual disability as having different statutory criteria for detention and treatment. If that is indeed what the government intends, it has to be made clear through new legislation or clarification, rather than be left in a state of constructive ambiguity with little concrete guidance.

5. The option of allowing more intrusive supervision regimes in the community for patients can be considered as an alternative to hospital treatment. This would involve a further strengthening of the provisions of community treatment orders, a step that was considered when the Mental Health Act was last reviewed, but abandoned in the face of adverse comment. If the government is so inclined, this may well be worth revisiting for those people with intellectual disability and a mental disorder under the Mental Health Act, who are deemed to have the capacity to decide where they want to live, but need safeguards for the protection of others. That could then address the concerns over de facto detention that would be a problem with the community treatment orders in the current legislative framework.

6. A National Institute of Health Research funded study currently under way has highlighted the practice elsewhere in Europe- particularly Germany and Netherlands (NIHR Evaluation, Trials and Studies Coordinating Centre, 2015). The latter has a national strategy for long-stay forensic care and have provided specific long-stay forensic units since 1999. Patients admitted to these facilities are those thought to have no realistic prospect of discharge after treatment of at least six years duration in two different treatment units. The focus in such units is not on treatment to reduce risks, but on improving quality of life, while managing entrenched risks. These models have demonstrated advantages in terms of both service user satisfaction and service costs. Differences in funding, service provision, governance and legal frameworks would make the implementation of these international service models in the UK context challenging, but a systematic exploration of this options is required. If

this approach is accepted, you could quite conceivably do away with the majority of the current Category 4 beds.

7. Finally, there is the truly radical solution of removing altogether intellectual disability from the list of mental disorders in the Mental Health Act. Even assuming that excellent community services reduce crisis situations and the potential for violence, it would be impossible to eliminate them altogether. If intellectual disability is no longer a mental disorder, then diversion from the criminal justice system, for long a cornerstone of government policy (Department of Health, 2009), will become problematic and there will be a real risk of many people with this condition who have committed serious acts of violence being incarcerated. This option may not be very politically or morally palatable.

At a recent public accounts committee hearing, the NHS Chief Executive has committed to a hospital closure programme that will come into effect within an 18 month timeframe (Public Accounts Committee, 2015; Brindle, 2015). The exact detail on how this is to be achieved is unclear, but there is no doubting the political will to drive it through. If implemented without careful consideration to the clinical realities on the ground, what appears to be a well-intentioned initiative to prevent inappropriate hospitalisation and abuse will result in further disadvantaging an already disadvantaged population. Policy makers and clinicians need to move away from seeing community and hospital provision as an “either or” situation, and instead see them as complementary services to secure the best outcomes for people with intellectual disability and mental health or behavioural problems. The approach set out in the tiered model of healthcare (Royal College of Psychiatrists’ Faculty of Psychiatry of Intellectual Disability, 2011; 2013; 2014) captures this balance and the practical steps spelt out in this paper offer a considered way forward.

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