



Services for adults with intellectual disability and mental illness: Are we getting it right?

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Abstract

There is increasing evidence to support the high prevalence of mental illness in adults with intellectual disability and some studies suggest that the prevalence of mental illness may be higher than that of the general population. It is not uncommon for adults with intellectual disability to be referred to local community mental health centres or psychiatric hospitals because of the presence of challenging behaviours, such as aggression or criminal offending behaviour. Despite the emerging research in the area of diagnosis and treatment of mental illness in adults with intellectual disability, many are often not provided with appropriate and adequate mental health services. Two case studies illustrate the difficulties in accessing mental health services for this 'invisible' group of individuals with intellectual disability, and demonstrate the gaps in service delivery and clinical practice. The paper argues that mental health concerns should be considered when challenging behaviours are present in persons with intellectual disability. There is an urgent need for mental health services to re-examine their understanding of and clinical practice with adults with intellectual disability and mental illness.

Keywords

intellectual disability, mental illness, dual diagnosis, forensic, challenging behaviours

Introduction

There is substantial research to support the view that persons with intellectual disability are more at risk of a wide range of mental illness compared to the general population (Holland & Koot, 1998; Hudson & Chan, 2002; McCarthy & Boyd, 2002; Moss, Bouras & Holt, 2000). The prevalence of mental illness in people with intellectual disability is complicated by several issues, such as the definition of intellectual disability and mental illness, the problems of research sampling, that clinical presentations of

mental illness may be masked by poor communication and language skills of the person with intellectual disability, or the fact that mental health concerns are usually reported to the mental health practitioner via the carer rather than the person with the intellectual disability (Hudson & Chan, 2002). While there is debate regarding the definitive prevalence rates of mental illness in persons with intellectual disability, it is more important for mental health practitioners to appreciate and understand the risk factors that might increase the likelihood of people with intellectual disability having mental

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health problems (Holland & Koot, 1998; Hudson & Chan, 2002). There is also emerging evidence of the risk of adults with intellectual disability coming into contact with the criminal justice system (Barron, Hassiotis & Banes, 2002; Chan, Hudson & Sigafos, 2003; Lindsay, 2002; Johnston & Halstead, 2000; Mason & Murphy, 2002). It is not the scope of this paper to examine whether adults with intellectual disability and mental illness are more at risk of criminal offending, rather it is to highlight the vulnerability of this population to risks such as criminal offending behaviour (Chan et al., 2003).

A review of the literature by Hudson and Chan (2002) indicates a high prevalence of mental illness in adults with intellectual disability. They highlight the wide range of mental health problems that adults with intellectual disability might experience, such as depression and anxiety, post-traumatic stress disorder, bipolar disorder, personality disorder, psychosis, or schizophrenia. Recent advances in research provide further evidence of depression (McBrien, 2003), bipolar disorders (Cain, Davidson, Burhan et al., 2003) psychological stress (Bramston, Fogarty & Cummins, 1999) and personality disorder (Torr, 2003), in persons with intellectual disability. In a review of the literature on stress, coping and attachment, to foster explanations for the development of challenging behaviour in people with intellectual disability, Janssen, Schuengel and Stolk (2002) found evidence to suggest that people with intellectual disability are more vulnerable to stress and use less effective coping strategies. Therefore people with intellectual disability may be vulnerable to mental illness.

According to Hudson and Chan (2002), there appear to be several service delivery options in the assessment and treatment of adults with mental illness and intellectual disability. While there has been some progress in this area, there appears to be a tendency for mental health practitioners to see the presenting challenging behaviours as resulting from the intellectual disability rather than as symptomatic of mental illness (Holland & Koot, 1998; Hudson & Chan, 2002). The research indicates that adults with intellectual disability referred to community mental health facilities or psychiatric hospitals present with a range of challenging behaviours

(Holland & Koot, 1998; Hudson & Chan, 2002; Hurley, Folstein & Lam, 2003; McCarthy & Boyd, 2002; Moss et al., 2000). In a study of individuals with and without intellectual disability referred to a psychiatric facility, Hurley et al. (2003) reported that persons with intellectual disability were more likely to present with aggression, self-injury or physical complaints whereas persons without an intellectual disability presented more frequently with depression and anxiety concerns.

The review by Hudson and Chan (2002) also demonstrated that many adults with intellectual disabilities present with high levels of challenging behaviours when referred to regular mental health facilities or to crisis intervention centres. It is also important to recognize the complexity and difficulty of distinguishing between true psychiatric disorder and issues that may arise from the person's level of adaptive behaviour skills or inappropriately learned behaviour (Holland & Koot, 1998; Moss et al., 2000; Tsiouris, Mann, Patti & Sturme, 2003). For example, Tsiouris et al. (2003) caution clinicians not to assume challenging behaviours as depressive equivalents in persons with intellectual disability, rather as indicators of potential underlying psychopathology. They advised that the assessment of depression in persons with intellectual disability should focus on the core DSM-IV (American Psychiatric Association, 1994) symptoms of depression.

Many adults with intellectual disability and mental illness continue to face barriers in accessing appropriate and adequate mental health services that they urgently require (Cooper, 1999; Einfeld & Tonge, 1996; Gustafsson, 1997; Mohr, Curran, Coutts & Dennis, 2002). For example, Gustafsson (1997) reported a low frequency of psychiatric care use among people with mental illness and psychiatric disorders compared to the proportion of access of mental health services among people with psychiatric disorders in the general population. Hudson and Chan (2002) have attempted to explain the barriers to mental health services. Briefly, there is still a lack of understanding of mental illness and intellectual disability by mental health practitioners; a lack of specialised training; and communication problems between the clinician and the person

with intellectual disability. Further, the person with intellectual disability and mental illness may not necessarily articulate his or her problems due to a lack of language competency. Mohr et al. (2002) highlight the 'us' versus 'them' demarcation issue between mental health and intellectual disability services regarding roles and responsibilities in assessment, treatment and on-going management of people with intellectual disability and mental health issues. The demarcation, according to Mohr et al. (2002), often leads to a lack of coordination and adequate services for this population group.

Mohr et al. (2002) suggest that only through a collaborative effort between both mental health and intellectual disability services will people with intellectual disability be appropriately provided a service. Using a case study approach, Mohr et al. (2002) illustrate the key elements of collaboration, such as shared understanding of the different models of both mental health and disability services, effective communication, respect, multi-disciplinary input, adequate resources and commitment to resolve differences. Despite these barriers, mental health practitioners can do better in ensuring appropriate mental health care is provided. Two case studies are presented in this paper to illustrate the day-to-day difficulties faced by adults with intellectual disability and mental health concerns, and their carers, in accessing mental health services. The case studies also highlight that where coordination of both mental health and disability services occurred, appropriate care and support lead to better health outcomes. The case studies draw on documentation of personal histories, medical and other health care plans and reports, and data where appropriate to demonstrate progress.

Case Study 1

Mr SM is a 53-year old man with mild intellectual disability and bipolar disorder as diagnosed by a psychiatrist. SM had lived in several disability accommodation services, predominantly in institutions or hostels. A period of homelessness was also indicated in his case history notes. In 1999, he was transitioned into a 24-hour supported community living service with three other men with intellectual disability

from the same institution, with a staffing ratio of one staff member to four individuals. There was paucity in medical and social history provided to the community disability service. He also worked part-time in an employment service for people with intellectual disability. He was known to the local psychiatric hospital and community mental health service as he had been referred to the service when he was living in the institution. His history of challenging behaviours included verbal aggression, physical threats, absconding, sexual disinhibition and inappropriate sexual behaviour. He had also been in contact with the criminal justice system for theft.

Since his transition into supported community living, there appeared to be an increase in challenging behaviours, such as verbal aggression, absconding and sexual disinhibition. There were allegations of sexual assault against SM, however these allegations were not substantiated. Documentation in SM's case file indicated that there had not been any formal mental health management plan or case review by the local mental health service, nor had his psychotropic medication been reviewed for several years. As such, the disability service made several referrals to the local psychiatric hospital and community mental health service for a review of his mental health condition and psychotropic medication.

Each time the referral was made, the disability service was informed that SM's condition was a result of his challenging behaviours and unrelated to his mental health condition. SM's condition and challenging behaviour deteriorated for nearly a year as evidenced by increased verbal aggression and sexual disinhibition (e.g., undressing at his workplace). When SM admitted himself voluntarily to the psychiatric hospital, he was discharged without an appropriate management plan or a referral to the community mental health service for follow-up. As a result, there was no improvement in SM's behaviour after discharge from the psychiatric hospital.

In late 2001, SM was reported to the local police for a critical incident that resulted in him having to be transitioned into a temporary hostel for homeless men in another suburb. SM's mental health condition further deteriorated as he

demonstrated aggression that threatened staff members at the temporary hostel. Two days later, he was promptly admitted to another psychiatric hospital in a different metropolitan region, with police escort. At this psychiatric facility, his mental health condition and medication were reviewed. His medication was changed and reduced. He stayed in the psychiatric hospital for about two weeks. Prior to his discharge, a clinical case conference was organized and SM was moved into another community house in an inner city region in December 2001. The discharge plan included referral to the local community mental health service in the new suburb to which SM was to be moved.

Since his discharge, SM's mental health condition had improved significantly. It is difficult to provide accurate quantitative data regarding number of incidents (challenging behaviour and/or referrals to mental health service) prior to 2001. Data that were systematically collected after 2001 demonstrated a decrease from 19 incidents for the period January to September 2002 to 4 incidents for the same period in 2003. Although there were continuing behaviour problems, the number, intensity and frequency of these behaviours were reduced. SM is in regular contact with his mental health case manager. Recently SM evidenced an increase in challenging behaviours after experiencing a traumatic stressor in his life (his girlfriend of nearly 9 years was admitted for palliative care). He expressed a strong attachment to his girlfriend and appeared to be having difficulty coping. While the community mental health case manager did not provide any further advice on how staff should manage the significant traumatic event in SM's life, the service maintains regular contact with the case manager to ensure appropriate care and support if the situation deteriorates.

Case Study 2

Mr YW is a 41-year old man diagnosed with mild intellectual disability and schizophrenia by a psychiatrist. Like SM, YW is also known to the local psychiatric hospital and mental health service as both had lived in the same institution prior to transition into a 24-hour supported community living service. Like SM, there was a

paucity of information regarding YW's accommodation, medical or social history. His history of challenging behaviours included verbal aggression, physical threats and physical intimidation, and non-compliance with simple daily routines. YW also presented with other physical health issues, such as obesity, excessive smoking, reflux, arthritis and disturbed sleeping pattern. Due to his previous forensic history, YW has a fear of the police. On occasions when staff had contacted police, it only increased his challenging behaviours when the police left the premises. YW had also reported his suspicion and paranoia about staff members and the neighbours. He made threats to staff and neighbours who he claimed were "out to get him".

As for SM, the disability service made several unsuccessful referrals to the local community mental health service for a case management review. The response of the local community mental health service was that YW's challenging behaviours were unrelated to his mental health condition. After several futile attempts to access follow-up mental health services for YW, the disability service referred him to a private psychiatric service and a private psychological consultant with expertise in dual diagnosis. Private mental health services were engaged to assist in the mental health and behaviour support management plan. Incident reports of YW for the period January 2002 to September 2003 did not indicate any significant improvement since the engagement of private psychiatric and behaviour management services in early 2003. However there were positive reports of behaviour change for October 2003.

In both cases referrals were made during crises to the previous mental health service, however neither client received follow-up or admission for mental health care. The typical response from the previous mental health service was that the behaviours were related to the clients' intellectual disability and/or lack of adaptive skills, even when the police were called to escort the clients to the psychiatric service. The case history notes illustrate several examples of difficulties in accessing community mental health services or the psychiatric hospital. It is not the scope of this paper to discuss the rationale of the previous mental health service's

decision. However, it is important to highlight that appropriate and comprehensive assessments or reviews were not conducted to determine the need for mental health services.

Discussion

The case studies illustrate the difficulty of a disability service in accessing mental health service for adults with intellectual disability and mental health issues. In both case studies, referral to a mental health service was denied on the basis that the challenging behaviours were unrelated to the person's mental health condition. There was no mental health assessment and review, despite the fact that both men had a psychiatric disorder and were in need of assessment and treatment. Both men posed a risk to themselves and perhaps to others had they continued to be left without adequate mental health management and care.

SM finally received a review of his mental health condition and medication prescription in another psychiatric hospital following a critical incident that involved the police. There was a marked improvement in his mental health and behaviour following a review of his medication and mental health treatment management plan. SM was also appropriately referred to another local mental health service and was assigned a case manager following discharge from the other psychiatric hospital, and an appropriate clinical case conference was organized prior to discharge. While SM continued to demonstrate challenging behaviours, there was a decrease in the frequency and severity of the challenging behaviours. SM's case also demonstrated the importance of collaboration between local mental health and disability services in ensuring adequate care and support (Mohr et al., 2002).

In YW's case, a private psychological service was engaged to provide support and a management plan to the disability service provider, following several unsuccessful referrals to the local community mental health team. The local mental health team did not provide a service as it was deemed that YW's challenging behaviours were a result of his lack of adaptive skills and intellectual disability, and unrelated to his mental health condition. Both case studies illustrate the lack of consistency in

mental health care service provision. For example in SM's case, his mental health condition and medication were reviewed by another psychiatric hospital, but not the psychiatric hospital where he was known for several years.

It may appear that there is a discrepancy in service provision in community mental health services depending on where the person resides. In the new suburb, SM receives local community mental health services whereas previously he did not. YW continues to reside in the same suburb, and does not receive a mental health service, for example, an assigned case manager. It is not the scope of this paper to analyse the discrepancy in service provision of the mental health services. For example, SM may have received community mental health services in the new suburb because the referral intake criteria included people with intellectual disability and mental health problems. Or the mental health team may have been trained, and more ready, to provide a service to people with intellectual disability. Rather the case studies demonstrate the difficulties experienced by people with intellectual disability in accessing adequate mental health care and support when it is most needed.

There is emerging evidence of appropriate mental health service delivery options for people with intellectual disability, in terms of assessment and treatment (Hudson & Chan, 2002). While the complexity of providing such services is acknowledged (Holland & Kroot, 1998), it is crucial that appropriate mental health services are provided to adults who also have an intellectual disability. There are several ways in which mental health and disability services can work in partnership to serve this population group. These include: providing inter-agency continuing education about roles and responsibilities, or education about mental health and intellectual disability; joint case management and assessment; shared resources to provide services; and other options noted by Hudson and Chan (2002) and Mohr et al. (2002). Given the prevalence of mental health issues in adults with intellectual disability, it is time to re-examine service delivery and 'get it right' for people with intellectual disability who require mental health services.

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