Title:

Understanding systemic problems in providing mental health services to people with an intellectual disability and co-morbid mental disorders in Victoria

Author:

Chad ND Bennett, Clinical Director,

Affiliations

The Victorian Dual Disability Service

St Vincent's Hospital (Melbourne)

Victoria

Australia

Corresponding author:

Chad Bennett, The Victorian Dual Disability Service, St Vincent's hospital, PO Box 2900, Fitzroy, Victoria 3065, Australia.

Email: Chad.Bennett@svhm.org.au

Abstract

People with intellectual disability (ID) have high levels of mental health need. Generic services have difficulty responding to these needs due to a range of patient, professional and service system factors as well as some of the conceptual issues underpinning policy and legislation. The objective of this paper is to explore the difficulties the services system in Victoria has in responding to people with intellectual disability and mental health problems and to identify the underlying assumptions that have led to these. These issues are discussed and where possible put into a Victorian context with the intention of informing service development in the area of Dual Disability (co-morbid mental disorders in people with intellectual disability).

Key words

Intellectual disability, Mental health, Mental health services

Dec 2010: A mother called because she could no longer cope with caring for her intellectually disabled daughter who was aggressive, not sleeping and refusing to leave the house. Her GP has started her on risperidone. The mental health service would not respond as in their view the intellectual disability explained the problems, which were 'behavioural'. Also she was non verbal and so would not meet the criteria for any mental illness in DSM IV. Disability services could not respond as the daughter would refuse to see them and they have no power of coercion nor capacity to remove her from the family home for assessment. The mother called the specialist VDDS having trawled the internet but all VDDS could advise her was the only way she could get a service was to get her daughter to the emergency department; however, this would probably involve using the police if she refused to go into an ambulance. When last spoken to she

could not bring herself to call the police with the intention of abandoning her daughter in an emergency department.

Introduction

People with intellectual disability (PWID) and mental health problems present different issues to services and stakeholders.

For Mental Health Services (MHS) they can present with a range of behaviour related problems that are 'not appropriate' for service provision. When accepted for management they are experienced as being difficult to assess, treat and discharge. Staff do not feel qualified or responsible for managing this group and may not want to deal with them [1,2]. If admitted their cognitive impairment, vulnerability and behaviour problems mean they often do not fit standard models of care. Consequently they may require extra resources and can distort key performance indicators used for reporting such as seclusion rates

The problem for Disability Services (DS) is in trying to provide services to PWID with significant behaviour problems. Many of the difficult behaviours don't respond to behaviour interventions or the administration of psychotropic medication[3]. The problem is often perceived to be a mental health problem or 'not just due to their disability' but staff are frustrated by the inability to access mental health services who will usually ascribe the problem to the intellectual disability[4] and will only respond if there is clear

evidence of mental illness. Usually a range of professional opinions are sought and provided which explain the problems to varying degrees but often conclude with a range of technical interventions that there is no infrastructure to implement. Finding accommodation for a person with difficult behaviour is extremely difficult with the result they are frequently placed in temporary housing with locum staff for lengthy periods of time. Crises often involve assaults and are difficult to manage in a shared home environment. However staff are reluctant to involve the police and often decide not to press charges PWID as they are unlikely to be convicted[5,6]. When charged the courts often perceive PWID as not having full responsibility for their actions, to be too vulnerable to send to jail and become frustrated with the lack of suitable placement options that can contain and manage difficult behaviour. Sentences often include requirements to attend appointments for assessment and therapy[7] and extra resources may be needed to ensure that the person is compliant with the court orders.

The inability to access appropriate services and treatment means that PWID and mental health problems are often subject restrictive interventions, socially isolated, lack meaningful activities and often inappropriately prescribed psychotropic medication [8,9]

Carers of people with intellectual disability and mental health problems have a high burden of care [10.] Parents may have to take time off work and respite is often not available. The emotional impact of physical assault and damage to property can be exacerbated by the lack of obvious solutions and help. Parents may blame themselves

for the problems and feel guilty at being unable to spend time with their other children. Work capacity is often affected and the financial effect creates additional stress on strained relationships [11].

Background to problems

The problems arise because of the way services have evolved since the time of deinstitutionalisation. The role of modern mental health services is to provide treatment and throughput has become a fundamental feature of the service model. The focus is on serious mental illness; usually taken to be the psychotic illnesses and the major mood disorders.

The DS model was established based on the understanding that the appropriate service response for PWID is to provide long-term support to enable a 'normal' life [12]. The types of supports delivered depend on the degree of disability; those with more severe disabilities might need help with basic activities such as washing and dressing whilst those with more mild disabilities might need help only with community based activities such as using public transport and banking. Any other needs were assumed to be the same as everyone else's and could be met by the generic service system if needed. Disability legislation is primarily about the provision of services and although there is legislation to provide consent on a person's behalf there is a very limited capacity to force people to receive services against their will. Consequently DS have difficulty in managing the behaviour problems which require disorder specific management

strategies and containment. These types of problem require a model of care based on an understanding of the underlying disorder and the application of therapeutic interventions that may be required long term and sometimes administered on an involuntary basis.

This service model creates a gap is for people who have mental disorders that do not recover with treatment. These include diagnoses such as acquired brain injury, early onset dementia, personality disorder, behaviour disorders and autism. This is particularly problematic for people with an intellectual disability as these are common co-morbidities. People with these disorders have a range of psychological impairments that are associated with vulnerability, disability, distress and are often associated with significant restriction of rights. People with these disorders do not fit into the current mental health model as they do not recover with treatment. On occasion services are not provided because of the lack of skills and facilities to provide treatment. For example a PWID is seen is too vulnerable to be admitted to an acute psychiatric ward where they risk assault and abuse. Neither does this population fit into the DS model which can offer support but not the specific management strategies required to manage these disorders nor the capacity to contain the inherent risks they present with. For example managing people with autism requires skilled staff implementing specific strategies to

address the communication impairments, the social deficits, the difficulties in managing change and the sensory hypersensitivities [13].

Part of the explanation for the difficulties experienced by the current service system lies in the following false assumptions made at the time of deinstitutionalisation:

1. That there are low rates of mental illness in PWID
2. The challenging behaviours in PWID, were largely due to an institutional model of care and would improve with community placement [14].
3. The behavioural problems in PWID can be explained by the intellectual disability [15]
4. The generic service system would be able to meet the needs of PWID [16].

With the passage of time these assumptions can be seen to be false.

a) Rates of mental illness in PWID

It is now widely accepted that there are high rates of mental illness in PWID and that they can experience the full range of mental illnesses. The prevalence of mental illness in PWID is somewhere between 30 and 50% [17]. This compares to a rate of about 24% in the general population [18]. The high rates of mental illness are attributed to the high rates of risk factors in this group

b) The behaviours problems associated with PWID would improve with community living.

> Despite these initial hopes in a review Emerson [18] concluded: "The available evidence does suggest that severe challenging behaviour may be highly persistent despite discharge from specialized congregate care settings or significant changes in staffing resources and the quality of the physical environment"

c) The challenging behaviours in PWID can be explained by the intellectual disability

The challenging behaviours seen in PWID are often attributed to the ID itself. However although ID is listed as a mental disorder in DSM-V[22] it is not an illness and is not useful as an explanation for problematic behaviour. Intellectual disability is no more of an explanation for problem behaviour than psychiatric disability and neither concept can inform treatment, management or prognosis. Its main utility is to identify a heterogeneous group of people who need additional help and support because of cognitive limitations[23].

The challenging behaviours in PWID can arguably be best conceptualised as the manifestation of mental illnesses in PWID in that it is a problem arising from disturbed psychological function that requires intervention to minimise distress and disability. This assertion is consistent with the similarities in the aetiology, assessment and management approach to both challenging behaviour and mental illness. Understanding

both requires collecting information in biological, psychological and social domains and integrating these into an explanation to inform management. Management of either often involves using psychiatric technologies including psychotropic medication, psychotherapy and behaviour management as well as addressing social needs

d) People with an intellectual disability would have their needs met by the generic service system

It was assumed that PWID would be able to access the generic service system to have their needs met. However, this fails to recognise that PWID have specific needs that are different from the general population. PWID are dependent on their carers to identify and access appropriate services, which requires training and ongoing support and supervision. Staff in the generic health system lack training and exposure in working with PWID[24] and do not know how to account for the cognitive impairments and communication deficits in their assessment and treatment. There are also difficulties in recognising and managing some of the common co-morbidities in PWID such as autism, sensory impairments, limited mobility and epilepsy. Standard assessment and therapeutic approaches developed for the general population are often not applicable for PWID who may require the format and mode of delivery of therapy to be modified and may need significantly more sessions and time to benefit [25]. Often the service response is to exclude PWID rather than to modify or develop alternative strategies. These difficulties are compounded by discrimination and dislike of a stigmatised, poorly

valued population [26, 27] and exacerbated by a lack of accountability and reporting in relation to providing mental health services to PWID.

Concluding remarks

To account for the reconsideration of these assumptions the services system the service system would needs to develop a model that recognises the high rates of mental disorder in PWID and their long term nature, the difficulties the generic system has in meeting the specific needs of PWID with mental health problems, and that approaches the behaviour disorders in PWID as mental health problems that require treatment.
This would best be achieved by establishing a specialist mental health service for adults with intellectual disability. The target group would be people with a developmental disability who need treatment and management because of a clinically significant behaviour disorder that makes it difficult for normal community supports and services to care for them. The service model would need to develop a continuum of care that includes crises response, outpatient management, specialist acute inpatient services, rehabilitation. Long term specialised models of care for people with persistent mental disorders that present with significant risks are also required. Specialisation would be needed to allow for the development of appropriate models of care to deal with specific disorders such as autism. The intention should be to help people access normal

community facilities but the service will need the capacity to provide alternatives when this is not feasible. A specialist mental health service for PWID would provide the opportunity to train staff to work with this population and staff specifically designated this responsibility might be less likely to feel resentful and more likely to learn the skills required to manage this population.

Establishing a specialist service would ensure clear accountability and responsibility for providing a comprehensive approach to the behaviour problems in PWID. Carers and patients would be clear about who is responsible for meeting their needs and avoid the current shifting of responsibility between services.

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