

Services for a person with a dual disability.

A review of how different services have evolved and the effect of this on a patient.

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Objective: To describe how a patient's current provision of service is dependant on the underpinning philosophies and legal frameworks used to establish services and the historical background behind this.

Method: Factors relevant to the development of services are reviewed to explain the current services structure. The effectiveness of these systems are explored in relation to Dual Disability (co-existing intellectual and psychiatric illness) with particular reference to a case example.

Results: There are a number of deficiencies in the current system that prevent optimal care being received by people with a dual disability.

Conclusions: That changes to the current service system need to occur at a number of levels for services to people with a dual disability to improve.

Key words: Mental health services, Mental retardation

Introduction.

Two years ago there was a young man who was repeatedly banging his head and other body parts against the corners and sharp edges in his room, day in and day out for several months. His face was bruised and bleeding and his forearms disfigured by the calcification of blood clots as a result of repeated trauma. Despite being on high doses of psychotropic medication he had not received any consistent medical supervision and was at one time unable to find a medical practitioner willing to provide him with services. The scenario raises the question 'how can someone as disturbed as this not find access to medical or psychiatric services?'

The simple answer is that there was no medical service specifically designated to take responsibility for him regardless of intake criteria or financial reward. Consequently no service has developed the skills and resources to manage the complexities of his presentation. The more detailed answer requires an examination of how the current service systems have evolved.

The institutions

Historically people with an ID or psychiatric illness, although recognised as being different, were treated as being essentially the same. For example, in the 1840 census in the USA they were both included in the one category of 'idiocy/insanity' [1] For society they presented with difficulties in behaviour, thought and emotion that required some kind of intervention. In Western countries prevailing beliefs about potential genetic contamination and

subsequent degeneration led to a policy of segregation [2]. The policy was operationalised in the form of institutions which housed increasing numbers of people until the late 50's and early 60's. These provided for the basic needs of their inmates, albeit at the cost of personal liberty and sadly, in some cases, personal injury. In this setting care was delivered under the supervision of a 'superintendent', usually a psychiatrist. Despite the many disadvantages of institutions there was a clear line of responsibility for all aspects of the residents' welfare. In the better institutions a range of services were available that could cover work, recreation and health. Clinics were often held on site by visiting specialists and the concentration of disabled people in one site allowed staff to develop skills in the assessment and treatment of all members of this population, regardless of type of disability. If there was a problem at least it was clear who was responsible and there was a range of other professionals on site to call upon [3].

The development of effective treatment for some psychiatric disorders in the late 50's and the inappropriateness of treating people with an intellectual disability under a 'parental' (medical model) as being 'ill' were two of the main factors that led to the concept of separate services for people with either an intellectual disability or a mental illness. People with mental illness were seen as needing therapeutic interventions to alleviate their illness and those with an intellectual disability needed appropriate social supports and educational activities to maximise their potential. By implication the two groups were seen as independent categories, partly based on the belief that people with an intellectual disability lacked the mental capacities to develop mental illnesses [4] To some degree the problem behaviours exhibited by both groups of patients were seen as being secondary to institutionalisation [5] and the hope was that care in a different environment would see these problems diminish.

In many Western countries what was one service that cared for both groups of people was split into two. In Victoria these are now DisAbility services and Mental Health Services, both of which are branches of Human services.

Thus as the institutions were closed down the residents were placed under the umbrella of either one service or the other. This involved determining whether their disability was primarily psychiatric or intellectual. As time passed this distinction has remained one of the primary considerations in determining which service is accessed. This process implies that there is a clear difference between the two categories. Closer examination of what is meant by mental illness or intellectual disability can dispel this superficial simplicity.

Classification issues.

Perhaps surprisingly there is no adequate definition as to what constitutes a mental illness, for example where does normal human sadness end and depression begin? Nor are there diagnostic tests that can prove one way or another that an individual has a specific illness such as schizophrenia. A person is said to have a mental illness if an appropriately qualified professional can elicit the necessary symptoms to meet pre-set criteria to diagnose certain conditions. Often this is subjective and can become 'a matter of opinion' rather than proven fact. Because of this, and other factors, the diagnosis of mental illness is not always a reliable and consistent process, particularly in the more complicated patients such as those who have a co-existing intellectual disability [6].

The presence or not of an intellectual disability can be more clearly delineated using psychometric intelligence testing in conjunction with evidence of functional deficits and onset before the age of 18. Although intellectual disability is classified as a mental disorder its main use is as a bureaucratic category to determine eligibility for services [7]. However classifying mental retardation as a mental disorder led many psychiatrists to regard all unusual behaviours in people with an intellectual disability as part of the disability itself rather than seeking alternative diagnostic hypotheses [4]. In addition using the category of intellectual disability in this way means that the underlying cause for the disability is not considered although this may have very significant implications for treatment in a health context. If a medical framework is applied then an intellectual disability can be seen as a symptom of a number of disorders or illnesses. For example a symptom of Down's syndrome is intellectual impairment. The associated health implications of this are that there is a higher risk for a number of disorders including dementia, hypothyroidism, depression and cardiovascular malformations [8].

In the recent past psychiatric illnesses were seen as being malfunctions of the mind and not necessarily to have a basis in the structure and working of the brain. [9] At the same time, with some exceptions, mild to moderate intellectual disability was seen as being part of 'normality' as intelligence exists on a continuum with the general population and was not therefore an illness.[10.] However recent advances in science, particularly at a cellular and genetic level, are demonstrating a significant biological basis for both psychiatric illness and intellectual disability [11 & 12]. In addition some genetic syndromes are associated with both intellectual disability and psychiatric illness such as the psychosis in Velo-Cardio-Facial syndrome [13] or the over eating behaviour in Prader Willi syndrome [14]. Prevalence studies have also demonstrated that the intellectually disabled population have high rates of psychiatric illness[4]. This suggests that the two conditions have more in common than might have been

previously thought, and at a fundamental level both may be due to brain dysfunction that leads to a disturbance of thought, behaviour and/or emotion.

Although there are many differences in the types of problems that are presented by the two disorders there is also considerable overlap, particularly in the day to day problems that both groups face. For example in facing stigma, holding down a job or accommodation, maintaining relationships, managing money, displaying inappropriate behaviours etc. Some of the broad treatment approaches are also similar and include practical and psychological support as well as educational, vocational and recreational assistance.

It should not be surprising that if it is difficult to separate the two groups of people at a conceptual and practical level that this will translate into practical difficulties at an operational level. All too often service providers are in the position of having to determine whether a problem, such as a behaviour, is related to a person's intellectual disability or a psychiatric illness so they can work out which service has what responsibilities.

The impact of classification

In the case described above the patient did not meet any of the standard criteria for a mental illness. However the current classification systems in use were designed for the normal population and require a basic level of communication skills on the part of the patient which, in this case, he lacked. Despite this he had been given a diagnosis of schizophrenia at different times in the past and was on treatment for this illness. Thus when seen by mental health services, despite the severe nature of his disturbance, they correctly decided he did not have a mental illness based on current classification methodology and on this basis he was not eligible to receive their services. The patient had an IQ of around 40 which put him in the moderately to severely disabled group and clearly eligible for services under the Intellectually Disabled persons' Services act (1986). He had also been diagnosed with autism, which occurs in a high association with intellectual disability [15]

Underpinning philosophies and legal framework for DisAbility services

A knock on effect of the separation of services has been that each service has evolved along different philosophies leading to different service structures and legal frameworks. One of the principles guiding the development of DisAbility Services has been that of 'Normalisation' [16 & 17] and 'social role valorisation' [18]. The underpinning of this service philosophy is to provide appropriate assistance to persons with an intellectual disability to lead a

'normal' life and develop to live as independently as possible. Within this framework as far as possible they should have the same choices and opportunities as the normal population. Consequently people with an intellectual disability have the same rights as the general population and in Australia should access generic services, including health services. DisAbility Services role has become more one of assisting people with a disability and acting in their best interests to ensure these needs are met. The emphasis is on accessing existing services rather than to directly providing them[19], with some exceptions such as direct accommodation and Behaviour Intervention Support Teams (BIST).

The legal framework for those with an intellectual disability is based on the same principles and is that of participation on a voluntary basis which requires the consent of the individual for service delivery. A potential difficulty is that a significant number of people with an intellectual disability will lack the cognitive capacity to give informed consent to treatment [20] and presumably to either accept or refuse services. Thus services may not be delivered to some people who would clearly benefit because they refuse. This causes problems in a small, but significant, percentage who present a high degree of risk to either themselves or others and it could be argued that this is the price we pay for freedom of choice. Mental health practitioners can be frustrated by the failure to compel dually disabled patients to access DisAbility services when there is a perceived need. Additionally many people with an intellectual disability will not be able to access services independently, or in some cases recognise the need to do so. Thus the current model requires that the staff working directly with the patient have the skills to detect and appropriately refer problems and advocate on their clients behalf if there are service gaps. This process has been hampered to some extent by the de-professionalisation of the care for intellectually disabled people as evidenced by the disappearance of the mental retardation nurses (MRN's) previously a division of registration for the Nursing Board of Victoria [21].

In this patients' case although his father had been appointed as health guardian and reporting was being undertaken as required by the Intellectual Disability Review Panel there was no one qualified to determine the either the appropriateness or quality of the treatment he was receiving. (It is perhaps relevant to note that in America lawsuits have been won on the basis of disabled patients receiving inappropriate treatment that was not monitored. [22]) Meanwhile he was requiring both seclusion and chemical and physical restraint sometimes several times a day in attempts to protect staff and ensure his safety. Although this was probably necessary, the legal mechanisms to allow staff to undertake this were not specifically addressed [23]. It was essentially being performed under an assumption of 'duty of care' with the implicit approval of his health guardian. This could have been difficult to

defend in a law suit if the patient had been injured as a result of a restraint procedure. The direct care staff, who had received between three months and one years training, although not prepared for this situation attempted to manage as best they could and engage other services. BIST had assessed the client and given advice to staff about management strategies but with little change in his behaviour. He was being administered large doses of medication on a regular basis though staff were not trained in monitoring and managing side effects.

Health Service delivery to people with an intellectual disability

Meanwhile Mental Health Services have developed independently and to some extent, under an assumption that people with an intellectual disability are solely the responsibility of DisAbility services who would provide for all their needs. Perhaps this is partly explained historically as this is the manner in which both services functioned when they were united and one which mental health services continues to adhere to, at least to some extent. This belief has been reinforced by the fact that DisAbility services do actually provide some direct services and in particular BIST teams who deal with behavioural problems. As mental illnesses can often present with behavioural problems this has often meant that Area Mental Health Services (AMHS) could expect a BIST team to deal with these issues including determining if there is a medical or psychiatric cause for the behaviour.

One of the consequences of this was until recently a person with an intellectual disability could be excluded from receiving some psychiatric services, despite the expectation by DisAbility services that they should be able to access exactly these generic services. Another unforeseen outcome of normalisation has been that the potential need for specialist health services for this group of people has not been identified. DisAbility services assuming that mainstream services are willing and able to provide adequate treatment, and health services not needing to develop a particular focus on this group who will usually only form a small percentage of patients seen by any one service or practitioner. This is despite the fact that this population has a mortality rate 10x that of the normal population, they see doctors twice as often, hospital admissions are twice as long, more than half take prescription medication daily and psychiatric illness is estimated to be three to four times as common as in the general population and they may form the most expensive population to provide services to [24 & 25]

Public mental health services have evolved using 'the least restrictive environment' as one guiding principle and have increasingly focused on 'serious mental illness' (though what this means is not precisely defined) [26]. In this process public mental health have become experts in the treatment of schizophrenia and other psychoses but will

often lack the expertise and resources to treat other disorders or mental illnesses [27] with the expectation that this group will be seen by either GP's or private psychiatrists. The patient discussed had autism and AMHS currently do not have experience in treating this group and consequently do not have the appropriate resources, skills or service structure to manage this type of patient.

The Gaps

The private system has certain limitations in treating this type of patient. Medicare rebates mean that there is no financial rebate for the 'extracurricular' work that is needed to effectively service this group as with a few exceptions only face to face contact is rebated. Much of the work in this case involved gathering information from the patients' carers and reviewing old files as well as seeing the patient at his 'home' and unlike public services the private system is difficult to influence by the introduction of state policy initiatives. In addition, people with a dual disability are more complex and are sometimes beyond the resources of a single practitioner and probably have their needs best met by a multi-disciplinary team. In rural areas there is a lack of private psychiatrists and even in the urban areas there are long waiting lists making this option less viable[27].

These limitations of the private system, with some exceptions, suggest that public mental health services are in the best position to manage this group. However the difficulty in the retention and recruitment of psychiatrists in this system (particularly in rural areas) [27] limits the availability of specialist medical advice. The current mental health service model has difficulty in performing the prolonged, detailed and protracted assessments that some of these patients require [28]. The assessment is often based around the issue of access to the mental health system and the potential role of consultation and provision of advice to other services with appropriate follow up is not usually formally considered. Resources, such as beds and case managers, are limited and already under pressure and it is difficult to demand they take on extra work load without extra resources including the additional training, education and ongoing supervision that would be required. Intellectually disabled patients are often vulnerable to abuse on in-patient units and their behaviours often exceed the capacity of the ward to manage them [28]. Difficulty in finding long term accommodation leads to initial resistance in admitting a patient that will potentially block a bed for a prolonged period, or in precipitous, hopeful discharge usually to a special accommodation setting. Most DisAbility services lack an after hours crises response and by default CAT teams often end up

responding inappropriately to an intellectually disabled person in some form of crises to which they have no solution with consequent loss of goodwill and reluctance to respond in the future.

In this case the CAT team had been involved for about a week. He had been commenced on benzodiazepines to manage his behaviour though methods for measuring the effectiveness of this were not established. He was discharged to a GP with no follow up arrangements or on going consultation from AMHS. His behaviour was thought to require a long term strategy and was not amenable to a crises response as despite it's severity it was now chronic and should be managed by his current carers. The explanation for his behaviour was that it was related to his autism and intellectual disability though this formulation did not lend itself to the development of practical management strategies. On closer examination neither of these conditions can on their own explain his behaviour though clearly need to be taken into account when trying to understand his behaviour.

In the past his treatment had been undertaken by a succession of GP's, often providing a repeat prescription at the request of staff. However, it is perhaps not surprising that the GP's, without any support and lacking skill in the treatment of this group of patients, had declined to manage this patient in the longer term. This lack of consistent medical input had been exacerbated by his behaviour causing a series of changes in accommodation. It had not been possible to find a private psychiatrist able to see him.

Interagency issues.

The division of care into two departments has meant a division of resources not necessarily accompanied by a clear demarcation of the division of responsibilities. The staff in each department have developed their own cultures and language that leads to confused and difficult interactions because there is no shared understanding. In relation to this case the local AMHS did not see a need for a case manager as he already had a case manager from DisAbility services. There was no understanding that the role of the DisAbility case manger is mainly that of brokerage of services and is not able to undertake the same role as a case manager in an AMHS who can act as a 'therapeutic agent' in their own right and undertake activities which include monitoring mental states and for side effects of medication or accessing assistance from other health professionals forming the multidisciplinary team.

Despite a considerable overlap of patients or clients it is rare for local areas to have developed meaningful protocols to prevent misunderstanding and allow for easy referral processes and transfer of information or flexible collaborative working relationships. There is often a history of discord and mistrust between the departments and this was evident in this case when mental health reported that a similar patient had cost them an large amount of

money when left in the ward because there was no other setting that could manage the degree of disturbed behaviour. They understandably did not want a repetition of this and were reluctant to grant people with similar presentations the status of a psychiatric patient with access to their services without clear, definite evidence for a psychiatric illness. This is compounded at a professional level by staff in both services developing skills and knowledge in either the field of psychiatric or intellectual disability but usually not the other. This leads to difficulties in detection, appropriate referral, management and working with both types of disability when they occur in the one person. In this patients' case the AMHS lacked the experience in assessing non-verbal patients, an area where DisAbility have more expertise and conversely DisAbility services lacked the training, facilities and legal framework to manage his disturbed behaviour which is more the province of Mental health Services.

Conclusion

In conclusion there are many factors that have had an impact on the delivery of mental health services to the dually disabled and understanding these could help in optimising the actual services received. These have been illustrated in relation to an actual patient. To assist people with an intellectual disability to access services requires that direct care staff working with them have an adequate understanding of their needs and of the services available and, if services are not available, how to identify this and advocate on their client's behalf. To assess and treat them requires that appropriately trained staff and resources are available and preferably specifically designated this responsibility. In addition, appropriate local protocols that might alleviate some of the tension between departments with built in review mechanisms and education processes so that the differing roles are clearly understood and articulated and enhanced would be of benefit.

An appropriate framework in the current legislative structure that addresses the following issues would be of benefit:

- (i) the capacity to monitor that the treatment received is of a sufficient standard
- (ii) to ensure that treatment is delivered in a manner that meets current legal requirements.
- (iii) to direct changes where indicated.
- (iv) that addresses issues related to consent and restraint

Quality assurance processes to ensure that needs are correctly identified and met would be highly desirable.

Recognition of some of these difficulties at a Mental Health Branch level lead to the recent establishment of the Victorian Dual Disability service [29]. The service aims to address some of these issues by providing secondary

consultation services about specific patients and training to AMHS staff in the area of dual disability to improve their assessment and treatment skills as well as assist in identifying policy and service structure issues that may affect service delivery to the dually disabled.

The patient discussed earlier turned out to have oesophagitis, a painful medical condition, initially identified by his father, which when treated in conjunction with rationalising his psychotropic medication and reinforcing autism appropriate management strategies resulted in resolution of his behavioural problems. Mental health services may have been justified in their original decision not to be involved, as it eventually transpired that he probably did not have a mental illness. A behavioural approach as used by BIST was not going to effectively treat this condition and although it may have lessened the impact it would still leave the patient in pain and at risk of complications including oesophageal perforation. Other medical specialists, such as GP's or physicians, are not trained in the analysis and treatment of patients presenting with behavioural problems and cannot be expected to take a lead role in this type of situation but would need to be advised as to how proceed by an appropriately qualified specialist.

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