Submission to
Senate Select Committee on Mental Health

This submission focuses on issues pertaining to mental health services, particular to the Office of the Protective Commissioner's experience in working with clients with a psychiatric disability

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Office of the Protective Commissioner
Attorney General's
department of nsw

BACKGROUND TO THE OFFICE OF THE PROTECTIVE COMMISSIONER

The Office of the Protective Commissioner (OPC) is an organisation with 130 years of experience in managing the financial affairs of people with impaired decision making ability in N.S.W. OPC is part of the NSW Attorney General's Department.

The OPC provides its services following the making of a financial management order under the *Protected Estates Act 1983* (NSW) or *Guardianship Act 1987* (NSW). Such an Order empowers the Protective Commissioner of New South Wales to manage the affairs of persons deemed incapable of managing their own financial affairs due to impaired decision making ability. The powers are contained in the Protected Estates Act, *Supreme Court Act 1970* (NSW) and NSW Supreme Court Rules.

From the inception of the NSW Supreme Court, which derived its jurisdiction from the Charter of Justice, provision has been made for the protection of incapable persons. The *Lunacy Act 1878* consolidated the law relating to the "insane" and provided for the formal appointment of the Master in Equity as the Master in Lunacy. The functions of the Master (now known as the Protective Commissioner) devolved as a result of the passing of the Supreme Court Act, into the Office of the Protective Commissioner.

Whilst the role of OPC (substitute decision making in financial management) has remained substantially unchanged over time, the historical, social and political contexts within which it has operated have experienced substantial change, especially since the late 1970s.

The philosophical basis of the OPC's role is represented in its adherence to two principles of decision-making, "substituted judgement" and "best interests" on behalf of protected persons[1]. Issues of person and property are often inseparable, with welfare and lifestyle interests closely tied to issues of economic security and financial management. These principles, in conjunction with the guiding principles of the *Disability Services Act 1993* (NSW), the *Guardianship Act 1987* (NSW) and the principles of financial decision-making, attempt to combine welfare, self-determination and rights within the framework of financial protection. This framework ensures that decisions are made in the global best interests of protected persons, not merely in their financial best interests.

OPC CLIENT PROFILE

The major client groups referred to OPC are people with a brain injury (acquired, traumatic and alcohol related), dementia, intellectual, neurological and psychiatric disability. OPC currently has 9793 clients[2], 8,026 whose estates are under the management of the Protective Commissioner and 1,767 who have a private manager managing their estates under the direction and authorisation of the Protective Commissioner.

Approximately 43 per cent of OPC's clients have a psychiatric disability. However, we note this category provides for a broader definition than that which would be seen as the legal definition of mental illness. Many of our clients have multiple diagnoses

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[1] A person who has had a financial management order made under the *Protected Estates Act 1983*
[2] OPC Annual Report 2004

relating to substance abuse, brain injury and some have ill-defined mental and psychological conditions often classified as “personality disorder”.

Of these clients 44.2% reside in congregate care settings.

The OPC has a specialised unit (Clarence Street) which assists clients with high support needs. Clients of this centre require regular cash allowances, are often itinerant, isolated, ad hoc users of support services and present with challenging behaviours. Of the 295 clients assisted by this service approximately 80% have a psychiatric disability as their primary disability. The extent of support required by these clients from OPC is indicative of a demand for such needs to be met and highlights gaps in service provision in the community.

Analysis of the location of clients with a psychiatric disability highlights the concentration of clients in Sydney's inner city and inner west. This might be due to a high proportion of itinerant clients and boarding houses within these areas. Other OPC clients with this disability are for the most part relatively evenly represented in all areas of NSW.

OPC’S INTEREST IN THE INQUIRY

To be effective when making financial decisions, an appreciation of the client’s disability and the impact this has on their capacity, their ability to contribute to the decision making process, their lifestyle needs and an appreciation of how their quality of life can be enhanced, is required. The complexity of such issues results in those vested with decision-making authority having extensive contact with a broad range of government, non-government and charitable, as well as private paid and non-paid services. The OPC exposure to this variety of organisational systems makes it well placed to provide comment on its experiences and that of our clients in using such services in NSW.

OPC’s particular interest in this inquiry relates to its clients with a psychiatric disability that have been affected by developments in the mental health system. Many of OPC’s clients with a psychiatric disability form part of a vulnerable group, some highly visible and others invisible, whose obvious societal neglect belies community education efforts to promote tolerance and integration.

They are clients with severe and chronic/intractable conditions, the latter often brought on by years of institutionalisation. Many of these clients had their financial affairs placed automatically under the management of the Protective Commissioner by virtue of the provisions of the *Mental Health Act 1958* (NSW) and have been clients of OPC for many years. For others, financial management orders have been made because of a combination of factors such as itinerancy, challenging behaviour, severity of incapacity, absence of family, significant others or advocacy assistance, absence of less intrusive alternative financial management options and evidence of exposure to exploitation, neglect or abuse. Often OPC is the sole agency/significant other in their life.

OPC applauds the priorities of early intervention, prevention and community education which are an important feature of the mental health system. However, clients who have particular needs which have not been adequately met should not be overlooked because of their relative invisibility or the complexity of their

presentation. Many of OPC's clients with a psychiatric disability have not had the benefit of the numerous advances in the care and treatment of the mentally ill and their illnesses are of a long standing nature.

OPC's EXPERIENCE

The following issues have been identified by OPC staff as major challenges to mental health services currently:

- the variation in resources between Areas
- the difficulty of attracting staff to certain Areas
- shortened stays in hospital
- appropriate discharge planning between hospital and community
- appropriate follow up after discharge
- comprehensive hand over between communities upon clients' relocation
- limited social, recreational and vocational programs
- appropriate models of case management

TERMS OF REFERENCE

This submission is based on information drawn from OPC staff's day to day experience. It mirrors a submission made to the Select Committee Inquiry on Mental Health in New South Wales in 2002.

The extent to which the National Mental Health Strategy, the resources committed to it and the division of responsibility for policy and funding between all levels of government have achieved its aims and objectives, and the barriers to progress;

It appears that current methods of funding still reflect decision making based on the historical aftermath of the de-institutionalisation process and the inherited models from that system. Currently services seem to be driven by service criteria requiring clients to match themselves to the service, rather than services responding to the needs of clients. Until this is addressed it is difficult to assess the levels of funding required and the appropriateness of the arrangements.

OPC notes that in the evaluation of the Second National Mental Health Plan in 1998 it was generally felt that the directions of the plan were sound but the implementation was the issue. The concept of the continuum of care within and across sectors remain an appropriate priority but requires commitment of resources, major development in services partnerships and ongoing consumer and carer feedback combined with research if it is to succeed.

The adequacy of various modes of care for people with a mental illness, in particular, prevention, early intervention, acute care, community care, after hours crisis services and respite care;

Generally OPC supports the changes brought about by the Richmond Report in NSW in that they emphasise support for people in the community. However whilst ideologically sound difficulties have been encountered in practice. What seems to have been less than adequately considered are the requirements for community

living. This is particularly an issue for people who have had all such needs previously met by the institution. A key benefit that has been overlooked in developing community services to date is the need to have other places which provide the structure, support, security and sanctuary that such institutions could afford. To leave people, who have had years of institutional living languishing in the community is a source of concern. The question becomes what models of support and care can provide such benefits to people without returning to the days of large institutions.

Staff report that OPC clients have experienced a lack of continuity in care and support. The key issues that arise relate to:

- Inconsistency of service across regional areas
- Poor linkages between hospitalisation and/or community relocations
- Lack of accommodation and support services

The issue of continuity of care is represented at all levels, hospital to community, community to hospital, Health Area to Health Area upon relocation, as well as in the community intake process. There does not appear to be the infrastructure, referral procedures, systems to manage information exchange or follow-up protocols required. Whatever might exist in this regard seems not to be understood by those at the frontline. In addition, once a particular service stops providing a client with support there seems little flexibility to reopen the matter if circumstances change.

Many comments from OPC staff reflect the belief that stability is a key factor to contributing to wellness. The fundamental requirement for stability is felt to be securing appropriate accommodation. OPC staff comment that early discharge from hospital combined with inappropriate placements very quickly led to a cycle of decline. Whilst people should not stay in hospital any longer than necessary, discharge to inappropriate settings only exacerbates problems and potentially creates new ones.

This process is compounded by the seemingly unwieldy methods of information exchange between service outlets. Whilst awaiting access to full information staff are proceeding with sketchy and inadequate information at a critical time of re-integration for the client back into the community. Peter's situation exemplifies these issues.

CASE STUDY

Peter is 28 years old and is currently itinerant moving between two rural Health Areas. He has an acquired brain injury and an undiagnosed mental illness. The local brain injury service says it is unable to work with him effectively without the support of the local mental health service. The mental health service refuses to do so reportedly because of his brain injury.

The mental health service in the adjacent region provides services to people with a brain injury. However, this is in the absence of a brain injury service in that region.

Peter's behaviour brings him into contact with the criminal justice system, and has spent time in gaol. To add to the problems the NSW Department of Housing says it will not consider his application for housing unless he is supported by appropriate services.

Peter has a legally appointed guardian who has been persistently advocating for 12 months for a resolution to these problems. The matter is now the subject of ministerial correspondence.

Peter continues to have less than appropriate supports to assist him to live in the community and continues to have encounters with the criminal justice system.

The lack of a continuum of care and support reflects a style of case management currently prevalent. It is suggested that this model remains generally based on a medical model, focussing on the dispensing of and compliance with medication. Consequently, the focus is on treatment. Some suggest that not enough attention is paid to psychosocial aspects of a person's life which might facilitate and enhance such treatments. The current approach falls far short of good practice in case management, which emphasises a more holistic approach to the co-ordination, provision and monitoring of services.

Opportunities for improving coordination and delivery of funding and services at all levels of government to ensure appropriate and comprehensive care is provided throughout the episode of care; and **The appropriate role of the private and non-government sectors;** and **The extent to which unmet need in supported accommodation, employment, family and social support services, is a barrier to better mental health outcomes;**

The experience of OPC staff suggests the legal definition of mental illness can be used to avoid service provision. This outcome is believed to be a result of the devolution of mental health institutions. It would appear that a significant number of current models of service delivery are based on values and principles of an old medically based system.

Whilst OPC supports client self-determination, to place unqualified emphasis on it for clients is not always prudent, when by the very nature of their conditions they rarely self-initiate. It would also seem problematic for those whose mental health status has deteriorated beyond their capacity to seek or appreciate the benefit of intervention. OPC's experience suggests that this approach is often used to mask the system's inability to provide a service to clients due to other issues such as having insufficient resources, lack of staff, limited staff training and the difficulty in 'contracting' with such clients.

Survey results suggest that for clients to obtain a service they themselves must be able to request it and accept it. This means a significant challenge in those cases when clients show limited insight, yet do not fit definitions of mental illness or mental disorder. There must be a balance between the client's right to receive support and have their needs met and the need for intervention to ensure protection.

It appears that in the absence of skilled advocacy, service is only provided in crisis situations. This often works against the much more positive focus on prevention and

community acceptance of people with a mental illness, and is often too late to prevent hospital admission.

There appears to be a correlation between what OPC staff have identified as the reasons clients may or may not receive a service and the factors they identified as having changed in mental health services over the past 5 years. Staff identified that in addition to clients being expected to access generic health services, more private and voluntary services were providing a service without the necessary knowledge or expertise to do so.

It is felt that homelessness is an ongoing issue. It is believed that this is related to a lack of community understanding of mental illness and the related difficulty in finding or maintaining suitable accommodation. The feedback OPC staff receive is that families have become increasingly distressed by the additional burdens on their carer role due to difficulties in accessing mental health services. They report that it has become increasingly difficult to link clients with appropriate services; there is a large turnover in mental health staff; there is an increased "burnout" rate in caseworkers; and those that remain appear unable to develop creative solutions to client problems.

The special needs of groups such as children, adolescents, the aged, Indigenous Australians, the socially and geographically isolated and of people with complex and co-morbid conditions and drug and alcohol dependence; and **The role and adequacy of training and support for primary carers in the treatment, recovery and support of people with a mental illness;**

Carers play an integral role in the provision of mental health services. They are often a 'hidden' and somewhat neglected part of the overall support system. They often provide the bulk of care and provide the vast majority of support to people, who require such levels of support, post discharge from acute care facilities. Carers, however, become very frustrated when they are denied access to information and are not recognised as part of the 'team' of people providing support to the person with a psychiatric disability. Better role clarity, training about mental illness, recognition as being an intrinsic part of the team, receiving information which assists them in their role and adds meaningfully to clinical decision making and support would assist in developing a much more coherent and cohesive mental health system.

There are challenges in respect of carers' formal involvement in supporting people with a mental health problem. Privacy legislation or claims of confidentiality are often used to restrict information flow or exclude carers from participation. If the aim is to provide the best possible treatment and/or support for a person, these issues need to be addressed through early discussions and documentation. The key being planning ahead.

The overrepresentation of people with a mental illness in the criminal justice system and in custody, the extent to which these environments give rise to mental illness, the adequacy of legislation and processes in protecting their human rights and the use of diversion programs for such people; and **The proficiency and accountability of agencies, such as housing, employment, law**

enforcement and general health services, in dealing appropriately with people affected by mental illness;

The issue of dual/multiple diagnoses has been a long-standing problem. It is often used as a reason for not providing services by over-stretched workers and services dealing with waiting lists and their capacity to manage people who present with complex problems. Service providers appear to devote time to debating primary diagnoses in an attempt to refer the person to another service provider instead of exploring what the service can offer their clients in conjunction with other agencies. In OPC's experience engaging in debates about the hierarchy of diagnoses rarely results in any benefit to clients with a psychiatric disability, as the case of Joe illustrates below.

Concern must be expressed about the lack of co-ordination between agencies which at times leads people to fall through the gaps. The reasons states often include resource constraints or the person not fitting the service criteria.

CASE STUDY

Joe has a mild intellectual disability and an ill-defined mental health problem, which have resulted in numerous admissions to psychiatric hospitals.

Joe has no family supports and presents with challenging behaviour. When OPC referred Joe to mental health services (he was previously known to them) they refused to visit him on the basis that he "chooses" to be difficult. Intellectual disability services were providing a service that they regarded was limited by the response of the mental health services. When they identified a deterioration in Joe's mental state they sought the assistance of the local mental health team. The mental health team refused a service, following a visit, re-iterating their view about the client's choice of lifestyle.

Joe's "choices" were described as him boarding himself up in his flat, boarding up windows, up-ending furniture to block doorways and believing that the cockroaches infesting the flat had been put there by his neighbour who was trying to take over his flat. Given their frustration with this situation, intellectual disability services were considering withdrawing their service. This would have resulted in the client having no services, no support and no monitoring of his situation. Joe was left in a most vulnerable position. He falls through the gaps of service provision for both of his disabilities, due to his dual diagnoses.

Mental health workers have different approaches to the frequency of contact with a client, the level of their involvement and in deciding in what circumstances to 'contract' with clients. The perception is that the client must fit the selection criteria for the service rather than the service responding to the needs of the clients. This is complicated by the existence of ill-defined definitions of who qualifies for the service, the triggers for obtaining a service and the amount of service available to be provided.

The likelihood of receiving services is minimised when factors such as lack of medication compliance, isolation, transience and challenging behaviour exist. The

clients who experience these kinds of difficulties are those least likely to have support networks or advocacy services available, are at the lower end of the socio-economic scale, come into contact with the criminal justice system and are generally the most vulnerable.

In the experience of staff of OPC, the critical factors that determine whether a service is received and its quality would seem to depend on:

- geographical location and service accessibility
- nature and type of diagnoses
- behaviour
- medication compliance
- support networks
- presence and persistence of guardians, families and advocates
- availability, continuity and stability of accommodation and support services
- regional differences in resources
- regional interpretations of service criteria

CONCLUSIONS

Unlike other areas of disability services, there is no overarching organisation or legislation to ensure that people with psychiatric disabilities residing in the community receive appropriate care and support services, regardless of diagnosis, its severity and other factors. Some protection is offered to inpatients as a result of legislative obligation in NSW through the Official Visitor provisions of the *Mental Health Act 1990,* and outpatients through community treatment and counselling orders. These approaches assume service from the perspective of medical treatment and only capture clients whose condition is serious enough to get them hospitalised.

At present this places the onus on the State to ensure accountability mechanisms and monitoring systems are in place to evaluate the work being done within Area mental health settings. A compounding problem here is the structural dilemma of the Area Health Service model. Whilst the Centre for Mental Health offers some opportunity for state-wide overview of the strategic issues pertaining to mental health services, the provision and management of services through Area Health Services can sometimes be experienced as disjointed, if not inconsistent or absent.

Relevant service delivery models and service standards need to be clearly articulated to frontline staff within mental health services as well as to the community. Possibly more emphasis is required on a bio-psycho-social model which requires a shift in thinking away from a medical model to a model that has at its core the concept of client needs within the whole of their life.

Whilst policies and protocols are in place an operational evaluation is required at the practice level in relation to partnerships between organisations associated interagency policies and protocols, referral practices, discharge planning, the role and parameters of community mental health services, in order to ensure clear allocation of service responsibilities and to ensure a comprehensive support and treatment system is available.

There needs to be clearer processes and systems in place for the exchange of information between those who determine the policies and those vested with the

practical implementation within and between areas. This standardisation of service would better meet the needs of individual clients who relocate.

Whilst some interagency protocols have existed in the past it has been the experience of OPC that its frontline staff are unaware of the existence of these protocols. Ongoing inter-departmental partnerships/agreements need to be fostered between government service providers and brain injury and aged care services regarding the provision of and access to the whole range of services. Such agreements would identify areas where services can complement or work in concert to ensure a package of services that results in continuity of the care and support.

Staff training needs to focus more on ensuring standardisation of practice across areas in order to ensure more consistency in the following areas:

- Roles, functions and parameters of mental health workers and services;
- Induction training in state wide and local policies, procedures and protocols not just local service issues;
- Criteria for service provision and knowledge of the infrastructure in order to clarify and monitor referrals that fall outside the criteria;
- Good practice standards training in the interpretation and application of these in the practice situation.

The development of mental health services since the Richmond Report has brought about a much needed focus on the individual's right to be supported in the community for as long possible. Admission to a mental health facility is generally, and correctly, seen as last resort option.

However, the interpretation of service access and admission criteria can sometimes significantly impact on the ability of the service system as a whole to appropriately support someone with a psychiatric disability. Arguments about whether someone's primary diagnosis is psychiatric, or of some other aetiology, whilst academically meritorious sometimes forgets that there is a person with significant support needs who is sometimes abandoned by everyone because they do not have the expertise or resources to support the person on their own.

The OPC's experience suggests that there needs to be better service co-ordination across acute inpatient and community settings, between government and non government service providers supporting people with a psychiatric disability in the community and between mental health services and services to people with concomitant or "dual" diagnoses such as brain injury and developmental disability. These service provision difficulties are longstanding problems to which solutions have been previously implemented with limited impact at the service outlet level.

Area based government mental health services and an apparent lack of a workable whole of government approach to providing a service to people with dual or multiple disabilities, including psychiatric disabilities, pose significant barriers to continuity of service for people with a psychiatric disability. Rather than being provided with a service which meets their individual needs these people often end up receiving no service whatsoever as the presentation of their disabilities is such that no service provider on their own feels resourced to support them appropriately, or the service defines them out of service eligibility.

That is not to say that significant developments have not occurred and that at the Area Health Service level concerted efforts have not been made to address these issues, together with other agencies. OPC's impression is that despite these efforts the solutions arrived at to date have not met the needs of a significant number of people with disabilities appropriately.

People with a psychiatric disability in New South Wales have a much more sophisticated and individualised service system now than prior to the Richmond Report. The focus on early intervention, rehabilitation, vocational support community based case management and assertive treatment services are all positive initiatives which must be applauded and continued.

A more co-ordinated approach to service delivery with consistent service access criteria known by service outlet staff and an appropriate number of case managers for people with a psychiatric disability would go a long way to providing a truly seamless service across all relevant government agencies and non-government services. This has been the aim of the sector for many years. It is possible to achieve.

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