16 July 2008

Review of the Office of the Protective Commissioner
Independent Pricing and Regulatory Tribunal
PO Box Q290
QVB Post Office NSW 1230

Dear Tribunal

I want to comment on your recently published Issues Paper on the Review of fees of the Office of the Protective Commissioner.

Right at the start I want to say that my comments will be limited and could be considered a generalisation. In part this is because of my time limitations as I have the full time responsibility of caring for an adult son with severe brain damage. It is also because I feel that others are more qualified to provide comment in detail on the individual questions you raise.

By way of background I indicate that I have had a very long involvement of more than thirty years with the OPC and its officers. That involvement ranges from the Commissioner level to the direct contact staff.

This involvement has its genesis in the fact that through my personal association with disability, I became a member of a large Sydney based parent support group which had (and still has) a membership base across New South Wales. In that capacity I took a leadership role in seeking out information for other parents, including the important area of understanding the income their adult children were receiving (mostly from Federal Government pensions) and the charges levied on the accommodation and services they received (mostly in the NSW Government's large institutions).

In the following submission I intend to confine my comments to:

1. my views based on my experiences from my involvement with the OPC on behalf of a large number of parents of people with disabilities, and
2. my views based on my experiences as a Private Financial Manager of my son's finances, an appointment made by the NSW Guardianship Tribunal.

1. My views based on my experiences from my involvement with the OPC on behalf of a large number of parents of people with disabilities

I can say quite categorically that fees charged by the OPC are not an issue with the parents I know. Specifically, they accept that if their son or daughter has money and there is a need to have that money safeguarded, then it is acceptable for a fee to be charged. If their son or daughter is not yet the beneficiary of an estate and has savings limited to a small amount from the

pension, then those parents appreciate the ‘social caring role’ of the OPC in keeping the fee for safeguarding that money to a minimum.

Overwhelmingly I can say that the parents I am associated with, mainly through the parent support group, have considerable confidence in the OPC. I believe that confidence comes from the nature of the involvement of the parent support group over a period of three decades. To those parents the OPC is not a remote organisation. It has a human face which is quite an achievement for a large organisation.

And, in order to appreciate why ‘confidence’ in an organisation such as the OPC is being laboured, I need to make the following comments.

Parents of people with disabilities (especially intellectual disability with which I am most closely associated), worry all their lives, every day, about their disabled child. The fact that their child, in their growth to adulthood, may move to living in full time accommodation away from the family home, and is guaranteed that accommodation and care for the rest of that person’s life, does not lessen their worry.

- They worry about the staff that are provided and their qualifications to look after their child
- They worry about the reliability of the staff; can they be relied on to see when their son or daughter is in difficulties and act appropriately to sort out those difficulties
- They worry about whether staff really care; are they honest; do they comfort and support their child
- They worry about whether their child gets good and sufficient food
- They worry about the clothes their child wears; they are despondent when they see their child wearing inappropriate clothing, or some one else’s clothes, when they know there are plenty of appropriate clothes available for their son or daughter
- They worry about the government of the day and whether their promises to people with disabilities can be relied on.

These are some of the matters that remain at the top of the list of parents worries. It is a matter of fact that all these personal care and quality of life matters are the priority. Coming right down the list, after all the personal and life worries, is money.

I first became concerned about the lack of information parents had about money matters soon after the parent support group was set up in 1976. In those days parents rarely questioned authority. They were used to ‘being told’ how things were. They were not used to seeking information.

Hence, a ‘search for information’ goal led us to the first contact our parent group had with the OPC. In the past thirty years, a number of issues on disability matters have followed because of that initial goal. Because those issues are ‘historical’ by nature, and may be not relevant to the current IPART Review, I will seek to summarise them. They illustrate the positive standing of

the OPC and my assertion in the first paragraph of this section of my submission, that fees charged by the OPC are not an issue with the parents I know.

I strongly believe that the proactive and cooperative nature of the parent group's relationship with the OPC over a long period of time is one of the key factors in parents understanding of the services provided - and hence, a ready acceptance of the fees charged as they are at present.

1.1 Willingness to provide information – as a service to the community

Just on thirty years ago – at a time when the Government policy was to:

- charge indeterminate amounts of money from disability pensions, often leaving people with disabilities with no personal funds
- not recognise any private medical insurance held by people with disabilities when they entered the 5th Schedule hospitals of the State
- pursue the financial debt they considered owed when the person left the 5th Schedule hospital to the extent that beneficiaries were denied their beneficial interest in the estate of their parent,

the parent group made its first contact with the Office of the Protective Commissioner.

The result of that contact created a relationship which has been ongoing over the years and, most importantly, provided an understanding of financial matters which has been so positive for so many parents.

Thirty years ago parents generally considered they were powerless. They had accepted, gratefully, accommodation the State provided for their child with a disability. (My predominant experience is with families whose children have an intellectual disability.)

Those parents were often called upon to provide significant financial contributions to the care provided by the State if their child was a young child or early teenager. When the child reached adulthood and became eligible for the Social Services Disability pension of the day, those same parents remained grateful for the care and accommodation provided and did not question the amount of money taken out of the pension by the accommodation providers.

When parents wanted to know more about pensions and allowances and how things worked in the money field for people with disabilities, it was then that we made our first contact with the OPC.

By 1980 the trust that had developed between parents and the OPC, based mostly on the willing exchange of information, had grown to the extent that we collaborated with the OPC to produce a booklet, written in an easy question and answer format, to answer many of the worries families had expressed.

We were told that this was the first time the role and responsibilities, as well as the services provided by the OPC had been explained in a way that was easily understood. It provided an understanding for parents of what the options for the future could involve.

1.2 Providing financial safeguards for people with disability unable to manage their own money

1.2.1 *Acknowledgement and action from politicians – leading to opportunities for an increased number of people to have financial savings where none had previously existed.*

From the understanding and growing awareness of money matters parents now had, came the recognition that the State was acting unfairly in the handling of finances for people with disabilities. In 1981, the year of State Government elections in NSW, the

parent group pursued a public challenge to the political parties of the day. This challenge (accepted and confirmed in a letter provided by the Premier, the Hon Neville Wran) resulted in the:

- abolition of fees for the provision of accommodation of children
- the fixing of a percentage of the pension as the agreed fee that the State would levy for the provision of accommodation and services
- the waiving of all previous debts (often accrued by people with mental illness) of people who had been discharged from the State's 5th Schedule hospitals.

This new undertaking by the NSW Government commenced operation on 1 November 1981. It underpins, in principle, the financial system in place today for people with disabilities.

The OPC was heavily involved in the implementation of the changed financial arrangements. This political decision also meant that, apart from those people whose funds were already being managed by the OPC (often as a result of Magistrate's orders), more people with disabilities started to accumulate savings from the balance remaining from their pensions or as beneficiaries of a family estate.

1.2.2 *A further financial safeguard*

A further safeguard for people with disabilities living in the State's 5th Schedule hospitals and large institutions became necessary towards the end of the 1980s. It had become obvious that the institutions, in holding the pensions of many people with disabilities who did not have a financial manager, was not always making good financial decisions for those individuals.

An arrangement was negotiated in 1989 whereby the OPC would act as 'the banker' for the individual bank accounts of all residents who did not have appropriate financial arrangements. Instead of the pension going to the institution, it would go to the OPC and be drawn on by the institutions on a monthly basis to recoup acknowledged fees and services.

As a result of this arrangement the resident's savings were protected. (Referred to in IPART Review at 3.1.3)

Overwhelmingly from my contact with parents I know that this arrangement was welcomed. The informal protection of an individual's savings through the banking of those savings with the OPC provided an "arm's distance" from the charges made by the institution. Parents understood the security provided by the OPC as 'the bank' and the freely available accounting statements from the OPC of charges made by the institution and recouped through 'the bank' gave parents the information they needed, if they saw it as necessary, to challenge any specific charge.

The protection of an individual's savings, was a very positive step forward. In many cases parents saw this arrangement as the best protective accountability they could have for their child's finances.

This is not to say that all parents took up the opportunity to question charges made by the institutions. Despite the growing advocacy of the 1980s and 1990s, many parents kept to the view that to question the institution exposed their child's vulnerability and risked the withdrawal of the accommodation and services their child received. The good relationship between the parent support group and the OPC has provided a supportive conduit for questioning charges without an individual parent feeling, or having the perception that to question a charge will be 'marked' against them. There are numerous examples of how I, as an individual or as a representative of the parent support group, or other parent support group officers, have worked cooperatively with the OPC to clarify concerns and confusion.

1.2.3 *The OPC – responsibly concerned about their role as "banker"*

During the 1990s, through the very positive contact on behalf of parents I had with the OPC, I was made aware by the OPC of their concern that not all institutions were diligent in advising the OPC when residents left the institution, either through a move to accommodation in the community, or through death.

As a result of submissions to the Dept of Community Services, it was determined that all "banker arrangements" would be reviewed and those arrangements that had not been 'active' for some time would be investigated. This review, a joint effort of DoCS (now DADHC), the OPC, the parent group I am associated with – and the Guardianship Tribunal, led to agreements which continue to this day and will eventually see all remaining 'banker clients' personal capabilities and need or otherwise for a formal financial manager to be determined on the basis of individual need, i.e. whether an informal arrangement, perhaps with the support of a family member is appropriate, or whether there is the need for a formally appointed financial manager, either a Private Manager or the OPC. *(I note that the Review at 3.1.3 referred only to a process leading to formal financial management orders; IPART would be aware that the Guardianship Tribunal, in considering financial management applications made to it, can also determine whether informal arrangements offered would be sufficient without the need for a formal financial management order.)*

In looking to the future as financial management applications for individual "banker arrangement" clients come before the Guardianship Tribunal, I know that the parents I have contact with overwhelmingly express their confidence in what they perceive as the security the OPC financial management provides. While in many cases there are siblings in a family, parents talk about the peace of mind they feel about savings being managed by the OPC, the fact that that arrangement is not affected by their own ill health or death, and that it leaves the disabled person's siblings free to concentrate on the quality of life of their brother or sister. In other words, the financial arrangements for their son or daughter have "been taken care of" and that is a great load off their minds.

1.3 On the nature of OPC fees

In all my conversations with parents over the years I cannot recall the fees charged by the OPC for either the formal management of a person's finances or the fees charged under 'the banker arrangement', to have been a cause for concern. Parents accept that a financial service involves the payment of a fee for that service.

To my understanding, the basis on which the fee structure for people who have the OPC as their financial manager is accepted, and not disputed, by parents of people with disabilities I have contact with, particularly those parents who are members of the parent support group.

This may not be the case with other parent groups. I attribute the recognition of the role of the OPC, the knowledge base that parents from the parent support group come from which is borne out of a long and productive association with the OPC, has not necessarily been the experience of other parents.

Apart from my involvement with families in the Sydney area, as an advocate in the disability field I have frequently been asked by parents from across New South Wales for advice on matters affecting their sons and daughters. I do not recall anyone at any time raising with me any specific concerns about the fees charged by the OPC.

1.4 Decision-making by the OPC, particularly on matters of conflict

Parents of people with intellectual disability have many years of practical experience of dealing with those who provide accommodation and services for their children. When it comes to decision making by the OPC, generally there is little conflict between family and friends for the OPC to consider, simply because the nature of the life-long disability generally sees the parents or close family united in their aspirations for their disabled family member.

I know from my experience elsewhere that this is not necessarily so for decisions around people with other disabilities, eg, dementia, where family and friends may have just come to the appreciation of the disability and have varied ideas on the decisions which should be made. In those cases I support the obligation of the OPC to listen to those varied views and to make decisions based on the consideration of those views, together with the OPC's considerable experience in the various disability fields.

1.5 In summary

From the sum total of my experiences with parents and people with disabilities over the past thirty years, I believe that there is a balance to be struck in fees charged by the OPC.

I believe that the people I have been involved with over the years accept the fee structure currently in operation at the OPC.

As an individual, I believe that it is very important that there is an ongoing acceptance by the NSW Government of the variable financial position that will always be faced by the OPC as a money manager because of the considerable percentage of its clients who are socially and financially disadvantaged. The position taken by the NSW Government in recent years of contributing to OPC's finances is valued and should be maintained. It is not acceptable for the fees of people whose finances are under management to be bolstered in order to cover the cost of services to those clients who have very limited financial resources.

OPC is striking the right balance in the current fee structure that acknowledges that it has social as well as financial obligations to a percentage of its clients by virtue of those clients financial disadvantage – evidenced by a minimum fee structure. That minimum fee structure is a valued and appreciated consideration by those who have an appreciation of what the minimising of fees means for the financial viability of the OPC.