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Submission No. 997
(Inq into better support for carers)

Mr James Catchpole
Committee Secretary
House of Representatives Standing Committee on Family, Community,
Housing and Youth
PO Box 6021,
Parliament House,
Canberra ACT 2600

Dear Mr Catchpole

Submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers

Background

The Office of the Protective Commissioner makes substitute financial management decisions for people with disabilities. In accordance with the provisions of the Protected Estates Act 1983, the OPC can be appointed to:-

Manage the affairs of those persons who are not able to manage their own affairs and whose affairs have been formally committed to management by an order under the Protected Estates Act.

Authorise and direct performance of the obligations and duties of private managers appointed by the Supreme Court or the Guardianship Tribunal.

In 2007 the Protective Commissioner directly managed the affairs of 8,786 persons and authorised and directed the performance of 2,252 private financial managers. The people whose financial affairs are managed under the Protected Estates Act have been found to lack the necessary decision making ability due to a mental illness, brain injury, intellectual disability, psychiatric disability, developmental disability, dementia or other disability. The majority of our clients (44.8%) have a psychiatric disability. People with developmental disabilities are the next highest client group (20.7%) followed by people with dementia (15.6%) and brain injury (13.8%).

Many clients of the OPC rely on the support of carers to continue to live in the community. The OPC works closely with those carers to achieve good outcomes for clients who rely on their care.

care hours from care workers from a reliable agency, more skilled professional support when care needs increase, information about support options such as palliative care services at home, etc.

Recommendations

The OPC makes the following recommendations for consideration by the Standing Committee

- **Preventive intervention by supplying professional case management services to all carers.** Carers will frequently indicate that their resources are already so stretched through the demands of care that they do not have the time or knowledge to arrange for respite, day care or additional care services to which they might be entitled and to access information about the person's condition and how to better help them. We know that depression and carer burnout are common for carers who then become unable to advocate for their own needs and less able to provide good care. Hence case management is recommended for all carers as a preventive measure and to provide them with an advocate, ready source of relevant information and support and to monitor and coordinate assistance to meet the needs of both the carer and the person they support.
- **Increased respite and day care** options that will provide carers with a balance in the responsibility of caring. OPC has observed many situations where a carer has not received support through access to respite. This has contributed to the breakdown of the care relationship and is a contributing factor to placement into long term residential care.
- **Public awareness programs** aimed both at employers (more flexible work arrangements to support the worker and retain experienced workers) and at communities to challenge the assumption that health and support are individual or family matters, part of the private sphere and therefore not a matter for the community.

Conclusion

The OPC is pleased to provide this brief submission to the Inquiry. Should further information be requested Ms Meredith Coote, Assistant Director Disability Advisory Service will be available to assist and can be contacted via our main address.

Yours sincerely

Imelda Dodds
Protective Commissioner and Public Guardian

without any tangible reward 24/7 and with minimal support, is one end of a continuum of care arrangements, albeit the most in need of additional services and support.

Informal carers may also receive payment for care. It is not unusual for OPC to pay family members a wage for the care they provide. OPC also finds that some family members of clients had entered into agreements to provide care for their relative in return for free accommodation. These arrangements are in place when our clients come under management of the OPC and can include transferring the title for their property into the name of the carer in return for the care provided. Many informal carers also receive Centrelink payments in recognition of their care role –either the Carer Payment or supplementary payment, the Carer Allowance. Sometimes informal carers also elect to do part time paid work as care workers supporting strangers to remain independent in their own home.

It is not unusual for OPC to receive Financial Management orders which have been triggered by accusations or proven instances of exploitation or abuse of vulnerable people by their carers – both in the case of informal and formal care. The risk factors for abuse or exploitation by carers are well understood. The relationship between a carer and a person with a disability or a frail elderly person is an unequal relationship in terms of power because of the dependency of the person they support. The risk of abuse or exploitation by carers is greater because care activities are typically invisible - in the person's home away from the sight and support of others. Furthermore, providing care for a confused or highly dependent person is extremely stressful and can understandably provoke anger, depression and resentment in the carer that might lead to abuse in spite of the bonds between the two. On the other hand the care relationship and common scenario of confusion and distress in the person receiving care, includes the risk of abuse of carers by the person they seek to assist. The more support and sharing of the care role that can be provided to carers the lower the risk of abuse by or of carers and the earlier evidence of carer burnout will emerge.

OPC assists informal carers in a variety of ways including the provision of information that may assist them in their role, such as respite services, advocating for their needs and entitlements as carers, referral for additional services when needed, and assisting with professional needs assessments for their loved ones when their condition or circumstances may change, etc. OPC's role as described above thus differs little from the role of other agencies which assist carers, e.g., Aged Care Assessment Teams, hospitals, Disability Support Services (government and non government), community mental health services, etc. Yet OPC, by way of its substitute decision making role in regard to the financial affairs of its clients has additional functions in relation to carers:

- Employment of carers. The Office has a significant number of carers on its payroll – paid from the estate of the person they support. Typically such carers are parents of people with disabilities or spouses or children of people with dementia who may have sufficient funds to pay for their own care and who may be precluded, because of the size of their estate, from accessing low cost government funded services such as Community Options.
- Monitoring and assessment of needs of the person and the carer to identify when the carer may need more assistance in their role such as respite, additional

OPC deals with both formal (professional/paid) carers or care workers and informal carers (frequently family members who provide the care based on bonds of affection but may or may not receive recompense or remuneration for that role).

The OPC is also currently undergoing a restructure of its operations and we apologise for the somewhat brief nature of our submissions to your Inquiry.

In this document we will outline our experience with:
unpaid and informal carers – typically family
informal carers who are also paid
professional carers
We will also highlight the risks of abuse that can arise in all of the above. We stress that this does not occur in all cases but is a reality of our work.

Submission

From the terms of reference of this enquiry, only carers who do not receive payment for their caring activities are the subject of this enquiry. Therefore our comments will focus on that group in this submission. However before proceeding it is suggested that care in Australia should not be conceived as a dichotomy between formal and informal care but a continuum: the reality is that any Australian with a disability or who is elderly and frail, at any one time may well be receiving a combination of formal and informal care, often from a variety of sources. The following case example is illustrative. To preserve confidentiality aliases have been used
:
Mrs. Smith, a widow aged 80 who has dementia. Her 50 year old daughter Alice has recently moved back home to provide her with support at night and on weekends but works full time (and receives, as is her entitlement, the supplementary Carer Allowance from Centrelink. During the work week Mrs. Smith receives government subsidised support from care workers from an agency. This amounts to several hours per day as part of a Community Aged Care package plus some additional supplementary private (self funded) full fee for service care hours. Mrs. Smith's granddaughter, a student aged 20, also provides some support and supervision each afternoon during the week - in return receiving the Centrelink Carer Payment (equivalent to the Aged Pension. The man next door helps by putting out the rubbish and bringing it back in for her each week and another neighbour will drive Mrs. Smith and her daughter to the shops on Saturdays as Mrs. Smith has relinquished her car and Alice does not drive.
It falls to Alice to coordinate all these arrangements.
As her mother's condition worsens Alice becomes more stressed – her sleep is increasingly disturbed as her mother becomes more confused at night and requires frequent assistance to use the toilet, and she finds her social life has disappeared because she has no spare time to maintain or develop friendships. She accesses some respite services but these are limited given the great need for similar help by others and she occasionally contacts the Carers Association for emotional support. Despite all this she is aware that she will not be able to continue doing this indefinitely as the role is so stressful.

Thus the typical care scenario is a mix of arrangements and the stereotypical picture of one relative bound to the person by bonds of love and providing the care alone