



Review of the Community Services (Complaints, Reviews and Monitoring) Act 1993, Committee on the Office of the Ombudsman and Police Integrity Commission

Submission by Carers NSW

27 July 2007

Introduction

There are at least 750,000 carers in NSW. These are family members and friends providing care to people with disabilities, mental illness, chronic conditions or frail aged people in an unpaid capacity. Carers come from all walks of life, cultural backgrounds and age groups. They assist people with a range of activities including personal care, provision of transport, assistance with mobility and supervision. Carers are also often advocates for the people they support.

Carers NSW is the peak body representing the 750,000 carers in this state.

This submission to the Committee on the Office of the Ombudsman and Police Integrity Commission has as its focus the issues for carers of people with disabilities, mental illness and older people. The information used for this submission is primarily based on feedback received directly from carers using the range of services that Carers NSW provides and from the relevant research on caring.

To provide a brief snapshot of caring, of the 750,000 carers in NSW¹:

- 150,000 (20%) are primary carers, meaning they provide the majority of support to someone;
- 90,200 (12%) are young carers (aged under 25);
- 135,000 (18%) are ageing carers (aged 65 and over);
- 76% are workforce age;
- 45% of primary carers spend 40 hours or more caring each week;
- 64% of primary carers and 45% of all carers are not in the labour force.

The Community Services (Complaints, Reviews and Monitoring) Act 1993

The Community Services (Complaints, Reviews and Monitoring) Act 1993 (the Act) relates to the provision of community services, Official Community Visitors, the Ombudsman and the Administrative Decisions Tribunal.

The Act has seven key objectives (Appendix 1) pertaining to complaints, reviews and monitoring of community services, including services provided by the Department of Disability, Ageing and Home Care (DADHC), government funded service providers and the Home Care Service of NSW.

The Act affects many carers who act on behalf of, and advocate for, their relatives and friends with disabilities who access services.

Overall Carers NSW supports the objectives and the terms of the Act. This submission raises some particular issues that carers have raised with Carers NSW which may lead to more effective outcomes to emerge from this legislation and its functions.

Key issues for carers affecting the objectives of the Act

There are a number of issues that carers advise Carers NSW of which may have implications for the objectives of the Act.

Carers NSW receives a high volume of calls from carers who have complaints about services that fall under the jurisdiction of the Act. These complaints generally fall into the following categories:

- Gap in services or inappropriate services being delivered
- Unreliable or inconsistent service provided
- Negligence or abuse of the person with a disability by the service provider

¹ ABS (2004) Survey of Disability, Ageing and Carers 2003: NSW Tables, Australian Bureau of Statistics, Canberra.

For example Carers NSW² was recently contacted by a carer of her twenty-one year old daughter with severe disability to complain about a service. The carer was concerned that the level of host family respite they were receiving had been reduced dramatically following a case conference with the Department of Ageing, Disability and Home Care. The carer followed the complaints procedure and continued discussions with both the service provider and the Department but expressed to Carers NSW that the process had caused great stress to the family and detriment to her husband's (also a carer) health, and they had not achieved a successful outcome.

Many people with disabilities and their carers, although knowledgeable of complaints procedures and mechanisms, are fearful to make complaints about the services they receive. This occurs for a number of reasons including fear of retribution from the service provider, fear of withdrawal of service and in rural and remote areas particularly knowledge that there are no alternative services available can render making complaints pointless in the view of many people.

These factors are further exacerbated by high demand for disability services in many areas leading to long waiting lists and difficulty accessing services. As a result many people with disabilities and their carers are reluctant to complain knowing the difficulty involved in accessing services.

The complaints process can be complicated for consumers and their carers by the funding structures of the services and programs they access (in particular the mix of Commonwealth and State funded services). In addition complaints are often generated by issues that fall between the gaps of different service systems – eg the health and community care systems.

Many of the complaints that carers raise are generated by systemic issues such as lack of funding to provide appropriate levels of service and high cost of services to the consumer.

There are also many people with disabilities and their carers who are unaware of complaints procedures and their rights in terms of service delivery and making complaints.

There is some evidence³ that carers from culturally and linguistically diverse (CALD) backgrounds are less likely to both access services and voice concern about services received. Some explanations for this include stigma and prejudice surrounding disability and notions of entitlement and citizenship rights meaning that carers from CALD backgrounds may be inclined to accept services the way they are and not want to burden the service system.

Carers NSW is aware of some issues relating to complaints mechanisms and Aboriginal and Torres Strait Islander (ATSI) service users. In particular ATSI service users and carers can be reluctant to make complaints particularly to Aboriginal-run services where the family may have close links in the community with the service provider. While ATSI people are more likely to use community services than the general population, the disability rate for ATSI people is 2.4 times that of the general population⁴ and literacy rates are low considering that ATSI people are only half as likely as non-ATSI people, to complete Year 12 (18% compared with 45%)⁵. Therefore ensuring access by ATSI people to the complaints procedures covered by the jurisdiction of the Act should be of fundamental importance in considering its objectives and terms.

In light of these diverse issues for CALD and ATSI carers the approach taken to resolving complaints made by these service users may be different from that of mainstream service users. Indeed the approach taken to identifying complaints or issues with services may also vary.

Therefore the complexity of issues that lead to complaints by people with disabilities and their carers create a challenge for the objectives of the Act and the terms to meet those objectives.

² March 2007.

³ Cardona B, Chalmers S, Neilson B (2006) 'Diverse Strategies for Diverse Carers: The cultural context of family carers in NSW, Centre for Cultural Research, University of Western Sydney for the NSW Department of Disability, Ageing and Carers.

⁴ AIHW (2006) Disability Support Services 2004-05, National data on services provided under the Commonwealth State/Territory Disability Agreement.

⁵ ABS (2007) Census of Population and Housing, Australian Bureau of Statistics, Canberra.

Conclusions

Based on the feedback and contact that Carers NSW has with carers who have poor experiences with quality of services and sometimes even experience concerning neglect or abuse of the person they support by service providers, the effects on carers are clear.

Where complaints are unresolved, unaddressed or drawn out for long periods of time the service user and their carer may go without adequate services or any services at all. From the carer's perspective this can result in withdrawal or reduction of hours from the workforce, in high costs of alternative services or in an increase in the level of care provided by the carer.

There is now ample evidence to demonstrate that carers experience poorer health, wellbeing and financial outcomes overall than the general population⁶. Therefore any legislation that impacts on services that can improve outcomes for people with disabilities, mental illness and older people should recognise the positive impacts these services can have on carers.

The complaints process itself can be stressful and lead to poor health outcomes for carers, particularly those who are ageing themselves or who have disabilities themselves. While many people with disabilities and their carers are successful in improving services through the complaints procedure this submission to the Committee on the Office of the Ombudsman and Policy Integrity Commission has raised the issues that many carers experience presently relevant to this review.

Carers NSW recommends that the Committee assesses the relevance of the Act and its objectives in relation to the key issues that have been raised in this submission:

1. The changing environment of increased pressure on community care systems for people with disabilities, mental illness, older people and their carers.
2. Complex funding arrangements for the provision of services which may place many community services outside the jurisdiction of the Act.
3. Specific issues pertaining to CALD and ATSI service users and carers where objectives of the Act may be difficult to achieve.
4. Regional issues, particularly in rural and remote parts of the state, where service users have no choice of service provider.

Currently there is no legislation or policy in NSW which stipulates the rights of carers or responsibilities of government in relation to carers and community services. A NSW Carer Act or Charter would enable clearer guidelines for carers in regards to making complaints on their own behalf concerning service delivery.

Currently Queensland, South Australia, Western Australia and the Australian Capital Territory all have, or are in the process of developing carer legislation. Carers NSW recommends that the NSW government work towards introducing carer legislation and a carer policy that complement the existing NSW Carers Action Plan 2007-2012.

This submission has provided a brief overview of the issues that carers have raised with Carers NSW. Upon request by the Committee Carers NSW will be willing to provide further information if required.

⁶ See for example AIHW (2004) Carers in Australia: Assisting frail older people and people with a disability; Schofield et al (1998) Family Caregivers: Disability, illness and ageing', Allen and Unwin.

Appendix 1

(1) The objects of this Act are as follows:

- (a) to foster, in community services and programs, and in related services and programs, an atmosphere in which complaints and independent monitoring are viewed positively as ways of enhancing the delivery of those services and programs,
- (b) to provide for the resolution of complaints about community services and programs, especially complaints by persons who are eligible to receive, or receive, those services, by families and by persons advocating on behalf of such persons or families,
- (c) to encourage, wherever reasonable and practicable, the resolution of complaints at a local level,
- (d) to encourage, wherever reasonable and practicable, the resolution of complaints through alternative dispute resolution,
- (e) to provide independent and accessible mechanisms for the resolution of complaints, for the review of administrative decisions and for the monitoring of services, programs and complaint procedures,
- (f) to encourage compliance with, and facilitate awareness of, the objects, principles and provisions of the community welfare legislation,
- (g) to provide for independent monitoring of community services and programs, both generally and in particular cases.

(2) The following principles must be observed in exercising functions under this Act:

- (a) the paramount consideration in providing a service for a person must be the best interests of the person,
- (b) a person who is eligible to receive, or receives, a community service is also to receive an adequate explanation of the service, is to be heard in relation to the service and may question decisions or actions that affect the person in relation to the service,
- (c) a service provider is to promote and respect the legal and human rights of a person who receives a community service and must respect any need for privacy or confidentiality,
- (d) a service provider is, to the best of his or her ability, to provide such information about the service as may enable an appropriate decision to be made by the person for whom the service is, or is to be, provided,
- (e) a service provider is to enable a complaint about the service to be dealt with fairly, informally and quickly and at a place convenient to the complainant,
- (f) a complaint about the provision of a service is to be dealt with even if it is made by another person on behalf of the person eligible to receive, or receiving, the service.