Auditor General's Report, No 3 of 2009

The ACT Community Living Project Inc (CLP) believes that the Auditor General's Report is a valid assessment of the situation with government provided respite care in the ACT, given the time available for the audit, but the Report's conclusions under-emphasise the systemic failure behind management of respite services in the ACT.

In regards to private and non-government respite: CLP is not aware of any mechanism for families to obtain information about whether private and non-government agencies delivering respite services meet the National Disability Service Standards, nor is it aware if any of this information is made public.

CLP believes that a similar, rigorous audit should be completed for all non-government agencies providing respite services to enable families and the community to have confidence in the quality of services delivered to people with a disability in the ACT.

Supporting people with a disability (Chapter 3)

CLP agrees that it is imperative that DACT's policies and procedures clearly reference the National Disability Service Standards (NDSS) and that these standards be a practical and ongoing element of DACT's day-to-day activities. CLP notes with concern that the audit found that support staff working in government respite houses were aware of the NDSS but feel that it is not relevant to the services they provide to young people under their care.

CLP has an interest in what changes DACT will make to bring the required improvements into effect. We note that DACT has given an undertaking to "promote" the relevant policies and procedures on the DACT website (for use also as a template for the use of community providers). The policies and procedures are not yet on the website despite the fact that the audit was completed almost 12 months ago. This may be because DACT advised Audit only that it would "consider" making its policies and procedures more widely available to the general public (see 3.22).

Access, eligibility and priority (Chapter 4)

CLP believes that the eligibility criteria for specialist disability services should be defined in the ACT *Disability Services Act, 1991*, as it is in most other jurisdictions. CLP asks that the ACT Government give this serious consideration.

Further, it is imperative that DACT formalise procedures and guidelines used in assessing an individual's eligibility for services. Based on the experience of CLP families, we believe that the lack of formal standards, procedures and guidelines in respite care is at the heart of the poor performance of DACT highlighted in the report.

CLP believes that the inconsistent and fragmented record keeping by DACT noted in the audit report, is a critical safety issue for respite care clients in the ACT. Relying on the accumulated corporate knowledge of key staff is inherently dangerous in a service providing critical care to young people with a disability (see also below in Management of respite care services).

We note that DACT relies on the Registration of Interest as the mechanism for compiling demand for services. We believe that this is inadequate given that it is well known that

services are in short supply and a severe funding shortfall exists. People may be dissuaded from registration in the belief that services are not available (and this may be evidenced by the limited number of names on the register). We believe that it would be more meaningful for DACT to register people at the time they are diagnosed with a disability. In this case, most would be registered when they are born or within the first three years of life.

CLP notes DACT's undertaking to review and enhance record-keeping and associated refresher training to ensure consistent procedures and service delivery. This is an essential first step but we believe it will be ineffective without improved management and supervision in the department.

Management of respite care services (Chapter 5)

CLP believes that the audit of Respite Care Plans (RCP) for a sample of clients shows a systemic failure of management in DACT. We note that 66% of files did not have a current RCP in place and 71% did not have up to date consent forms. Many files had not been updated since 2003 or 2005. Most files lacked visit records, file notes, progress notes and even essential information about medical history. We regard this as a gross failure at all levels of management and supervision in government respite houses.

CLP also believes that inconsistencies in record-keeping practices between the four government respite houses is a critical problem for staff moving between respite houses (particularly for casual or new staff) and this puts the clients at risk.

We note with alarm the Auditor-General's comments about the failure of DACT to manage its respite clients' risks effectively, particularly when more than one-third of all incidents are not reported on a timely basis and some not recorded in Riskman at all. Given the problems noted with record keeping and completion of communication books, the precise level of incidents would be difficult to ascertain. The audit report notes that DACT reported almost 11 incidents per month across four centres with an average 2 per month being critical. With little risk assessment, poor record keeping and inconsistent practices and procedures, parents and carers of young people with a disability are understandably concerned about the risks to their children in DACT's care.

We note DACT's undertaking to improve its risk management processes, including the timeliness and reporting of incidents. However, we believe that the failure of senior management in DACT to recognize the critical nature of proper record keeping is reflected in the non-compliance of staff with policies, procedures and practices – i.e., the failure to keep individual records, risk management assessments, incident reporting, medication and client alerts etc.

Likewise the training of staff also relies for its effect on proper management and supervision in the department. We believe that the best training will be ineffective unless senior management are checking that training requirements are understood and implemented, reviewed and updated – and that there are consequences for non-compliance.

CLP notes that DACT has sound practices for managing complaints to the Minister and the Human Rights Commissioner. However, CLP's experience is that DACT does not have an effective management system for handling complaints from clients or carer

families. CLP families report that their complaints are dealt with in a cavalier fashion, if at all.

DACT noted in its response regarding the Auditor-General's recommendation about implementation of a Quality Management Framework and Quality Improvement System (Recommendation 12) that quality management processes were introduced in the department following an inquiry in 2000. The last six-monthly government report about the implementation of the inquiry recommendations was released in September 2004. We believe that the systemic failure evident in the Auditor-General's report only 5 years later (May 2009) gives no comfort that improvements will be effected following this review.

CLP notes that the audit did not review the respite care services provided by non-government organizations outsourced by DHCS. However, the experience of CLP families is that management arrangements with DACT's service providers appear to be equally deficient. CLP notes that DACT has not conducted any reviews under the annual self-assessment process since mid-2006 and, on the current rate of review, providers would be reviewed only every 8 years. We regard this situation as extremely high risk and it is a real concern to CLP member families.

Assessment of the performance of respite care services (Chapter 6)

CLP agrees that access to respite services in the ACT has not increased proportionately to meet the demand for services, in recent years. However, we believe that DACT does not have a clear view of the level of real unmet demand and it also seems to be largely ineffective in influencing government for increased funding (see Unmet Need below).

The Needs of Care Recipients

CLP notes that 26% of 386 clients and carers (about 100) responded to the DACT's client satisfaction survey in 2007 – and that they recorded an overall satisfaction level of 85%. CLP believes this is a very unflattering result given the level of unmet need in the ACT - evidenced by the fact that the Australian Institute of Health and Welfare (AIHW) has projected that 20,600 people in the ACT live with a severe or profound core activity limitation. The low level of engagement with the department is a worrying situation.

In early 2009, CLP undertook a survey of the needs of families in the ACT known to be caring for a person with an intellectual disability. The survey was sent to about 500 families in the ACT and 250 responded (a response rate of 50%). Given that many people receiving the CLP survey were not in a position to take advantage of the "urban village" concept, it shows that families who need services are keen to engage with those seeking to help.

About 12.5% of respondents to the survey were currently seeking accommodation options for a care recipient and about 60% said they would be seeking supported accommodation options in the next 10 years, as both carer and care recipients age.

The survey showed that there is a high level of supervision needed for most care recipients in the survey group. About 85% of those in the survey group needed moderate, high or one-on-one supervision. Many need ongoing assistance with communication.

Almost all the care recipients included in the survey are still living in their family home. Respite services provide much-needed support to carer and care recipients alike.

The Needs of Staff who provide Respite Care

CLP acknowledges that respite care staff often provide services in a difficult environment. However, the failure of DACT to provide appropriate processes and procedures, risk management systems and proper record keeping would make their task additionally difficult and stressful.

We believe also that inconsistencies in record-keeping practices between the four government respite houses is a critical problem for staff moving between houses (particularly for casual or new staff) and this puts the clients at the centres at risk.

CLP believes that respite care staff need a high level of training and support and they need to be backed up by processes that ensure a high level of professionalism and safety. CLP acknowledges that staff turnover is a critical issue for respite services and one that requires proper funding and professional back-up from the department.

Range, Availability and suitability of Services, including Unmet Need

CLP agrees that the level of respite services in the ACT is far below those provided in other states and that DACT has been unable to keep up with the demand for these services in the ACT.

The audit report noted that funding for all disability services in the ACT is not sufficient to meet demand. Only $2.8 million was granted in 2007-08 from applications amounting to $11.1 million (25%). The shortfall in funding of $8.3 million represents the amount of "known unmet demand".

The audit report noted that AIHW has estimated that in 2010, 20,600 people in the ACT live with a severe or profound core activity limitation.

We noted above that DACT's reliance on the registration of Interest as the mechanism for compiling demand for services is inadequate given that it is well known that services are in short supply and the funding shortfall was over $8 million (in 2007-08). We believe that it would be more meaningful for DACT to register people when they are diagnosed with a disability of the sort that meets the NDSS criteria.

This would provide DACT with a better understanding of unmet support needs in the ACT and put them in a better position to influence government in decisions about future funding.

Interaction between Government and Non-Government providers

CLP has no comment to make on the interaction between government and non-government respite care providers other than to note that, as far as possible, the care

experience and the level of safety and professionalism should be largely identical in both systems. Any move between one type of provider and another should feel seamless to the user.

CLP also notes the complex relationship between DACT and the Non-Government Accommodation Support Providers where the department is both a regulator of the non-government providers and a supplier of services (effectively in competition to the private providers). Proper separation of these roles in DACT is essential. DACT is able to have a major influence on the viability of the non-government support providers both through its regulatory role and the fact that the private providers rely on DACT for all or most of their funding.

The Experience of Service Users

CLP families have extensive experience as users of government respite services. Some families report that the government respite service is unsafe, unsuitable for individual needs, unwieldy and not worth the effort. Meal preparation is poor and there is no medical supervision available. An unwieldy system is in place that requires families to speak to DACT managers and not directly to respite centre staff.

Many families don't use the government respite service because there is little social interaction and limited opportunities for residents to be gainfully occupied during their stay. This view accords with the view of the auditors that government respite services meet basic care needs of clients but are unlikely to enhance their experience and quality of life (5.86).

The experience of users of the non-government respite providers has been highly varied depending on the commitment and professionalism of those providing the service. Some CLP families report a high level of care in a long-term relationship between a care recipient and a provider and others have reported alarming breaches of duty of care and of safety. Unfortunately, there have been injuries and at least one death of a care recipient in the last few years in the ACT, while in the care of a private provider.

Conclusion

CLP is a group of families who have come together seeking supported accommodation for a family member with a disability; it exists because of the lack of adequate care for these family members. CLP believes that if more respite, in-home support and disability services were available, there would be less call for supported accommodation in the short term. The current urgent need for supported accommodation could be alleviated, at least in part, by adequate levels of safe respite and in-home care (see *"Who Cares ….?"* by the Standing Committee on Family, Community, Housing and Youth, 2009)

CLP views the current situation with respite care in the ACT highlighted in the Auditor-General's report, with some alarm. CLP families believe that the lack of formal standards, procedures and guidelines in respite care in the ACT is at the heart of the poor performance of DACT highlighted in the report.

CLP believes that the inconsistent and fragmented record keeping by DACT noted in the audit report, is a critical safety issue for respite care clients in the ACT. Relying on the accumulated corporate knowledge of key staff is inherently dangerous in a service providing critical care to people with a disability.

Further, CLP believes there has been failure at all levels of management and supervision in government respite houses in the ACT. CLP notes the things that DACT has agreed to do to rectify the situation but we believe that improved management and supervision in the department is essential to make for lasting change.

Given that an inquiry was held in 2000 following the deaths of 3 people in government care, how can families be assured about Disability ACT's ability to provide adequate care for their family member when the 2009 report is equally damning? The last six monthly government report about the implementation of the inquiry recommendations was released in September 2004. We believe that the systemic failure evident in the Auditor-General's report only 5 years later (May 2009) gives little comfort that improvements will be effected following the Auditor' review.

What genuine changes and improvements are DACT going to make that will have lasting benefits to clients and their families?

CLP families are seeking three main things for their family members with disability – a place to live that they can call 'home 'when their family can no longer care for them, meaningful things to do each day, and adequate and timely medical and dental services.

Just an ordinary life.

Our plea is summed up in the following paragraph:

"We live in one of the wealthiest countries in the world and yet all too often people with disabilities struggle to access the very necessities of life—somewhere to live, somewhere to work. All too often they are unable to access education, health care, recreation and sport—the very things most people in the community take for granted. They are denied access to kindergartens, schools, shopping centres and participation in community groups. They are often isolated and alone. Their lives are a constant struggle for resources and support." (Rhonda Galbally, **Shut Out: The Experience of People with Disabilities**, 2009, Preface)

CLP is currently conducting a feasibility study about establishing an 'urban village' living environment providing supported accommodation, training, employment and lifestyle options for people with moderate to severe intellectual disability, many of whom also have physical and/or health challenges. Many families in Canberra would like to be able choose such an option for their family member with a disability, when they can no longer care for them in the family home. A Concept Plan which details this option is attached for the Committee's information.

CLP Executive members would like the opportunity to discuss these issues further with Standing Committee members, if this can be arranged.