Public Advocate of the ACT (PA ACT) Response to
ACT Inquiry into Respite Care Services
Standing Committee on Health, Community and Social Services

1. Introduction

The Public Advocate of the ACT (PA ACT) has been approached by the Standing Committee on Health, Community and Social Services to make a submission to the Inquiry into Respite Care Services.

The Public Advocate Act 2005, Section 10, outlines the functions of the PA ACT, which include acting as advocate for the rights of people with a disability, children and young people, fostering the provision of services and facilities for them and encouraging the development of programmes. We also represent people with a disability at hearings before the ACT Civil and Administrative Tribunal (ACAT). In relation to children and young people, the PA ACT monitors the provision of services for their protection.

The PA ACT has a key role in advocating for service improvements as a result of our responsibilities in individual and systemic advocacy and in providing guardianship services for individuals with a decision making disability. In light of these functions and in representing the 'best interests' of our clients we are well placed to identify some of the service issues which exist in regard to the provision of respite care.

2. PA ACT support to Auditor General Recommendations

The PA ACT has reviewed the ACT Auditor General's Performance Audit Report on the Management of Respite Care Services, May 2009 and supports the recommendations put forward for practice improvement. The performance audit identified a number of issues regarding access to respite care services, the quality of respite services when compared with national standards, accountability and governance frameworks and the measurement of needs and demands.

It is concerning to the PA ACT that respite care services in the territory only met clients' basic needs for safety and respite care, and that accountability structures were not adequate for records management, client information systems, risk management and quality performance management. These areas are critical for continuous service improvement processes.

The PA ACT does not seek to duplicate findings or recommendations made by the Auditor General. The focus of this response will be given to key issues or concerns which have come to the attention of the PA ACT as a result of the statutory responsibilities associated with advocating for the rights and best interests of vulnerable people within the ACT community.

3. Developing a clear understanding on the meaning and role of respite.

Consultation within the Office of the Public Advocate has shown that there can be different interpretations about respite care and the purpose or role. These can impact upon access to services and ongoing development. It would also seem that in the ACT the families and clients must fit into or accept what respite is currently available. A more optimal approach would be a raft of service options that take into account the interface and connection between the needs of the client and those of the family and how these priorities are determined/and or responded to.

To address these dilemmas it is important that individual needs are clarified through a comprehensive assessment which considers the requirements and wishes of the individual client and their carer and the best type of respite that suits both parties. Clarification and dialogue about the meaning of respite and what it entails is essential in facilitating access to services which are relevant and match needs.

Research conducted overseas indicates the mismatch in views between carers and professionals about respite care which impacts on carers' being able to access services that meet their needs.[1] In the development of optimal respite care in the territory it is important that there is a clear and shared definition of the meaning of respite care and how it is to be delivered so that both the client and carer have greater choice.

The adoption of common assessment tools for use across the sector would assist with this. It is understood the Department of Disability, Housing and Community Services in its Strategic Priorities for Disability Services 2009-2014, (Priority 5: "I want to tell my story once"), is considering some mechanisms regarding the collection of baseline needs assessment information.

4. Adopting positive terminology- "short breaks"

The PA ACT is of the view that the term "respite care" can be stigmatising and can carry some negative connotations. For example, carers can feel that accepting respite support implies they are not coping and or are failing in some way, or suggests that their loved one is a burden. The PA ACT would support the use of the term "short breaks" in preference to "respite care", as

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[1] Mansell, I & Wilson, C. (2009). Current perceptions of respite care: experiences of family and informal carers of people with a learning disability, *Journal of Intellectual Disabilities*, Vol. **13**, No. 4, 255-267

this does more to normalise having these supports in place. Overseas trends do suggest some movement away from this terminology, this being evident in the United Kingdom for children with complex heath needs and disabilities [2] and in Scotland as part of their National Care Standards for adults where respite and short breaks are required. [3]

5. Need to increase knowledge of respite care options and early access

Increasing knowledge about what resources are available to carers is foremost to improving access. It is acknowledged that Commonwealth Respite and Carelink Centres exist and that Disability ACT provides a centralised information service to assist in the provision of information to families about options in the community and where and how to access respite.

These are positive developments in facilitating information being available to the broader community about services although additional strategies could be utilised for distributing material such as brochures and information leaflets being located in community centres, doctors' surgeries, libraries, on relevant websites and so forth, if this is not already occurring.

The PA ACT has been contacted by school counsellors (both government and private) about respite supports for young people with mental health issues and other disabilities, where parents have come to them for assistance. These may be families that have not previously been part of the formal service system, and hence are not involved with disability or child protection services, or Child and Adolescent Mental Health; they have generally been managing in the community with little support, or relying on family or friends.

The availability of respite support for families at the early intervention phase is often critical in assisting to prevent escalation of crisis within the family. For example, the PA ACT is notified by the ACT Children's Court Magistrate when a criminal proceeding for a young person is adjourned for 15 days, allowing further assessment of care and protection issues. In our last reporting period, the PA ACT received 22 referrals of this nature. The lack of early intervention supports, which may include forms of respite, has on several occasions become evident when the history of the case is reviewed.

A family may have been struggling to manage the challenging behaviour of their child for sometime and it may only be at the point of crisis that supports are offered. Some families have expressed to the PA ACT they didn't know where to go for help. Identifying families and children early on, where respite supports may be required, is significant and may enable families to manage better in the longer term.

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[2] Social Care Institute for Excellence. (2008). Children's and Families Services SCIE Guide 25, Having a Break: good practice in short breaks for families with children who have complex health needs and disabilities.

[3] Scottish Executive. (2005). National Care Standards, short breaks and respite care services for adults.

6. Supply not able to match demand

It is the reality for many clients and families that they are simply unable to obtain the level of respite they require due to specified funding allocations and limitations in respect of how much service they can access. This is not a new issue; current supply is not able to match increasing demands.

Obtaining funding through the Individual Service Plan process, as required by Disability ACT, can be a difficult process for clients to manage. Clients have expressed to the PA ACT their frustration with the system in trying to access respite care, and the difficulties surrounding the complexities of applying for funding. The process of applying for funds can only occur when new funds are made available through annual government budgets.

There may be families and individuals who do not meet the threshold or criteria as they are not considered the greatest priority for allocated ISP funding although they still require support. How can respite care service provision in the territory still ensure some support for these families?

Families too have expressed frustration and recounted their experiences of having to contact multiple agencies to see if they could obtain assistance when they needed it. The need to contact numerous agencies may in some ways be minimised by linking with the major brokerage agencies that purchase the services on behalf of clients. The negative aspect of funding such agencies is the degree to which available funds are eroded through administration fees charged by the brokerage agency and the agency from whom the services are being purchased.

The lack of supply and shortfall in available respite services was brought to the Inquiry undertaken by the House of Representatives Standing Committee on Family, Community, Housing and Youth- Who Cares...? which focused on better support for carers. Carers felt services are inadequate, in short supply and are not meeting their needs to the level required.[4]

The PA ACT advocates for additional funding for respite care where this is possible, but also seeks that there be broader consideration of different types and models of provision within the community, which may have cost benefits as well as being able to better meet the individual needs of clients and families who seek assistance.

7. Further exploration of alternative funding options

Due to finite budget allocations, further exploration could occur regarding the pooling of government funds with funding from the community, particularly from private and philanthropic organisations. The Public Advocate would like to see additional private companies and corporations come together working

[4] House of Representatives Standing Committee on Family, Community, Housing and Youth. (2009) Who Cares ...? Report on the inquiry into better support for carers, The Parliament of the Commonwealth of Australia

with government and community agencies in delivering and sharing in the development of additional respite care options in the territory.

Respite care is not just a government responsibility; it is a whole of community responsibility, only achieved through strong and resilient partnerships between government, service providers and the corporate sector. The PA ACT understands that Disability ACT has worked on strategies of this nature, which is commendable. The PA ACT would support further scoping of opportunities with insurance companies and other private corporations in providing additional contributions towards the overall funding mix for respite care.

8. Rethinking respite care and developing flexible alternative models

It is noted that Disability ACT operates respite in residential group homes for clients with a disability. This option may be the only one available for a family, although it may not ideally match the needs of the client or the family.

For example due to eligibility criteria, limited availability and high demands for the service a family may just have to accept whatever weekends or weeks in the year they are offered, no matter how inconvenient or unsuitable, or forgo the service altogether. This may afford the family limited or no choice in meeting their individual needs. The model of residential care, whilst it may offer some benefits for an organisation, may not ideally match client and family needs.

The PA ACT understands that non government agencies in the territory provide different forms of respite such as home based provisions and that their focus is on meeting individual goals, needs and requirements. The PA ACT would like to encourage and support the further development of additional alternative models or programmes of this nature which introduce more choice and personalisation of care.

Some years ago a programme existed in the territory where clients with a disability were taken on holidays for 1-2 weeks. This programme is no longer funded but is an example of thinking more creatively about how respite care can be provided. The existence of a dedicated programme, rather than a system allowing ad hoc purchases of holidays, meant that holidays could be specifically designed around the particular needs of clients, in the company of carers with appropriate and relevant skills and experience, and in a way which allowed for relationships to be built with providers, enhancing both the quality and the cost-effectiveness of the holiday.

Alzheimer's Australia highlights the need to have a supply of respite services that are "better attuned to the needs of people with dementia and their carers" and are flexible which means choice when respite is available, where it occurs

and having the choice in activities so that community engagement and social networks can continue.[5]

Material reviewed from overseas jurisdictions also suggests that service reform is towards more innovative forms of respite. The National Care Standards in Scotland include a variety of options from specialist guest houses, breaks in respite units or in care homes, breaks in the home of another individual or family who have been recruited to undertake this work, breaks in the client's home, holiday breaks, and supported breaks together for both a client and their carer. [6]

9. Scoping opportunities via cross-border arrangements.

With the move towards nationally-consistent assessment frameworks and quality assurance systems the potential for innovative options, particularly with bordering NSW communities should not be discounted.

Where appropriate, and providing relevant agreements or working arrangements are developed, there may be potential for enhanced service delivery through the development of cross-border agreements. Formalised cross-border arrangements are in place concerning Canberra Hospital and child protection interventions. There may be untapped opportunities which could be explored regarding respite care. The PA ACT however would want to ensure evidence of ongoing monitoring of service standards and that agencies providing a service are accountable for this.

10. Need for monitoring, compliance and regulatory framework

Some of the findings from the Auditor General suggest a lack of accountability and oversight on the daily operations of respite services by Disability ACT even when policy and procedures may have been established eg risk management frameworks, processes for review and management of Individual Respite Care Plans.

In addition to internal review processes of Disability ACT, there perhaps is a need for improved external compliance monitoring of specific aspects of respite care services. This should be separate to complaint management processes which involve the Disability Commissioner or Ombudsman and reporting arrangements established under the Commonwealth States and Territories Disability Agreement CSTDA.

The development of regular statutory oversight mechanisms aimed at informing continuous improvement strategies should be a priority. There may be future scope for the Public Advocate to have some responsibility in this area, particularly as this office has statutory oversight roles in child protection, youth justice and with mental health services in the ACT. The PA ACT

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[5] Warwick, B & Howe, A. (2009). Respite Care for People Living with Dementia "It's more than just a short break," Discussion Paper 17, May, Alzheimer's Australia.

[6] Scottish Executive. (2005). National Care Standards, short breaks and respite care services for adults.

however would need to have the resource capacity to undertake any additional compliance monitoring role and this would have to be agreed by government.

Alternatively consideration could be given to the introduction of an Official Visitor Scheme for disabilities and the aged to visit group homes and respite establishments within the ACT.

The PA ACT would also want to ensure there be some direction of additional resources towards the monitoring and review of service provision by non-government agencies. The aged care sector has accreditation frameworks in place however, it would appear there is need for a more comprehensive regulatory system in the territory to ensure that funded services are adequately meeting National Disability Standards and expectations required in funding agreements.

Agency self-assessment processes, it is understood, are utilised along with a periodic independent review of the service provider's performance. The PA ACT would ideally like to see an increase in the capacity of Disability ACT to monitor these service providers. The monitoring of respite services and care standards needs to be prioritised. If insufficient attention is given to this area there may be adverse outcomes regarding the care, safety and wellbeing of clients.

11. Case Coordination for complex cases

Clients with complex support needs often have a number of agencies working with them, some of which may be providing some form respite care. If there are different agencies involved with a client, it is essential that case coordination and case management processes are in place otherwise roles and responsibilities can blur and communication between agencies may become problematic. There could also be multiple assessments and duplication of services.

The PA ACT coordinates the Management Assessment Panel (MAP) which is a service to facilitate the coordination of care planning and service provision for members of the community whose complex service needs are poorly coordinated or not adequately met.

Through the MAP process, the PA ACT has evidence of the lack of coordinated provision and case management for referred clients and how this adversely impacts on client outcomes. It is therefore important that where a client's plan involves a number of agencies providing different forms of respite care that this be coordinated and those agencies are kept on track with their responsibilities under the client's individual plan. Identifying a lead agency is critical to this process.

12. Work force and human resource issues

Workforce and human resource issues continue to impact on the service provision in this area as identified by the Auditor General. Collective strategies involving agencies and government are required to deal with the ongoing concerns regarding the recruitment of quality and experienced staff and their ongoing training and support.

13. Best practice and high standards of excellence

The Public Advocate supports that the standards for service delivery must be best practice and of a high standard of excellence. Policy frameworks need to be clearly benchmarked against national and international expectations, standards and trends. Service delivery must be in accordance with these contemporary practice standards and directions.

For example Scotland has developed policy material such as the "Guidance on Short Breaks (respite)" which assists community providers improve respite services for both adults and children in accordance with principles such as improving planning, moving towards preventative support and personalising support options for clients and carers.[7] Comprehensive policy development of this nature is aimed at facilitating best practice.

14. Research and evaluation

In developing optimal services which are achieving the positive outcomes with clients and families it is important that consideration be given to undertaking further research across the territory to ensure services are matching client requirements and that there is a clear understanding on what service structures are needed. It is also imperative that some evaluation framework be put in place so that performance outcomes can be measured.

15. Conclusion

I thank you for the invitation to provide a submission to the Inquiry into Respite Care services. The Public Advocate is committed to working with government and service providers in collaboration and partnership so that respite care services and disability services more generally are optimal and provide quality and high standards of care to meet the needs and requirements of clients.

Findings from the Auditor General indicate the need for more robust and comprehensive policy development, adherence to risk management processes, improvement in communication with staff, and better case management process for clients and more robust record management. These recommendations may be relevant to the sector as a whole.

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[7] Scottish Government. (2008). Guidance on Short Breaks (respite), Community Care Circular CCD 4/2008.

The PA ACT advocates for a whole of government and community approach in the ongoing improvement of respite care in the territory. The best outcomes, it is believed, will only be achieved in a policy environment which promotes interagency partnerships, shared commitment and ownership.

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