

Submission
No 98

**INQUIRY INTO SERVICES PROVIDED OR FUNDED BY
THE DEPARTMENT OF AGEING, DISABILITY AND
HOME CARE**

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The Benevolent Society
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Contents

1. Introduction	1
1.1. About The Benevolent Society	1
2. The extent of unmet need	3
3. Variations in waiting lists	4
4. Client funding arrangements and client-focused service delivery	5
5. Program evaluation	7

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1. Introduction

Thank you for the opportunity to make a submission to the inquiry into services provided or funded by NSW Ageing, Disability and Home Care (ADHC).

Our submission focuses on the need to allow services more flexibility in how they meet people's needs, preferences and choices. This would include ADHC adopting a more outcomes-focused approach to its funded services.

1.1. About The Benevolent Society

The Benevolent Society is Australia's first charity. We are a secular, not-for-profit organisation working to bring about positive social change in response to community needs. Since 1813, we have identified major social challenges and worked to meet them head on.

Our purpose is to create caring and inclusive communities and a just society. We deliver leading edge programs and services, find innovative solutions to complex social issues and advocate for a more just society. We take pride in delivering effective services and are constantly looking for new and better ways of working. We help the most vulnerable people in society, and support people from all backgrounds including Indigenous Australians and people from culturally and linguistically diverse communities.

The Benevolent Society runs a number of community-based services in metropolitan Sydney funded by ADHC that support older people, people with a disability and their carers. Through the Home and Community Care (HACC) program this includes domestic assistance, respite care, food services, centre-based day care, case managed brokered services (Community Options) and social and peer support programs. We also receive funding through the Disability Services Program to provide respite for older people caring for a son or daughter with a disability and respite for people with a disability.

Our suite of community care programs also includes a range of other services for older people, people with a disability, people with mental health problems and carers funded by NSW Health and by the Australian Government.

Our services aim to support people to live in their own homes as independently as possible and involved in their communities. Our approach depends on the needs of the clients and their family members and the program and service guidelines. However it is characterised by a focus on people's strengths (building on what they can do, rather than what they cannot) and on the outcomes we are aiming, with the client, to achieve. This means:

- holistic assessment in consultation with clients and carers and family members so that the services we provide are responsive to their needs and preferences
- addressing clients' social wellbeing, as well as their physical and mental/emotional wellbeing
- building carers' resilience to continue as carers, by looking after their needs as well those of the person they are caring for
- being as flexible as possible in what we offer, and allowing for services to change over time
- stability of staff/client relationships, where possible
- training and supervision of staff to ensure they are fully equipped to support clients
- assisting clients to obtain other services and support and, if the time comes that we are no longer able to provide the level of care they need, assisting them to obtain help elsewhere.

Snapshot of The Benevolent Society

- TBS is a company limited by guarantee with an independent Board.
- 700 staff and 600 volunteers support more than 17,550 children and adults each year in New South Wales and in Queensland.
- We deliver 124 programs in 48 locations with support from local, state and federal government departments, businesses, community partners, trusts and foundations.
- Our revenue in 2009 was \$59.8 million. Approximately 85% is spent directly on our services. A further 8% is spent on our leadership programs, social initiatives and research.
- In 2009, 73% of our income came from government sources, of which 50% was from the NSW Government. Fundraising, trust and foundation grants provided another 5%, client fees generated 12% and our investment portfolio contributed a further 10% of our income.

We are aware of and support the decision by the Council of Australian Governments (COAG) for funding and administration of HACC-funded community care services for older people to be transferred to the Australian Government. The future directions we suggest below would remain relevant in relation to funding and provision of community care services for people with a disability and their carers.

2. The extent of unmet need

There are many gaps in our knowledge about the extent of unmet need. At present, the data collection required of ADHC-funded services are not sufficient to provide an accurate picture of unmet need. HACC-funded services, for example, are required to provide information about 'outputs', such as the number of clients that have received a service. This approach does not allow service providers, or the government, to build a complete picture of the extent to which a service is responding to clients' or local needs.

A more useful approach would be for all services to be involved in combined local planning. This might include exploring regional trends in needs, demands and supply and information about infrastructure, and would introduce a joint problem-solving approach to local service delivery. The Benevolent Society established local provider forums in the St George/Sutherland region for this purpose.

It is also typically left to individual funded organisations to decide how, or if, they collect information about clients who they are not able to support, or not adequately. As discussed below at 3, variations in approaches to waiting lists add to the difficulty involved in assessing unmet need.

All services (government and non-government provided) within an area should be involved in joint local planning and data collection, in order to better meet the needs of local communities.

The planning of community care services tends to be based around existing service types and configurations, resulting in lost opportunities to address unmet needs in different and perhaps cheaper ways. For example, unmet needs for community transport are considerable. Whereas some of this unmet need could be addressed by, for example, assisting people to become confident in using public transport, the service type description for transport¹ is confined to group and individual transport services.

Our experience is that there are several dimensions of unmet need:

- *for particular client groups*: especially ageing parent carers, people with poor mental health, people who are living in squalor, people with early onset dementia and people with complex or specialised conditions requiring case management

¹ http://www.dadhc.nsw.gov.au/dadhc/Doing+business+with+us/service_type_descriptions.htm

- *in certain types of support, due to service inflexibility*; especially transport options, social support for people with high levels of need and home modification options for people living in private rental properties
- *as a result of funding models*; current funding guidelines have the effect of restricting clients' ability to exercise true choice; boundaries between programs /services and rules to prevent 'double dipping' have the effect of reducing the ability of services to respond appropriately to clients' needs and to provide continuity of care
- *as a result of differences in funding across regions and local government areas*: services are available in some areas but not others; the system is fragmented, inequitable and complex for clients to navigate.

Of great concern are the waiting lists for respite care for parents of children with a disability. This group needs to be able to have regular, planned respite care over potentially a long period of time, often for 20 years or more. Under current funding levels and with clients remaining with a service for many years, there are very few places available for new clients. The Benevolent Society currently has a waiting list of 120 families in the St George and Sutherland area alone. We estimate that an additional \$2 million per annum would be required to properly assist these families.

Funding for respite for parents of children with a disability needs to be increased, to address unmet needs and future long term needs..
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Also of great concern is lack of *timely* access to clinical and disability case management (whether through ADHC itself or a funded case management service), for example, for children with a disability with behavioural difficulties requiring a specialised behaviour plan.

Our experience, particularly of our Community Options services, is that many HACC-funded services refuse to support people with mental health issues saying they do have the resources or expertise to support them.

3. Variations in waiting lists

There is considerable variation in services' approach to waiting lists. Some do not keep waiting lists at all, as is the case with the Home Care Service. Others manage waiting lists up to a certain number, such as our disability respite programs. Still others, such as some disability services, manage demand by reducing the level of service provided to existing clients in order to improve their capacity to work with more people.

One result is that people may be on multiple waiting lists. Another is that people simply do not get the care required when it is needed, resulting in poor quality of life and/or a deterioration in their health or other circumstances. People who are unable to look after their own personal care, or whose needs are complex, usually need assistance promptly or the situation will quickly deteriorate.

It also means that carers, for example, cannot be assured that they will be able to access respite when they need it, over the long term, without the threat of it being reduced or taken away because of increased local demand on services.

4. Client funding arrangements and client-focused service delivery

The Benevolent Society believes that focusing on clients' *individual* needs has the greatest impact on wellbeing. Currently, however, service providers are restrained by funding guidelines and have limited flexibility in how they work with clients. This is, in part, due to ADHC's focus on delivering and measuring outputs. For example, the HACC Program funds service providers to provide domestic assistance to X number of clients, rather than to support clients to learn or relearn the skills and confidence to undertake some or all domestic assistance tasks themselves or to find new ways of dealing with them.

Such service-focused delivery models can create dependency, rather than enabling clients to achieve their goals and resolve their own problems.

While some service providers, such as The Benevolent Society, work hard to be innovative and flexible within funding restrictions, sometimes this is not possible. One example of how services are unnecessarily restrictive is the In-Home Respite Care program. Organisations with contracts to provide in-home respite services, and which follow the program guidelines, can only provide a worker to sit with the person in their home while their carer goes out. The worker cannot do anything useful around the house at the same time, such as ironing, cleaning or making a meal, that would provide some practical assistance to the carer. Nor can they take the person out for a change of scenery or a social activity, giving them some support as well as respite for the carer. Furthermore, the carer is literally expected to go out while the worker is present - they cannot stay at home and get some respite from being on duty as a carer.

The Benevolent Society recognises that this inflexibility is partly a reflection of unnecessarily rigid and detailed government program and sub-program guidelines, but also of the culture of many service providers. An aversion to risk also has a tendency to create conservative programs with unimaginative goals.

ADHC's guidelines should allow for the diversity of caring relationships, and allow people to define the nature of their own caring relationships so that services can be appropriately tailored to their circumstances.

Funding programs should provide for people to receive flexible care based on their needs, circumstances and preferences, and be able to adapt as these change. Options for consumer-directed care and individualised funding that give community care clients more control over their care need to be developed, subject to ensuring that the quality of care and outcomes are not undermined.

There are, however, some examples of ADHC-funded service models that allow greater flexibility, thus allowing service providers to focus more on their clients' needs:

- *The Ageing Parent Carer Respite model* allows funded services to provide a range of respite services for parents over 65 years (45 years for Aboriginal and Torres Strait Islander parents) who care for a son or daughter with a disability. Each package provides \$7,500 per family and the service provider and the family can together assess how best to direct those funds to meet their needs.
- *The High Needs Pool/Attendant Care Program* provides funds for older people, young people with a disability, and their carers, who require high levels of support. The funding is portable, so that as people move geographically or between organisations this funding 'stays with them'.

The availability of brokerage funds, even quite modest amounts, can also make a big difference to the ability of services to provide appropriate support for clients. For example, it may be difficult or impossible for some children or young people with high needs to take part in group-based social support activities. However, if brokerage funds are available, they can be used to pay for extra one-to-one support thus enable the young person to take part in services that they would otherwise be excluded from.

Encouragingly, there is an increasing focus on capacity building and restorative approach to community care referred to as the 'Impact'² model in NSW and called variously in different states 'active service models', 're-ablement', or 'wellness' approaches. There is increasing evidence of their potential to make a difference to people's lives and for cost effectiveness.

Wider implementation of these approaches will require improved access to allied health services such as physiotherapy and occupational therapy that can be very important in

² See <http://www.agedservices.asn.au/products-services/community-care/impact>

enabling people to (re)gain functional skills. Recent UK research suggests prompt supply of equipment and independent living aids and staff (re)training and supervision are also vital.³

5. Service evaluation

Evaluation is a priority for The Benevolent Society, and we are working towards making evaluation an integral part of all our services. We are currently undertaking a pilot evaluation of our community care programs to better understand and measure levels of social and emotional wellbeing of clients, explore the potential of our community care services to have a greater impact on these aspects of wellbeing and to identify areas for practice improvement, innovation and policy development.

At present, however, any such evaluations of ADHC-funded services must be funded internally by service providers.

ADHC-funded service providers are largely accountable on the basis of *outputs* (e.g. client numbers, service duration and intensity) and *processes* (e.g. service accessibility, responsiveness of services). While these contribute to giving a picture of the quality of services, government funders do not currently require that service providers collect data on wellbeing *outcomes*.

Revisions need to be made to the types of data which services are required to provide to ADHC and how they are used. Service providers commonly experience a "black hole" phenomenon whereby data is submitted to government and then is never seen again in a format that is useful to the service provider. The Benevolent Society does not, for example, receive any feedback as how our ADHC -funded services are tracking nor how we could support clients better. The exception is if we fail to produce and report on contractual level of outputs, and even then typically we are notified long after the event.

Developing a more outcomes-focussed approach, combined with a better use of mandatory data reporting, would be a practical strategy for quality improvement. It could bring a better understanding of the needs of clients, of gaps in funding or services, and of the impact on wellbeing of clients with different socio-economic characteristics or service dosage/type.

A focus on outputs has the effect of elevating efficiency over quality when, in reality, both are important. An outcomes approach, while more time-consuming, requires services to provide data that gives a much fuller picture of the quality of the service provided, the extent to which

³Rabiee R and Glendenning C, 2010, The organisation and content of home care re-ablement services. Research Works No. 2010 -01, Social Policy Research Unit, The University of York

it responds to local needs and circumstances, the clients supported and (to an extent) the results achieved for those clients.

ADHC should support and fund the evaluation of community and disability care services in order to improve the understanding of the impact of those services on clients' wellbeing.

6. Other issues

Problems resulting from poor coordination and lack collaboration between key parts of the services system continue to hinder effective support of older people, people with disabilities and their carers.

ADHC should take a lead role in developing appropriate agreements and protocols with NSW Health to address long standing problems such as poor or inadequate discharge planning by hospitals, failure to organise short term post-acute care community assistance through NSW ComPacks and wrong assumptions made about caring relationships and responsibilities.

A recent example is illustrative: A woman from Victoria flew to Sydney to be with her elderly father while he was in hospital. He was discharged from hospital without the personal care service he would require (short-term) during his recovery period in order to transition back to living independently at home. He was discharged without any community support being arranged as it was assumed that his daughter was his 'carer' and would take care of this need.

7. In conclusion

ADHC's March 2010 document, *New directions for disability respite services in NSW*, echoes a number of the issues raised in our submission and is very encouraging in its description of a service system that would be more responsive to the needs of people with a disability and their families and carers. What is needed now is a clear program of action and timetable, with appropriate funding, to implement these new directions.