

## Submission to: Queensland Health and Community Services Committee Palliative Care Services and Home and Community Care Services Inquiry



### Introducing Leading Age Services Australia Queensland

Leading Age Services Australia (LASA) is the peak national body representing the age services industry in Australia.

As part of the LASA national federation, Leading Age Services Queensland (LASA Q) advocates on behalf of providers of aged and community care and residential and retirement living services in Queensland.

With a membership exceeding 400 organisations over approximately 800 sites across the State, LASA Q provides leadership, advocacy, and representation on industry related issues to assist members adapt to a dynamic and continuously maturing market place.

LASA Q supports members across the state in four key streams:

- **Community Care** – providing member support in policy development, government liaison and consumer enquires across programs such as community care, community aged care packages, extended aged care at home, national respite, veteran’s home care, day therapy and consumer directed care programs.
- **Residential Care** – providing member support across areas including, consumer enquiries, aged care accreditation and certification, the Aged Care Funding Instrument, clinical care, acute care, nursing and Medicare locals.
- **Retirement Living** – providing member support in regard to retirement village accreditation, senior housing and health policy development and consumer enquiries.
- **Education** – providing members and the aged care industry in Queensland with access to relevant industry driven vocation education and training through the member owned and registered training Education Institute.

LASA Q and our members value this opportunity to contribute to the Palliative Care Services and Home and Community Care Services Inquiry and wish to thank the Queensland Health and Community Services Committee for their due consideration of this submission.

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## Background

LASA Q advocates on behalf of providers of aged and community care and residential and retirement living services in Queensland as follows:

- Community Care – providing member support in policy development, government liaison and consumer enquires across programs such as community care, community aged care packages, extended aged care at home, national respite, veteran’s home care, day therapy and consumer directed care programs.
- Residential Care – providing member support across areas including, consumer enquiries, aged care accreditation and certification, the Aged Care Funding Instrument, clinical care, acute care, nursing and Medicare locals.
- Retirement Living – providing member support in regard to retirement village accreditation, senior housing and health policy development and consumer enquiries.
- Education – providing members and the aged care industry in Queensland with access to relevant industry driven vocation education and training through the member owned and registered training Education Institute.

In consultation with association members, LASA Q has developed this submission against the Health and Community Services Committee Terms of Reference (TOR) and in consideration of the Issues Paper.

Context was also derived from resources including (but not limited to) the Federal Government’s *Guidelines for a Palliative Approach for Aged Care in the Community Setting – Best practice guidelines for the Australian context*, the *Transitions Alliance Directions Paper for an Integrated Health System in Queensland*, and the National Aged Care Alliance paper *Aged Care Reform Series – Palliative Care*.

The submission consists of two sections, covering Palliative Care services and Home and Community Care services separately, under headings reflective of the TOR and Issues Paper.

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## Palliative Care

### Effectiveness, efficiency and adequacy

#### Funding

Palliative and end of life care services currently have multiple funding sources and operate under a variety of fee-for-service and salaried arrangements, crossing Federal and Queensland jurisdictions and professional boundaries. As a result, the Palliative Care service arrangements are many and varied across Queensland.

Unlike funding for residential care under the Aged Care Funding Instrument (ACFI), funding for community age services through Community Aged Care Packages (CACPs), Extended Aged Care at Home (EACH) packages and Extended Aged Care at Home Dementia (EACH D) packages does not cover a Palliative Care program, although EACH packages do allow for qualified nursing input.

In addition, Palliative Care for community aged care package recipients is sometimes provided in cooperation with state operated out-reach or in-home Palliative Care services. Policies which govern the extent to which there can be co-funding and cooperation vary, including in relation to Home and Community Care (HACC) program services.

In the community care space, the highest level of aged care funding available from the Federal Government is through the EACH and EACHD programs. However EACH and EACHD clients are not eligible for HACC funded nursing and the package can be charged (average \$75-\$100/hr with minimum 1-4hrs) for clients to be seen.

This cost burden is unnecessarily prohibitive, particularly when these clients are usually at the maximum funding level of their packages as a result of their needs for personal care, equipment hire, continence management and a range of other non-clinical services.

There are also inconsistencies in how these services (co) operate, with reported confusion and lack of consistency about access to these services.

Many other areas of Palliative Care service delivery are affected by funding disconnect and overlap. Just one example is the demarcation of transport services for clients to hospital and specialist appointments, some being delivered by HACC funded services and some by the Ambulance transport service. Often clients do not fall within the funding eligibility requirements for either service.

Community care service providers are then often left with having a difficult conversation with the client and family over what is able to be achieved under their funding package, and if this will meet the client's needs. Often this means a client has no choice but to be removed from their homes to remain an inpatient in hospital or be transferred to a nursing home until they die.

### Delivery

The net result of complicated and 'siloe'd' funding and governance arrangements are significant difficulties in delivering palliative and end of life care on the preferred multidisciplinary team model. Primarily this is because this model requires strong networking and cooperative partnerships across service providers and across the separately funded programs.

Equally, the variety of arrangements makes it difficult for older people and their families to exercise care control and choice as it is difficult to understand what services are available and how to access them.

This situation leads to the common criticism that current Palliative Care services are fragmented, variable in availability and quality, are not person centred and are difficult to understand and access. It also means that access to quality Palliative Care services depends on the location in which a person lives.

Anecdotal reporting indicates varying degrees of satisfaction amongst age service providers in terms of the scope and effectiveness of the Specialist Palliative Care Units they interact with across the state. In some Hospital and Health Services (HHS) regions there are reports of a strong commitment to partner with residential and community age services providers, highlighting the following as such examples:

The Sunshine Coast Hospital and Health Service, through the Dove Palliative Care Unit <http://www.scdgp.org.au/content/Document/pall%20/Pall%20Care.pdf>, is well regarded for its collaboration with community care providers in the region to provide education, advice and support to clinical and non-clinical staff.

Gold Coast Hospital Emergency Department has an innovative program where they provide clinical expertise (involving the Registrar and Clinical Nurse team) to the area's residential services. They work with local residential services to assess clients who are unwell and provide expertise to support improved clinical care - which includes follow up and other referrals to clinical resources if required. This has significantly reduced inappropriate admissions to hospital, provided avenues to access additional resources, and seen the mentoring of residential clinicians and additional staff training opportunities. This is compelling evidence that sections of the health sector can work collaboratively to provide better outcomes for residents and reduce costs (through inappropriate admissions to hospitals) as well improve RN skills.

However, this level of collaboration and ongoing support is not uniform across the state, resulting in a complex and fragmented picture.

Another reported inconsistency is around the lack of GP support in attending to a palliative client's needs, whether this be through visiting a client's home, working with nursing and allied staff to discuss the treatment of end of life symptoms (including ordering and accessing medication), and/or explaining the outcomes of taking (or not taking) a course of action to the family.

This is further restricted by what appears to be little to no specific funding to encourage GP's to provide this level of service. One LASA Q age service provider member provided these comments on the issue:

"I have found dedicated GP's, or those that have treated a client for a length of time, will offer this (level of) service. I have had (only a few) experiences where GP's have made themselves available to families 24/7 in order to support a client dying at home. (I believe) adding a financial incentive to GP's through Medicare to visit client's at home with palliative needs may help encourage more GP's to provide this service".

In the case of regional, rural and remote communities, isolation, remoteness and distance compounds access problems. This is true also for Culturally and Linguistically Diverse (CALD), Aboriginal and Torres Strait Islander (ATSI), and marginalised groups that experience access problems due to barriers around language, culture, education and so on.

There is an increased financial burden for older people and their families from regional, rural and remote locations as they often need to travel to metropolitan or regional centres for care, often incurring accommodation and travel costs, and loss of earnings for accompanying family members.

There are also additional costs for service providers related to difficulties in attracting and retaining qualified staff; the inability to achieve economies of scale; and the additional cost of service delivery generally in some regional, rural and remote areas.

Access to specialist services in Residential Care is also limited and sometimes non-existent, in regional, rural and remote areas. In these environments, access to GP's is often further impacted by a GP's existing community case load, their attitude towards the aged and knowledge/ experience in Palliative Care.

This is further complicated again by the level of skill, knowledge and experience of staff within the residential care setting.

There is also a gap between what services purport to deliver and what is actually delivered and the outcomes achieved. Palliative Specialist services within regional, rural and remote regions are not as well developed and/or are based in hospitals many kilometres away for the service, reducing the ability to respond effectively or provide timely Palliative Care support.

Finally, Palliative Care specialist resources are delivered differently in different regions. For example some specialists visit the residential services, providing services to the client (inclusive of developing a care plan) as well as providing mentoring and education to the staff. Other Palliative Care services provide phone consultation only.

### **Capacity and future needs**

The gaps and inconsistencies highlighted in the previous paragraphs, when combined with an ever increasing, ageing, Queensland population, make it clear that action must be taken to create a standardised level of Palliative Care, across a coordinated system, which provides clarity and direction to

service providers and health care professionals, and choice and peace of mind to clients and their families.

Meeting the Palliative Care capacity and future needs of Queensland will require consideration and action around:

- collaborative discussions between the Queensland and Federal Governments to provide adequate resourcing/funding of Palliative Care services
- nationally recognised standards, such as the *Guidelines for a Palliative Approach for Aged Care in the Community Setting*, which are systematically implemented, monitored and reviewed
- legislative changes to Advanced Care Planning to reflect a nationally consistent approach, with implementation occurring state-wide
- publicity campaigns that provide the community and clients with information on Palliative Care, focusing on normalising death and dying
- additional support directed to updating Telehealth services in(to) regional, rural and remote areas, to facilitate both service delivery and provide training and up-skilling opportunities
- understanding current and future palliative care workforce needs, and the measures required to meet these
- the uniqueness (and challenges) encountered in providing regional, rural and remote, CALD and ATSI services.

### Recommendations

Addressing the current and future Palliative Care and end of life challenges around simplified funding arrangements, better service coordination and delivery – in both metropolitan and regional, rural remote settings, and the better use and development of technologies in care provision are by no means an easy task. However opportunities exist to incrementally improve the current system but would require significant and ongoing commitment from governments and providers to:

- making Palliative Care a focus for health promotion
- implementing/imbedding the *Australian Government Guidelines for a Palliative Approach for Aged Care in the Community Setting* as best practice in Queensland
- improving collaboration between the many, multi-service delivery groups and reviewing the (re) allocation of funding to support coordinated service delivery. This could occur through the

review and reform of existing services, a more appropriate (re)allocation of care resources, and the continued development of Telehealth and eHealth initiatives.

- implementing and coordinating a multidisciplinary approach to Palliative Care across regions
- allocating dedicated funding (coordinated state and federal) to resource regional, rural and remote health services to provide coordinated Palliative Care to reduce duplication and increase care coverage. This could include developing resourcing formulas that assess local population Palliative Care needs and the cost of service delivery to develop flexible funding arrangements.
- coordinating appropriate and accessible hospital and specialist transportation arrangements for clients
- ensuring major and regional hospitals have adequately staffed palliative consultative services inclusive of a Community Nurse Practitioner
- ensuring services provided in a residential and community context are inclusive of palliative care practice staff and that training and liaison with GPs, Geriatricians and other medical specialists is prioritised
- incentivizing GP's to work more closely with residential and community services providers in supporting Palliative Care clients and their families.

## Home and Community Care

### Capacity and future needs

The HACC Program was first established in 1985 and has been one of the few government programs to have a commitment to growth funding year after year. The requirements, established by the Federal Government as the major funding contributor, also meant all growth funding was allocated against specific service types in each planning region, and until now, usually targeted further to specific suburbs or statistical local areas.

While the administration behind this often presented significant delays in the funding actually reaching service providers, it did create a truly state-wide program that has significant reach into some of the most regional, rural and remote parts of Queensland.

It has also ensured effective targeting to diversity including Aboriginal and Torres Strait Islanders, people from CALD backgrounds, people experiencing or at risk of homelessness, and people with dementia.

It should be noted that while the majority of the funding is allocated to the non-government sector, Queensland Health, through the various HHS, remains the second largest funded provider in Queensland.

While there are synergies in HACC funded allied health and nursing care, with the role and service offerings of HHS Community Health Centers, the fact remains that large metropolitan HHS are still significant providers of services such as domestic assistance and social support.

The further compounding factor is that the HHS does not charge any client fee or co-contribution for domestic services while all non-government funded organisations have been required to do so.

LASA Q understands this is a Queensland Health wide commitment to provide universal access to health services; however it creates significant tensions between clients who receive a free service and those required to pay a contribution.

The issues paper identified the ageing population as the single factor impacting on future needs. As a result of the split of the HACC Program, the Federal Government has assumed full responsibility for this component of the population.

LASA Q would like to highlight that the Committee consider the future needs of the population eligible to access the Queensland Community Care Services program (the State component of HACC) – that is, the population under 65 years (under 50 years for Aboriginal and Torres Strait Islander persons) with a functional impairment requiring basic community care services.

Eligible clients are not only those with a physical or intellectual disability, but include people suffering chronic health conditions, mental health conditions, homelessness and early onset dementia. The



benefits and value of the early intervention and preventative services currently provided through the QCCS (formerly HACC) program must be fully recognised and maintained.

While LASAQ supports a new and better resourced disability system through the creation of a National Disability Insurance Scheme, we do not want to see it created at the expense or redirection of funds from the early intervention services currently provided through QCCS (formerly HACC).

### **Effectiveness, efficiency, adequacy**

The effectiveness and efficiency of the HACC Program can be best measured by the Department of Communities as there is detailed data available through the Minimum Data Set and other reporting arrangements.

Specialised evaluation from a client and carer perspective has been undertaken by a consortium of three consumer organisations including Council on the Ageing Queensland (COTAQ), Carers Queensland, and Queensland Aged and Disability Advocacy (QADA). LASA Q recommends the Committee obtain access to this detailed reporting and evaluation methodology of recent years to fully understand the client/carer experience.

Appropriate funding plays a significant part in ensuring effective services, and unlike specialist disability programs, HACC funded organisations have not had the opportunity to renegotiate their unit costs or outputs since 2005. Furthermore indexation applied to recurrent funding in the HACC program has been under two percent for several years while many other State Government programs have received 3.5% per annum or higher.

LASA Q members are also concerned that governments see efficiency in streamlining or reducing the number of funded providers at the expense of diversity and innovation. There is a growing level of uncertainty amongst providers of HACC/QCCS services that beyond the current contractual period of 2-3 years, they may not continue receiving the level and types of funding they have had for many years.

### **Innovation**

Throughout the history of the HACC Program in Queensland, there have been many examples of innovation and sector development in response to emerging and real needs of supporting diverse communities and marginalised groups. However, there is concern that with the recent funding split and new standardised contractual arrangements, that innovation and diversity in service offerings will be lost or no longer valued by Government.

In 2011, the HACC Program released a small amount of one-off funding to service providers to trial Smart Assistive Technology applications with reference to community care service provision, and also to begin embedding a stronger Functional Independence Framework into the basic maintenance and support program.

Anecdotal reports from providers' fortunate enough to secure some of this funding suggest the trial was largely successful, however there has been no formal evaluation report made publicly available for the benefit of the whole sector.

In contrast, New South Wales, Victoria and Western Australia have all formulated comprehensive policy frameworks in the area of functional independence/wellness/active service with informative examples and tools to support service providers adapt to a more enabling service at the basic community care level.

A further round of one-off funding was announced by Minister Tracy Davis in early July 2012, however service providers are yet to receive departmental advice on the exact scope of the funding and if they were successful. Without an overarching public policy framework and educational resources, funded organisations will either duplicate effort or struggle to successfully transition to this new paradigm.

Unfortunately the restrictive service type guidelines and output funding arrangements of HACC have also prevented and/or discouraged HACC service providers from embracing Telehealth and Telecare in a significant way.

There are some strong examples of the effective application of telehealth and telecare in community care being achieved through the community packaged care programs of CACP, EACH and EACHD, including the following:

Feros Care, a not for profit Aged Care service provider operating throughout Queensland and New South Wales, has pioneered the use of TeleCare and Telehealthcare in community care. In early 2010 Feros entered into relationship with Tunstall Australasia to conduct a pilot program, using an extensive range of products within both Telecare and Telehealth Technologies, deployed to aged clients who were receiving Feros Care Community services.

The Pilot Program provided a general endorsement that Telehealthcare technologies can improve the likelihood of clients being able to remain safely in their own homes for longer than would otherwise be possible with:

- 80% of Clients reporting Telecare had improved their quality of life during the program
- 69% of Clients reporting being less concerned about the daily severity of their condition
- 44% of Clients feeling they needed to visit their General Practitioner (GP) less frequently
- 44% of Clients feeling their quality of life had improved relative to the beginning of the program.

Telecare services reportedly increased client confidence, and reduced the fear of both clients and carers that a client's fall at home may be undetected.

**Telehealthcare – Supporting People to Live Safely and Independently at home: An Australian Pilot Program 2010**

<http://www.lifelinkresponse.com.au/wp-content/uploads/2010/10/Telehealthcare-report-Feros.pdf>

### **Segmenting on age, client and carer needs, service provider needs**

With the split only just taking effect from 1 July 2012, it is too early to provide significant feedback or insight into the effectiveness of segmenting the program on age. However LASA Q has consistently

advocated to both levels of government that they continue to recognise and maintain the diversity of service provision and localised responses to client and carer needs at an early intervention level.

Our particular concerns relate to the inevitable integration of a broad based eligibility program like HACC into a more targeted and specialised disability services system. While the reportable data available under the HACC Program doesn't identify diagnosis or condition of individual clients, it is widely known that the HACC Program has met the gap in areas such as community mental health, early onset dementia and chronic or age-related conditions that may not be recognised under the Disability Services Act or a National Disability Insurance Scheme.

### **Opportunities to improve collaboration and coordination between chronic, disability and other health services**

LASA Q contributed to significant conversations and policy development around integrated health services with a Transitions Alliance facilitated by Queensland Health. This discussion and public consultation culminated in the development of the document *Directions paper for an integrated health system in Queensland* and LASA Q recommends the Committee review this paper in full.

In particular the Transitions Alliance agreed on key enablers to an integrated health system as follows:

- **Clinical leadership and governance structures to affect change.** Effective clinical leadership and governance are achieved through a number of interlinked structures and activities, including stakeholder partnerships that are designed to ensure that managers, clinicians and those who govern health services are aware of their roles and responsibilities, and have the appropriate structures and processes to affect robust governance.
- **Service re-design (connectivity, and information flow to support clinical decision making and performance).** Service redesign is an approach to improving outcomes and efficiency in health. Service redesign includes evaluating existing structures and workforce models, referral pathways and protocols, information sharing mechanisms, and the efficiency of the services provided.
- **Organisational and workforce development to support the new skills needed to operate new organisations and form effective relationships.** To address the need for integration, it is critical to improve health workforce expertise through education and training, building workforce capacity, promoting knowledge translation and exploring opportunities for strategic level development.
- **Incentives aligned with desired outcomes.** Properly selected and administered tangible incentives, such as funding, can dramatically increase achievements against Key Performance Indicators. Research indicates that programs using outcomes based incentives.

However there is concern that much of this work will be lost as the State moves to a more localised administration of HHS regions with minimal state-wide coordination or strategic policy responses.

## Recommendations

LASA Q has developed several key recommendations aimed at addressing some of the current and future issues detailed in the earlier paragraphs. Governments will need to consider the following actions if the HACC program is to deliver effective and innovative services to the diverse range and increasing numbers of aged clients throughout Queensland:

- a review of the scope of service provision provided by Queensland Health HHS under the Commonwealth HACC and Queensland Community Care Services programs, with particular regard to the fees exemption policy currently applied
- full consideration and preservation of the current and future needs of those with a functional impairment requiring basic community care services, in the event of a National Disability Insurance Scheme being created
- recognition of the true inflation in costs and wage increases when indexation is applied to Queensland Community Care Services
- recognition of the value of a diverse service sector that is able to respond locally to community needs, through existing funding and contractual arrangements
- release of the findings (by Department of Communities) from trials in the use of Smart Assistive Technology and Functional Independence, along with development of an overarching policy and educational resources for service providers
- development and enforcement of a state-wide framework to guide stronger integration of services at a local and regional level.