LEADING AGE SERVICES
AUSTRALIA

The voice of aged care

REFORMS TO HUMAN SERVICES: LASA RESPONSE TO THE PRODUCTIVITY COMMISSION'S ISSUES PAPER

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Leading Age Services Australia (LASA)

Leading Age Services Australia (LASA) is the national peak body representing providers of age services across residential care, home care and retirement living. We represent our Members by advocating their views on issues of importance and we support our Members by providing information, services and events that improve their performance and sustainability.

Our vision is to create a high performing, respected, sustainable aged services industry delivering affordable, accessible, quality care and services for older Australians.

Thank you for the opportunity to comment on the Reforms to Human Services: Issues Paper. This submission will address the questions raised in Section 6 of the Issues Paper.

Should you have any questions regarding this submission, please don't hesitate to contact Dr Brent Davis, General Manager – Policy and Advocacy, or Ms Kay Richards, National Policy Manager, on 02 6230 1676.

Background and Context

The Federal Government in April 2016 requested the Productivity Commission to undertake an inquiry, and provide a report into, the delivery of human services in Australia. Health and aged care were specifically identified as key human services.

In the Terms of Reference for the inquiry, the Federal Government emphasised successive governments had to that date made progress in introducing competition, contestability and user choice into, and in promoting the efficiency and effectiveness in the delivery of, human services. However, they also noted the Australian human services sector (which includes health and aged care) are already experiencing significant challenges, in particular the increasing demand for services associated with the ageing of the Australian population and more complex demands being placed on service providers.

The key theme of the Terms of Reference called upon the Productivity Commission to develop policy options to create principles for competition, contestability and user choice in the supply of human services. Self-evidently, such principles, and their application, in aged care and in health are of particular importance to LASA and its members.

The Productivity Commission in December 2016 released an Issues Paper identifying and discussing a number of priority areas where reforms could potentially deliver the greatest net benefits in individual well-being and community welfare. The Commission identified end-of-life care services on this priority list. Consistent with its broader approach to public policy research and analysis, the Commission emphasised (at page 2) *"… greater competition, contestability and informed consumer choice can improve the effectiveness of human services."* LASA shares this view, where **the broader legislative, policy, principles and regulatory frameworks are well-designed (in conjunction with critical stakeholders), and implemented in a practical and realistic manner.**

The Issues Paper (at pp 22 – 23) made a number of constructive observations regarding end-of-life care, a matter of particular importance to the aged care sector. Most notable amongst these were: inadequate attention has been paid to ensuring people get the end-of-life care they want at that point in their life-cycle; end-of-life care needs to be more responsive to the preferences of the individual, both as to where and when the care occurs; it should take into account not just the need of the person concerned, but also their families and carers; and, there needs to be deeper integration of end-of-life are in the service delivery chain (such as the services provided by primary, community, hospital and aged care facilities).

Summary of Recommendations

LASA advocates:

- **the broader legislative, policy, principles and regulatory frameworks for age care in general, and end-of-life care in particular, need to be well-designed (in conjunction with critical stakeholders), and implemented in a practical and realistic manner;**
- **a defined financial supplement for palliative care services in both home and the residential setting;**
- **any work undertaken to improve consumer choice needs to take into account the lack of public awareness and perception of death and dying. Improved awareness would also need to support the relevant workforce that may have these discussions with people, including those working in aged care, general practice, and the acute sector.**
- **the use of advanced care plans and directives at any stage in a person's life.**
- **a community awareness campaign demonstrating advanced care planning should be considered at pertinent times in a person life needs to be undertaken.**
- **the need for better training; this should not only be for health professionals but also aged services workers, through the Vocational, Education and Training (VET) system.**
- **the existing tools are seen in isolation and outcomes of the activities are not always well published, and a more concerted framework of information is required.**
- **the silos of care delivery options and demarcation lines in end-of-life care need to be broken down, with better communication especially between health and aged care services.**

What type of services and settings to include in the definition of end-of-life care?

As identified in the Australian Institute of Health and Welfare (AIHW) report on *Use of aged care services before death* (2015), 77% of people who died in 2010-11 aged 65 and older had used aged care services in the 12 months before their death. The likelihood of using aged care services increases with age, with just under 90% of people aged 85 years and older accessing aged care services at some point in the year they died. Two thirds of people who died whilst receiving aged care services where in permanent residential aged care. The report goes on to highlight there was a marked increase in service up-take in the final 6 months of life but that about 10% of people cease accessing aged care services in the final 3 months of their life. It is suggested this decrease is due to people accessing alternative services either through the hospital system or a specialist palliative care service[i].

The end-of-life and palliative care services utilised in the community setting are less well defined, as, from an aged care perspective, funding is not allocated in the same manner as residential aged care. Care and services for home and community care recipients are not as extensive due to people historically transiting into residential care as their needs increase, or when they seek assistance outside of the Commonwealth funded aged care system. Given the Commonwealth aged care policy shifts are designed to assist people to remain in their home longer, increased resourcing to home and community services to promote people to *age in place*, it is likely the needs of people accessing aged care in the community will also shift.

Having said that, as identified in the Issues Paper, many people do not have their choice upheld as they near the end-of-life. Numerous factors impact on the setting for the delivery of palliative care, and despite a person's choice to remain in their own home, this may not be possible for families to achieve. In delivering Commonwealth funded aged care services, understanding a person's wishes and ensuring their choices are upheld is assisted when an advance care plan is developed. Despite best intentions there are unfortunately many instances where these documents are either not developed or followed. In the LASA Planning Ahead Position Statement (www.lasa.asn.au), LASA argues that if a person has not been provided with information about advance care planning or a conversation has not been initiated prior to their admission into residential services then the system has failed them. A community awareness campaign on the importance of this information is required and health professionals should be made aware that following the directions of plans and directives (known by various names in each State/Territory) is vital to ensure the needs, preferences, and wishes of a person are upheld.

The delivery of specialist palliative care services varies across jurisdictions, where often, especially in residential services, access to specialist palliative care professionals can be very limited. There is often a misunderstanding that people residing in residential services are not eligible to receive state based services such as specialist care. This misconception needs to change.

Current government funding and eligibility criteria

Dementia care is core business for age services. LASA also suggest palliative care is another component of core business for aged services providers. As defined in the Discussion Paper, the Australian Commission on Safety and Quality in Health Care defines end-of-life care over a twelve-month period, however the Aged Care Funding Instrument (ACFI) defines end-of-life as days or the last week of life. A higher level of funding for residential services, is only available for approximately 7 days, which certainly does not encourage nor support end-of-life care and services to the resident, let alone the family and others.

The Aged Care Funding Instrument (ACFI) is utilised to assess the relative care needs of a resident in residential aged care and is used by the Commonwealth to allocate subsidy to aged care providers for the delivery of this care. The data currently available through the AIHW regarding the delivery of palliative care through residential aged care providers is based on the ACFI claiming data. This data shows that 9,144 palliative care claims (through ACFI) were made in 2014-15 and that about 55,600 people died whilst in permanent residential care in that same year[ii], suggesting about 16% of people that die whilst in permanent residential care receive palliative care. However, data collected through the Decision Assist (a project funded by the Department of Health) would suggest a substantial number of organisations are unable to claim additional funding to support the care they are providing as they have claimed the maximum amount for the specific domain of the ACFI tool. This suggests a disconnect between the funding is provided for care and the actual care people receive in residential aged care.

For people accessing care and services through a Home Care Package, increased services for end-of-life care is provided through the funding at the level of package received. For instance, in a Level Four Package (the highest level), the consumer may already be receiving care that fully exhausts the funding level. As their care needs increase, they either forgo services to access palliative care, or they go outside of the Package. Generally that would be through state and private hospital services and GP services. This disconnect is contrary to a seamless approach for care delivery and the system can be difficult for the consumer to navigate.

How eligibility for end-of-life care should be defined, and who should have responsibility for determining whether a person is eligible for care

As mentioned above, there are a range of definitions, and often they are specifically used to suite a funding model, rather than supporting the person requiring care and services. Not all people who are at their end-of-life need *specialist* care and services. For many care recipients receiving Commonwealth funded aged care services, their care is planned based on best practice guidelines following the *Palliative Approach*, which aims to improve the quality of life for individuals with a life-limiting illness and their families, by reducing their suffering through early identification, assessment and treatment of pain, physical, cultural, psychological, social, and spiritual needs.

It is the Specialist Palliative Care Services who are best placed to define access criteria. However, given the variation within these services, their location and reach, it may be difficult to have a unified access definition and may need to be based on good clinical judgement decisions and the location of the services. As described above, the misconception of eligibility based on the type of residence (aged care facilities) a person has, should definitely be redefined.

Whether care services should be considered as a ‘bundle’ or individually, and who should determine which services a person can access

As outlined in the *Quality of Care Principles 2014*, residential providers are required to provide specific care and services for all care recipients that require them. This is referred to as the Schedule of Specified Care and Services and is subsidised by the Commonwealth through the ACFI. As such, current legislation has resulted in bundling of care needs in residential aged care, as determined by specified health care professionals. Similarly, for Home Care Packages, the Home Care Common Standards also define what is required to be delivered.

In Commonwealth funded services the person at the centre of care is the one who should decide what care and services they need and want, within a given envelop of subsidy. Currently, assessment to access age services is through *My Aged Care* where screening and assessment is undertaken by direct referral or through Regional Assessment Services and or the Aged Care Assessment Team. They do not refer to specialist palliative care services. **LASA would support a defined financial supplement for palliative care services in both home and the residential setting.**

How best to coordinate care across different settings and the supports needed to ensure patients remain at the centre of service provision

In the community setting for aged care, advance care planning may be one of the areas that is impacted by the introduction of Consumer Directed Care (CDC) as the person now nominates specifically what they would and would not like to spend their available funds on. Given that advance care planning conversations often take some time and may require clinical, and therefore more expensive, staff, there is a possibility CDC has inadvertently introduced a new barrier to advance care planning in an aged care context. Furthermore, the staff need to be supported to discuss advance care planning, both in raising the topic and having an informed and constructive conversation that helps the person to identify what they would and would not want if they were unable to make their own decisions, including where they would prefer to die. Data collected through the Decision Assist project shows there was a shift in the place of death following the education of the aged care service staff in advance care planning and palliative care, with almost 60% of people dying in their home after the delivery of workshops compared to 46% beforehand. The majority of this shift has resulted in less people dying in hospital.

The feedback LASA has received regarding the provision of end-of-life services in the community is there is often no single person/organisation responsible for the coordination of services for an individual and therefore this role may fall to a family member or a friend. One of the challenges raised with LASA concerns the provision of coordinated care in the community setting is not only that providers need to be aware of service availability but the arrangements to speak to other professionals are often informal and ad hoc and generally involve people who have very limited availability. Improved, formal linkages between organisations may assist in improving this but does not necessarily address existing resource constraints. There are a large number of projects are seeking to improve the options available to people so they can avoid transfers to hospital if possible, including the utilisation of ambulance officers with pain management and education of carers so they can undertake some of clinical care without having to contact the relevant service. However, these projects are often limited to a defined population for a specific amount of time, as defined by the funding organisation. A challenge exists for how to improve the sustainability of this type of work and outcome dissemination.

LASA is aware of specific arrangements that exist between specialist palliative care providers and aged care providers, predominately in residential aged care, that supports both organisations to provide care for a resident, and therefore avoid potential transfer/s to a hospice or hospital. However, these are generally individualised arrangements between specific providers. The Decision Assist project includes a linkage project component that seeks to formalise these types of arrangements and provides options for how this can be achieved. The initial 20 demonstration projects included some minor funding for approximately nine months, and included consideration on the sustainability of the arrangements. The initial findings of these projects indicates mixed results and suggests funding in and of itself is not sufficient to make the required changes to establish formal linkages between organisations that already have some intention to do so.

The feasibility of offering users' greater choice of service, or of provider, and how this differs between regions

LASA understands it is not uncommon for an individual and/or their family to request transfer to hospital at the end-of-life, as 'that is where you go to die'. In conjunction with this idea, is the continuing challenging of public awareness and willingness to discuss death and dying, including the undertaking of advance care planning. Therefore, **LASA recommends any work undertaken to improve consumer choice needs to take into account the lack of public awareness and perception of death and dying. Improved awareness would also need to support the relevant workforce that may have these discussions with people, including those working in aged care, general practice, and the acute sector.**

The potential for greater contestability, particularly for services and regions where choice is not practical

LASA continues to be concerned restrictions on service delivery in both the home and residential settings, confines services to a limited range of options. Given specialist services are State run, vary across jurisdictions, and vary in who can obtain access to a service, there needs to be a fundamental shift in the way these services are run.

Patients and careers could be better supported to plan for care in advance

LASA supports the use of advanced care plans and directives at any stage in a person's life. The community in general and many health professionals often think that these tools are only applicable for the older person. LASA believes the sooner a person considers how they would want to be treated in a circumstance where they could not speak for themselves, the better the service they may receive. However, the general community still hold a stigma against discussing death and dying. **A community awareness campaign demonstrating advanced care planning should be considered at pertinent times in a person life needs to be undertaken.** These touch points of when a person turns 18, when they marry, have children, reach an older age or have a medical event (and possibly other times) should prompt a rethink of what a person wants to happen to them in the event they can't decide for and/or express themselves. Advance care planning can be an iterative process, as the person goes through life and what is vital is that people have conversations with family, friends and health professionals to ensure they know what the person feels and wants, when and where required.

Patients could be better informed about end-of-life care options available to them and how to access that care

My Aged Care and Carers Gateway are important information portals; however, these may not be commonly known about by the general public. General Practitioners, and other health professionals should have ready access to end-of-life care options so that when required they are easily accessed. Public health campaigns, are required. However, there are a range of information sites that are not well known about by health professionals, such as CareSearch, Decision Assist and Palliative Care Australia, to name a few, and Apps that are available for download such as palliAGED nurse and palliAGEDgp.

Healthcare professionals could be better trained, assisted or incentivised to identify people who would benefit from end-of-life care, and to initiate and guide end-of-life conversations

LASA supports the need for better training; this should not only be for health professionals but also aged services workers, through the Vocational, Education and Training (VET) system. LASA is undertaking a programme to support Registered Training Organisations (RTOs) in providing tools in the form of videos and fact sheets to support curriculum delivery. There are numerous activities that are designed to support those caring for a person and their family at end-of-life. However**, the existing tools for end-of-life care are often seen in isolation and outcomes of the activities are not always well published, and a more concerted framework of information is required.**

Patient preferences for end-of-life care could be better documented and communicated across healthcare settings & barriers to implementing patients' expressed preferences (including those in advance care plans) could be overcome

The silos of care delivery options and demarcation lines in end-of-life care need to be broken down. LASA supports better communication especially between health and aged care services. The GP should be the centre of information sharing as they are the professionals who can see their patient in whatever setting they reside. However, GPs are often marginalised when a person enters the health system and either while the person is in hospital and at post discharge, GP are often not notified of updates to a person care.

A person's wishes should be recognised, and where documented evidence of those wishes are available they should be followed. Unfortunately, risk aversion by third parties can often outweigh a person's expectation that their wishes will be respected and followed. At the same time, differences between the States and Territories in how a person documents their wishes need to be removed, and an Australia-wide process should be developed.

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[i] Australian Institute of Health and Welfare 2015, *Use of aged care services before death*, data linkage service no. 19, cat. no. CSI 21, AIHW, Canberra.

[ii] Australian Institute of Health and Welfare 2016, *Palliative care in residential aged care*, AIHW, Canberra.