Dear Commissioners

Re: Older Women's Network NSW's Submission on Aged Care System Redesign

The Older Women's Network NSW (OWN) appreciates this opportunity to provide feedback to the Royal Commission into Aged Care Quality and Safety's Consultation Paper 1, *Aged Care Program Redesign: Services For The Future*.

About OWN

OWN NSW is a community-based organisation that is run by older women, for older women. Established in 1987, OWN aims to promote the rights, dignity and wellbeing of older women. We encourage mutual support and friendship amongst our members, and work to foster a positive attitude toward ageing. Members of our organisation are older women who have a strong interest in ensuring that aged care in this country is adequately funded, compassionately delivered and respectful of the needs of older people.

We have based our feedback in light of our aims and objectives of working towards a society which values the contribution of older people and respects the human rights of all. Our feedback relates specifically to design questions 1, 2, 3, 4 and 10.

Principles

Good design is guided by principles which provide the framework on which it is based. We agree with all the principles set out in the discussion paper. We would like to offer the following additional principles for consideration.

1. **Aged care should be viewed as part of life and living, and society must come to terms with ageing in all its aspects.** Consequently, the aged care system should be based on principles that support a continuum of planning for ageing, not just end of life care. Aged care should be viewed as part of a life plan, which is part of the continuum of planning, health services and care for

an individual. This will mean that just as it is natural for parents to plan for the schooling of their children, so it should be for us to have in place advance care directives and legal documents such as wills as a normal preparation undertaken by all. It should be mandatory for all our housing to be built to be accessible for both people with disability, as well as older people. Superannuation should include advice and planning for both housing, health and lifestyle issues for when we are older. Professionals that provide services to adults such as financial planners should include arrangements for ageing as part of their discussions.

2. **Strong support of community services must be a guiding principle of the aged care system**. A public health response to ageing would change the focus from end of life care to funding across the life spectrum, and such a response would begin while people are active and living in the community. The current principles do not allow for responses to community-based services for the independent and active older person, or those with early onset dementia where supported interventions could prolong their cognitive capacity.

   Dementia ranks as the third highest in disability costs in Australia overall, and is the greatest cause of disability in Australians over the age of 65 years (Health Direct , 2018). There is growing evidence that lifestyle issues, taking effect at an earlier age, can make a difference in maintaining cognitive capacity for longer. Such a principle that indicates 'supporting people as they age to maintain their lifestyle and wellbeing' would mean the need to adequately fund community based services that deliver activities to promote information, fitness and wellbeing, including social activities.

   As an organisation which provides wellness activities to our members who range in age from the 50s to the 90s, we have found that activities such as tai-chi, movement/dance classes and those involving music and theatre are vital in keeping older women socially connected, physically active and ageing in the best way possible. Our experience also shows that unless these activities are supported by the government, whether local or state (we do not receive Commonwealth funding), the costs of attending these activities limit the numbers who would otherwise like to attend. This is evidenced in the attendance between centres which receive government support, and those which do not, with attendances in the former far outstripping those of the

latter. We can provide more information on this to the Commission if necessary.

Supporting community based activities to keep citizens active, more healthy, better engaged and connected is a cost-saving exercise because healthier and happier people do not need to access health services as often as those who are not. It also promotes independent living, thereby putting the pressure off aged care facilities.

3. **Autonomy should be the primary goal and a lead principle because we have seen that concepts of safety as currently expressed can be used to limit the self-determination of a person.** We would like to note that the framing of the principles in the discussion paper positions the older person as the subject of care, and not the decision maker in their life. Older people rarely define themselves by their health condition, but view their quality of life by the degree of autonomy they exercise. Such a principle allows an older person to determine the degree of risk they are willing to take.

   The use of physical restraints and psychotropic medications is justified by residential providers as a means to 'prevent falls'. In reality, not allowing a person to be free to move makes it easier to keep to institutional schedules and allows for fewer necessary staff. Linking aged care services, funding and regulation to a broader concept of autonomy and facilitating an individual to maintain their lifestyle and improve their wellbeing would also encourage a move away from the current institutional set-up.

4. **Commitment to uphold the UN Principles of Older Persons (1991) and the Convention on the Rights of Persons with Disability.** The UN Principles of Older Persons (1991) states that *Older persons should be able to enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility, including full respect for their dignity, beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives.* Australia endorsed these principles at the General Assembly, and is one of the original signatories to the Convention on the Rights of Persons with Disability. We should uphold this principle, and convention, to guide our design of aged care.

   Upholding the UN Principles of Older Persons and CRPD call for a planned approach to move away from the current set-up of institutional care, and make

institutional care an option of last resort. The nature of institutions, as we have learned from the Royal Commission into Institutional Child Abuse, is not conducive to good care and more likely to lead to abuse as we have heard from this Royal Commission. Institutional care is fundamentally a deeply flawed model on which to base quality and safe care.

We also believe that aged care facilities should be monitored by the Human Rights Commission as per articles 33 – 39 of the CRPD as the majority of residents in aged care have a disability.

5. **Strongly support interfaces with all sectors and services that individuals need to maintain their lifestyle and improve their wellbeing**. The list of interfaces to health and disability is too narrow. It does not include 'transport', for example, which is vital for people to remain connected to their community and to obtain medical services. A broader description would also allow this principle to be adapted to developments and advancements in society. For example, information technology and access to the internet should be viewed as essential to the facilitation of wellbeing.

6. **The aged care system should uphold principles of diversity and commitment to inclusivity.** In referring to diversity, particular reference should also be made to people living with **dementia** as this is such a significant reason for entering institutional care.

7. **Commitment to ongoing monitoring and evaluation.** However, we want to make it clear that ongoing monitoring and evaluation must be undertaken with the parallel commitment to fund the necessary changes to ensure that best practice and lessons learnt are actually able to be implemented with each cycle of monitoring and evaluation.

8. **The aged care system has to be fully funded by government, and should not be subject to market forces.** Just as every child in Australia is entitled to an education and is not subject to a waitlist and therefore have to miss out on their education, the same should apply to every older person and their access to good quality aged care.

The following section covers issues related to the design of aged care.

A) Finding and receiving care

We believe in the necessity of having personal, **face to face support** as an integral part of aged care design. Older people need to have face-face support to assist them to find and receive the appropriate care and help they need**.** This enables the older person to ask the necessary questions and understand the services that are available to them. In addition, this type of support helps address the specific needs of vulnerable groups and those who would otherwise be reluctant to access the services for a range of reasons, including their inability to navigate an internet based system. Personal guidance in aged care creates the supportive and safe environment that is needed to guide people through the services**.**

It is important to place an emphasis on **pre-emptive planning**. Early engagement and interaction with aged care services is critical in avoiding crises-based responses. Face-to-face aged care support should be designed to be approachable by all adults to encourage early aged care planning. This manifests the principles of autonomy and choice as older people are more able to make informed decisions at a time when they are not facing a crisis. Younger people can be supported through **community education campaigns** targeting different age groups to encourage them to think about advance directives, financial planning and superannuation. Educating younger people to be literate about ageing is important.

Please see **Appendix A** which shows a modified version of the proposed model for the aged care system. The need for support and services before entering the aged care system is critical to the effectiveness of the aged care system. We have proposed an additional stream that supports advanced life planning and community based organisations that keep older people active and socially engaged BEFORE they need to access aged care proper. This early support will be beneficial for the aged care system as a whole because of cost savings from fewer people needing to access aged care services earlier; and reducing the costs of health services overall because they have better health.

B) The design of aged care

Residential Aged Care Facilities (RACFs) are available for older people who are unable to continue living independently in their own homes. It costs the Australian government $11.5 billion each year to care for people living in RACFs. Large RACFs

dominate the aged care landscape. 54% of RACFs in major Australian cities had more than 60 residential places in 2010-2011. We have seen that profit driven incentives for aged care providers undermine the quality of care. An increase in home care packages during 2019 had consequences for aged care providers as they are experiencing a decrease in occupancy (Cheu, 2020). Other factors in the decrease in occupancy include wait times, accreditation and complaints. The average waiting time increased to 121 days in 2018 from 84 in 2016. The Productivity Commissions (PC) report reveals that less than half of older people entered residential care within three months of their Aged Care Assessment Team approval (Egan, 2019).

We propose a **Community-based Integrated Care System** instead. Of the top ten rated countries to grow old, Sweden and Japan are two that adopt a community-based model. The Japanese Community-based Integrated Care System provides health care, nursing care, housing and livelihood support to the elderly within a local community (Zaidi, 2014). This Japanese aged care model is based on the Swedish and Scandinavian model of care. Reforms in Sweden introduced a decentralised aged care system where the responsibility for elderly care was given to local municipalities. Government funds are invested in developing the competence of local/ municipal care managers and workers (Seniors Matter, 2017). The emphasis of the model is placed on community involvement, public accountability and citizen involvement.

This model engages the entire community. Sweden is investing in community housing polices for the elderly with the focus on local decision-making. The elderly and disabled qualify for municipality funded home-help services that provide them with assistance so they can remain at home, and transportation services such as taxis for those who are unable to travel on public transport. In addition, municipality “fixers” help people with tasks like changing light bulbs in the home (Swedish Institute, 2018). The personal level of service provided in this model of aged care is what we want to see here in Australia, and we urge the Commissioners to consider this as one of the underpinnings in the redesign of our aged care system.

Lessening social isolation and improving community connection is critical to the design of the aged care system. The current Home Care packages and aged care homes are limited in meeting the personalised support needed as people grow older. In order to age in place and remain engaged in social activities, as well as receive aged care support, a **clustered residential model** may be considered.

The need for older people to live in a self-determined manner is being recognised and the small, clustered domestic models of care are proposed to support this. The

smaller, clustered residential model includes smaller living units that are designed to feel more like homes than health care facilities. Staffing models and design of the units support the residents' choice in routines and access. Facilities that simulate a home-like environment and lifestyle have been reported by the WHO to have advantages for older people, families, and carers and improve quality of care (Dyer, et al., 2018). Initial research on this model demonstrates a reduction in the number of re-hospitalisations, catheter use and pressure ulcers.

The criteria of clustered domestic model of care include:

- small living units (15 or fewer residents)
- independently accessible outdoor areas
- allocation of care staff to specific living units
- meals cooked in the units
- self-service of meals by residents
- residents' participation in meal preparation

The standard Australian model of care generally meets no more than 2 of these criteria above. A study on this model of care reveals that residing in a clustered domestic model of care was associated with a significantly higher quality of life and fewer hospitalisations compared with residing in a standard model of care (Dyer, et al., 2018). The same study also presents a 21% savings in government funding for the clustered model- a function of in-hospital and out-of-hospital costs (Dyer, et al., 2018). A similar model exists in a community in France. The case of the "Babayagas" is a self-managed social housing project devised and run by a community of dynamic female senior citizens who want to keep their independence, but live communally (Hird, 2013) . Innovation in aged care homes and service providers is critical to the successful and impactful redesign of the aged care sector.

Innovative aged care models were presented at the recent Ageing Asia forum held in Singapore. The models emphasise the importance and need for individualised and holistic care, which we believe should be the underlying ethos of the aged care system in Australia. This focal concept of care was influenced by Tom Kitwood's Person Centred Care model that was proposed in 1988 to support the needs of people living with dementia (Shears, 2018). Person Centred Care is based on meeting the social and psychological needs of a person with dementia through maintaining their sense of identify and wellbeing. Today it remains very relevant in meeting the needs of older people requiring care.

Similar to the Person centred Care model, Dr Bill Thomas, an American Geriatrician, proposed a model of care described as Multi-Ability, multi-Generational, Inclusive Community (MAGIC) living. “Minka” is the accommodation solution he introduced that offers support for older people and enables them to maintain their independence by living in clusters of small houses designed in a way to support their needs. These mindfully designed small houses are clustered in existing residential areas which maximise opportunities for social connection and access to community activities. Current aged care residential facilities segregate older people from society that contribute to issues of loneliness and isolation. Dr Thomas believes that segregation of people through residential aged care or care needs perpetuates the issues and ageist attitudes. This also applies to perpetuating isolation of people living with dementia.

In Australia, “NewDirection Care” is an innovative residential model that is underpinned by similar concepts of aged care and is probably the closest example to Dr Thomas’ Minka model. NewDirection Care is a small scale living community in an urban area of Bellmere, north of Brisbane (NewDirection Care, 2020). Residents live in seven-bedroom homes and have “house companions” who provide relationship-based support. Individual needs and preferences are recognised and the model of care promotes the autonomy of older people. Through individualised eating times and visitor times for example, this model supports older people to live independent lives. Resembling a typical Australian suburb, the facility creates a community with access to a town centre providing services like a GP, café, salon and a wellness centre. This space is open to residents and the wider community. Creating a social connection and a sense of community is critical to supporting older people and maintaining their wellbeing.

Residential aged care facilities can also provide opportunities for rehabilitation and training as outlined by Thomas Krarup, a keynote speaker at the forum. The Danish model espoused by Krarup is subsidised by government funding. It invests in workforce training and state-of the art equipment for rehabilitation. Investment in allied health involvement including Occupational Therapy and physiotherapy is seen as part of the design for residential aged care models. The models of aged care demonstrated through MAGIC living, NewDirection Care and the Danish model investing in allied health care emphasise a holistic approach to ageing and aged care support in ways that promote autonomy of older people and community-based aged care. We propose that these innovative models inform the redesign of the aged care model.

We have noted above that the principle of inclusivity needs to recognise that we have a growing population who is affected by dementia. Aged care redesign must include the creation of **communities that are dementia friendly and inclusive** of those living with dementia. There are more than 400 000 people in Australia with dementia, with more than 50% living in residential aged care facilities (Health Direct , 2018). The government funded Home Care Packages and residential aged care do not currently meet the demands of older people and especially those with disabilities. The traditional hospital-like facilities of aged care are limited in providing the holistic support which we believe is essential to aged care. Dementia Care Units (DCUs) have been developed in response to the needs of people with dementia in aged care facilities, but despite offering specialised services, they perpetuate isolation and hinder wellbeing by being separated from other parts of the community (Steele, Swaffer, Phillipson, & Fleming, 2019).

Environments that support engagement with a variety of activities and amenities have proven to improve the quality of life of people living with dementia. In the specific context of residential aged care facilities in Australia, a recent journal article draws on the United Nations Convention on the Rights of Persons with Disabilities (CRPD) to frame this segregation as an injustice and human rights violation. This is an important issue that we feel has been overlooked in the aged care system. According to the CRPD, people have the right to non-discrimination, accessibility, independent living and community inclusion (Steele, Swaffer, Phillipson, & Fleming, 2019). The current aged care system does not respect these rights and there is a strong need for special consideration of this population group.

Dementia should be deinstitutionalised and structural reforms made to aged care facilities to include and support people with disabilities. It is recommended that the design of the aged care system must take into account the protection of people living with dementia and make special consideration around issues of coercive control and isolation. More resources should be channelled into developing sustainable alternatives to segregation in nursing homes (Steele, Swaffer, Phillipson, & Fleming, 2019). The aged care system needs to support and foster dementia friendly communities to maintain the rights of persons living with disabilities.

C) Financing Aged care

We believe strongly that good quality and comprehensive aged care must be accessible by all who need it, regardless of their economic status. For this reason, we also believe that the financing of aged care has to be viewed within the totality of the income generating streams of the federal government, and not focus on the simplistic question of 'how do we get older Australians to pay for their aged care'. The question should instead be framed as: 'how can the government earn the revenue it needs to provide essential services like quality aged care?' It is ageist and unjust to expect older people to fully fund their aged care needs. As a nation, we support the child-care and education needs of our young. In the same way, we should also fund the aged care needs of our older people.

The fundamental question which has to be addressed is how we can ensure **revenue** is rightly generated from those whose wealth enables them to pay proportionately more taxes. It is a fact that wealthy people, financial institutions and multinational corporations have established a complex web of tax havens, aided and abetted by accountants, tax and corporate lawyers, as well as lobbyists, all in the name of tax avoidance. In Australia, a third of large Australian companies pay zero tax (Khadem, Gothe-Snape, & Ryan, 2018). Yet, they use publicly funded infrastructure and publicly-educated workforces to generate profits. This type of systemic tax avoidance (both legal and illegal) deprives us of the income necessary to fund social services such as aged care. The ACTU's report in 2017 noted that the 732 companies which paid no tax cost Australians $13.4 billion (ACTU, 2017). We believe that the Commissioners should underscore the necessity for the government to implement progressive and distributive tax policies, and to close all loopholes which enable these billions to be siphoned away from the public purse.

We also strongly believe that aged care is a vital service, and **should not be privatised.** We have seen that the profit motive in the aged care sector has resulted in shocking abuse and neglect. Take BUPA for example. More than half of the nursing homes run by Bupa are failing basic standards of care and 30 per cent are putting the health and safety of the elderly at "serious risk" (Connolly & Stewart, 2019)**.** This is while BUPA is making $1.459 billion dollars in profit.

There is also a need for more **transparency** and explanation as to where the funds being spent on aged care are going. Older people may not be concerned about paying a greater share in their care, but they would like to know that it is going towards their care and not to shareholders' profits or other not-for-profit services (however well-meaning they may be). This applies as much to not-for-profits as it does for corporations. For example, creaming funds from aged care to pay for a

homeless service is unconscionable. It is not the role of one vulnerable group to pay for the service of another disadvantaged group. We would encourage the Commissioners to advise the public on how the current funds are being used, and what percentage is going to other areas of 'management' in all provider organisations.

D) Quality regulation

The Commission should release quality assurance reports to the public. Draft reports should be given to residents and their family so they can make comments to be included in any report. The report should not be limited to the organisation selecting clients and family members to be interviewed as part of the review. There could be public notices or notices sent to all clients that a review is taking place and seeking their comments as part of the process. None of this is of use if the Quality Assurance body cannot impose directions for change, with the corresponding penalties for providers which do not comply. Some differing regulation is needed for institutions, particularly in closed communities where people are more vulnerable. The dynamics for residents and families are very different when dealing with an institution as family members and decision makers are trying to maintain a relationship with staff so their family member or friend is not abused, or visitors are declared 'trespassing' if they enter. There must be external and independent reviewers.

Conclusion

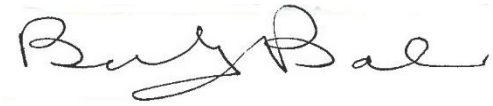
The redesign of aged care in Australia must take into consideration the appropriate human resources to make it work well. The economics of aged care should be calculated not on how much it costs, but how much more it would cost if we do not get it right. Adequately trained staff, the right number of qualified staff, and properly remunerated staff must all be factored into the equation; or we will once again be left with the same situation as we currently face.

We believe that a bi-partisan approach to aged care is critical and it is our hope that the Aged Care Royal Commission can encourage the political parties to come to the table to make a commitment to this effect. We should have guaranteed funding for aged care, irrespective of which political party is in power.

We thank the Commissioners for this opportunity to provide our feedback, and welcome any questions which arise from our submission. The work of the Aged Care Royal Commission is vital in reshaping our deeply flawed aged care system, and we

trust that the Commission will be able to cast its net far and wide to capture the important insights to inform the design of a more humane and better supported system. It is a matter of deep concern to us that older people are still being abused and mistreated in these facilities, and many older women continue to be sexually abused.

Yours sincerely

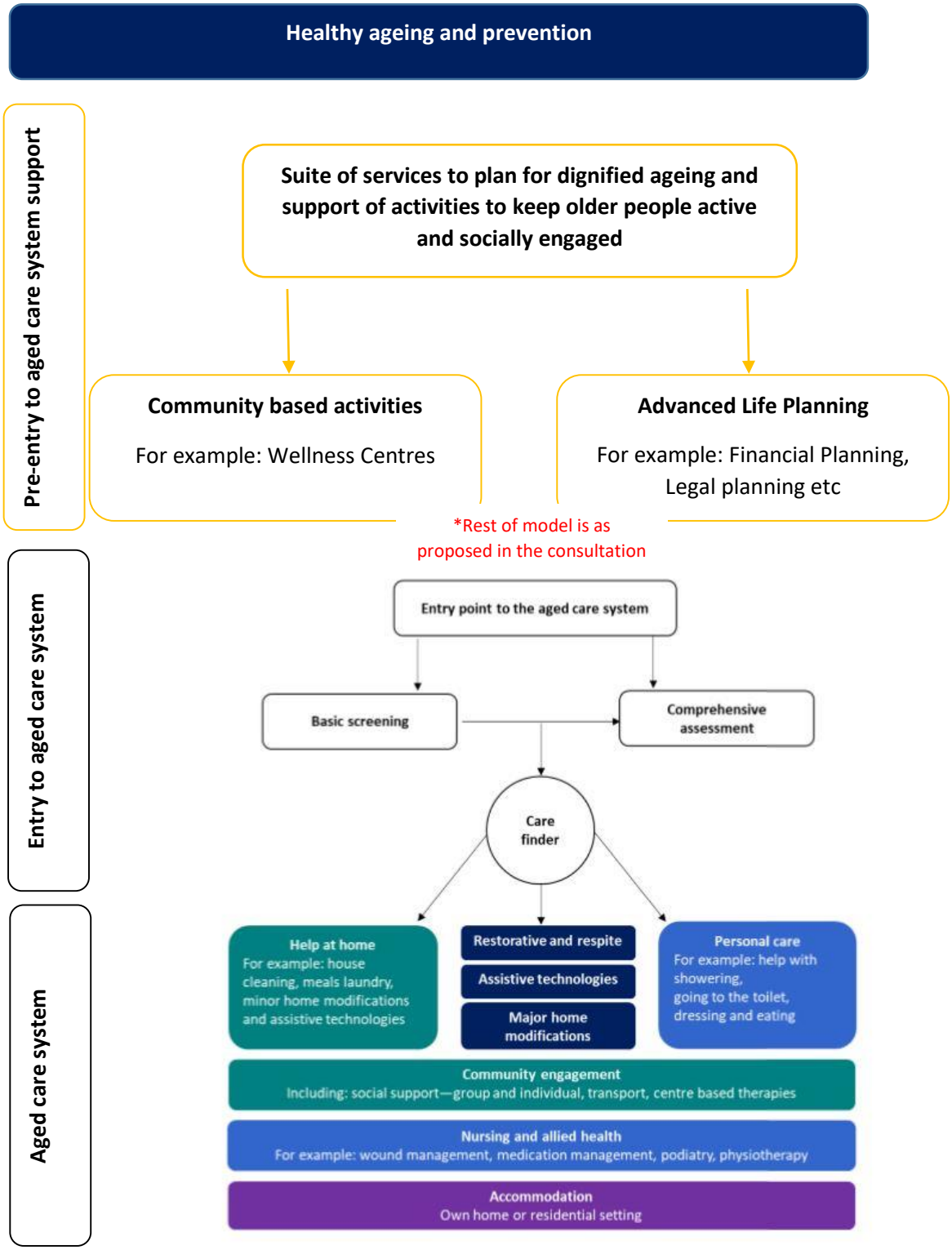


Beverly Baker
Chair
Older Women's Network NSW Inc
8 – 10 Victoria Street
Newtown
NSW 2042
Tel: 9519 8044
Email: chair@ownnsw.org.au

Appendix A

Modified proposed model for aged care system

Adapted from Aged care program redesign consultation paper 1, page 7 of 27



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