## Guiding Questions for the focus areas of the IX Session of the Open-ended Working Group on Ageing: Long-term care and palliative care

- 1) Long-term care for older persons in New Zealand is defined in the Social Security (Long-term Residential Care) Amendment Acts<sup>1</sup> (2004 and 2006)<sup>2</sup>. Support and services for older persons are found in the Age Related Residential Care Services for the Provision of Age Related Residential Care Agreement (2015), as well as the Residential Care Loan and Subsidy Scheme.<sup>3</sup> Support and services are offered according to a needs-based assessment which ascertains whether older persons needs are best met at a rest home, specialist dementia unit, long-term hospital or a psycho-geriatric unit level.<sup>4</sup>
- 2) The ability of older persons to access a high-standard of long-term care is dependent on the financial requirements and constraints imposed by the current system. Currently Residential Aged Care (RAC) is contracted to District Health Boards (DHBs) that help subsidise RAC programs. However, residents can still be charged for additional or more specialised services such as specialised equipment or travel to external services that fall outside the confines of these contracts. For less wealthy older persons, or those with more complex needs and assistance that extend beyond the contracts, they are required to fund their own access to the standard of care they need.<sup>5</sup> The existing assets threshold assessment administered by Work and Income New Zealand can create a binary relationship between residents and their care. Residents with finances above this threshold pay for their care to the maximum, with a small weekly personal allowance, while the remainder apply for a subsidy through their DHB. Some residents that exceed the asset threshold, but have little leverage in between can be negatively affected by this. This in turn can affect the quality of the care they receive.<sup>6</sup>

<sup>&</sup>lt;sup>1</sup> New Zealand Legislation. "Social Security (Long-term Residential Care) Amendment Act 2004. Retrieved from <u>http://www.legislation.govt.nz/act/public/2004/0101/latest/DLM322931.html</u> (Accessed 16/03/18

<sup>&</sup>lt;sup>2</sup> Ministry of Health. "Long-term residential care" Retrieved from <u>https://www.health.govt.nz/our-work/life-stages/health-older-people/long-term-residential-care</u> (accessed on 13/03/18)

<sup>&</sup>lt;sup>3</sup> Ministry of Health. "Long-term Residential Agreement" Retrieved from <u>https://www.health.govt.nz/our-work/life-stages/health-older-people/long-term-residential-care/age-related-residential-care-services-agreement</u> (accessed on 13/03/18)

<sup>&</sup>lt;sup>4</sup> Ministry of Health. "Long-term Residential Care for Older People" – What you need to know" Retrieved from <u>https://www.health.govt.nz/system/files/documents/publications/long-term-residential-care-older-people-2012-jan16.pdf</u> (Accessed on 13/03/18)

<sup>&</sup>lt;sup>5</sup> Dale, M. C., John, S. S., & Hanna, J. (2013). *Financing of Long-term Care and Long-term Care Insurance for the Aged: A Literature-based Comparison of Seven OECD Countries*. Retirement Policy and Research Centre, Economics Department, Business School, The University of Auckland. Pp.13-14

<sup>&</sup>lt;sup>6</sup> New Zealand Treasury. "Long-term care and fiscal sustainability". Retrieved from http://www.treasury.govt.nz/government/longterm/externalpanel/pdfs/ltfep-s4-02.pdf (Accessed 13/03/18).

- 3) A needs-based assessment to ascertain the best interests of the older person takes place before any care is provided.<sup>7</sup> Older persons are eligible to apply for a residential subsidy to assist with their long-term care.<sup>8</sup> This subsidy is dependent on asset and income thresholds as above. Resources and advice about residential long-term care are provided by both government agencies and private organisations to help educate and inform older persons.<sup>9</sup> A recent pay equity settlement that significantly raised the wages and earnings of care workers has also made care work and those associated with it more valued as a profession<sup>10</sup>
- 4) While there are no specific international recognition/enshrined rights of older persons; human rights are intersectional, and by extension, rights to life, a high quality of life, freedom from discrimination and persecution. In many of these areas, the lack of protections for older persons affect their ability to fully access and enjoy the right to long-term care and the certainty of the care and support they need.
- 5) Provision of/for palliative care in New Zealand has not been formally legislated but has been integrated frameworks within the Ministry of Health. This includes a palliative care team that has been established in the Ministry of Health<sup>11</sup> which publishes a Palliative Care Action Plan.<sup>12</sup> In New Zealand, palliative care is defined broadly as 'care for a person of any age who has a life-limiting condition' and it aims to optimize that person's quality of life and support the individual's family.<sup>13</sup>
- 6) Gott et al. (2013) found that a clear majority of palliative cases lacked documented planning and discussion of care between families and nurses in New Zealand. <sup>14</sup> A secondary study by Gott et al. (2012) found that policy definitions and discussion palliative care were not being effectively or clearly translated into care service provision.

<sup>13</sup>Ministry of Health, "Review of Palliative Care Services in New Zealand" Retrieved from

<sup>&</sup>lt;sup>7</sup> Ministry of Health. "Needs Assessment and Support Services for Older People" Retrieved from <u>https://www.health.govt.nz/publication/needs-assessment-and-support-services-older-people-what-you-need-know</u> (Accessed 15/03/18)

 <sup>&</sup>lt;sup>8</sup> Ministry of Social Development. "Residential care subsidy". Retrieved from
<u>https://www.workandincome.govt.nz/products/a-z-benefits/residential-care-subsidy.html</u> (accessed 15/03/18)
<sup>9</sup> Age Concern. "Housing and Care". Retrieved from

https://www.ageconcern.org.nz/ACNZ Public/Housing and Care.aspx (15/03/18)

<sup>&</sup>lt;sup>10</sup> Ministry of Health. "Care and Support Workers Pay Equity Settlement". Retrieved from

https://www.health.govt.nz/new-zealand-health-system/care-and-support-workers-pay-equity-settlement. (accessed 15/03/18).

<sup>&</sup>lt;sup>11</sup> Ministry of Health, "Your Palliative Care Services" Retrieved from <u>https://www.health.govt.nz/your-</u>health/services-and-support/health-care-services/palliative-care (Accessed 16/03/18)

<sup>&</sup>lt;sup>12</sup> Ministry of Health, "Palliative Care Action Plan" Retrieved from

https://www.health.govt.nz/publication/palliative-care-action-plan (accessed 16/03/18)

https://www.health.govt.nz/publication/review-adult-palliative-care-services-new-zealand (accessed 16/03/18) <sup>14</sup> Gott, M., Frey, R., Raphael, D., O'Callaghan, A., Robinson, J., & Boyd, M. (2013). Palliative care need and

management in the acute hospital setting: a census of one New Zealand Hospital. BMC palliative care, 12(1), 15.

They also found problems integrating generalized palliative care into generalized nursing workloads. <sup>15</sup>

- 7) Access to palliative care in New Zealand is "variable", dependent on several factors; including geographical location, the actual diagnosis and the availability of existing services. Furthermore, Māori and Pacific Islanders, long-term care residents, and those living rural are more likely to struggle to access proper palliative care services.<sup>16</sup>
- 8) The resources and capability framework calls for greater integration of palliative care into long-term/residential care business and strategy planning, citing a lack of understanding of palliative care services among aged-care facilities. Palliative care in New Zealand is incorporated into specific nurse training, which can be either generalised or specialised in palliative care service and administration through universities<sup>17</sup> or other care-related organisations.<sup>18</sup> The major providers of palliative care services in New Zealand are through Hospices.<sup>19</sup> Other support/provider organisations include Palliative Care Nurses New Zealand and the National Advance Care Planning Cooperative.<sup>20</sup> Encapsulated in palliative care services are traditional medical and nursing care, pain and symptom control, but also rehabilitation, complementary therapies, alongside bereavement and spiritual support.<sup>21</sup>
- *9)* Long-term care and palliative care in New Zealand are grounded in a human rights perspective. They both attempt to uphold the fundamental human rights and dignity through the alleviation of suffering and optimizing the quality of patients in their given time. Both practices also aim to integrate Māori frameworks of health and well-being, to accommodate for patients who may desire alternative models of care, but also to ground the services provided in a different philosophy.<sup>22</sup>

<sup>22</sup> Ministry of Health, "Maori Health Perspective in Palliative Care" Retrieved from <u>https://www.health.govt.nz/publication/palliative-care-and-maori-health-literacy-perspective</u> (accessed 16/03/18)

<sup>&</sup>lt;sup>15</sup> Gott, M., Seymour, J., Ingleton, C., Gardiner, C., & Bellamy, G. (2012). 'That's part of everybody's job': the perspectives of health care staff in England and New Zealand on the meaning and remit of palliative care. *Palliative Medicine*, *26*(3), 232-241.

<sup>&</sup>lt;sup>16</sup> Ministry of Health, "Resource and Capability framework of Palliative Care In New Zealand" Retrieved from <u>https://www.health.govt.nz/publication/resource-and-capability-framework-integrated-adult-palliative-care-services-new-zealand</u>. (Accessed 16/03/18)

<sup>&</sup>lt;sup>17</sup> University of Auckland. "Palliative Care". Retrieved from https://www.auckland.ac.nz/studyoptions/subject/7777/palliative-care. (Accessed 15/03/18).

<sup>&</sup>lt;sup>18</sup> Hospice New Zealand. "Hospice Education". Retrieved from <u>http://www.hospice.org.nz/education-and-training</u>. (Accessed 15/03/18).

<sup>&</sup>lt;sup>19</sup> Hospice New Zealand. "What is Hospice" retrieved from <u>http://www.hospice.org.nz/hospice-care/what-is-hospice</u>. (Accessed 15/03/18).

<sup>&</sup>lt;sup>20</sup> Ministry of Health. 'key Palliative Care Organisations. Retrieved from https://www.health.govt.nz/our-work/life-stages/palliative-care/key-palliative-care-organisations. (accessed 15/03/18).

<sup>&</sup>lt;sup>21</sup> Hospice New Zealand. "What is Hospice" retrieved from <u>http://www.hospice.org.nz/hospice-care/what-is-hospice</u>. (Accessed 15/03/18).