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Care and Support for Older Persons: Post Covid-19

Prof. Israel Issi Doron
Chair, CRSA – Center for Research & Study of Aging
University of Haifa, Haifa, Israel, 31905; idoron@univ.haifa.ac.il

Part 1: Key Known Fundamentals

1. The Complex and diverse reality of care and support

Most often, long term care and support services (LTCSS) are referred to as a wide range of services that meet the needs of frail older people and other adults with functional limitations (Cox, Doron, & Buckley, Submitted). In its most generic format, long term care refers to all of the supports, ranging from those in the community and home to institutional care, both formal and informal, that assist the older adult and enhance functioning and independence.

Historically, there are several key classifications of LTCSS. One is related to the "location" of care: home/community v. residential/institutional with most of discussions focused on institutional or nursing home care, giving little recognition to the other supports. However, beginning in the 1970s and as part of the "Aging in Place" movement, a greater emphasis was given to home and community LTCSS (Kane, Kane, & Ladd, 1998). The basic premise of Ageing in Place is that helping older people to remain living at home is a fundamental human right and also positively contributes to an increase in well-being, independence, social participation and healthy ageing (Sixsmith & Sixsmith, 2008).

The provider of LTCSS is another key distinguishing characteristic of the system. Formal LTCSS are usually defined as being provided by paid and professional care-givers, while informal services are associated mostly with family members acting as caregivers, often with no financial compensation or any special professional skills. In this context, it is known that the majority of LTCSS services are provided by informal caregivers, i.e. family members.

In reality, the actual structure, content, and frameworks of national and local policies, legislation, and rights with regards to LTCSS vary significantly from country to country, and most times even from locality to locality. Eventually, they are an outcome of unique local histories, values, economics, cultures and politics.

2. Human Rights and the significance and importance of care and support

There is a well recognized theoretical connection between human rights of older persons and the right to LTCSS. This connection is well recognized conceptually (e.g. Doron, 2008), and formally (e.g. in various binding and non-binding elder-rights documents such as in MIPAA – Madrid International Plan of Action on Ageing, The European Social Charter, or the Inter-American Convention on Protecting the Rights of Older Persons, and more.)

However, although there is a diverse body of literature on LTCSS in general and the need for it, there is much less available empirical research on its relationship to human rights of older persons.

The most recent examples in the field focus mostly on the need for a human rights approach within the context of residential/institutional care of older persons (E.g. Meenan, Rees, & Doron, 2016)

Part 2: Covid-19

3.   Covid-19 and the Care and Support Systems for Older Persons

In light of various aspects of the Covid-19 pandemic, and its unique characteristics, both with regards to the higher death-risk for older persons, as well as with the unprecedented measures that were adopted to combat it (e.g. broad social and economic closures, and far-reaching social distancing policies) – LTCSS were all placed under a test. In many cases, the ability of older persons to survive the pandemic, was dependent on the functioning (or dis-functioning) of the LTCSS. Hence, the actual experiences, successes and failures of the LTCSS must be taken into account when looking into the future.

4.   Some Key Insights for Post-Covid 19

It is beyond the scope of this short paper to fully describe and analyze the ways in which LTCSS functioned around the world during the Covid-19 pandemic. Much more data and research is needed in the field. But, with the limited and partial experience that has already been collected, and from my personsl perspective and experience in Israel, here are some key insights in the field (followed by recommendations based on the Joint Submission by Age Platform Europe et al., to the 10th Session of the UN OEWG, 2019).

a.   Voice, Participation and Inclusions of Older Persons in Macro Care and Support Policy Making

Throughout the Covid-19 crisis, government had to shape and adopt new policies, emergency measures, and even new laws and regulations – which influenced or were related to LTCSS for older persons. In many cases, during these policy making processes, older persons were not heard, their representatives were not part of the discussions, and overall their voices were not taken into account (See for example Age International Report, 2020).
- Any post Covid-19 policy needs to ensure that older persons have the opportunity to participate in policy decision-making process on all forms of LTCSS.

b.   Voice, Participation and Inclusion of Older Persons in Micro/Local/Private LTCSS

Throughout the Covid-19 crisis, various local and private service providers of LTCSS (e.g. managers of assisted living facilities) had to shape and adopt new policies, emergency measures, and local practices – which directly influenced their older clients. In many cases, during these policy making processes, older persons were not heard, their representatives were not part to the discussions, and overall their voices were not taken into account.
- (Recommendation: same as above)

c.   Equality and Anti-Discrimination in LTCSS: The Price of Ageism

As have been reported in various documents, the Covid-19 crisis was followed by ageist narratives such as both viewing the older population as a "vulnerable" population, as well as a "burden" on society (e.g. Ayalon, 2020). The outcome of this public – and mostly negative - discourse was not

only visible in ageist expressions on public media, but was followed in discriminatory practices within the LTCSS. These policies were sometime carried out by using the sole criteria of chronological age – with total disregard to individualistic characteristics or needs; Or, in other cases, preference was given to younger or working-age populations over older adults.

- Any post Covid-19 policy needs to ensure that older persons enjoy equal rights, are not subject to ageism, and are not subject to discrimination based on their age with regards to LTCSS.

d. Autonomy, Freedom of Choice, and Control

In some cases, the outcome of various Covid-19 related policies, such as closures, social distancing, and limitations of various social activities, disproportionately affected older adults, and hampered their autonomy, control, and choice with regards to their LTCSS. For example, suspending non-urgent medical services, or differential treatment placing older adults in specific restrictive policies, prevented older adults with choices that other (and younger) groups were open to.

- Any post Covid-19 policy needs to ensure that older persons have choice and control over care and support services which are adapted to their individual needs and preferences;

e. The significance of family members and informal caregivers and their legal rights & the significance of LTCSS for those without informal/family support

There is a growing body of evidence showing how the social isolation, social distancing, and physical and the social disconnect from family members and informal social support networks, have negatively effected older persons and their family members (e.g. Sepulveda-Loyola, W., et al. 2020). These negative influences were exemplified in various forms such as stress, anxiety, depression, poor sleep quality, and deterioration in general health.
At the same time, those older persons without any familial or informal support networks, who were totally disconnected from the formal community-based LTCSS they rely on (e.g. due to closures) – were left sometimes totally neglected without any support what so ever.

- Any post Covid-19 policy needs to ensure that the significance of LTCSS, both formal and informal, as a fundamental human right of older persons - is formally recognized and anchored in national legislation.

f. The failure of institutions and the need to advance home-based and community-based long term care and support services

Various preliminary findings indicate how nursing homes throughout the world have failed to protect their older residents (e.g. NY Attorney General Report, 2020). These reports point to many issues such as lack of sufficient staffing, lack of compliance with infection control protocols, insufficient protective equipment, insufficient testing, and much more. The outcome of these failures was the significant and disproportionate death rates of older residents in nursing homes. This reality mandates a re-assessment of the legitimacy of residential and institutional care for older persons as part of the LTCSS in the field.

- Any post Covid-19 policy needs to ensure that the right "to age in place" in not only a slogan or a policy issue, but rather a mandated human right which aims at the eventual abolishment of institutional care for older persons.

In Sum

It is my view, that to some degree, the failures in the LTCSS for older persons described above, only mirrored the well known existing reality which exited prior to Covid-19: (1) The absence of a human rights discourse within the LTCSS realm; and (2) The lack of a binding international framework to set clear standards and expectations in the field. Looking into the post Covid-19 era – and if we want to prevent the same failures in the future - we need to amend both of these insufficiencies.

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