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From disability rights towards a rights-based approach to long-term care in Europe:

Building an index of rights-based policies for older people

Working Paper II: Conceptual framework for a human rights-based approach to care and support for older individuals

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1. A rights-based framework for care & support for older individuals

1.1 The need for a new framework & important limitations

Countries across Europe, and indeed around the world, are confronting the social, economic and political challenges of an ageing population. Among the most pressing of these challenges is the organisation and financing of long-term care (LTC) and support for older people. While people are living longer than previous generations, they are not necessarily living these additional years in good health, and most will require some form of care or assistance in later life (Colombo et al., 2011). This working paper, the second in the series attached to the project "From disability rights towards a rights-based approach to long-term care in Europe: Building an index of rights-based policies for older people", presents a conceptual framework for a human rights-based approach to care and support services, and attempts to detail what the fulfilment of universal human rights entails when applied to the particular case of older people with care and support needs.

As discussed in our earlier work (Schulmann et al., 2017) there is growing consensus that long-term care services should look beyond a medical model of 'care' to take a broader, more holistic view in which older people's wellbeing and quality of life and their preferences regarding care and support are central to the design of services. In past decades, the debate surrounding the role of the state, the family, and the community in bearing the financing and provision of long-term care services has been framed primarily as a question of state's obligations vis-à-vis its citizens, with the issue of sustainability of public sector financing serving as a pivotal aspect of the discussion. More recently, another branch of the discourse has emerged, emanating primarily from the NGO and advocacy sector but increasingly being taken up by policymakers internationally and at the European Union (EU) level. This branch explores the issue from within the frame of human rights. The influence and impact of this approach is evidenced by the inclusion of the right to long-term care in the recently signed European Union's Pillar of Social Rights, the ongoing work of the UN Open-ended Working Group on Ageing, the recently concluded research study by the European Network of National Human Rights Institutions (ENNHRI) on the rights of

older people in residential long-term care, and the work of AGE Platform Europe in collaboration with other advocacy groups as part of the DAPHNE Eustacea project to develop the European Charter on the Rights and Responsibilities of Older People in Need of Long-term Care and Assistance, among many others. Taking the stance that older individuals, as rights holders, possess certain inviolable, universal rights—including the rights to dignity, autonomy, equality and non-discrimination—a human rights approach secures older people's legal right to access quality care and support should they require it and so choose. A human rights approach does not give much credence or space to economic theories of cost-utility and care rationing, a fact which constitutes a considerable part of its appeal for those who consider access to care and support for older people to be an issue of equality and social justice, but which has also proven to be a barrier to the realisation of rights across a range of domains (AGE Platform Europe, 2016; HelpAge International, 2013 & 2015; Bershtling et al., 2016). In recognition of this barrier, human rights standards—comprised of international, regional and national human rights legal instruments—typically include 'progressive realisation' clauses, conceding that a lack of resources can be an obstacle in the realisation or fulfilment of human rights and that certain rights can only fully be achieved over a longer period of time (UN CESCR, 2000).

In exploring a human rights-based approach to care and support for older people in this project and in working to develop a framework grounded in human rights, the authors acknowledge a number of limitations. While existing human rights standards do provide provisions for the fulfilment of the universal rights (including social, economic, cultural, and civil and political rights) of all individuals including older adults, there is currently no distinct international or regional convention specifically addressing the rights of older people that is comparable to the instruments targeting women, children, or people with disabilities[1]. The provisions set down in the UN Convention on the Rights of Persons with Disabilities (UN CRPD) come closest to addressing the rights of older people with care and support needs. Yet in the detailing of the basic principles and rights underpinning the Convention, and in its interpretation in multiple General Comments by the Committee on the Rights of Persons with Disabilities[2], some scholars are of the opinion that older people *ageing into* disability and their particular circumstances are not well represented (Harpur, 2016). This may explain the documented implementation gap in the enforcement of the rights of older individuals with care and support needs which has proven difficult to breach (Council of Europe, 2014; Doron & Apter, 2010). The UN Open-ended

[1] UN Convention on the Elimination of All Forms of Discrimination against Women (1979), UN Convention on the Rights of the Child (1989), UN Convention on the Rights of Persons with Disabilities (2007), respectively.

[2] In particular, General Comment No. 5 (2017) on article 19: Living independently and being included in the community; General Comment No. 1 (2014) on Article 12: Equal recognition before the law; General Comment No. 3 (2016) on Article 6: Women and girls with disabilities.

Working Group on Ageing has been discussing the topic of a new UN convention on the rights of older people generally (i.e not restricted to older people with care and support needs), and advocacy groups like AGE Platform Europe, HelpAge International, and ENNHRI have advanced the discourse in this regard, indicating widespread agreement that the rights of older people are afforded insufficient consideration within current human rights standards. On the other hand, several UN Member States, citing the aforementioned implementation gap, oppose a new convention on the grounds that it is the role of national governments to implement stronger legal protections and/or enforcement mechanisms (Poffé, 2015). Setting this debate aside, there nonetheless seems to be a need to examine how the rights of older people with care and support needs can most effectively be protected and enforced through the application of a rights-based approach.

The theoretical starting point for the literature review discussed in the first working paper (Schulmann et al., 2017) was a comparison of the distinct discourses emerging around the rights of people with disabilities and the rights of older people with care needs, due to the unique overlaps in the support needs of both groups. And while the findings of the literature review confirmed certain commonalities between the two groups in the context of a rights-based approach, it also revealed important differences and nuances to the case of older people that must be taken into account. Among others, these include very different perceptions of and attitudes towards the concept of care and support, and the distinct form of age-based discrimination experienced by older people known as ageism. Ageism is systemic and pervades inter-personal interactions, decision-making at the systems level, and most insidiously, the self-perceptions and identities of older individuals themselves (see §4.2, in Schulmann et al., 2017). It is also important to note and to be clear that while the work presented here engages particularly heavily with the model for a rights-based approach to support for people with disabilities provided by the UN CRPD, the two cannot and should not be compared side by side. First, for the obvious reason that one is a legal text and the other is not; and second, because the framework discussed here—and ultimately the index whose construction it will inform—is significantly narrower in scope than the CRPD. Our focus here is strictly on the rights of older people *with care and support needs.* It does not address the rights of older people more generally and is intended to guide and support policymakers in the evaluation of LTC system interventions and reforms, rather than as an input to the political debate. While the aim of the framework and the index to follow is to serve as a tool for policymakers, the work presented in this working paper and in the project as a whole is academic and exploratory in nature and should be treated as such.

1.2 Methodology

The conceptual framework presented in the next section was informed by a literature review of academic and grey sources carried out in the first stage of the project and described in detail in earlier work (see §1.3, in Schulmann et al., 2017). The findings from the literature review were validated and elaborated through an expert workshop held in October, 2017, which convened 9 experts from several European countries with different professional backgrounds—including human rights law, social policy, and sociology—and institutional affiliations—including advocacy organisations, service providers, and academia. Based on the discussions during the workshop and the input generated by the experts, the authors reviewed a limited number of additional grey sources, primarily human rights instruments and the supplementary texts pertaining to them (e.g. general comments by the committees of various UN conventions).

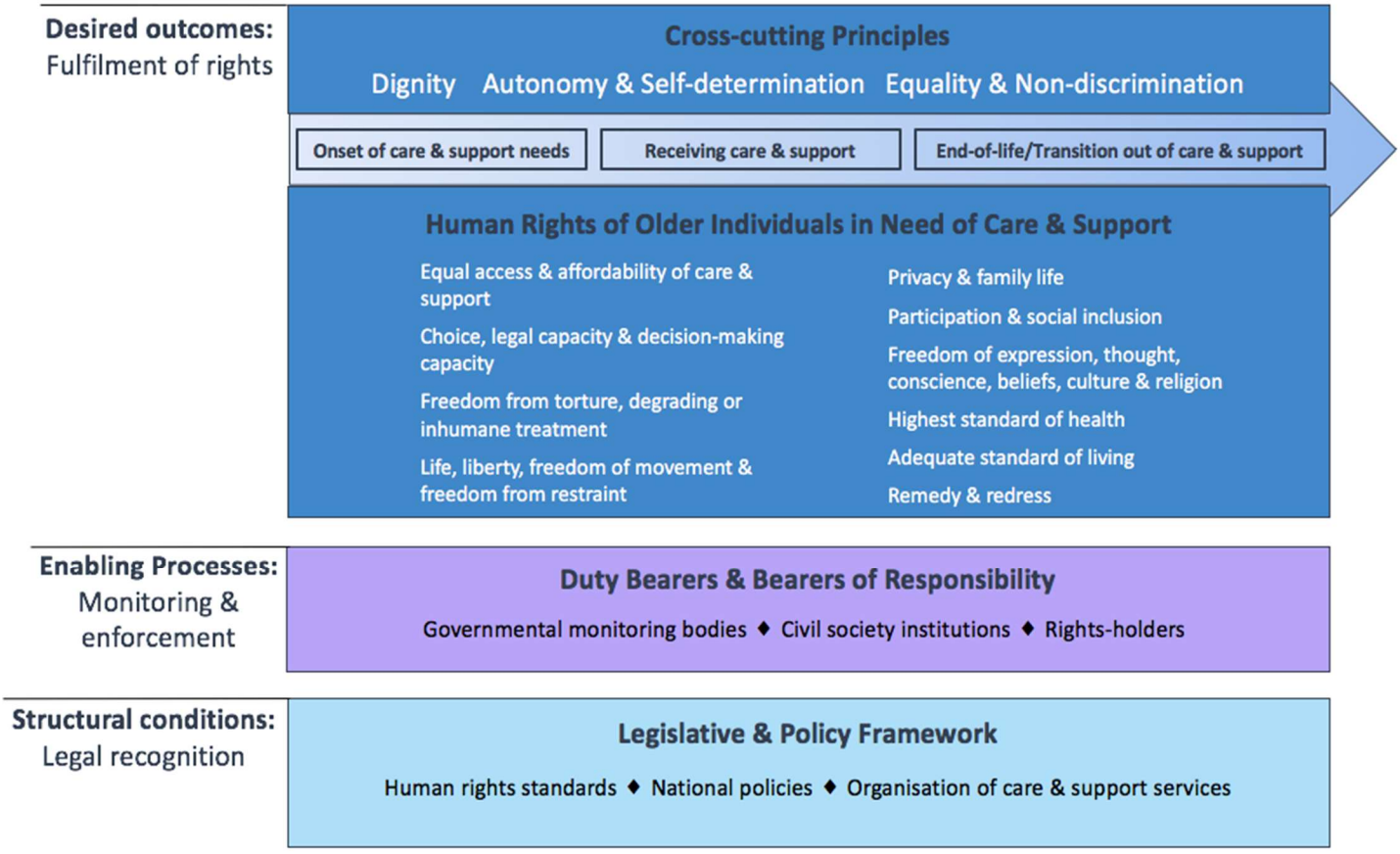
2. Presenting the conceptual framework

2.1 The framework, its domains and its underlying principles

The conceptual framework for a human rights-based approach to care and support for older people is presented in Figure 1 below. Following the work of the United Nations office of the High Commissioner for Human Rights (UN OHCHR, 2012) and the European Union Agency for Fundamental Rights (FRA, 2014), and grounded in the structure-process-outcome model of care quality evaluation (Donabedian, 1988), the framework is organised according to three key domains: 1) Desired outcomes: fulfilment of rights; 2) Enabling processes: monitoring and enforcement; and 3) Structural conditions: legal recognition. These three domains correspond with three areas across which the implementation of fundamental rights can be measured: results (outcome indicators); effort (process indicators); and commitment (structural indicators) (FRA, 2014). The following paragraphs in this section describe each of these three domains in detail and their interlinkages. Homing in on the principles and rights identified in the framework, the next section (§2.2) proceeds to detail older persons' "applied rights". Applied rights are defined by the authors as the

interpretation and extension of universal or more general rights to the specific case of older people with care and support needs. This category of rights has been referred to in other contexts as "substantive" or "incidental" rights (Harpur, 2012; UN, 2006). The identification and synthesis of relevant principles and human rights captured in the first domain receives the most attention in the framework, and together with the subsequent detailing of applied rights, constitutes the authors' main contribution to the scholarship in this area and on this topic.

Figure 1: Conceptual framework for a human rights-based approach to care & support for older individuals



The ***Desired outcomes: fulfilment of rights*** domain represents the central aim or outcome of a human rights-based approach to care and support for older individuals with care and support needs, namely the realisation of their rights. The cross-cutting principles and rights identified in the literature as most relevant for older people are presented in this first domain and include: dignity, autonomy and self-determination, and equality and non-discrimination. These principles constitute the cornerstone of

a human rights approach and are referenced extensively in international and regional human rights standards[3] and soft law[4].

Dignity refers to the inherent worth of every person and the right of every individual to be valued and treated with respect (UN OHCHR, 2012). Because it is such a fundamental concept, one which affirms the essential personhood and value of every individual, the principle of dignity is reflected in each and every of the ten universal rights identified in our framework, beginning with the right to *Equal access and affordability of care & support* through to the right to *Remedy & redress*. Valuing every older person means supporting their wellbeing, which entails not only meeting their care needs but also ensuring that services promote quality of life and opportunities for personal growth and aspirations. Upholding the principle of dignity is perhaps most clearly reflected in and exemplified by the rights to *Privacy & family life*, *Freedom from torture, degrading or inhumane treatment,* and *Participation & social inclusion*. If we accept that every person must be treated with dignity this also means that care and support services cannot intrude on or interfere with an older individual's right to privacy and their right to maintain and form new personal relationships, including intimate relationships. Importantly, and of increasing relevance amidst developments in Ambient Assisted Living and Smart Home initiatives, reflecting on older individuals' right to dignity also requires consideration of how assistive devices and technologies are being used to monitor and collect data on their movements, behaviour and health conditions. While such technologies have definite benefits (notably, for fall prevention and monitoring of chronic health conditions) and can be positive additions to more traditional forms of care and support, they may also constitute an invasion of privacy if they are implemented without the full awareness and consent of the user (Kornfeld-Matte, 2017). This is especially relevant and potentially problematic in the case of people with dementia, where monitoring devices are commonly employed. Notably, the principle of dignity also underpins the right to *Freedom from torture, degrading or inhumane treatment,* with direct relevance for the issue of elder abuse (Phelan, 2008; AGE Platform Europe, 2014; Kornfeld-Matte, 2017). The principle of dignity is clearly reflected also in the right to *Participation & social inclusion,* in that to treat someone with dignity means recognising their full personhood, individuality and role in the community, rather than perceiving them solely as a patient to whom care is administered.

[3] UN Universal Declaration of Human Rights (1948); Council of Europe European Convention on Human Rights (1953); UN International Covenant on Civil and Political Rights (1966); UN International Covenant on Economic, Social and Cultural Rights (1966); UN Convention on the Removal of All Forms of Discrimination Against Women (1979); UN Convention on the Rights of Persons with Disabilities (2006).

[4] European Pillar of Social Rights (2017); UN Principles for Older People (1991); UN Madrid International Plan of Action on Ageing (2002) European Charter on the Rights and Responsibilities of Older People in Need of LTC (2010).

Having ***Autonomy and self-determination*** means being in control of every aspect of one's life and having one's choices and decisions respected (UN OHCHR, 2012). These two linked principles are crucial in the empowerment of older people and in shifting the power balance between older users of care services and other stakeholders, including family members, doctors, care professionals and other service providers. The UN CRPD in particular emphasises the principles of autonomy and self-determination and the ability to make choices for one's self as fundamental to enabling people with disabilities to live full lives with the same opportunities as everyone else. This links to the distinction between decisional and executional autonomy in the context of disability or dependency (Collopy, 1995). Autonomy and self-determination is of particular relevance in discussions surrounding the rights to *Choice, legal capacity and decision-making.* Irrespective of the capacity to make decisions (which may become impaired due to dementia and other neuro-degenerative diseases), older people should have the right to retain their legal capacity by virtue of being autonomous beings. This is a right that is not currently being upheld in many countries due to a reliance on guardianship laws, whereby decision-making authority is transferred to family members or other court-appointed legal guardians. In lieu of guardianship, the right to legal capacity calls for the use of *supported* decision-making, whereby a range of strategies and tools including counseling, alternative communication strategies and advanced directives are employed to assist older people in making decisions that concern their care and more general wellbeing. The principles of autonomy and self-determination also strongly underpin the rights of older people to *Life, liberty, freedom of movement and freedom from restraint*. Despite increasing evidence of their potential harm and the proliferation of guidelines directing care professionals against their use, both physical (i.e. bed rails, belts, door alarms) and chemical (i.e. psychotropic medications) restraints are still commonly used in many nursing homes (WHO, 2015; Kornfeld-Matte, 2016), with lack of sufficient resources and understaffing cited as common reasons for continuation of the practice. Under the auspices of preventing wandering and safety risks, many persons with dementia continue to be segregated on locked wards. Both of these practices constitute breaches of older people's rights as autonomous human beings. Older people with care needs, whether opting for home-based or residential care services, must be supported in their right to move about freely and to not have their movements restrained. The latter has close links to the rights of older persons to *Freedom from torture, degrading or inhumane treatment* as well. Lastly, technology has an increasingly important role to play in supporting older people in exercising their autonomy, by making information available online and enabling them to inform themselves about and select from among different care options. The flip side of that coin, however, is that access to technology is inconsistent for a number of reasons (including availability, affordability, user literacy) and can just as easily prove to be a barrier to older people's autonomy and ability to make choices (Kornfeld-Matte, 2017; AGE Platform Europe, 2014).

The third set of fundamental principles, ***Equality and non-discrimation***, are closely related albeit distinct concepts. Equality refers to the creation of societal conditions that respect difference and address disadvantage in order to ensure that all persons can participate in society on equal terms (UN OHCHR, 2012). Non-discrimination means that "all rights are guaranteed to everyone without distinction, exclusion or restriction based on disability or on race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, age, or any other status" (UN OHCHR, 2012: 19). Equality is commonly referred to as a positive right and non-discrimination as a negative right, where the former requires concerted action on the part of policymakers, while the latter requires only that the state not interfere (Stein & Stein, 2007). Taken together, the principles of *Equality and non-discrimination* form the basic premise for a rights-based approach to care and support for older people and underpin each of the rights identified in the framework's first domain. All individuals, regardless of age, have the right to *Equal access and affordability of care & support services*, to the *Highest standard of health*, and to an *Adequate standard of living;* rights that are currently endangered in many countries by social welfare policies that use age as legitimate grounds for discriminatory policies. Such policies include age-based care rationing and the draining of private assets towards the payment of long-term care services (Giordano, 2005; Sloan, 2016). In addition to its relevance for ensuring inter-group equity, equality and non-discrimination demands that all identified rights, including notably the rights to access affordable and high-quality services and to social participation, be promoted and upheld for particularly vulnerable groups of older people. Vulnerable groups include but are not limited to women, ethnic/racial minorities, people living in poverty and in low-resource areas, members of the LGBTQ community, people with non-age-related disabilities and people with cognitive impairments.

Drawing on the work of ENNHRI and their formulation of the rights of older people in residential long-term care (ENNHRI, 2017), our framework uses the *Care trajectory* as its main organising principle. The care trajectory refers to the older person's progressive interaction with long-term care and support services, from *Onset of care & support needs*, to *Receiving care & support*, through to *End-of-life (EoL) care* OR the *Transition out of care & support*. Regaining independence and transitioning out of care and support entirely may be a relatively rare occurrence, particularly among the oldest care users, yet services should nonetheless be designed around the goal of reablement (Aspinal et al., 2016). Running through the middle of the framework's first domain, the *Care trajectory* arrow implies that the relevance and specificity of each right will vary as an individual's care and support needs evolve and as their interaction with service providers changes. Though not visually represented in the framework, we also recognise that the *Care setting* can alter the fulfilment of rights. Depending on the care setting, which can include the person's home, the community

(e.g. day care centres) or residential facilities, the application or interpretation of a given right may vary.

Likewise, though the important role of carers in the fulfilment of the rights of older people in need of care—and indeed their own rights as care providers— is not visually represented in the framework, consideration of the interdependent relationship often characterising care and support for older people is woven into the formulation of the applied rights detailed in the next section. Because our framework is rooted in the human rights tradition with its strong emphasis on individual rights, the focus must be on the rights of people in need of care and support. We encourage future research and discussion on the rights of formal and informal carers and how their rights can be reconciled with the rights of the users of care and support services.

The second domain, ***Enabling processes: monitoring & enforcement***, represents the obligation and authority of national governmental bodies to uphold human rights. According to the definition provided by the European Union's Agency for Fundamental Rights in its work defining indicators to measure the fulfilment of rights, the process domain captures the initiatives and efforts of governmental institutions to achieve the desired outcomes (FRA, 2014). States may fulfill their obligations through various monitoring and enforcement mechanisms, and it is essential that non-governmental stakeholders be involved in the process in order to hold the designated governmental bodies accountable. These include civil society institutions, including advocacy organisations, as well as rights-holders themselves. The third domain, ***Structural conditions: legal recognition***, represents the institutional aspects of states' commitments to human rights (FRA, 2014) and addresses the importance of human rights standards at the international, regional and national level. While human rights standards form the legal foundation and so the very basis for older individuals with care and support needs to claim their rights, it has been widely established that there is often a significant gap between *de jure* and *de facto* protections (Chung, 2010; Doron & Apter, 2010). It is therefore necessary to closely link legal recognition to sound monitoring and enforcement structures in order to achieve a fulfillment of rights.

2.2 Applied rights of older individuals in need of care & support

In the following section, the ten universal or more general human rights listed in the first domain of the framework (see Figure 1) are elaborated on and developed into what have been termed "applied rights". As described earlier, the starting point for development of the applied rights was to pin down the most important and most relevant elements of each of the general rights in the context of providing the kind of

quality care and support that promotes older people's wellbeing. This approach is modelled on the structure of the UN CRPD in which each article of the convention stipulates the specific provisions that states must enact to ensure that the universal human rights of people with disabilities are realised in practice (UN CRPD, 2006; Harpur, 2012). For each of the ten general rights identified in the framework, the table below (see Table 1) presents our interpretation of what the right means in practice across each of the three stages of the care trajectory: at the onset of care and support needs; while receiving care and support; and at the end-of-life, or in the transition out of care and support services. The applied rights have been defined based on the findings from the literature review carried out in the first phase of the research study (Schulmann et al., 2017), as well as a supplemental review of specific human rights standards, input from international experts, and the authors' expertise in the areas of ageing and long-term care. In formulating the applied rights defined below, the authors aimed to achieve a level of specificity and detail that can be useful for policymaking at a strategic or programmatic level. The applied rights provide the baseline for the selection of indicators to be included in the construction of the index, which will follow in the next stage of the project.

Table 1: The ten *general rights* and respective *applied rights* of older people in need of care & support, across the three stages of the care trajectory

Cross-cutting principles **Dignity** **Autonomy & Self-determination** **Equality & Non-discrimination**		
Onset of care & support needs	**Receiving care & support**	**End-of-life (EoL) / Transition out of care**
1. Equal access to & affordability of care & support		
Universal access to and ownership of assessment of care & support needs[5] Universal access to prevention/rehabilitation/ information & counselling[6] Universal access to adapted housing and enabling living environments[7]	Equal access to a range of care & support services (needs, preferences & setting specific) for assessed equal need Accessible (proximity, barrier-free) care services	Equal access to palliative, EoL and a range of other care services (needs, preferences & setting specific) for assessed equal need Accessible (proximity, barrier-free) care services

[5] Irrespective of income/wealth, rural/urban residence, gender, sexual orientation or ethnicity/race.
[6] Ibid.
[7] Ibid.

2. Choice, legal capacity & decision-making capacity		
Initiate needs assessment Active participation in the needs assessment process Decision-making capacity and supported decision-making Control over choice of care and support services, setting & provider in accordance with user's individual requirements and personal preferences Advanced care planning (ACP) Information & counseling on care and support options (including assistive devices/technologies) that is accessible in its content and format and upon which the user can act	Control over choice of care and support service(s), care setting & provider Control over daily routine and maintain usual habits Advanced care planning (ACP) Decision-making-capacity and supported decision-making Information & counseling on care and support options (including assistive devices/technologies) that is accessible in its content and format and upon which the user can act	Information & counseling on palliative & EoL care options (including assistive devices/technologies) that is accessible in its content and format and upon which the user can act Have one's wishes and preferences with regard to EoL & palliative care and support respected (as outlined in advanced care directives) Decision-making capacity and supported decision-making Control over choice to terminate care and support services Control over place of death
3. Freedom from torture, degrading or inhumane treatment		
Not be abused or mistreated, humiliated or degraded by care providers or family members	Not be abused or mistreated, humiliated or degraded by care providers or family members Pain management	Not be abused or mistreated, humiliated or degraded by care providers or family members Die free from pain (to the extent possible)
4. Life, liberty, freedom of movement & freedom from restraint		
Not be held against one's will during needs assessment	Not be coerced into any kind of care or support service (including assistive devices/technologies), or care facility Not be held against one's will in a 'closed unit' Not be physically or chemically restrained Not have one's movements surveilled without informed consent (e.g. through assistive devices/technologies) Control over one's mobility (e.g. driver's license) unless deemed dangerous to others by a competent authority	Not be coerced into any kind of care or support service (including assistive devices/technologies), or care facility Not have one's movements surveilled without consent Not be physically or chemically restrained
5. Privacy & family life		
Privacy of personal and medical data and informational self-determination Consideration of one's responsibilities and preferences	Privacy of personal and medical data and informational self-determination Maintain family relationships (inclusive of co-habitation with partner/other family members	Privacy of personal and medical data and informational self-determination Physical & emotional privacy within EoL care arrangement including choice over sharing a

vis-à-vis family members within needs assessment	in residential care; and regular & meaningful contact) Physical & emotional privacy within care and support and living arrangement (inclusive of the use of assistive devices/technology)	room (and inclusive of use of assistive devices/technology) Maintain family relationships (inclusive of co-habitation with partner/other family members in residential care; and regular & meaningful contact) Have preferences related to dying respected Form & maintain sexual/intimate relationships
6. Participation & social inclusion		
Access to a range of home-based, residential and other community support services necessary to support living and inclusion in the community Inclusive and age-friendly living environment/public space. Barrier-free technology and simple and accessible information (as to its content, format and means of access) and other support in how to use it Facilities and grounds that are open and allow free movement to users and to family members and members of the community	Access to a range of home-based, residential and other community support services necessary to support living and inclusion in the community Inclusive and age-friendly living environment/public space. Barrier-free technology and simple and accessible information (as to its content, format and means of access) and other support in how to use it Facilities and grounds that are open and allow free movement to users and to family members and members of the community	Access to a range of home-based, residential and other community support services necessary to support living and inclusion in the community Inclusive and age-friendly living environment/public space. Barrier-free technology and simple and accessible information (as to its content, format and means of access) and other support in how to use it Facilities and grounds that are open and allow free movement to users and to family members and members of the community
7. Freedom of expression, freedom of thought, conscience, beliefs, culture and religion		
Have cultural, political and religious beliefs (and potential related resources) and sexual identity respected in needs assessment process Have cultural, political and religious beliefs (and potential related resources) and sexual identity respected in choice of care setting & provider	Have cultural, political and religious beliefs (and potential related resources) and sexual identity respected by care providers	Have cultural, political and religious beliefs (and potential related resources) and sexual identity respected in EoL care
8. Highest standard of health		
Available, accessible, acceptable and quality prevention services (inclusive of health information) & rehabilitation services	A range of available, accessible, acceptable and quality care & support services (inclusive of mental health services) according to assessed need Supported health information (understandable, accessible and	Available, accessible, acceptable and quality palliative & EoL care and a range of other care and support services according to assessed need Psychological counselling related to EoL

Available, accessible, acceptable and quality mental health services Available, accessible, acceptable and quality timely and appropriate needs assessment & diagnostic services	which users can act) & counselling	Information & counseling on EoL care and discharge from care options (including assistive devices/technologies) that is accessible in its content and format and upon which the user can act
9. Adequate standard of living		
Secure housing with modern sanitation and pleasant environment Nutritious & enjoyable food & potable water Access to social protection programmes and poverty reduction programs[8] Maintain adequate financial resources for personal expenses after accounting for care and living expenses	Secure housing with modern sanitation (inclusive of private homes & residential facilities) and pleasant environment Barrier-free and adapted housing according to assessed need Nutritious & enjoyable food & potable water Availability of support services and assistive devices and technologies in conformity with the rights and needs of the user Maintain enough financial resources for personal expenses after accounting for care and living expenses	Secure housing with modern sanitation (inclusive of private homes & residential facilities) and pleasant environment Barrier-free and adapted housing according to assessed need Nutritious & enjoyable food & potable water
10. Remedy & redress		
Receive information on complaint & contestation procedures without fear of reprisal in case access to a range of care services and/or needs assessment is hindered Complain and contest without fear of reprisal in case needs are not addressed for a range of reasons Have complaints heard by institutional body with the authority to enforce remedy & redress	Receive information on complaint & contestation procedures without fear of reprisal in case access to a range of care services is hindered Complain and contest without fear of reprisal in case access to a range of appropriate care services is hindered Complain and contest without fear of reprisal in case of abuse and mistreatment Have complaints heard by institutional body with the authority to enforce remedy & redress	Receive information on complaint & contestation procedures without fear of reprisal in case access to appropriate palliative & EoL and a range of other care services is hindered Complain and contest without fear of reprisal in case access to appropriate palliative & EoL and a range of other care services is hindered Complain and contest without fear of reprisal in case of abuse and mistreatment Have complaints heard by institutional body with the authority to enforce remedy & redress

[8] Irrespective of rural/urban residence, gender, sexual orientation or ethnicity/race.

3.Conclusions and next steps

The conceptual framework and applied rights presented in this working paper build on existing human rights standards and on a critical synthesis of the scholarship regarding the most important components of a rights-based approach to care and support for older people. While the discourse surrounding the disability rights movement provides an illuminating model for what such a framework might look like, it also brings into sharp relief certain aspects of caring for and supporting older people in their daily lives that are intrinsically different and unique to this group of the population. The applied rights defined in the previous section serve to put into context and articulate the nuanced situation of older persons with care and support needs within the established architecture of human rights. The aim of the study is to develop a framework—and ultimately an index—with which to monitor and assess the extent to which states are upholding the rights of older people *with care and support needs* who come into contact with the long-term care system. Our definition of long-term care is comprehensive (see §4.2.1 in Schulmann et al., 2017) and includes services to support social participation and inclusion in the community. The literature review and the consultation with experts in the field reaffirmed the need to go beyond a traditional, medical view of long-term care, one which renders 'care' as the main outcome of interest rather than the wellbeing of the older person. In the development of the framework, we aimed to achieve a balance between the essential principles of autonomy and self-determination from within the human rights discourse, and the often-interdependent relationship between older individuals and the family members and/or professionals providing care and assistance.

The framework described in this working paper lays the conceptual groundwork for the development of the index's domains and indicators—particularly in its construction around structural, process, and outcome factors in the fulfilment of rights.

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