

Submission based on seminar with Europe-based experts on the Human Rights of Older Persons

Convening in Brussels in April 2018

30th April 2018

Introduction

This document constitutes a summary of points arising from a European experts and rights-holders meeting on the human rights of older persons convened in Brussels, Belgium, 12-13 April 2018 by the UN Human Rights Regional Office for Europe (OHCHR ROE) and AGE Platform Europe. The objectives of the meeting included:

- To explore conceptions of human rights of older people utilizing the expert knowledge of human rights advocates and practitioners;
- To empower key stakeholders and older people through increased awareness of human rights concepts, and how they apply in older age situations;
- To feed into ongoing discussions around the human rights of older person, including by identifying normative gaps and conceptual language for the advancement of the human rights of older persons.

The document presented here does not necessarily reflect a consensus position agreed by the participants of the seminar or the organisations they represent. The document also does not necessarily reflect the views of OHCHR or of AGE Platform Europe. The sole purpose of this document is to capture some of the key issues, challenges and questions raised during this key seminar which it could usefully inform discussions in the 9th session of the UN OEWG.

The April 2018 meeting took place over one and a half days. It included full plenary discussions on the themes of (1) Autonomy and Independence and (2) Long-Term and Palliative Care, as well as focussed group discussions on (3) Equality and Non-Discrimination and (4) Violence, Abuse and Neglect. In the view of the group, the discussion on Autonomy, Independence and Long-Term and Palliative Care was in effect one same discussion, taking place over two days. The sessions on Equality and Non-Discrimination, and Violence, Abuse and Neglect, aimed to make deeper progress in articulating normative language in the given areas, for the reason that these themes were the subject of discussion by the Open Ended Working Group in 2017, and thus required less general treatment and more focussed attention in detail. Reflections on questions of rights-holder and duty-bearer – also addressed during the two-day meeting -- are provided in the conclusion.

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1. Autonomy and Independence

Structural ageism acts as a deep-seated and as yet unaddressed obstacle to all aspects of autonomy and self-determination.

Stigma is a core problem, including as concerns the development of a human rights movement among older persons; many older persons do not want to be associated with an identity based on age, and may hold ageist prejudices themselves. Work to develop a human rights-based civil society movement of older persons is needed, including an emphasis on promoting pride.

The relationship between the human rights of older persons as developing/emerging on the one hand, and some of the conceptual bases developed under the Convention on the Rights of Persons with Disabilities (CRPD) and available for possible adaptation and use in the current context, was a running theme of the two-day seminar. Some of the ideas tabled included:

1. A core focus should be on rendering visible older persons in the human rights system, as older persons are currently invisible, similar to the state-of-play existing for persons with disabilities prior to the development of CRPD;
2. The focus should be on “rights” rather than “needs”, and to continue to move away from medical and charity to human rights-based approach.
3. Human rights developments concerning the human rights of older persons should focus on situating them in their social environment – and what is this environment doing to limit or permit effective exercise of human rights -- and what rights should be secured to overcome these barriers.
4. Substantive equality approaches should be strengthened.
5. The focus should be on how to develop systems of support to exercise rights.

The question of equal legal capacity, about which understanding has evolved from its starting point in the International Covenant on Civil and Political Rights, is of core relevance for the human rights of older persons. The concept is now, pursuant to a number of decades of advances, understood clearly to mean the right both to hold rights and to exercise rights. Universal legal capacity now has no legitimate exceptions under international law. States need to abolish all types of legislation that limit legal capacity, and this should be recognised also as covering older persons. Guardianship and other forms of substituted decision-making should be explicitly prohibited. A positive obligation on States to develop supported decision-making arrangements should be explicitly recognized. States should be explicitly required to provide safeguards to ensure rights, will and preferences of the person.

In an older person’s context, “best interests” doctrines are inappropriate and should not be used. Similarly, the focus on “safety and security” in some discussions of policy on older persons is potentially regressive, and should be avoided.

Advance directives, with free, informed, genuine and revocable consent, are an important mode for securing and acting on autonomy, will and preferences during certain key periods.

Participation is an important factor in the autonomy and independence of older persons. Age-specific limitations are drivers of arbitrary limitations on autonomy, including – among others - in areas such as:

- Mortgages;
- Insurance;
- Marriage;
- Health and long-term care;
- Employment;
- Inheritance, where decision-making powers of older persons are in some cases restricted.

Lack of access to insurance in many cases has knock-on effects of blocking possibilities for even voluntary work. There is a need for a new conceptualization of participation and a new conception of the cultures and communities and roles to which older persons want to – and should be able to – participate.

At present, lack of knowledge about available support is widespread. It is often difficult if not impossible for older persons to seek redress for the denial of their right to autonomy and independence.

The terms “choice” and “right to choose” were also discussed, with participants noting their possible use in advancing autonomy rights. However, there were also risks noted about the possibility of introducing an “either-or” dynamic into autonomous decision-making, as well as potentially opening the door to service providers to put pressure to erode standards. In any case, the human rights normative framework should recognize and celebrate the older person as the autonomous decider, with possible requirements of support for autonomous decision-making.

New technologies can be valuable for supporting older persons, as well as potentially leaving persons at risk of abuse.

2. Long-Term and Palliative Care

Long-term and palliative care are very much intertwined. The legal basis for both long-term and palliative care is Article 12 of the International Covenant on Economic, Social and Cultural Rights, setting out the right to enjoyment of the highest attainable standard of physical and mental health.

The question of the appropriateness of the term “care” was discussed in detail, burdened as it potentially is with infantilizing, paternalistic or other non-human rights-based approaches. We should be rethinking the notion “care” and understand it in a complementary and integrated way, or alternately to replace “care” entirely with “support”. The Convention on the Rights of Persons with Disabilities (CRPD) provides good language, namely the need to secure the “autonomy, will and preferences” of the persons concerned. We should maximize the extent to which older persons are involved in the design of services and support. It was noted that a definition of care has been provided by the UN Independent Expert on the human rights of older persons. “Care should be understood as support to creating or regaining the optimal level of physical, mental and emotional well-being.” “Support” should be a basic starting point, seeing it as a broad notion that will ultimately lead to the liberation and full participation of the person.

There is a growing imbalance in supply and demand which leads to a growing reliance on informal care and more pressure on families. There are big regional differences in fact in the provision of long term care.

Informal caretakers and informal caretaking settings are often encouraged by the State and sometimes even enshrined in law. Indeed, there are palpable threats of legal action and even in some countries criminal prosecution in cases of lapses of duties of care by family care-givers. It would be a highly problematic outcome of these deliberations were a new instrument to result in heightened threats of negative consequences for acts or omissions by family or other non-state care-providers. The focus of the new instrument should be clearly identify the role of the state as duty bearer.

The fact that family carers are overwhelmingly women was noted as introducing heavily gendered dynamics into provision of support.

With regard to palliative care, there was common understanding that it is much more than assistance in dying. It is a way to allow persons with a life-threatening condition to live better and/or longer, and can be delivered alongside cure. . Holistic palliative care – i.e. dealing with the physical, spiritual/existential and psycho-social needs of the person – should not be strictly associated with end-of-life situations but delivered for as long as needed as it can help a person advance in terms of realising their rights to autonomy, will and preferences. Palliative care is key to the provision of person-centered care and support and should be seen as an integral element of the continuum of care everyone should have access to.

Restrictions in access to palliative care are related to a narrow understanding that associates it to specific illnesses (typically terminally ill cancer patients) and to imminent death; thus, lack of access affects disproportionately older persons with chronic or insufficiently diagnosed illnesses who may need it over an extended period of time.

3. Equality and Non-Discrimination

The problem of age-specific limitations was discussed not only in the session on equality and non-discrimination, but indeed throughout the meeting, in particular as providing arbitrary and often severe limitations on autonomy. There is very widespread use at present of tie-breaker provisions in favour of younger people in the allocation of scarce resources. Positive obligations to review all aspects of law and policy are needed, as noted below.

Affirmation of the right

In addition to enshrining this right in a specific provision, equality and non-discrimination should be one of the general principles of a future convention or related instrument. It should also be reiterated, articulated and advanced in various articles of a new instrument.

Personal scope

Defining older people only in terms of chronological age is too limited as being old/treated as an old person is also a social construct linked to social realities and perceptions. In addition, understanding of older age will vary according to policy field. For example, in employment, the experience of age discrimination starts as early as 50, if not earlier; access to social security systems is tied with pensionable age – 65; challenges in terms of availability, affordability of long-term care, often in late 70s. The right to equality and non-discrimination should not be based only on a definition of older persons through chronological criteria. The definition of older persons for the purposes of a new instrument could draw on the CRPD and the Council of Europe Recommendation(2014)², focussing on societal barriers that in combination with old age impede the equal enjoyment of human rights

Material scope and state obligations

The right to equality and non-discrimination should draw on and reaffirm universal definitions that exist under international law¹, as well as developing and articulating substantive elements particularly relevant for older persons.

In a first band of core content, the ban on discrimination as relates to older persons should include standard definitions derived from settled law, covering inter alia, direct, indirect discrimination, harassment, instruction to discriminate, victimisation, and discrimination by association, as well as other core elements.

In a second band, the right to equality and non-discrimination as related to older persons should include – and where relevant adapt -- conceptual items included in the CRPD, in particular:

- An explicit recognition of equality before the law, equal legal capacity;

¹ CERD, CEDAW and CRPD

- Denial of reasonable accommodation as a form of discrimination, covering all aspects of life (i.e beyond employment);
- A right to accessibility.

Third, the right to equality and non-discrimination as related to older persons might develop additional definitions and conceptions particular to older persons, for example exploring the meaning of perception of declining capacity, and the threat of unequal treatment arising from these.

The right to equality and non-discrimination should cover all areas of life.

- The right should cover systemic discrimination and ageism;
- The right should create the immediate obligation to abolish laws, policies and practices that are discriminatory, including an obligation to review age limits and exceptions to the rule of age equality, in order to evaluate the impact on older people's rights and to challenge ageist assumptions upon which age-based restrictions may lie;
- The right should cover all forms of multiple discrimination, possibly drawing on existing language, such as CRPD;
- The interpretation and implementation of the right should aim at achieving substantive and transformative equality, drawing on CEDAW and CRPD;
- States should have an obligation to provide reasonable accommodation to overcome barriers in the exercise of rights and to adopt positive measures that are necessary to achieve de facto equality;
- States should have an obligation to assist older people in seeking accountability and ensure access to justice and redress.

Challenges

It must be recognized that no human rights treaty includes derogations to the rule of equality and non-discrimination and including general exceptions in a new treaty may weaken the protection on the ground of age. However, the interpretation of this right by treaty bodies allows for differential treatment on the basis of reasonable and objective justification.² It may therefore be sufficient to rely on this interpretation without explicitly providing for exceptions.

A distinction must be made between age-based criteria that are used to *facilitate* access to rights as opposed to those that are used to *restrict* access to rights. As a general rule differential treatment on the basis of age should promote the enjoyment of rights and not undermine human rights principles.

² General Comment No. 20, Non-discrimination in economic, social and cultural rights (art. 2, para. 2, of the International Covenant on Economic, Social and Cultural Rights), 2009, para 13

4. Freedom from Violence, Abuse and Neglect

Definition of the right

- There is currently no universal definition of abuse, violence and neglect of older persons. The closer to a widely accepted definition is that of WHO, “a single or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older person”. The “expectation of trust” element causes controversy.
- Violence, abuse and neglect should be clearly defined in the text of any future normative instrument.
- The definition of neglect should encompass not reacting to situations of abuse they may be witnessing.
- Definitions should include all acts that may result in any kind of suffering/harm, even death. They should also include abandonment and deprivation of liberty.
- Reflections around definitions should integrate the notion of hate crime; there are cases of attacks against older people simply because they are old.
- It is important to make a distinction between elder abuse and other forms of violence and abuse that an old person is suffering. For instance, intimate partner violence is also prevalent among older couples – and might have been going on for years –, and does not lose its gender-based dimension by the sole virtue of age. Although such acts may fall out of the definition of elder abuse, protection available to women suffering violence should be available on equal basis to older women.
- Definitions should also cover economic exploitation of older persons.

Scope of right

- The right should cover all forms of violence, abuse and neglect, whether intentional or not, including harmful traditional customs and institutional practices that can lead to violence, abuse or neglect of older persons.
- The right should cover all settings, both public and private
- The right should recognize the structural and systemic character of violence, abuse and neglect of older persons, in particular the role of ageism as a driver of abuse

State obligations:

- Measures to fight ageism and increase awareness of older people’s rights
- Measures to prevent violence, abuse and neglect, should include training not only for professionals in the care context, but all those who may be providing any services to older persons; these should include state bodies and employees of public services, notably police and law enforcement officers.
- Measures to prevent violence, abuse and neglect should be proportionate and not collude with older persons’ rights to autonomy and independence.
- Attention should be paid not only to intersectional forms of discrimination resulting in violence, abuse and neglect, but also to any other factors that drive abuse and that may not be linked to the combination of ageism and other form of discrimination.

- Timely, effective and appropriate access to support services should be guaranteed to victims, survivors and also persons at risk of violence, abuse and neglect.
- Even if a crime is not identified and/or prosecution is not possible, states should have the obligation to offer other forms of remedy and compensation, such as mediation services.
- State obligations should include reaching out to all victims or potential victims, including specific measures to reach out to those whom, for whichever reason – including dementia or other physical and/or psychological impairments – do not have the conditions to report violence, abuse and neglect on their own, without support.
- The obligation to gather comprehensive and quality data on forms and prevalence should include all age cohorts.

Conclusions

The rights holders of any new instrument or standard should be older persons themselves. We should not muddy the waters by adding the rights of carers. The duty bearer clearly needs to be the state in an international instrument; introducing other duty bearers into international treaty law can potentially give rise to problematic legal developments.

As concerns the question of chronology, while it may be that some exploration of the definition of older persons in a chronological sense may need to be explored, it is recommended that at present, the conceptual basis be identified and explored, and that questions of definitional chronology should ideally be identified at a later stage of discussion.

The experts involved in the seminar concluded by affirming strongly that, whatever developments are agreed, these cannot and should not erode existing standards. Any new instruments agreed in this regard must strengthen the existing human rights *acquis*. A new instrument should expand our understanding of rights, expand protection, and not introduce restrictions or provisions undercutting the existing framework. Any new normative standard should aim to raise protection levels, as well as to safeguard a minimum floor. The only reason to undertake a new normative instrument would be to raise protection standards, and to elucidate a way forward toward strengthened protection. Any new standard should seal in and safeguard the existing protections available under the human rights treaties.
