INTRODUCTION

The Global Alliance of National Human Rights Institutions (GANHRI) is a representative body of national human rights institutions from all parts of the globe. Its aim is to assist in establishing and strengthening independent and effective NHRI, which meet the international standards set out in the Paris Principles. National Human Rights Institutions (NHRI) provide an important link between the international and national level and play a significant role in the promotion and protection of human rights and the implementation of international standards at the national level. GANHRI has established a working group on the human rights of older persons to support the work of the Open-Ended Working Group and its member NHRI in this field, including their contributions to and participation in the work of the OEWGA.

While NHRI representatives have participated as expert panelists in the work of the OEWGA form its early sessions, NHRI enjoying ‘A’ status were first invited to participate formally in its work as institutions from its 8th session in 2017. GANHRI and its members welcome the opportunity for NHRI to participate formally in the work of the OEWGA and look forward to that opportunity being extended to NHRI’s global and regional coordinating committees, as it was the drafting of the Convention on the Rights of Persons with Disabilities (CRPD).

NHRI CONTRIBUTIONS TO THE WORKING GROUP

For the 9th session of the OEWGA 25 NHRI and one regional coordinating committee of NHRI have made written submissions in response to the call for input on the two themes selected for discussion, autonomy and independence and long-term and palliative care. NHRI made 22 submissions to the 8th session of the OEWGA held in 2017 on the themes of equality and non-discrimination and neglect, violence and abuse.

The submissions from NHRI to the 9th session (as those to the 8th session) provide a great deal of information about the nature and extent of the protection of the rights of older persons at the national level and the gaps in that protection, and identify ways in which problems and shortfalls can be addressed. The purpose of this paper is not to summarise in detail the information and insights contained in those submissions; and some of that material has also been referred to in the helpful substantive reports on Long-term and Palliative Care prepared by DESA and on Autonomy and Independence prepared by OHCHR for the 9th session.

* Revised and corrected version (25 July 2018)
The purpose of this paper is rather to highlight a number of aspects of NHRI submissions to the 9th session which offer insights into the limitations of existing approaches generally and in relation to the themes of the 9th session and to reinforce the case for the adoption of a convention sooner rather than later.

The information and analysis provided by NHRIs shows that there has been significant progress in efforts to promote and protect the human rights of older persons generally and in the areas covered by the themes for the 9th session. However, at the same time the submissions show that this progress has been variable as between different countries (and within individual countries). In some countries much has been done in terms of legal protection, policy measures and practical implementation, while in other countries efforts are less well-advanced. Nonetheless, despite the efforts of government and civil society, in all countries the enjoyment of human rights by older persons falls short of existing international and national human rights standards. GANHRI considers that the case for the development of a new instrument to reinforce the struggle to achieve justice for older persons is compelling.

C. AUTONOMY AND INDEPENDENCE

Respect for and promotion of a person’s right to exercise autonomy and enjoy independence in the conduct of their life is fundamental to ensuring human dignity and is at the core of a human rights approach to the rights of older persons. The right to autonomy and independence extends to all areas of life.

The NHRI of Portugal provided a detailed explanation of autonomy and independence:

The right to autonomy encompasses the rights of older persons to manage their own affairs and to make decisions and choices about their life. They have the right do it freely, by themselves and without the interference or control by others. Besides having the right to make their own decisions, the elderly also enjoy respect for their options and have access to a remedy in case of failure to respect their choices or in case of being prevented to make their own decisions.

Within this framework, protection of the rights of the elderly also claims for a legal regime concerning those who lack (either temporarily or on a more enduring basis) capacity to take decisions in an informed and autonomous manner, or to express or execute such decisions. Such legal regime must fully respect their dignity and take into account the particular circumstances of the specific case, so as to prevent abuse and exploitation by third persons (such as manipulation aimed at obtaining advantages on legal transactions, testamentary dispositions or granting of a proxy or powers of representation).¹

The legal and practical recognition of older persons’ legal and other decision-making capacity has often been influenced by ageist assumptions about the (lack of) capabilities of older persons, in the same way that assumptions have been made about the lack of capacity of

¹ Provedor de Justiça of Portugal, Submission on Autonomy and Independence, p 1.
person with disabilities to exercise legal capacity and make decisions about their own lives.\(^2\) This may be seen particularly in areas such as decisions about choice of residence and in the context of different forms of long-term care where the right to exercise autonomy is easily violated.\(^3\) One example is provided by the Croatian NHRI who notes that, even though the right to autonomy is presumed in Croatia without being explicitly stated, nevertheless ‘autonomy and independence of older persons are often hindered, both as a consequence of legal proceedings to limit their legal capacity, as well as by a lack of support and understanding from their healthcare professional, social workers, and society in general.’\(^4\) The NHRI also noted that there was not yet a framework for supported decision-making in that country, a situation that is common to many countries.\(^5\) The European Network of National Human Rights Institutions (ENNHRI) referred in its submission to its major research project on older persons in long-term care and the problems identified in its research findings.\(^6\)

The German NHRI draws attention to the principle of autonomy set out in the CRPD as an important example of the principle of autonomy in human rights law.\(^7\) The German Institute states that ‘autonomy does not describe a human right as such. It is rather a human rights principle, which has to be used to interpret all human rights contained in the treaty.’ The German NHRI also underlines that autonomy must not be undermined by patronising assumptions and unjustified external limits on the exercise by older persons of that right:

> It is important to note, that autonomy must not be influenced by an externally induced a-priori limitation (e.g. ‘older person’s well-being’). Autonomy necessarily requires options and the information of the individual. The will of the individual is always

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\(^2\) See in particular the discussion in Committee on the Rights of Persons with Disabilities, Committee on the Rights of Persons with Disabilities, General comment No. 1 (2014): Article 12: Equal recognition before the law, UN Doc CRPD/C/GC/1.

\(^3\) The South African National Human Rights Commission noted that under the Older Persons Act (No 13 of 2006) ‘an older person receiving community care has the right to reside at home as long as possible’.


\(^6\) European Network of National Human Rights Institutions (ENNHRI), Submission to the OEWG-Ageing: Autonomy and Independence, 5 May 2017, p 1.

\(^7\) Article 3 of the Convention on the Rights of Persons with Disabilities provides:

The principles of the present Convention shall be:

1. Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons;
2. Non-discrimination;
3. Full and effective participation and inclusion in society;
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
5. Equality of opportunity;
6. Accessibility;
7. Equality between men and women;
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.
decisive if it was decided with a full informed consent. That will have to be determined thoroughly and then be respected.  

The broad application of the principle of autonomy and independence is discussed in a number of submissions on the specific themes. However, it is important to emphasise that autonomy is a principle of broad application and is not confined just to the long-term care context. For example, the German NHRI notes that accessibility to transport and the built environment can be difficult for older persons (especially so for those in rural or remote regions) and this has a practical impact on older persons’ ability to exercise autonomy in a number of respects, including but not limited to liberty of movement. The Georgian and Tanzanian NHRIs make a similar point.

In terms of international standards ENNHRI concluded that ‘International and regional human rights standards on autonomy and independence are not adequately focused on age-related issues and are inconsistent in their interpretation and implementation. The findings therefore suggest that older persons’ right to autonomy and independence is inadequately protected.’

D. RIGHT TO LONG-TERM CARE

NHRI submissions make it clear that many countries have been developing legal and policy frameworks to address the issues to which an ageing population gives rise, in particular the need that older members of the community may have for assistance in carrying out their daily activities, whether that involves living in one’s own home or in the home of a family member (possibly with the provision of external support services), or living in some form of residential aged care.

The NHRI submissions provide considerable detail about the legislative and regulatory structures and policies concerning long-term care in their countries. In many countries there are definitions of ‘long-term care’ – some of which focus on residential institutions while others are more broadly drawn. In other countries there is no legislative or policy definition, in some cases because of an expectation that long-term care for older persons will for the most be provided within the family.

One example of a lack of definition is noted by the Nigerian NHRI, which reported that there was no legal or policy definition of long-term care for older persons in Nigeria ‘because there is a lack of a national policy [and] also no regulatory framework’, though it noted that there was currently a bill on long-term care and palliative care before the legislature. It also noted

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8 German Institute for Human Rights, Submission on Autonomy and Independence, p 2. The Ombudsman of the Republic of Croatia comments that ‘[o]lder persons should not be limited in their decision making even out of best of intentions, aiming to protect them.’ Submission on Autonomy and Independence, p 2.
9 Public Defender of Georgia, Submission, p 2; Human Rights Commission of Tanzania, Submission, p 2.
11 National Human Rights Commission of India, Submission, p 1 (‘Long-term care for older persons ... has always been a family affair’).
that long-term care was ‘still rudimentary in the country’ and this was due to ‘low capacity, lack of equipment[], lack of medications, lack of national policy, poor understanding of LTC, cultural beliefs.’

A number of NHRI s pointed out that in their countries there had traditionally been an expectation and practice that families would provide long-term care for older family members and that this was still the expectation, even though traditional family structures may have broken down or no longer be as strong as they once were. Some submissions noted that there was legislation in place under which older family members might be able to bring legal actions against their children in order to obtain support, while in other counties there was some state support available where no family support was available. In other countries NHRI s reported that there was a variety of supports available for older persons to allow them to continue living in their own homes where that was feasible, or to move other institutional settings. These are subsidised in part or whole by government in some countries, but not in others; financial difficulties in providing and in accessing quality long-term care was an issue generally.

These different policies and options raise important substantive questions about older persons’ right to autonomy and independence, including the right of older persons to decide where and with whom they will live, issues which gave rise to considerable debate in the context of the CRPD which guarantees the right of persons with disabilities.

Even in those countries where there is a policy commitment to the provision of different forms of long-term care, in nearly all cases NHRI s reported that the number of suitable long-term care places was outstripped by the demand for them. For example, the Georgian NHRI noted that the country’s National Health Care Strategy ‘does not mention long term care’ and that there were only a limited number of ‘daily specialized institutions’ as well as one shelter for those with mental health problems.

Even where such long-term care options were available, a common aspect identified in the NHRI submissions was the existence of substandard living conditions, poor monitoring and limited access to remedies for violations. For example, the Georgian NHRI noted that the monitoring of the institution which it had carried out showed that, despite the existence of legislative regulations, ‘the state lacks systematized approach of overseeing their enforcement. The relevant state agencies do not conduct systemic monitoring and thus fail to adequately react to existing violations.’

15 Article 19 (a) of the CRPD guarantees persons with disabilities ‘the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement …’. See generally Committee on the Rights of Persons with Disabilities, General comment No. 5 (2017) on living independently and being included in the community, UN Doc CRPD/C/GC/5.
16 Public Defender of Georgia, Submission, p 3.
17 Public Defender of Georgia, Submission, p 3.
Other NHRIs reported similar challenges in ensuring that the implementation of existing standards was properly monitored and that older persons who were living in long-term care (and their families) were able to raise and have resolved complaints about the way in which they were treated, including whether their autonomy and independence, including freedom of movement and the right to consent to medical treatment (eg the use of chemical and other restraints), were being respected. 18 For example, the Latvian NHRI identified the main challenges in relation to long-term care to be the quality of services provided, inadequate supervision and monitoring, and inadequate levels of training for staff 19 – issues identified by a number of other NHRIs. The German NHRI noted that human rights ‘are little known among those affected and the nursing staff’ and that the ‘German criteria for quality of care are not aligned with human rights.’20

Of particular relevance to this theme is the research project, *The Human Rights of Older Persons and Long-Term Care to improve the human rights of older persons in LTC, with particular emphasis on residential care*. This project, funded by the European Commission, was undertaken by the European Network of National Human Rights Institutions (ENNHRI) from 2015 to 2017 and involved research by NHRIs in six European countries. The findings of the project were widely disseminated at the 8th session of the Open-Ended Working Group.21 In its submission to the 9th session of the OEWGA, ENNHRI summarised some of the findings as follows:

In particular, the findings highlighted the challenges individuals can face in having their choice of where to receive LTC heard, in having their legal capacity respected and in accessing services. Textual analysis carried out by ENNHRI also highlighted that international human rights standards do not provide older people with an explicit right to long-term care and grey area in terms of the obligations of private (for- and non-profit) LTC providers.22

ENNHRI also reported on the results of a survey conducted among its membership, the results of which showed that many of its members were active in working on the human rights of older persons. The submission documents the range of activities undertaken by various

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18 See Office of the Commissioner of Human Rights of the Republic of Poland, pp 10-2; Submission, Ombudsman of the Republic of Croatia, Submission on Long-term Care and Palliative Care; Commissioner for Protection of Equality of Serbia, Submission on Autonomy and Independence, p 2.
20 German Institute of Human Rights, Submission on Long-term Care and Palliative Care, p 4.
22 European Network of National Human Rights Institutions (ENNHRI), Submission to the OEWG-Ageing: Long-term and Palliative Care, 9 April 2017, p 1 (footnotes omitted).
ENNHRI members: these include awareness-raising, preparation of toolkits, monitoring visits and special investigations, training, and receiving complaints. 23

E. RIGHT TO PALLIATIVE CARE

The NHRI submissions addressing the extent to which the right to palliative care is recognised and implemented in their jurisdictions show a varied picture. In a number of jurisdictions the concept of palliative care is embodied in legislation or policy,24 in others there is no such definition, and implementation may be relatively undeveloped. Even in those jurisdictions where the law, policy and health services are well-developed, the submissions show that the availability of palliative care services falls well short of demand. The reason for this are many, including lack of resources, lack of experienced trained staff, lack of awareness.25

ENNHRI also notes that ‘International and regional human rights standards do not explicitly provide for the right to either long-term or palliative care.’ It notes that the findings from its research project and survey of members show, as do other NHRI submissions, that the protection of the right to palliative care and provision of such services is inadequate. ENNHRI supports the adoption of a new binding instrument which will include an explicit right to long-term and palliative care.26

F. OTHER INSIGHTS FROM NHRI SUBMISSIONS

1. Need for a holistic human rights approach

What emerges from the analysis in a number of NHRI submissions is the importance of ensuring that all laws and policies relating to or having an impact on older persons be informed by a human rights-based approach that sees older persons as holders of rights and active agents in participating in society and making their own decisions about how they live their lives. This goal can be difficult to achieve because of assumptions about the abilities of older persons and legal and policy approaches that focus on presumed lack of capability of older persons and their role primarily as dependent beneficiaries of services and support.

For example, the New Zealand NHRI commented:

Older persons in New Zealand face a variety of issues and challenges that affect their autonomy and independence. The first is negative social perceptions that older persons are a ‘drain’ or a ‘liability’ on society that further marginalizes them and inhibits their rights to autonomy and independence. Such attitudes that form the basis

23 ENNHRI, Submission to the OEWG-Ageing: Long-term and Palliative Care, 9 April 2017, p 2.
24 See, eg, People’s Advocate Institution of Albania, Submission on Long-Term and Palliative Care, p 2.
26 ENNHRI, Submission to the OEWG-Ageing: Long-term and Palliative Care, 9 April 2017, p 3.
for discrimination, can hinder older persons from employment, education and housing opportunities.27

The Argentinian NHRI made observations to similar effect, noting that old age was often ‘regarded as obsolescence’ and that such an approach ‘assumes that adult contribution is only possible within the context of economic productivity’ (even narrowly defined).28 Of course, as other submissions point out, many older persons are in fact involved in ‘economically productive’ activities beyond standard retiring age and many others might wish to be but encounter barriers some of which are based on assumptions about the lack of capabilities of older persons in the workplace.29

The existence of widespread ageist attitudes potentially affects all areas of policy making and underlines the need for a coherent approach to the rights of older persons across the board based on a number of underlying principles similar to those contained in Article 3 of the Inter-American Convention. Further, such ageism means that States must be obliged to take measures to address stereotypical and discriminatory attitudes and action based on assumptions about the characteristics, capabilities and contributions of older persons.30

2. Constitutional and legislative protection of the rights of older persons

A number of NHRI s referred to the general or specific constitutional protections that protected or promoted the rights of older persons (in many cases along with all other citizens or in contrast rights enjoyed with other groups that were seen as ‘vulnerable’ or marginalised).31 Other submissions referred to the existence of laws relating to specifically to ‘older persons’ or ‘the elderly’;32 a number of these were general in application while others related to specific sectors, such as long-term care, employment, social support, or criminal

28 See also German Institute for Human Rights, Submission on Autonomy and Independence, p 1 (need to avoid terminology such as ‘productive ageing’, as this ‘leads to a negative stigmatization of older persons outside the labor market’).
29 National Human Rights Commission of Korea, Submission, p 2; Public Defender’s Office of Georgia, Submission, p 2.
30 See, eg, article 32 of the Inter-American Convention on Protecting the Human Rights of Older Persons; article 5(a) of the Convention on the Elimination of All Forms of Discrimination against Women; article 8 of the Convention on the Rights of Persons with Disabilities.
31 See, eg, Hungary, Morocco, Republic of Korea, Zimbabwe, and Portugal, among others. Article 34 of the Constitution of Morocco requires the state to develop and implement policies directed to the needs of older persons and other groups: Morocco Conseil national des droits de l’homme, Submission on long-term care and palliative care, p 1.
protections against abuse. Other submissions referred to protections against age discrimination in general laws, such as employment discrimination legislation. Other NHRIs reported that in their jurisdictions there were no such guarantees or laws, while in all cases where laws existed there were problems with full and effective implementation and remedies for violation were not always available or enjoyed in practice. Experience has shown that the adoption of a treaty requiring specific constitutional or legislative protection for groups can enhance the possibility of the enactment of such legislation; specific obligations to make such changes appear in most human rights treaties.

3. Linkages between human rights

A significant number of NHRI submissions stressed the interrelatedness of a wide range of human rights to the rights to autonomy and independence and to long-term-care and health. They included the right to information, freedom of movement, right to education and literacy, right to work, protection against violence abuse and neglect, the right to health, rights to an adequate standing of living, food and social security, the right to housing, right to participate in society and in political and cultural life, among others. The linkages between these rights suggest that there would be an advantage in any new international instrument in having a comprehensive statement of rights that apply to older persons.

4. The potential contribution of an older persons-specific international treaty

A number of NHRI submissions stress the important role that an international treaty focused on the rights of older persons can play in relation to the development and improvement of law, policy and resourcing relating to the human rights of older persons. For example, the Argentinian NHRI reported that the Inter-American Convention on the Rights of Older persons has constituted ‘the main legal framework in our country concerning human rights and fundamental liberties of older persons’, giving as one example of the impact of that Convention changes in approaches to thinking about the procedural rights of older persons.

The Mexican NHRI noted that, while Mexico had yet to ratify the Inter-American Convention, the Commission saw the ratification of the Convention as potentially leading to the amendment of laws and state structures and budgetary allocations that would strengthen existing general protections of the rights of older persons as well as embedding and helping to realise rights to long-term care and to palliative care. The Guatemalan NHRI drew attention to the fact that Guatemalan law lacked ‘a human rights based approach and there is no governing entity in charge of the care of older persons. Likewise, the issue of older

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33 See, eg Republic of Korea legislation on age discrimination in employment: National Human Rights Commission of Korea, Submission.
34 See, eg, Guatemala, Procuraduría de los Derechos Humanos, Submission, p 3: ‘At a national level, mechanisms of remedy and reparations for older persons who have been victims of violations of their autonomy and independence human rights, have not been identified.’
35 See, eg Morocco, pp 1-2, Malawi, p 2,
36 Argentina, Defensoría del Pueblo, Submission on Autonomy and Independence, p 1.
37 Argentina, Defensoría del Pueblo, Submission on Autonomy and Independence, p 2.
38 Mexico, Comisión Nacional de los Derechos Humanos, Submission, p 1.
people lacks inclusion in sectoral policies, social development and population.’\textsuperscript{39} It reported that it was advocating in Congress that the country become party to the Inter-American Convention, a move it considered ‘would favor the recognition and enjoyment of the right to the autonomy and independence of older persons in the country.’\textsuperscript{40}

The Philippines NHRI underlined the importance of normative standards that specifically address the situations that face older persons and provide detailed guidance on the steps that should be taken, in consultation with representative groups, to ensure the full enjoyment of those rights:

One of the findings of the National Human Rights Situation Report on Older Persons is related to the prevailing gaps to improve older people’s enjoyment of human rights through the adoption and implementation of national legislation. In addition, general provisions of international human rights law provide little guidance to States on how to apply these human rights in law and in practice to older persons and in the context of older age. This is apparent in the context of the Philippines where legislation, programs and services intended to benefit older people are not universal and have, in some cases, served to deepen inequality for older people since the most marginalized and disadvantaged older people do not benefit from them. These findings provide impetus to adopt a specific human rights instrument for older persons.\textsuperscript{41}

The Nigerian NHRI commented that the ‘lessons learned from human rights perspective is that a whole lot of human rights issues are being thrown up …. This shows a rights-based approach should be adopted in dealing with older persons issues in order to achieve a holistic result. ...There is therefore a need for an international binding legal framework to address such peculiarities. This will serve as a tool to work with for national human rights institutions human rights institutions as well as civil society groups in order to hold both government as well as non-state actors accountable for their actions and inactions.’\textsuperscript{42}

These views reflect the well-documented experience of the impact of the Convention on the Rights of Persons with Disabilities on the development of law and policy in States that have become parties to that treaty, as well as the experience under a number of other human rights treaties.

G. CONCLUSION

GANHRI has stated its support for the development of a new binding international instrument on the human rights of older persons which will complement and add new momentum and a coherent human-rights-based approach to ensuring the human rights of older persons. GANHRI considers that the information contained in submissions by NHRI to the OEWGA, taken together with the material submitted by States, civil society organisations and experts for this and the previous eight sessions of the Working Group, make clear the need for the

\textsuperscript{39} Guatemala, Procuraduría de los Derechos Humanos, Submission, p 3.
\textsuperscript{40} Guatemala, Procuraduría de los Derechos Humanos, Submission, p 3.
\textsuperscript{41} Commission on Human Rights of the Philippines, Submission, p 11.
\textsuperscript{42} Nigerian National Human Rights Commission, Submission, p 2.
Working Group to move from discussion of the problems that have been abundantly documented to drafting a new convention that can contribute concretely to their resolution. In that regard GANHRI considers the submissions of possible normative elements relating to specific rights provides a useful way forward, and welcomes in this regard the two background analytical overview papers containing compilations of suggested normative elements relating to the themes of equality and non-discrimination and neglect, violence and abuse. GANHRI and its members look forward to continuing to contribute to the work of the OEWGA.

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