



Joint Forum of Civil Society and Scientific Research

A fulfilling life throughout the life-course:
a joint effort of civil society and research in policy making

Rome, 15 June 2022

Report

Introduction

In the context of the review and appraisal process of MIPAA/RIS in the UNECE region, it was the first time that a Joint Forum of Civil Society and Scientific Research was organised on 15 June 2022 in Rome ahead of the Ministerial Conference on Ageing on 16 and 17 June 2022. Representatives of civil society and the research community thus discussed jointly, but from different perspectives, what has been achieved in the field of ageing over the last two decades, and which areas still need further action in the future. Politicians, experts and practitioners dealing with ageing-related issues in their daily practice were invited to participate in the discussions. The aims of the Joint Forum were therefore:

- To break down thinking and acting in separate silos and to enable a joint exchange of experiences and knowledge;
- To jointly discuss issues and findings to underpin the Ministerial Conference with experiences from civil society and evidence from research;
- To foster a dialogue around the most relevant future developments in the field of ageing and related areas from the perspectives of civil society, research and policy making;
- To identify priority areas for future policies on ageing across countries;
- To produce a joint Declaration.

The Joint Forum hosted presentations by representatives of civil society and scientific research, facilitated discussions with policy makers, and developed recommendations for future policies related to the three topics addressed by the Ministerial Conference:

- Promoting active and healthy ageing throughout life;
- Ensuring equal access to long-term care and support to families and caregivers;
- Mainstreaming ageing to advance a society for all ages.

Moreover, a Joint Civil Society and Scientific Research Declaration that had been drafted and elaborated in a joint participatory process involving NGOs and the research community was presented, discussed, and finalized.



Welcome Session

Chair: *Giovanni Lamura, INRCA IRCCS, Italy*

Elena Bonetti, Italian Ministry of Equal Opportunities and Family

Heidrun Mollenkopf, Joint Forum Organising Committee, AGE Platform Europe

Lidia Bratanova, UNECE Director of the Statistical Division

Keynote:

Navigating the Landscape: Advantages and Limitations of Madrid Implementation Plan of Action on Ageing (MIPAA) in delivering effective solutions

Amal Abou Rafeh, Chief of Programme on Ageing Section, UN DESA, USA

After the welcoming words of the session chair and of representatives of the Joint Forum Organising Committee and of UNECE, *Amal Abou Rafeh* delivered her keynote speech. She touched upon different issues, starting from the importance of a bottom-up initiative like the Joint Forum, which builds upon the expertise and experience of older persons and thus facilitates their participation in the MIPAA decision-making processes. At the same time scientific research is needed for effective policy and decision-making. Ms. Rafeh then moved to acknowledge that diversity is a defining characteristic of older age, and therefore we need to reflect this heterogeneity in public policies. The MIPAA is very helpful in this regard, as it represents the arena in which Governments agreed to link questions of dignity, longevity, and inequalities in ageing to other frameworks for social and economic development and human rights. However, she emphasized, major constraints identified to the implementation of MIPAA remained the same throughout the last three review and appraisal cycles, and awareness of MIPAA remains limited in some parts of the world. Her speech concluded with stressing that development and human rights are mutually beneficial, and a call for more effective investments in policies aimed at ensuring the full realization of the right to development, as a move to advance not only the implementation of MIPAA, but also the achievement of the 2030 Agenda.

Session 1: Promoting active and healthy ageing throughout life

Chair: *Kai Leichsenring, European Centre for Social Welfare Policy and Research, Austria*

Rapporteur: *Francesco Barbabella, National Institute of Health and Science on Ageing (IRCCS INRCA), Italy*

The first session of the Joint Forum concerned the link between active and healthy ageing with the MIPAA. The concepts of active and healthy ageing bring perspectives which are complementary to other discourses on experiences and patterns of ageing like long-term care, frailty or social vulnerability.

As first (online) presenter, *Ms. Barbro Westerholm, Member of Swedish Parliament*, talked about the importance of addressing the perspective of older persons and cover their perceived needs as proper human rights. She reminded the need to offer older people the freedom of making their own choices in life, overcoming ageism and age discrimination. These represent the biggest challenges to be addressed across all sectors of our societies, including for instance access to appropriate health care services. From a work perspective, Ms. Westerholm stressed the great contribution by older people to society, but also the need to allow individuals to decide whether to continue working and to better recognise the economic and societal value of such contribution. Furthermore, technological aids should be considered positive and helpful, but we cannot assume they are appropriate for everybody.

Ms. Lucie Vidovičová, professor at the Masaryk University and the Research Institute for Labour and Social Affairs (Czechia), offered an overview on the evidence from research in a life course perspective. A key issue is represented by how to consider time dynamics when policies are designed and implemented. The life course perspective provides tools to consider social contexts, individual changes and effects of changes over time. Research has been focusing on different areas, from how pregnancy and infancy have influence over life and generations, to gender-sensitive causes for sparse social networks, personal experiences of age discriminations, and grand challenges to life course like COVID-19 and climate change. The main lessons learnt were summarised as the following: to stop 'bullying' or foster age-based discrimination; to consider that it is never too early in an individual's life to intervene; to design better policies which go beyond silos and support a systemic life course understanding; to recognise the existence of different phases in our old age.

A concrete example of policy making was provided by the following speaker, *Ms. Renata Bagatin, former Regional Councillor in Friuli-Venezia Giulia (Italy)*. She discussed the longevity and ageing challenges from a perspective of a decision maker in a region with a substantial ageing society, where 27% of the population is 65 years or older. In recent years, the policy work at the Region Friuli-Venezia Giulia focused on understanding the impact on the welfare system and recognising new population needs. The region became a reference site for active and healthy ageing at European level. Furthermore, a regional law on active ageing was approved for strengthening interventions and social participation, as well as combating exclusion and discrimination, in addition to traditional health and social care services. The current three-year plan for 2022-2024 was launched and connected with the National Recovery and Resilience Plan (PNRR), as well as the Green Paper on Ageing by the European

Commission. The main issues for an effective implementation remain the overcoming of traditional cultural and political attitudes towards ageing, the better valorisation of individuals in any difference and condition, the search for innovation as a way to find new solutions to complex phenomena and needs, the incorporation of a life course approach in the policy design, the difficulties in implementation in more isolated and mountain areas.

The session was enriched by questions and answers from the audience. In general terms, the contents of the declaration related to active and healthy ageing were appreciated. Some points or suggestions were raised, including: the need for a more nuanced terminology and better age definition (as sometimes public discourse talk of people over 50 years old as older people); the negative impact of inequalities throughout the life course for active and healthy ageing; the possible introduction of 'geriatric practitioners' in public health care to better follow up health needs of the older population. All speakers agreed that active and healthy ageing should be seen as a guiding paradigm able to influence policies, research and practices, in the context of changing societies and new societal challenges.

Simone Scarlata, President of the Italian Society of Geriatrics and Gerontology - SIGG - Lazio SECTION, introduced the photo exhibition "Apartment n. 21": a photographic project on caregivers realized by the photographer Massimo Podio, under the aegis of the SIGG - Italian Society of Geriatrics and Gerontology.

Session 2: Ensuring equal access to long-term care and support to frail older persons and their caregivers

Chair: *Heidrun Mollenkopf, AGE Platform Europe, Germany*

Rapporteur: *Eszter Zólyomi, European Centre for Social Welfare Policy and Research, Austria*

Presentations:

Generosity and effectiveness of social protection for long-term care across OECD countries by Tiago Cravo Oliveira Hashiguchi, OECD, France

The presentation, based on OECD analysis, aimed to address the question whether social protection for long-term care (LTC) is equitable, effective and adequate.

Key messages:

- Social protection for LTC is absolutely essential; without it many older people would fall into poverty;
- Even when social protection is provided, older people in many OECD countries still struggle to cover their LTC costs (e.g., for home care);

- Large differences in policies and financing of LTC across countries (e.g., in a number of OECD countries, means-tests applied often cover not only income, but also assets);
- While women have fewer needs and receive generally more public support, they have lower income at their disposal, which puts them at a greater risk of not being able to cover costs when care needs arise.

Equal partners in care - a rights-based approach to supporting informal carers by Sebastian Fischer, Coalition of Carers in Scotland, UK & wir pflegen e.V., Germany.

Key messages:

- Carers often face discrimination and social exclusion;
- Importance of moving from recognition to rights – few countries have implemented measures where carers are recognised as equal partners, and are involved in the design, decision-making, and implementation of care strategies (a good example mentioned in this regard is the Scottish Care Strategies);
- Salient issues to consider include the mixed care economy (role of care budgets); care leave (currently too little, should ideally be 36 months); carers representation (important role of advocacy organisations);
- Future directions and important initiatives: EU initiatives, such as the European Pillar of Social Rights (EPSR) and the forthcoming EU Care Strategy, in particular, are welcomed, but more needs to be done to support informal carers through a rights-based approach.

Challenges and dilemmas in policy making by Sergio Murillo, Government of Biscay, Spain

The presentation provided an overview of recent public measures implemented in Biscay (Spain) to improve access to LTC:

- The concept, employed by policy-makers in Biscay, recognises the interlinks between health and social care and builds on the notion of shared care (publicly provided and based on community involvement);
- The policy approach taken focuses on enabling environment and developing support for carers (developing life projects);
- Several measures have already been implemented, such as community centres, digital services and devices, jointly developing a framework for LTC (policy-research interface);
- Main policy dilemmas: COVID-19 and other new challenges; how to find a good balance between supporting informal carers and enhancing formal home care; investing in residential care or focusing more on home care?

Questions/discussion:

While not included in the OECD presentation on LTC financing, the discussion highlighted the importance of broader social protection measures, beyond LTC, such as those related to the employment and income of older workers and carers (e.g., pensions policies). In responding to a question about the level of financing to prevent people falling into poverty because of LTC costs, the OECD representative said that it's difficult to set a specific share of GDP/expenditure that governments should allocate due to country differences and individual needs (e.g., people with the same care needs may get varied support).

In addition to the importance of advocating for carers, the issue of the training of informal carers was highlighted. Carers should have access to high-quality training and support, and not only to a minimum level of training. It's important to have advocacy for carers (information provision more effective), but also for providers of professional care.

The scarcity of professional carers, and how this shortage could be addressed (e.g., through improved access to training and support, providing professional certificates etc.), was also mentioned.

Finally, the issue of elder abuse in both formal and informal care should be acknowledged.

Commemoration of the World Elder Abuse Awareness Day (WEAAD)

Prior to the lunch break, a brief commemoration of the WEAAD, falling on 15 June, took place. The representative of UNDESA drew attention to a number of initiatives by international organisations in connection to elder abuse, including the WHO report on elder abuse, the UN Women data 2020 on older women and domestic violence (sexual abuse), and other related legal and binding instruments. However, current legal framework to protect from elder abuse is missing.

The WHO representative highlighted the importance of research on elder abuse, which is one of the five priorities of the UN Decade of Healthy Ageing. In particular, the need for more disaggregated data on elder abuse and an intersectional approach was mentioned.

More information and awareness-raising initiatives are also necessary for tackling elder abuse, e.g., the Refuse to Abuse campaign by Help Age International.

Dario Paoletti (AGE Platform Italy) presented the videos selected for the conference under the coordination of AGE Platform Italy.

Session 3: Mainstreaming ageing to advance a society for all ages

Chair: *Lisa Warth, UNECE, Standing Working Group on Ageing, Switzerland*

Rapporteur: *Ina Voelcker, BAGSO, Germany*

The third session of the Joint Forum focused on mainstreaming ageing, as an approach to systematically integrate questions of ageing and older persons across **all** policy fields at **all** levels, in order to create a society for **all** ages.

In her introductory remarks, *Lisa Warth of UNECE, Chair of the Session* acknowledged the progress achieved over the past 20 years of MIPAA implementation in the region of the UNECE. She highlighted the important role both civil society and the scientific community play in advancing the concept of mainstreaming ageing. By contributing information and data on demographic change as well as on the situation and needs of older people they provide an important asset. She further recognised the challenge of coordinating efforts and fostering productive collaboration between all stakeholders, including academia and civil society. Overall, the session provided insights on the work undertaken by the UNECE, a concrete example of a member State, namely Italy, and the experiences of civil society participation in international processes.

The need to take action, rather sooner than later, was emphasized by all panellists. The panellists also noted that further inaction will bring severe setbacks, e.g. in gender equality, intergenerational solidarity and human rights. Current crises such as the COVID-19 pandemic and the ongoing war in Ukraine further exacerbated the situation. The evidence for action is compelling – both in terms of demographic change, as set out by *Edmundo Martinho, Chair of the Standing Working Group on Ageing*, and in terms of elder abuse and other human rights violations against older persons, as shown by *Margaret Gillis, Co-President of the International Longevity Centre Global Alliance*.

Mr. Martinho presented the work of the UNECE Standing Working Group on Ageing to accelerate mainstreaming ageing. Mainstreaming ageing requires a coordinated whole-of-government and whole-of-society effort to respond to the challenges related to population ageing and to respect, protect and fulfil the human rights of older persons. He also reminded the audience that mainstreaming ageing has been recommended as a policy strategy already in 2002. To advance the implementation in the region, the UNECE developed Guidelines for Mainstreaming Ageing in a joint effort with government and civil society representatives. They aim to support countries in building a strategic framework for mainstreaming ageing.

Andrea Principi of the National Institute of Health & Science on Ageing presented how Italy developed a model for policy making and implementation in the field of active ageing for various levels of government. This has been developed in a systematic way. In a first step, the state of the art of active ageing policies at national and regional levels was identified. Central

to the development of the model was the creation of a comprehensive stakeholder network with participation of all regional governments, civil society and academia.

Margaret Gillis put an emphasis on the failure to protect the human rights of older persons. She recognised progress achieved so far, in particular by taking forward mainstreaming ageing, but questioned how member States continue to say that older persons are covered by other conventions when evidence shows the contrary. A Convention on the Rights for Older Persons would help to ensure MIPAA and the Guidelines on Mainstreaming Ageing are implemented.

The call for a UN Convention was also reaffirmed by the speakers from the audience who expressed their regrets for a lack of instruments at national, regional and international levels.

The session was summed up with recommendations on how to advance a society for all ages. The importance to use a wide array of measures to fulfil the human rights of older persons was highlighted. The panellists also called for a stronger collaboration across all sectors and stakeholders. Particular emphasis was placed on the need for a strategic framework providing clear direction, supported by strong legislation, at all levels, local, national, regional and international.

Session 4: Setting Priorities Beyond MIPAA 2022

Chair: *Giovanni Lamura, INRCA IRCCS, Italy*

Minutes: *Vijeth Iyengar, AARP, USA*

1. Introductory remarks by Civil Society and Scientific Research

Cristina Calvi, INRCA IRCCS, Italy

- The Joint Forum (JF) marked the first time the civil society and scientific research stakeholders have come together in solidarity to issue a Joint Declaration;
- The process of producing a JF Declaration involved a three-phase, participatory, bottom-up process engaging stakeholders from civil society and research communities;
- Stakeholders were asked, “*What are the three key topics that you – or the organisation you represent – would like to see on the agenda of future policies tackling the challenges of population ageing in the United Nations Economic Commission for Europe (UNECE) region?*”
- In phase I – of this three-phase approach – synthesis of the initial set of contributions focused on giving relevance to topics not found in previous Ministerial or Fora Declarations as well as reflections about future challenges that must be met;

- Upon completion of a first draft, in phase II, drafts were shared with stakeholders for improvements and comments. This yielded seven contributions of proposed revisions (five from civil society and two from research entities) with five stakeholders (two from civil society and three from research entities) approving the document without edits;
- In phase III, stakeholders were sent the revised version of the JF Declaration along with two questions: (1) *“Is there anything (e.g., any theme) in the Joint Forum declaration with which you disagree?”* and (2) *“In your opinion, how should the Joint Forum Declaration be implemented in the next five years?”*;
- A total of twenty responses (sixteen from civil society and four from research entities) were collected from phase III and the JF organising committee along with AARP revised the declaration to produce the final JF Declaration – a result from a bottom-up participatory process.

2. Presentation of the Joint Forum Declaration of Civil Society and Scientific Research¹

Heidrun Mollenkopf, Representative of Civil Society to the UNECE Standing Working Group on Ageing (SWGA), AGE Platform Europe, Germany;

Kai Leichsenring, Representative of Scientific Research to the UNECE SWGA, European Centre for Social Welfare Policy and Research, Austria

- The Joint Forum (JF) Declaration is complementary to the Ministerial Declaration 2022 (MD 2022) for the following reasons: (1) Focuses on topics that demand greater attention and detail than afforded in the MD 2022 and (2) Highlights topics suggested by civil society and research stakeholder communities deemed important and not (sufficiently) considered in the MD 2022;
- While the JF appreciates certain aspects of the MD 2022, a main concern from the JF is that the Madrid International Plan of Action on Ageing (MIPAA) is not universally applied and has failed to ensure that Member States respect, protect and fulfill the full enjoyment of human rights by older persons;
- Within the area of *promoting active and healthy ageing*, greater specification was deemed necessary by the JF in the following areas: (1) Recognizing the diversity of older persons in policy interventions, (2) Recognizing of unpaid care in combatting the gender pension gap and female poverty in old age, (3) Resisting the tendency to consider some physical and mental health condition as inevitable as one ages;

¹ The JF Declaration can be downloaded at the following link: https://unece.org/sites/default/files/2022-06/2022_Joint%20declaration%20of%20civil%20society%20and%20scientific%20research.pdf

- Within the area of *ensuring equal access to care and support to older persons and their caregivers*, greater specification was deemed necessary by the JF in the following areas:
 - (1) Greater recognition of societal changes (e.g., urbanization, increased mobility, changing family structures) and changing traditional concepts of care and (2) greater investment in home and community-based care, nursing home care, and for informal carers;
 - Within the area of *mainstreaming ageing to advance a society for all ages*, greater specification was deemed necessary by the JF in the following areas: (1) Research and development are needed to facilitate mutual learning especially concerning ageism and (2) Calls for the creation of appropriate structures in Member States to secure a human rights-based approach when dealing with demographic change and intergenerational solidarity, mainstreaming ageing, and related legislation;
 - The JF identified the following topics as particularly *urgent to address in future policies*:
 - (1) Enhancing awareness of ageism, sexism, racism, and all other forms of discrimination and intersectionality;
 - (2) Addressing social inequalities throughout the life course as well as inequities rising from digitalization and artificial intelligence on individuals and societies;
 - (3) Adapting relief operations and related interventions to the rights and needs of older people especially in light of wars, military interventions, climate change, and pandemics;
 - (4) Recognizing the challenges related to migration and ageing.
- 3. Discussion on Necessary Steps to Implement Aims set by the Joint Declaration in Civil Society, Policy Making and Research
 - The JF concluded several steps that can be undertaken towards the implementation of the MIPAA. This includes: (1) Creating a global network of associations and networks, (2) Drafting a Convention of the Rights of Older People, and (3) Combatting ageism through anti-discrimination regulations (policy) and campaigns (civil society).
- 4. Reflections and Comments from Attendees
 - Multiple attendees expressed appreciation of the joint forum declaration bringing together civil society and scientific research communities and recommended further collaboration between both stakeholder groups;

- Several attendees emphasized the importance of a Convention on the Rights of Older Persons, however the importance of monitoring and evaluating its implementation was also mentioned;
- The United Nations *Leave No One Behind* as a universal value was mentioned as was the need to mitigate female poverty, ensure sufficient resources to address elder abuse and in ensuring accessible and affordable help, and supporting digital learning;
- The acknowledgment of solidarity with the people of Ukraine and its inclusion into the JF Declaration was suggested;
- Calls to strengthen the Standing Working Group on Ageing, engage more with national-level policy makers, and greater need for the disaggregation of data was also offered;
- Greater clarity as to definitions for active versus healthy ageing as well as the need for greater inclusion of diverse populations were offered in addition to greater attention to environmental security in the face of climate change.

Concluding Remarks

Heidrun Mollenkopf, Age Platform Europe and representative of Civil Society, and Kai Leichsenring, European Centre for Social Welfare Policy and Research and representative of Scientific Research, closed the Joint Forum thanking the speakers and the audience for their constructive contributions. They confirmed that Civil Society and the Scientific Research Community stand ready to support the commitments set at the Ministerial Conference to ensure they are fully realized, and reiterated that the Joint Forum calls on governments to support the drafting of a United Nations Convention for the Rights of Older Persons to guarantee the equal application of universal human rights in older age both domestically and internationally to support the implementation of MIPAA policies.

Organising Committee

- Heidrun Mollenkopf, AGE Platform Europe and BAGSO
- Kai Leichsenring, European Centre for Social Welfare Policy and Research
- Dario Paoletti, AGE Platform Italy
- Giovanni Lamura, INRCA IRCCS – National Institute of Health and Science on Ageing
- Cristina Calvi, INRCA IRCCS – National Institute of Health and Science on Ageing