

**RECOGNITION - ACTION - IMPACT**

**Strategic Plan**  
2018-2022



## IACO VISION, MEMBERSHIP AND GOVERNANCE

Incorporated in 2012, the International Alliance of Carer Organizations (IACO) is a global entity that provides strategic leadership to build awareness and recognition, facilitate knowledge translation and advocate for comprehensive policies and programming to support the needs of carers.

**VISION:** To establish a global understanding and recognition of the essential role of carers with respect to care recipients, health and social care systems and society.

**MISSION:** To improve the quality of life and support the needs of carers through international partnerships and advocacy that strengthen and honour the voice of carers.

**MEMBERS:** IACO membership consists of full members (national non-governmental and nonprofit organisations) and associate members (regional nonprofit organisations and quasi-governmental agencies). Members work to advance the recognition and understanding of and support for carers and are committed to advancing person- and carer-centred health and social care. IACO members include:

- Association Française des Aidants (France)
- Care Alliance Ireland
- Caregivers Israel
- Carers Australia
- Carers Canada
- Carers Denmark
- Carers Finland
- Carers Hong Kong
- Carers Japan
- Carers New Zealand
- Carers UK
- Carers Worldwide
- Eurocarers (associate member)
- iHeartHub (associate member)
- NHS England (associate member)
- Swedish Family Care Competence Centre
- Taiwan Association of Family Caregivers
- National Alliance for Caregiving (United States)

### GOVERNANCE

IACO is governed by an elected board of directors that provides prudent fiscal management and effective operational oversight. To advance its mission and strategic initiatives and facilitate full member engagement, the organisation maintains a standing committee structure.

The Membership Recruitment and Engagement Committee facilitates the recruitment and engagement of IACO members to reflect a global carer voice and support the achievement of IACO's strategic goals.

The Policy and Stakeholder Relations Committee develops advocacy policies and position statements and identifies issues and opportunities that impact the achievement of IACO's strategic goals.

Strategic Projects and Communications advances the achievement of IACO's goals and objectives through proactive communications and effective project oversight and guidance.

IACO defines carer (also referred to as caregiver or family carer) as an unpaid individual, such as a family member, neighbour, friend or other significant individual, who takes on a caring role to support someone with a physical disability, a debilitating cognitive condition or a chronic life-limiting illness.

The 2018–2022 IACO strategic plan outlines four strategic priorities that will promote greater awareness and recognition of carers; inform decision-makers about the role and impact of caring; educate stakeholders about the effect carers have on health, social and economic viability; and set out a global strategic and action plan to meet carer priorities.

## FIVE YEAR STRATEGIC GOAL

By 2022, countries around the world will recognise carers and endorse a collective commitment to action.

## STRATEGIC PRIORITIES

### INCREASE AWARENESS AND RECOGNITION OF CARERS

IACO will increase global awareness and recognition of carers in countries across the globe and with prominent health and social organisations by 2021.

### ENHANCE UNDERSTANDING OF THE IMPACT OF CARING

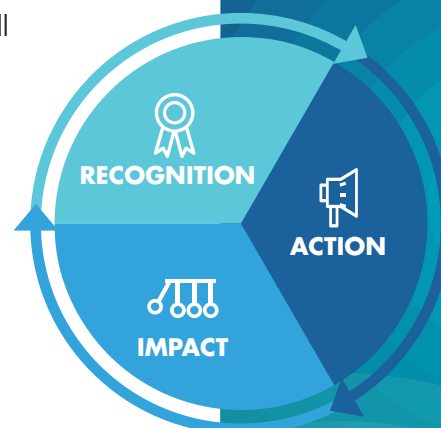
Beginning in 2018, IACO will promote awareness and understanding of the impact and influence carers have on care recipients' health outcomes, health and social care systems and economies.

### CREATE A GLOBAL STRATEGY AND COMMITMENT TO ACTION FOR CARERS

By 2022, IACO will provide an evidence-based foundation and call to action to foster a worldwide movement to recognise and support carers through the creation and promotion of a Global Carers Strategy and Action Plan.

### FACILITATE CAPACITY BUILDING

IACO will create a sustainable alliance recognised as a valued international source for networking, building awareness and facilitating action for carers across the world.



## CARERS: A GLOBAL PRIORITY

In every country around the world, individuals with disabilities, chronic health issues or frailty rely on unpaid care from family and friends. Known as carers, their role can range from helping with daily activities to more complex medical care. Although there are invaluable emotional benefits to providing care, being a carer can be time-consuming and take a heavy toll on the carer's health and well-being [IACO Global State of Care Report, 2018].

Both the number of carers and the hours of care they provide are increasing. Across the OECD, over 10% of adults over 50 years of age are carers. Approximately two-thirds are women, however the number of male carers is growing<sup>1</sup> [OECD, 2011]. The majority of long-term care is provided by carers. Carers account for more than twice the formal-care workforce in Denmark and more than ten times the formal-care workforce in Canada, New Zealand, the United States and the Netherlands<sup>1</sup> [OECD, 2013]. Health and social care systems are dependent upon formal health and social care providers and carers. Evidence shows that carers are more likely to continue caring if they are recognised, valued and supported. In order to ensure sustainable long-term care systems, the unique needs and contributions of carers must be considered in health and social policies and programming.

<sup>1</sup> Colombo, F., et al. (2011). Help Wanted? Providing and Paying for Long-Term Care. Paris: OECD Publishing. Available: <http://dx.doi.org/10.1787/9789264097759-en>.

<sup>2</sup> De La Maisonneuve, C. & Oliveira Martins, J. (2013). A Projection Method for Public Health and Long-Term Care Expenditures. Economics Department Working Papers No. 1048, OECD, Paris.

## STRATEGIC ACTIONS

### INCREASE AWARENESS AND RECOGNITION OF CARERS

Countries are beginning to recognise carers' important role and the impact and influence of caring. Through our broad membership base, IACO will inform the dialogue by creating resources for existing and emerging carer networks and facilitate the sharing of awareness campaigns and activities across the globe. Special consideration will be given to gender-based analysis, women and vulnerable populations.

#### GOAL

IACO will increase global awareness and recognition of carers around the world and with opinion leaders and key global health and social organisations.

#### OBJECTIVE

IACO will identify and actively disseminate information on:

- who carers are (diversity and numbers);
- what carers do; and
- how they are impacted by their caring role.

#### ACTIONS

Profile individual country carer legislation, policies and programmes, starting with IACO member countries and beyond.

- Launch the Global State of Care report in December 2018.
- Develop a plan to expand the Global State of Care report to more member countries.
- Promote leading carer practices and profile them as Innovative Carer Practices.

Promote data on carers and feature country awareness campaigns.

- Develop an estimation of the number of carers worldwide.
- Enhance and update the global carer stats information on the IACO website.
- Profile awareness campaigns hosted by IACO member countries on the IACO website.
- Provide advice for and guidance to Embracing Carers™ and align initiatives where appropriate.



## AWARENESS & RECOGNITION



## ENHANCE UNDERSTANDING OF THE IMPACT OF CARING

Although care recipients are often the focus of health and social care policies (e.g., long-term care, chronic disease management, etc.), effective, sustainable models require an equal emphasis on carers' and care recipients' education, support and behaviour modifications. In the absence of appropriate resources to ensure carer well-being, there is a high potential for serious negative health, safety and financial consequences. IACO members have insight and experience in bringing this important issue to light.

### GOAL

Promote awareness and understanding of the impact and influence carers have on care recipients' health outcomes, health and social care systems and economies.

### OBJECTIVE

Build awareness and understanding of the impact carers have on care recipients' health outcomes and the financial consequences (e.g., health and social care systems and global economies) of carers' involvement in looking after individuals with chronic conditions and seniors living with a frailty.

### ACTIONS

Build awareness of the role and impact of carers on specific patient populations with a focus on knowledge translation and promotion of existing IACO reports.

- Promote the findings of the International Study on Carers of Persons with Heart Failure.
- Inform knowledge translation of the Living with Multiple Sclerosis: The Carer's Perspective report.
- Explore alignment of carers' needs with the United Nations' Sustainable Development Goals.

Develop a white paper profiling the co-dependent relationship between caregiver well-being and the care recipient's health outcomes (i.e., needs, risks, opportunities, carer needs, etc.).

- Undertake a global synthesis and appraisal of relevant, best available research studies (i.e., published and grey literature) on the relationship between caregivers' influence and care recipients health outcomes.
- Link carer needs and available supports through IACO country members.



## IMPACT OF CARE & CARING

## CREATE A GLOBAL CARER STRATEGY AND COMMITMENT TO ACTION FOR CARERS

A global strategy and action plan for carers will provide a framework for IACO member organisations, other countries and IACO strategic partners to contribute to achieving the vision of a global understanding and recognition of the essential role of carers with respect to care recipients, health and social care systems and society. The global action plan will:

- foster a commitment to action for carers;
- encourage the development of carer-friendly policies and programmes;
- ensure inclusion of carers' experiences and voices in health and social policy planning;
- advance data collection and understanding of the current and evolving landscape for carers; and
- reinforce actions through measurement, monitoring, research and knowledge mobilization on carer issues.

### GOAL

Foster a worldwide movement to recognise and support carers through the creation and promotion of a Global Carers Strategy and Action Plan.

### OBJECTIVE

By 2022, IACO will provide an evidence-based foundation for actions to address the universal needs of carers around the globe.

### ACTIONS

Build awareness of leading evidence-informed practices that support carers from around the world.

- Launch the Innovative Carer Practices initiative in partnership with Embracing Carers™, beginning in 2018 with the identification, creation and dissemination of four Innovative Carer Practices.
- Create and adopt overarching principles for carers to guide IACO initiatives.

Develop a global action plan to address universal carers' needs.

- Create a framework for the action plan leveraging the experience and knowledge of IACO members to build a solid evidence-based foundation.
- Conduct broad-based consultations on a draft action plan with IACO members, partners and relevant stakeholders and encourage their input to identify alignment with current priorities beyond IACO membership.
- Host a consensus summit in 2021 to obtain agreement on the framework and action plan.
- Launch the global action plan using a comprehensive knowledge translation communication approach to maximize reach and impact.



## GLOBAL CARER STRATEGY



## FACILITATE CAPACITY BUILDING

### FACILITATE CAPACITY BUILDING

IACO members possess a wealth of knowledge and experience in supporting carers. Through the synergy of its members, IACO will identify and disseminate best practices, expertise and experience and act as a resource for carer organisations globally.

#### GOAL

IACO will become a sustainable alliance recognised as a valued international source for networking, building awareness and facilitating action for carers around the world.

#### OBJECTIVE

IACO will identify and disseminate best practices, expertise and experience and act as a resource for carer organisations globally.

#### ACTIONS

Ratify and launch the IACO Strategic Action Plan and develop an accountability framework with measurable outcomes and impacts.

- Renew the standing committee action plans and membership commitments annually.
- Align tactical work among all committees and support initiatives through the IACO secretariat team and strategic partnership agreements.
- Broadly promote IACO's strategic goals.

Build strategic partnerships that reinforce and align with IACO's goals.

- Create an ethical framework and guidelines for working with sponsors and strategic partners (2019).
- Develop sustainable, mutually beneficial relationships with funding partners.
- Set out stakeholder mapping of international influencers (e.g., UN, WHO, OECD, G20, Global Alliances, international labour organisations, IAPO, etc.) outlining goals, opportunities, engagement and actions.

Strengthen IACO's core secretariat functions and engagement of members.

- Promote awareness of IACO, its members and achievements.
- Increase the number of full IACO members from 15 to 20.
- Ensure fiscal and operational accountability through the adoption of updated bylaws, financial policies and operational processes.

# KEY MILESTONES

