

STRATEGIC BUSINESS PLAN

International Alliance of Carer Organizations (IACO)

2014 – 2018



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IACO VISION, MEMBERS & GOVERNANCE

Incorporated in 2012, IACO serves as an umbrella organization that provides cohesive direction, facilitates information sharing, and actively advocates for carers at an international level.

The terms caregiver, family caregiver and carer are used interchangeably by IACO members.

A caregiver, family caregiver or carer is defined by the IACO as an “individual that is significant for a patient or their care, who can represent the patient, for example, a partner, parent, family member or close friend.”

IACO 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.

IACO Mission

To improve the quality of life and support the needs of carers, through international partnerships and advocacy that strengthen and honor the voice of cares.

IACO Members

IACO members include both non-governmental organizations and multinational corporations that demonstrate an understanding of carers, a willingness to collaborate and communicate and a commitment to the IACO vision, mission and goals.

IACO held its inaugural meeting in Dublin Ireland in May 2013 where the founding member countries came together to share their strategic directions and initiatives and identify collective goals and objectives for the Alliance. The current IACO members include:

- **Canadian Caregiver Coalition (CCC)** (established in 2000) is a virtual alliance of diverse partner organizations that work collectively, and autonomously, to identify and respond to the needs of caregivers in Canada. The CCC provides leadership in advocacy, engagement and collaboration and building awareness of the role and value of family caregivers.
- **Care Alliance Ireland** (established in 1995) is the National Network of Voluntary Organisations supporting Family Carers. Its vision is that the role of Family Carers is fully recognised and valued by society in Ireland. The organisation exists to enhance the quality of life for Family Carers. It aims to achieve this by supporting its 95 member organisations in their direct work with Family Carers through the provision of information, developing research and policy, sharing resources, and instigating opportunities for collaboration.
- **Carers Australia** (established in 1993) is the national peak body representing Australia's carers, advocating on behalf of Australia's carers to influence policies and services at a

national level. It works collaboratively with partners and its member organisations, the network of state and territory Carers Associations, to deliver a range of essential national carer services.

- **Carers New Zealand** (established in the early 1990's) - Carers NZ, the national peak body supporting family, whanau, and aiga carers. A national registered charity, Cares NZ provides information, advice, learning and support for families with health and disability needs
- **Carers Sweden (Anhörigas Riksförbund)** (established in 1996) is a non-profit national carer organisation consisting of over sixty local associations together with other supporting organisations and individual members that supports all carers irrespective of the age, gender and diagnosis of the person they are caring for. It provides information and advice and lobbies to influence and inspire the development of support for carers. A key event is the annual national carer conference which attracts over 800 people from all major stakeholder groups. Carers Sweden is a key partner within the Swedish Family Care Competence Centre (Nationellt kompetenscentrum anhöriga), a national centre of excellence in the field of informal care.
- **Carers UK** (established in the early 1960's) supports carers and provides information and advice about caring, influence policy through research based on carers' real life experiences and campaign to make life better for carers.
- **Carers Worldwide**, a registered charity, set up in 2011 to address the issues facing carers in developing countries. Based in the UK, Carers Worldwide works internationally, in partnership with well-established organisations, to bring about improved quality of life for carers and those for whom they care. Currently Carers Worldwide is conducting programs in South and North India with three established partner organisations in addition to a consultation exercise with carers in Nepal to initiate programs with partner organisations there. (Joined IACO in 2014)
- **National Alliance for Caregiving** (Established in 1996 in the USA) is a non-profit coalition of national organizations focusing on advancing family caregiving through research, innovation and advocacy. The Alliance conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues.
- **The Central Association of Carers in Finland** (Omaishoitajat ja Läheiset -Liitto ry) is a support and advocacy association for carers and persons receiving care. The association specializes in improving the carers' social status and offers different kinds of support for people living in care situations. With seventy-one local associations, which have a total of nearly 10 000 individual members, the association makes legislative initiatives, gives statements, participates in planning and decision-making related to informal care at the national level, and monitors the realization and quality of support activities for carers.

GOVERNANCE OF IACO

The General Assembly of the IACO consists of delegates from each member organization and reflect an international presence. Each delegate is a member of the respective governing body of the member organization (chief executive, or of similar status) and possess specific skills that will be beneficial to the IACO.

The General Assembly elects a **Governing Board** to act on its behalf. The Governing Board representatives include the established committee chairs, the President / CEO of the secretariat organization and other identified representatives. The Governing Board ensures the collective interests of members are respected, obligations are fulfilled and the operational structure is effective.

The Governing Board can appoint **Special Advisors** from time to time as required. A Special Advisor may be someone with certain skills that add to those of the Governing Board Members. They may be able to assist the Board with a particular issue or project, or give more general support. IACO Special Advisors use their expertise and experience to assist the Governing Board in achieving their aims. These aims are all focused on fulfilling IACO's mission. Special Advisors have no voting rights within the Governing Board and no decision-making power.

The Communications Committee oversees the efficient and effective communications strategy for the organisation including strategic planning documents, branding and key messaging, website development/content and public/press statements.

The Membership/ Funding Committee contributes to the financial sustainability of IACO by actively identifying and securing funding partners. Activities include the development of a business case for involvement in IACO, structuring guiding terms of reference for funding organizations / associate members and sourcing new member organizations.

FIVE YEAR STRATEGIC GOAL

To have the role of caregivers recognized as a human right (in individual countries and / or through the United Nations).

PRIORITY GOALS

GOAL 1: DEVELOP AN IDENTITY (2014-16)

IACO members will increase awareness of caregivers, who they are, what they do.

Rationale: 'Self-identification' of caregivers is a challenge. Caregivers consider caring to be an inherently private, family and charitable activity. It is commonly reported that many people providing care in such situations 'do not identify themselves as caregivers'. Identification of individuals as caregivers is occurring through a number of indirect ways in various countries and IACO has the broad scope to identify and articulate these.

GOAL 2: ARTICULATE A NARRATIVE (2015-17)

Clearly define the detrimental effects of being a carer both within member countries and globally through IACO.

Rationale: Many countries are currently compiling evidence that assume a carer role has adverse social, economic, health and political consequences. IACO will explore the global consequences within two frames:

1. Health and well-being of the carers
2. Flexible workplaces for employed caregivers

GOAL 3: VERBALIZE A CREED (2017-18)

IACO will articulate a common and unifying issue that caregivers face across the globe.

Rationale: The availability and active involvement of family caregivers is vital to the provision of effective health and social care outside of institutions. An ageing global population together with greater life expectancy is resulting in greater levels of dependency ratios, with more people requiring care and support relative to the formal working population. For many patients or care recipients the concept of independence is not feasible - as in the case of an individual choosing to die at home, or someone with complex care needs that impact both physical and mental abilities. In order to have independence you must have interdependence.

STRATEGIC ACTIONS (2014 – 16)

ACTION 1: DEVELOP AN IDENTITY FOR CARERS WORLDWIDE

IACO members will increase awareness of carers – who they are, what they do

RATIONALE:

'Self-identification' of caregivers is a challenge. Caregivers consider caring to be an inherently private, family and charitable activity. It is commonly reported that many people providing care in such situations 'do not identify themselves as carers'. Identification of individuals as caregivers is occurring through a number of indirect ways in various countries and IACO has the broad scope to identify and articulate these.

ACTIONS:

- Identify which countries (beginning with member organizations) have legislation that supports carers.
- Collect Caregiver Bill of Rights materials that carer organizations have developed.
- Determine which countries include questions regarding carers in their national census reports or other politically recognized surveys.
- Amalgamate common carers data into one source (building on the caregiver data chart – see above).
- Determine which countries have programs to support employed carers and develop a communications piece to build awareness of initiatives.
- Leverage member country's awareness campaigns:
 - Public Relations/Advocacy – campaign "I am a carer" or "I am a caregiver."
 - Video that captures a person's whole life. If we do a montage, should include very senior carers. CDs on young carers in Ireland. Videos in Swedish and UK videos.
 - "Do I look like I care?" UK campaign
 - "What is a carer?"
- Create a World map that shows caregiver numbers and facts.
- Promote a common definition for carers – as articulated by IACO.

ACTON 2: BUILD AWARENESS OF IACO

IACO members and activities will be profiled through a global platform

RATIONALE:

IACO members bring individual strengths and collective influence to advancing the mission of global understanding and awareness of carers. An effective and sustainable communications vehicle is necessary to support cohesive, increase awareness and support the joint efforts of IACO members.

ACTIONS:

- Develop a style sheet and policy on how to use the IACO logo, branding and standard language.
- Distribute the communications tool kit to all member organizations.
- Develop a user friendly, sustainable IACO website that leverages and links to the member sites.

ACTION 3: FACILITATE CAPACITY BUILDING WITH CARER ORGANIZATIONS

IACO will facilitate the sharing of knowledge within member organizations and expand the network of organizations involved in IACO

RATIONALE:

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

ACTIONS:

- Actively seek two new member organizations for IACO to compliment the scope and influence.
- Develop a toolkit to support countries that want to develop carer groups within their country.
- Expand IACO associate members (funding organizations) to ensure a strong financial base for IACO activities.

ACTION 4: ENGAGE INTERNATIONAL INFLUENCERS

IACO will establish partnership with key influential stakeholders

RATIONALE:

IACO global influence will depend upon the strength of both member organizations and partnership that have been forged with IACO. Stakeholder partnership will be essential to advancing the five year goal of caring recognized as a human right.

ACTIONS:

- Explore engaging of International Labor Organizations (Finland member has connections).
- Develop a strategy to build recognition with the World Health Organization and United Nations on order to influence their agenda and priorities.
- Each member country to establish linkages with research organizations to support actions with data and facts.
- Explore the role and evolution of technology to support caregivers – possible opportunity to exploit.

INVESTMENT / BUDGET

ACTIVITY	RESOURCES	COSTS
ACTION 1: DEVELOP AN IDENTITY FOR CARERS WORLDWIDE		
Member scan for carers identified in: <ul style="list-style-type: none"> • Legislation • Census data • Bill of rights 	IACO Secretariat (NAC staff and intern)	\$15,000
Amalgamation of data and creation of “world map”	Communications committee & IACO members	In-kind contributions of the communication committee members and IACO members
Source and profile member “awareness campaigns”		
ACTON 2: BUILD AWARENESS OF IACO		
IACO website Functional site & design	Canadian Caregiver Coalition	In-kind contribution (\$10,000)
Information upload	IACO Secretariat (NAC)	\$5,000
Ongoing input & maintenance	IACO Secretariat (NAC)	\$10,000
Communications Kit development	Communications committee IACO Secretariat	\$100,000 * Outsourced contract
ACTION 3: FACILITATE CAPACITY BUILDING WITH CARER ORGANIZATIONS		
Members outreach	IACO Secretariat	\$10,000
New Members	Funding Committee	\$10,000
ACTION 4: ENGAGE INTERNATIONAL INFLUENCERS		
Stakeholder Engagement	All members	In-kind
Meetings with WHO & UN	TBD	\$20,000
Linkage with Labour Org.	TBD	
IACO CORE FUNCTIONS		
IACO Management	NAC	\$15,000
Committee teleconference	NAC	In-kind
Annual Meeting – General Assembly	NAC	\$20,000

KEY MILESTONE & PERFORMANCE MEASUREMENT

MILESTONE	DATE
Global data and scan completed (All member data submitted)	January 2015
World “Data”Map	Launch Sept 2, 2015
Caregiver Awareness Communication Sheet	January 2016
IACO Website	April 2015
Common Caregiver Definition	November 2014
Communication kit and guidelines	February 2015
2 New IACO members	September 2015
Toolkit for newly forming groups	December 2015
2 IACO funding members/ partners	September 2015
WHO engagement	December 2015
UN engagement	December 2015
Labour Org. discussion	December 2015
Annual meeting – general assembly	Sept 2, 2015 (Gothenburg Sweden)