
Ageing societies — General requirements and guidelines for carer-inclusive organizations

*Vieillessement de la population — Exigences générales et lignes
directrices pour les organisations favorisant et appuyant les aidants
naturels*

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Foreword

ISO (the International Organization for Standardization) is a worldwide federation of national standards bodies (ISO member bodies). The work of preparing International Standards is normally carried out through ISO technical committees. Each member body interested in a subject for which a technical committee has been established has the right to be represented on that committee. International organizations, governmental and non-governmental, in liaison with ISO, also take part in the work. ISO collaborates closely with the International Electrotechnical Commission (IEC) on all matters of electrotechnical standardization.

The procedures used to develop this document and those intended for its further maintenance are described in the ISO/IEC Directives, Part 1. In particular, the different approval criteria needed for the different types of ISO documents should be noted. This document was drafted in accordance with the editorial rules of the ISO/IEC Directives, Part 2 (see www.iso.org/directives).

Attention is drawn to the possibility that some of the elements of this document may be the subject of patent rights. ISO shall not be held responsible for identifying any or all such patent rights. Details of any patent rights identified during the development of the document will be in the Introduction and/or on the ISO list of patent declarations received (see www.iso.org/patents).

Any trade name used in this document is information given for the convenience of users and does not constitute an endorsement.

For an explanation of the voluntary nature of standards, the meaning of ISO specific terms and expressions related to conformity assessment, as well as information about ISO's adherence to the World Trade Organization (WTO) principles in the Technical Barriers to Trade (TBT), see www.iso.org/iso/foreword.html.

This document was prepared by Technical Committee ISO/TC 314, *Ageing societies*.

Any feedback or questions on this document should be directed to the user's national standards body. A complete listing of these bodies can be found at www.iso.org/members.html.

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Introduction

0.1 General

Worldwide, 349 million people are estimated to be care-dependent and of these, 101 million people are over the age of 60 years^[1]. The form that long-term care takes varies significantly among and within countries, from home care services to institutional hospital-based care. In most countries, individuals assume caregiving responsibilities for a spouse, family member, or friend who needs care because of limitations in their physical, mental or cognitive functioning and the majority of these carers are women. Although caregiving is a valued societal resource and often viewed positively by carers themselves, family/friend carers are largely a hidden and unacknowledged workforce.

Caregiving has become one of the most important social and economic issues worldwide and as population ages, carers will play an increasing critical role in every society, providing substantial economic value globally. For example, a study in Finland showed that the availability of unpaid care considerably reduces public care expenditure (estimated cost savings of 338 million euros)^[2]. As unpaid care reduces costs of health system expenditure, it needs to be recognized that both unpaid and paid care is more often done by women. This can result in women leaving paid work to meet the demands of their unpaid care work and/or experiencing workplace inequalities. Caregiving is impacting workforces, health care systems, families and societies in general.

One of the greatest challenges for working carers is trying to balance employment with caregiving responsibilities. For example, labour force participation (the percentage of working age people in an economy who are either employed or unemployed but actively looking for work) is significantly affected by the family care needs of the growing ageing population. At the same time, family sizes are decreasing, more women are employed in the labour force, mobility is increasing, life expectancy is increasing, and the number of older adults in need of care is projected to continue to grow. These trends are impacting the growing number of working carers. Studies^{[3][4][5][6]} show that their paid work is negatively impacted by becoming a carer and in most situations, employers do not have policies or programs in place to support these working carers^[7].

0.2 Supports for working carers

Employers can play a key role in supporting their employees who are also carers. Organizations can opt to sponsor benefits to working carers, such as education, skills training or supportive services, or to implement carer-supportive personnel policies and programs. These policies and programs help working carers to manage their paid work alongside their caring role, providing equal opportunities for them to remain in/or return to work, and help to reduce work-family conflict and/or support work-life balance. However, there is a lack of clear guidance for employers on how to support working carers.

The workplace is but one arena where working carers can be supported. Although the majority of waking hours are often spent at work, making it a key environment for carer supports, there are other arenas where carer supports are available. These include those available through the government or state, via the provision of public health care services and supports, such as family leaves. There are also a range of non-governmental, charitable and/or disease-specific organizations (i.e. cancer, dementia) that also provide supports, whether transportation services or personal care, for example. Finally, each working carer also has their own informal support system made up of extended family, friends and/or neighbours.

In some jurisdictions, working carers can be entitled to statutory care leaves, income support or credits, insurance schemes, financial support for care expenses, etc. For example, in June 2019, the European Union updated its Work-Life Balance Directive to introduce carer leaves and extended the right to request flexible working arrangements to working carers (previously available to working parents)^[8].

The intent of this document is to complement relevant existing programs and supports, whether state provided or otherwise.

0.3 Benefits of implementing a carer-inclusive program

Studies have shown that carer-inclusive policies and programs can help to:

- retain skilled staff;
- improve worker morale and productivity;
- reduce absenteeism and presenteeism;
- avoid the number of staff coming to work sick;
- reduce disability costs and mental health claims;
- give organizations a competitive advantage;
- build a more engaged workforce;
- support the organization's efforts for a more inclusive workforce;
- demonstrate the organization's investment in society through their support of working carers.

0.4 Application of document and relevant publications

This document can be selectively applied by organizations, recognizing that resources and supports available will differ from organization to organization depending on the size and sector of the organization and the jurisdiction. The development of a carer-inclusive program is seen as a process that requires flexibility in terms of implementation.

A carer-inclusive program can be as basic as recognizing working carers as recipients that would benefit from existing supports. For example, many organizations have existing employee support programs which can be used to support working carers. A carer-inclusive program can build on these existing supports or be a stand-alone program, if these are not available. Strategies need to include raising awareness of these supports and targeting them appropriately.

Achieving a carer-inclusive workplace requires a holistic approach and depends on the engagement of many stakeholders and integration of systems. For example, programs to address equity, diversity and inclusion, human resources management and health and safety management would be relevant to the application of this document. As such, there are related documents that can be used in conjunction with this document, e.g. ISO 30415, ISO TR 30406, ISO 45001 and ISO 45003.

0.5 Caregiving and sex/gender issues

A sex/gender lens is important to consider in developing carer-inclusive policies and practices. For example, estimates from across different countries indicate that 57 % to 81 % of all carers of older adults and others requiring long term care are females, and are likely to work outside the home^[9].

For female carers the impact that caregiving can have on employment can be considerable given that they provide significantly more caregiving hours than males. Recent European research shows that only 50 % of female working carers can work full-time and specifies that caregiving impacts their financial circumstances^{[10][11]}. In addition, when compared to males, female working carers are more likely to make job adjustments (change or leave jobs) as a result of their ongoing caregiving demands^[11]. In addition, female carers provide more emotional support to care recipients, which can have a greater impact on a carer's mental health and contribute to carer distress.

A sex/gender lens is key to establishing carer-inclusive policies and programs to help eliminate bias and to promote sex and gender equality. This will help to ensure that the needs of all are given equal consideration in organizational decisions and activities.

This document provides guidance to organizations on how to apply a sex/gender lens to the development of carer-inclusive programs. It supports the aims of United Nations Declaration on Gender

Responsive Standards and Standards Development to make standards more gender responsive^[12]. It also contributes to the achievement of the United Nations Sustainable Development Goal (SDG) 5: Achieve gender equality and empower all women and girls and specifically SDG Target 5.4: Recognize and value unpaid care and domestic work through the provision of public services, infrastructure and social protection policies and the promotion of shared responsibility within the household and the family as nationally appropriate. Further this document contributes to SDG 8: Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all, and specifically Target 8: To achieve full and productive employment and decent work for all women and men, including for young people and persons with disabilities, and for equal pay for work of equal value^{[13][14]}. Additional guidance on sex, gender and caregiving is provided in [Annex A](#).

0.6 Emerging and evolving issues for working carers

The COVID-19 pandemic has highlighted and increased risks for many working carers. Although providing certain advantages for working carers, such as working from home, COVID-19 has shown more clearly the gaps in supports for working carers in both social and health care systems. A UK survey showed that 70 % of family carers are providing more care due to the pandemic and many working carers have seen a dramatic reduction in their income due to lockdown policies^[15].

While not a new situation, one group particularly at risk are the “double duty” carers. Many of the frontline health care workers providing care to older adults are also providing unpaid care to their own older family members, friends or neighbours. These workers are at increased risk of contracting the virus, making it is difficult for them to carry out their family caring role.

Another critical group of working carers are the “sandwich carers”. These are people trying to look after frail and disabled elderly relatives, often their parents, or other older family or friends at the same time as looking after dependent children. During the pandemic, these working carers are often working from home, doing home schooling, parenting, and caring for their older relatives, friends or neighbours.

While this document focuses on working adults, there is increasing concern about the issues facing young carers who can also be students and workers. Some academic organizations and employers are beginning to address this issue, but at present, there is little guidance in this area.

Phrases and words related to caregiving have developed differently in individual languages and language communities, depending on the professional, social, economic, political, cultural, and linguistic factors. In addition, these words and phrases have evolved over recent decades with changes in health care systems and public views about the role of caregiving in an ageing society. Some phrases traditionally used in this field can now be viewed as misleading or inappropriate^[16]. In the development of this document, feedback from experts showed great variation in the use of these phrases in different countries and contexts.

The Technical Committee has developed an informative guide on terminology related to caregiving to show how these words and phrases are used across regions and disciplines and how they are evolving over time. See: Terminology Related to Caregiving, available on the TC 314 website at: <https://committee.iso.org/sites/tc314/home/projects/published/resources.html>^[17].

This document can assist organizations in identifying and responding to these issues for working carers.

In this document, the following verbal forms are used:

- “shall” indicates a requirement;
- “should” indicates a recommendation;
- “can” indicates a possibility or a capability;
- “may” indicates a permission.

Information marked as “NOTE” is intended to assist the understanding or use of the document. “Notes to entry” used in [Clause 3](#) provide additional information that supplements the terminological data and can contain requirements relating to the use of a term.

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1 Scope

This document specifies requirements and provides guidelines for an organizational program for working carers providing care to:

- adult care recipients (e.g. adults with cognitive, sensory, physical, and invisible disabilities, adults with chronic or episodic conditions and older dependents);
- long-term childcare recipients (e.g. due to chronic illness or permanent cognitive, sensory or physical disability or injury).

This document is applicable to any organization, regardless of size, sector or community setting (i.e. urban, rural or remote).

This document can be used in conjunction with an organization's management systems, human resource programs, and/or equity, diversity and inclusion programs, or on its own in the absence of a formal workplace program to support working carers.

2 Normative references

There are no normative references in this document.

3 Terms and definitions

For the purposes of this document, the following terms and definitions apply.

ISO and IEC maintain terminology databases for use in standardization at the following addresses:

- ISO Online browsing platform: available at <https://www.iso.org/obp>
- IEC Electropedia: available at <https://www.electropedia.org/>

3.1 care

activities/actions (social, physical, emotional, spiritual, mental) that take place across a variety of settings: in the home, community, institution and all care settings

Note 1 to entry: Applies to both paid and unpaid care.

3.2 care recipient

person who is receiving care from the working carer

3.3 care worker care provider

person who is paid to support someone who is ill, struggling or disabled and who could not manage without this help

Note 1 to entry: In some countries and regions, similar phrases include: home care provider, home health care professional, personal support worker, personal care assistant, certified caregiver, trained carer, care specialist, and health care professional.

3.4

carer

caregiver

family caregiver

person who cares, unpaid, for a family member, friend or significant person who, due to a lifelong condition, illness, disability, serious injury, a mental health condition or an addiction, cannot cope without their support

Note 1 to entry: This term includes carers who are generally unpaid but can receive some financial support for care they provide from time to time. It does not include trained care providers affiliated with home care agencies.

Note 2 to entry: Carers can provide emotional or financial support, as well as hands-on help with different tasks. Caregiving can also be done from long distance.

Note 3 to entry: The terms “carer”, “family caregiver” and “caregiver” are often used interchangeably. “Carer” is more commonly used in Europe, UK, New Zealand, and Australia. In North America, “caregiver” or “family caregiver” is more commonly used. In Asia “carer” more commonly refers to a paid care provider.

3.5

family

combination of two or more persons who are bound together over time by ties of mutual consent, birth and/or adoption or placement and who, together, assume responsibilities for various roles and functions

Note 1 to entry: The term “family” can include “chosen families,” such as strong friendships and communities where unrelated persons provide care normally provided by nuclear family members.

3.6

unpaid care

care provided without a monetary reward by carers

Note 1 to entry: “informal care” is often used to describe unpaid care but is becoming less acceptable as it does not reflect the complexity and essential nature of care that is provided. Unpaid care is labour and provides significant value to families, health care systems and the economy.

3.7

working carer

individual in full or part-time work who also provides care to a family member, friend or significant person and where the care responsibilities have a substantial impact on their working life

Note 1 to entry: Persons with disabilities can be working carers as well as care recipients.

Note 2 to entry: Commonly used term in UK, Nordic countries and Europe. In Canada, “carer-worker” or “employee carer” are also used.

3.8

young carer

children and young people who provide regular and prolonged care for ill or disabled family members, including those with addictions and mental health issues

Note 1 to entry: The upper age limit for young carers can vary from 18 to 25 years. Some countries are using the term young adult carers to distinguish between the age categories of young carers.

3.9

absenteeism

time taken off work, including periods of paid or unpaid leave, to attend to non-work-related responsibilities such as self-care or caregiving-related matters

Note 1 to entry: Absenteeism includes any kind or amount of time off work, such as sick or vacation days, leaving work early, or coming into work late.

3.10**accommodation**

intentional organizational actions, whether in policies, programs, or the organizational culture, which relieves work-family conflict

Note 1 to entry: Accommodation can include flexible work arrangements, such as working from home, flexible working hours, job sharing or giving workers more autonomy over their work schedules.

3.11**consultation**

process of seeking views before making a decision

Note 1 to entry: Consultation includes engaging health and safety committees and workers' representatives, where they exist.

[SOURCE: ISO 45001:2018, 3.5]

3.12**organizational culture**

values, beliefs and practices that influence the conduct, behaviour and knowledge of people and organizations

[SOURCE: ISO 30400:2016, 3.2, modified — "and knowledge" has been added.]

3.13**participation**

involvement in decision-making

Note 1 to entry: Participation includes engaging health and safety committees and workers' representatives, where they exist.

[SOURCE: ISO 45001:2018, 3.4]

3.14**presenteeism**

lost productivity that occurs when employees are not fully functioning in the workplace because of an illness, injury, or other condition

Note 1 to entry: Even though an employee can be physically at work, they might not be able to fully perform their duties, and this leads to loss of productivity due to preoccupation with carer-related burdens.

3.15**top management**

person or group of people who directs and controls an organization at the highest level

[SOURCE: ISO 45001:2018, 3.12]

3.16**worker**

person performing work or work-related activities that are under the control of the organization

Note 1 to entry: Persons perform work or work-related activities under various arrangements, paid or unpaid, such as regularly or temporarily, intermittently or seasonally, casually or on a part-time basis.

Note 2 to entry: Workers include top management, managerial, and non-managerial persons.

Note 3 to entry: The work or work-related activities performed under the control of the organization can be performed by workers employed by the organization, workers of external providers, contractors, individuals, agency workers, and by other persons to the extent the organization shares control over their work or work-related activities, according to the context of the organization.

Note 4 to entry: Workers can include students and volunteers.