
Ageing societies — Framework for dementia-inclusive communities

*Vieillissement de la population — Collectivités inclusives à l'égard des
personnes atteintes de démence*



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Published in Switzerland

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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.

Introduction

0.1 Overview

This document was developed in response to a worldwide recognition that individuals, families, and communities need to be more inclusive concerning persons with dementia. One goal of this document is to engage and include persons with dementia and their families, and carers, in communities of all types, sizes, and locations.

A dementia-inclusive community is one that is committed to working together to promote a better understanding of dementia, reduce stigma, raise public awareness, and that facilitates social inclusion and participation. By fostering a dementia-inclusive environment, communities can support persons with dementia to be independent citizens, to be connected as much as they want to, to feel safe and comfortable, and to be able to maximise their abilities and opportunities to participate.

0.2 Challenges and solutions

The worldwide rise in the number of persons with dementia has led to a growing need to increase understanding of dementia in all societies. Stigmatisation and discrimination towards persons with dementia sometimes occur within their community, creating barriers to diagnosis, treatment, and care, which can significantly impact their quality of life. Many societies do not support persons with dementia adequately and discourage them from exerting maximum control over their own lives. Additional support to enable continued engagement for persons with dementia in daily activities and community life, or to enable participation in decision-making in life, is often provided too late or not at all.

There is a need for education to address knowledge about what a dementia diagnosis can mean for persons with dementia and those around them, including treatment and care options as key elements, which would support development of a dementia-inclusive community within an integrated care approach.

NOTE Integrated care can include primary care, all allied health professionals, e.g. occupational therapists, social workers, physiotherapists, and dementia advisers.

The creation of supportive, safe, and inclusive communities for persons with dementia and those who care for them is essential to maximizing everyone's quality of life.

This document provides a comprehensive and interdisciplinary framework to develop a dementia-inclusive community.

Moreover, this document recognizes that training, resources, experience, personnel availability, and existing organizational structures are constraints that can have a direct impact on how quickly and effectively a dementia-inclusive community can be planned and implemented. Therefore, this document provides guidance on how to identify these constraints and address them as part of the process of designing a dementia-inclusive community.

A person with dementia possibly experiences physical, sensory, cognitive, social, and communication challenges and these need to be considered as part of a dementia-inclusive community. ISO/IEC Guide 71 provides information on various human capabilities and characteristics relevant to this document.

0.3 Expected outcomes and users of this document

Some of the expected outcomes from the use of this document include the following:

- improvement of the quality of life for anyone with dementia in a community;
- development of quality services for persons with dementia;
- ability to obtain recognition for establishing a dementia-inclusive community;
- optimization of the resources needed to develop a dementia-inclusive community;

- creation of new opportunities for all stakeholders in a dementia-inclusive community;
- more inclusive communities generally, where the participation of everybody, including persons with dementia, is facilitated and encouraged.

This document is aimed towards, but not limited to, user categories such as the following:

- authorities having jurisdiction within communities;
- organizations, congregations, and community groups;
- individuals, carers, and families;
- persons of interest in education, research, and development;
- decision makers;
- planners, designers, and providers of products, services, the built environment, and the community infrastructures.

0.4 Other requirements

There can exist other requirements, including regulatory requirements that can affect aspects of a dementia-inclusive community as addressed in this document (e.g. revoking drivers' licenses, provisions, and regulations for the restriction of freedom and decision-making in later stages of dementia). Consequently, those developing a dementia-inclusive community should identify potential regulatory, health and other requirements that can be in conflict with a dementia-inclusive community and discuss how these conflicts can be resolved or mitigated.

0.5 Approach and structure of this document

The challenges and solutions outlined above set the subject matter and objectives for this document.

An integrated community network is built on the development and integration of the community sectors, referred to as action areas.

[Clause 4](#) provides a process-based framework for the development, maintenance, and continuous improvement of dementia-inclusive communities. To transform into a dementia-inclusive community, a set of generic guiding principles is presented in [Clause 5](#). [Clause 6](#) provides a set of requirements for the design of a dementia-inclusive network, while [Clause 7](#) provides information about the action areas and integration between them.

The annexes provide additional information on aspects such as possible considerations when implementing requirements (see [Annexes A](#) and [B](#)) stages of dementia (see [Annex C](#)), other frameworks available for consideration (see [Annex D](#)), and a compact implementation and progress evaluation checklist (see [Annex E](#)).

Ageing societies — Framework for dementia-inclusive communities

1 Scope

This document provides a framework for dementia-inclusive communities, including principles and the considerations of inclusion, quality of life, built environments, special needs groups, and stakeholder engagement. It also provides guidance on how to systematically leverage, improve, and interconnect their existing assets and structures and transform efficiently into a dementia-inclusive community.

This document does not provide any clinical standards.

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

dementia

set of symptoms affecting brain function that are caused by neurodegenerative and vascular diseases or injuries

Note 1 to entry: Dementia is characterized by a decline in cognitive abilities such as memory; awareness of person, place, and time; language, basic math skills; judgement; and planning. Dementia can also affect mood and behaviour. As a chronic and progressive condition, dementia can significantly interfere with the ability to maintain activities of daily living, such as eating, bathing, toileting, and dressing.

Note 2 to entry: Alzheimer's disease, vascular disease, and other types of illnesses all contribute to dementia. Other common types of dementia include Lewy body dementia, frontotemporal dementia, and mixed dementias. In rare instances, dementia can be linked to infectious diseases, including Creutzfeldt-Jakob disease.

3.2

dementia-inclusive

providing equal access to opportunities and resources for persons with *dementia* (3.1), including, but not limited to, a focus on stigma reduction, *accessibility* (3.9), individual tailored services, and participation

Note 1 to entry: In a dementia-inclusive community, people are educated about dementia, its progression, and know that a person with dementia can sometimes experience the world differently. Persons with dementia, their families, and their carers are empowered, supported, and included in the community. The rights and full potential of the person with dementia are recognized and understood by all communities.

Note 2 to entry: In a dementia-inclusive community, the community facilitates persons with dementia and carers to optimize their health and wellbeing; live as independently as possible; be understood and supported; safely navigate and access their local communities, and to maintain their social networks.