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Ageing societies — Framework for dementia-inclusive communities

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Foreword

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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).

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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.

3.3
community
place or group of people with an arrangement of responsibilities, activities and relationships

Note 1 to entry: A location such as a city, town, neighbourhood, village, or rural area, but it can also include groups of people with shared interests or features, such as professional groups, religious organizations and businesses.

Note 2 to entry: In many, but not all, contexts, a community has a defined geographical boundary.

Note 3 to entry: The following are also considered as actors in the community:

— authorities having jurisdiction within the community;

— organizations, congregations, and community groups;

— individuals, carers, and families;

— persons of interest in education, research, and development;

— planners and providers of products, services, the built environment, and the community infrastructures.

[SOURCE: ISO/TS 37151:2015, 3.1, modified — "place or" has been added, Note 1 to entry has been modified, and Note 2 to entry and Note 3 to entry have been added.]

3.4
community-based services
community-based care
community-based programmes
health and social services integration provided to an individual or family at their place of residence or at other non-institutional locations within the *community* (3.3) for the purpose of promoting, maintaining, or restoring health, minimizing the effects of illness and disability, and supporting and facilitating *autonomy* (3.5) and self-care

Note 1 to entry: Services and programmes can include healthcare workers, befriending services, delivered meals, home care, community mental health, health education, screening, immunizations, family planning, sexual health, palliative care etc.

[SOURCE: ISO/IWA 18:2016, 2.2, modified — "health and social services integration provided to an individual or family at their place" has replaced "blend of health and social services provided to an individual or family in his/her place", "or at other non-institutional locations within the community" has been added, "on his/her normal lifestyle" has been removed, "and supporting and facilitating autonomy and self-care" has been added, Note 1 to entry has been removed, "community-based programmes" has been added as admitted term, and new Note 1 to entry has been added.]

3.5
autonomy
ability to control, cope with and make personal decisions about how one lives on a daily basis, according to one's own rules and preferences

3.6
independent living
living at home or in a *community* (3.3) without the need for continuous help from another person and with a degree of self-determination or control over one's activities

Note 1 to entry: Independent living can refer to a range of housing and community arrangements that maximize independence and self-determination.

[SOURCE: WHO Ageing and Health Technical Report, Vol.5 and U.S. National Library of Medicine]

3.7
participation
active involvement in a life/community situation

Note 1 to entry: Situation can also be understood to be the community.

[SOURCE: ICF 2001, WHO; ISO 9999:2016, 2.13, modified — "active" has been added, "life/community situation" has replaced "life situation", and Note 1 to entry has been added.]

3.8
engagement
involvement in, and contribution to, activities to achieve shared objectives

Note 1 to entry: This involves:

— active involvement of persons with dementia in activities (social, physical, mental) that have a positive influence on their health and wellbeing and eventually autonomy and independence;

— activities that strengthen their family life and relationships;

— active contributions to the community to enhance the persons with dementia feeling of being of value to their community.

3.9
accessibility
extent to which products, systems, services, environments and facilities can be used by people from a population with the widest range of user needs, characteristics and capabilities to achieve identified goals in identified contexts of use

Note 1 to entry: Context of use includes direct use or use supported by assistive technologies.

[SOURCE: ISO 9241-112:2017, 3.15]

3.10
meaningful life
construct having to do with the purpose, significance, fulfilment, *participation* (3.7), and satisfaction of life

Note 1 to entry: A meaningful life can signify many different things for different people depending on culture, age, etc.

Note 2 to entry: What is seen as a "meaningful life" varies between cultures.

[SOURCE: A Dementia Strategy for Canada, June 2019]

3.11
quality of life
product of the balance between social, spiritual, physical, and mental health, economic and environmental conditions that affect human and social development

Note 1 to entry: It is a broad-ranging concept, incorporating a person's physical health, psychological state, level of independence, social relationships, personal beliefs, and relationship to salient features in the environment.

[SOURCE: ISO/IWA 18:2016, 2.22, modified — "spiritual, physical, and mental" has been added.]

3.12
ethical aspect
aspect of organizational/community behaviour that is in accordance with a human rights-based approach with a focus on the values of honesty, equity, and integrity related to the creation, design/development, maintenance, and improvement of a *dementia-inclusive* (3.2) *community* (3.3)

3.13
prevention
action aimed at promoting, preserving, and restoring health when it is impaired and to minimize suffering and distress

Note 1 to entry: Prevention refers specifically to all aspects (medical, social, physical, cognitive, behavioural, etc.) potentially associated with having dementia.

Note 2 to entry: In public health, 'prevention' includes primary prevention, secondary prevention and tertiary prevention. Primary prevention refers to actions performed to prevent the development or delay the onset of diseases. Healthy lifestyle promotion and vaccinations are examples of primary prevention. Secondary prevention is the early detection of disease before the symptoms or signs of ill-health arise, to intervene and thereby prevent or delay their progress. Screening for chronic diseases and cancers fall under this category. Tertiary prevention aims to prevent a recurrence, complications, and further negative impact of the diseases after they have already occurred, to maximize longevity and quality of life. Examples of this include rehabilitation of a person who survives a stroke, and the environment enhancement for a person with dementia, etc.

[SOURCE: ISO/IWA 18:2016, 2.19, modified — Note 1 to entry, and Note 2 to entry have been added.]

3.14
care
provision of what is necessary for the health, welfare, maintenance, and protection of someone

3.15
carer
caregiver
person who provides *care* (3.14)

3.16
culturally appropriate care
consideration given to cultural background, personal experiences and norms in the context of providing any formal or informal services to a person with *dementia* (3.1)

[SOURCE: A Dementia Strategy for Canada, June 2019]

3.17
formal carer
formal caregiver
paid professional who provides regular *care* (3.14)

3.18
formal care
care (3.14) provided on a regular, paid basis by organizations or persons representing organizations or by other persons

Note 1 to entry: Organizations can be profit-making or non-profit-making, public or private. Persons typically exclude family, friends or neighbours.

3.19
informal carer
informal caregiver
generally unpaid person who provides *care* (3.14) from time to time

Note 1 to entry: This term does not include trained care providers affiliated with home care agencies when working with clients at those agencies.

Note 2 to entry: An informal carer is likely to be a family member, relative, close friend, neighbour or volunteer. Support provided by an informal carer may include assisting with the activities of daily living, and helping with advance care planning.

3.20
informal care
care (3.14) provided by family, friends, or neighbours

3.21
person-centred care
way of organising and conducting *care* (3.14) that promotes the provision of care centred on a specific person's needs and preferences, identity, and their *engagement* (3.8) in the care process

Note 1 to entry: Person-centred care usually relies on concepts such as individualisation, personalisation, autonomy, participation, and engagement to achieve its goals.

3.22
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: This can include "chosen families," such as strong friendships and communities where unrelated persons provide care normally provided by nuclear family members.

3.23
integrated community network
network of human relationships that facilitates *autonomy* (3.5), integration, and *engagement* (3.8) of persons with *dementia* (3.1) and their *carers* (3.15) and provides *community-based services* (3.4)

Note 1 to entry: The activities of the integrated community network are based on taking measures, such as the strengthening of family life, design of an integrated and phased health and social care network, and the integration across community sectors and the continuous improvement of the dementia inclusiveness of these sectors.

3.24
guiding principle
generic and essential principle or design specificity that informs the design of the *dementia-inclusive* (3.2) *community* (3.3) as a whole at all stages of planning, design, operation, and improvement

Note 1 to entry: In particular, guiding principles inform the design of the integrated community network and the design of the action areas.

3.25
action area
community sector involved in developing an *integrated community network* (3.24) to establish a *dementia-inclusive* (3.2) *community* (3.3)

Note 1 to entry: An action area, for example, can include housing, infrastructure, leisure, etc.

3.26
active assisted living
AAL
concepts, products, services, and systems combining technologies and social environment with the aim of improving the quality of people's lives

[SOURCE: IEC 60050-871: 2018, 871-01-02]

3.27
active assisted living service
AAL service
action or function of an AAL system creating an added value for customers

EXAMPLE An AAL service could comprise, for example

— configuration and maintenance of AAL systems,

— assistant systems to support the home environment.

Note 1 to entry: An AAL service can consist of several individual services.

[SOURCE: IEC 60050-871: 2018, 871-01-04]

3.28
assistive technology
equipment, product system, hardware, software or service that is used to increase, maintain or improve capabilities and safety of individuals

Note 1 to entry: Assistive technology can include assistive services and professional services needed for assessment, recommendation, and provision.

[SOURCE: ISO/IEC Guide 71: 2014, 2.16, modified — "and safety" has been added, Note 1 to entry has been removed, Note 2 to entry has become Note 1 to entry.]

3.29
assistive product
product (including devices, equipment, instruments and software), especially produced or generally available, used by or for persons with disability

Note 1 to entry: An assistive product can be used

— for participation,

— to protect, support, train, measure or substitute for body functions/structures and activities, or

— to prevent impairments, activity limitations or participation restrictions.

[SOURCE: ISO 9999:2016, 2.3, modified — Note 1 to entry has been removed, bullet points from definition have been added as new Note 1 to entry.]

3.30
process
set of interrelated or interacting activities that use inputs to deliver an intended result

Note 1 to entry: Whether the "intended result" of a process is called output, product, or service, depends on the context of the reference.

Note 2 to entry: Inputs to a process are generally the outputs of other processes and outputs of a process are generally the inputs to other processes.

Note 3 to entry: Two or more interrelated and interacting processes in series can also be referred to as a process.

[SOURCE: ISO 9000:2015, 3.4.1, modified — Notes 4, 5 and 6 to entry have been removed.]

3.31
elder abuse
single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older person

[SOURCE: WHO Fact sheet elder abuse, 2021]

4 Development of a dementia-inclusive community

4.1 General

The development of a dementia-inclusive community is a continuous and dynamic process.

4.2 Systematic development process

4.2.1 General

A systematic, formalised, and phased process should be applied to properly conceive, plan, implement, assess, and improve a dementia-inclusive community.

4.2.2 Establish the general process

The community shall establish, document, and maintain a systematic process for setting up, adjusting and developing the dementia-inclusive community. This process should guide the implementation of the requirements and recommendations set out in Clauses 5 to 7.

The process approach should:

— be coupled with a structured and cyclic development methodology such as the "Plan-Do-Check-Act" (PDCA) cycle;

— incorporate analysing and addressing possible risks.

NOTE 1 The PDCA cycle refers to a four-part management method that provides guidance for continuous improvement. It is also referred to as the Deming cycle[35].

Where applicable and desired, the development process and the incorporation of the requirements and recommendations provided in this document can be implemented in line with, or as part of a formalised management or quality management process.

NOTE 2 Management or quality management processes in this case refer to management structures already existing in the community, a quality management process (e.g. according to ISO 9001 or any domain specific quality management process or standard), or a management system standard.

4.3 Process elements of a dementia-inclusive community

4.3.1 General

Requirements and recommendations in this clause are process and management-oriented and facilitate the efficient implementation of the function and object-oriented requirements and recommendations in Clauses 5 to 7.

4.3.2 Establish basic processes elements

When establishing a systematic development process, the following aspects should be considered:

— build on and improve existing structures in the community, ensuring in particular the development and retention of an inclusive community identity and an efficient and effective development process and use of resources;

— apply risk governance and management strategies to ensure that there is adequate risk-benefit assessment, and assurance that the benefits outweigh the risks when implementing elements of the dementia-inclusive community;

— communicate plans and progress to persons with dementia, families, carers, other key stakeholders and the public in clear, transparent, appropriate, accessible formats, and provide updates at regular, planned intervals;

— throughout all process phases and iteration cycles, systematically identify, incorporate and ensure cross-compatibility with other relevant standards that can have relevance regarding any stage or action of the process of creating a dementia-inclusive community;

NOTE 1 To make its development process over time more efficient, the community can develop its own tools and templates based on the requirements and recommendations set out in this document.

NOTE 2 To facilitate that a holistic community development approach is adopted, Annex D provides an overview of other frameworks available for consideration. The framework presented in this document is open and encourages community specific additions and adaptations.

NOTE 3 The Bibliography contains a comprehensive but non-exhaustive list of potentially relevant standards.