Towards a dementia-inclusive society

WHO toolkit for dementia-friendly initiatives (DFIs)

World Health Organization

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Foreword

An estimated 50 million people live with dementia worldwide, 60% of whom in low- and middle-income countries. With approximately 10 million people diagnosed with dementia every year, dementia is projected to affect 152 million by 2050. Dementia has a profound impact on every aspect of a person's life and there continues to be much stigma and discrimination against people with dementia. Stigma exacerbates the already significant psychological, social, emotional and financial impacts of the disease - effects that have been amplified in light of the ongoing COVID-19 pandemic. Stigma also increases the likelihood of human rights violations in communities where people with dementia live.

To address dementia as a global challenge, the Seventieth World Health Assembly adopted the Global Action Plan on the Public Health Response to Dementia 2017-2025 *(1)* in May 2017. The action plan represents an international commitment to improving the lives of people with dementia, their carers, and families. It includes seven action areas: dementia as a public health priority; dementia awareness and friendliness; dementia risk reduction; dementia treatment, care, and support; support for dementia carers; information systems for dementia; and dementia research and innovation. The action area focusing on dementia awareness and friendliness specifically aims to improve communities' understanding of dementia and create dementia-inclusive societies where people with dementia can live meaningfully, safely and with dignity. Understanding the unique and multifaceted needs of people with dementia and their carers is particularly important within the context of COVID-19.

WHO developed *Towards a dementia-inclusive society: WHO toolkit for dementia-friendly initiatives* to support individuals, communities and countries in empowering people with dementia to remain in, and be a significant part of, their community. The toolkit's person-centered, rights-based approach is grounded in international commitments such as the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), the 2030 Agenda for Sustainable Development and its Sustainable Development Goals (SDGs) and Universal Health Coverage (UHC) *(2)(3)(4)*. The toolkit can be easily and effectively implemented by communities worldwide to raise awareness of dementia and improve the lives of those affected by the disease.

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Abbreviations

CRPD	Convention on the Rights of Persons with Disabilities (United Nations)
DFI	dementia-friendly initiative
LMICs	low- and middle-income countries
M&E	monitoring and evaluation
NCDs	noncommunicable diseases
NGO	nongovernmental organization
SDGs	Sustainable Development Goals
UN	United Nations
WHO	World Health Organization

Glossary

Activity: For the purpose of this toolkit, an activity refers to any action that promotes lasting change to the social and/or physical environment to help build dementia-inclusive societies.

Carer/caregiver: A person who provides care and support to a person with dementia. Such support may include:

- Helping with self-care, household tasks, mobility, social participation and meaningful activities.
- Offering information, advice and emotional support, as well as engaging in advocacy, providing support for decision-making and peer support, and helping with advance care planning.
- Offering respite services.
- Engaging in activities to foster intrinsic capacity.

Carers/caregivers may include relatives or extended family members as well as close friends, neighbours and paid lay persons or volunteers.

Civil society: Refers to the wide array of nongovernmental and not-for-profit organizations that have a presence in public life, expressing the interests and values of their members or others, based on ethical, cultural, political, scientific, religious or philanthropic considerations. Civil society is the “third” sector of society, along with government and business *(31)*.

Community: A group of people unified by common interests or characteristics living together within a larger society.

Convention: A formal agreement between country leaders, politicians, and states on common matters, e.g. human rights.

Coordination: Refers to the guidance and direction provided through a governance mechanism, such as a coordinating team, in implementing, integrating, evaluating and/or scaling-up a DFI.

Coordinating team: A team of individuals, organizations and/or partners responsible for the oversight, management and coordination involved in developing a new DFI, integrating dementia into an existing initiative, monitoring and evaluating a DFI and/or scaling-up a DFI.

Dementia: Dementia is a syndrome due to disease of the brain – usually of a chronic or progressive nature – in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer’s disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain, such as motor neurone diseases, Prion disease, Parkinson’s disease and related disorders, Huntington’s disease, spinocerebellar ataxia, and spinal muscular atrophy. The following International Classification of Diseases (ICD) codes relate to dementia – ICD-9: 290, 330–331; ICD-9 BTO: B222, B210; ICD-10: F01, F02, F03, G30–G31.

Dementia-friendly initiative (DFI): The activities being undertaken to make society more inclusive of people with dementia.

Dementia-inclusive society: A society in which people with dementia and their carers fully participate in society and have a place in it. It is a society where they enjoy respect, freedom, dignity, equality, accessibility and quality of life. It is one where they are empowered to live independently, free from stigma, discrimination, exploitation, violence or abuse.

Disability: The UN CRPD recognizes disability as "an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others" *(2)*

Discrimination: Unfair treatment or negative behaviour towards a person or group of people. The UN CRPD defines discrimination on the basis of disability as "any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation."*(2)*

Engagement: In this context, the process of consulting with, and gathering feedback and opinions from, people with dementia and other partners and applying this input throughout all phases of the DFI.

Evaluation: The process of tracking key outcomes and impacts related to the different elements of the DFI and its associated activities, and assessing whether the vision and expected outcomes are being achieved. Information gathered through an evaluation can be used to guide future planning, budgeting and scaling activities.

Evaluation indicators: Help determine what information and data to collect so as to answer the evaluation questions (see Evaluation question). Evaluation indicators will vary based on the type of evaluation selected.

Evaluation question: Specifies what will be measured through the evaluation. Evaluation questions vary based on the type of evaluation selected.

Financial resources: see Resources.

Habilitation: Refers to enabling people with disability to attain, keep or improve skills and functioning for daily living; services include physical, occupational and speech-language therapy, pain management treatments, audiology and other services offered in hospital and outpatient settings (RI Global, see: http://www.riglobal.org/projects/habilitation-rehabilitation/).

Health (care) system: Refers to: a) all the activities intended to promote, restore and/or maintain health; and b) the people, institutions and resources, arranged together in accordance with established policies to improve the health of the population they serve, while responding to people's legitimate expectations and protecting them against the cost of ill-health through a variety of activities that intend to improve health.

Health care provider: A professional providing health care to people, including health advice and disease prevention, promotion and treatment; and who implements care, treatment and referral plans. They have completed formal training in medicine, or a related health care discipline, at a recognized, university-level school for a diploma or degree, or have acquired extensive on-the-job training.

Human resources: see Resources.

Human rights of people with dementia: Action related to the following issues to ensure the protection of a person's human rights: least restrictive care, informed consent to treatment, confidentiality, avoidance of restraint and seclusion when possible, voluntary and involuntary admission and treatment procedures, discharge procedures, complaints and appeals processes, protection from abuse by staff, and protection of user property. In the context of dementia, this means human rights for people with dementia include a comprehensive approach including the full spectrum of civil, political, economic, social and cultural rights.

Human rights violation: When a country fails in its obligations to ensure that the economic, social and cultural rights of people, including people with dementia, are enjoyed without discrimination or in its obligation to respect, protect and fulfil them. Often a violation of one of the rights is linked to a violation of other rights *(10)*.

Impact: The last step in a logic model; in this context, refers to the achievement of, or movement towards, the DFI's stated vision, following an action or sequence of actions taken as part of the DFI, or associated activities.

Implementation: The process of putting a decision or plan into effect.

Input: The first step in a logic model; refers to activities, sets of interventions and/or resources that produce a series of results (i.e. outputs and outcomes).

Key principles: A set of precepts or values that guide the creation of a dementia-inclusive society, including the development of a new DFI, integration of dementia into an existing initiative, monitoring and evaluating a DFI and/or scaling-up a DFI. For the purpose of this toolkit, there are four key principles: participation, collaboration, coordination and sustainability.

Law/laws: A rule or set of rules, which have been enacted by the governing bodies in a country. For the purpose of this toolkit, laws refer to rules that apply to people with dementia, persons with disabilities, older people and/or the population as a whole and typically focus on issues such as civil and human rights protection.

Leadership: In this context, refers to the action of leading a group of people or organizations through the process of developing a new DFI, integrating dementia into an existing initiative, monitoring and evaluating a DFI and/or scaling-up a DFI and associated activities. In the case of this toolkit, the leadership is likely community-based but may also be political, administrative, academic and/or clinical in nature.

Legal capacity: The formal ability to hold and exercise rights and duties under the law *(32)*. Everyone has a right to legal capacity; the UN CRPD safeguards the legal capacity of persons with disability, including people with dementia.

Logic model: A causally linked step-wise framework that identifies how resources (or inputs) make it possible to carry out DFI activities. These in turn produce a series of results (or outputs and outcomes) and move the DFI towards achieving its stated vision (or impact).

Monitoring: The ongoing action of collecting information about all project/programme activities. In this context, it determines whether the DFI, and its associated activities, are being implemented as intended and helps individuals identify and solve problems quickly.

Monitoring and evaluation (M&E): A process that provides information on what an initiative is doing, how well it is performing and whether it is achieving its vision and expected outcomes.

Multisectoral: Involving individuals, agencies and/or organizations from the different sectors of society, including governments, NGOs, academia, and civil society working, within and beyond the health sector.

Multisectoral collaboration: Refers to the involvement of multiple sectors, partners, and levels of government to ensure that the DFI reflects the complex needs and preferences of people with dementia, their carers and families, leading to a shared, mutually beneficial outcome.

Myth: A widely held but false belief or idea that is not based on proven facts or evidence.

Noncommunicable diseases (NCDs): Diseases not passed from person to person. They are of long duration and generally slow progression. The four main types of NCDs are cardiovascular diseases (e.g. heart attack and stroke), cancers, chronic respiratory diseases (e.g. chronic obstructed pulmonary disease or asthma) and diabetes. Dementia represents an NCD.

Nongovernmental organizations (NGOs): NGOs are created and operated to contribute to the public’s benefit. The ways that NGOs pursue that goal vary widely and they usually work on a not-for-profit basis. They can be organized on a local, national or international level. Task-oriented and driven by people with a common interest, they perform a variety of service and humanitarian functions. Examples include charities, missions, faith-based organizations, patient and consumer organizations, etc.

Not-for-profit organization: Refers to organizations that are created and operated to contribute to the public’s benefit and do not seek to make a profit. The ways that not-for-profit organization pursue that goal vary widely and can be organized on a local, national or international level. Task-oriented and driven by people with a common interest, they perform a variety of service and humanitarian functions. Examples include charities, missions, faith-based organizations, patient and consumer organizations, etc.

Outcome: In this context, the result or consequence of an action or sequence of actions taken as part of the DFI, or associated activities, which move the DFI towards achieving its stated vision (i.e. impact).

Output: In this context, what is produced as a result or consequence of an action or sequence of actions taken as part of the DFI, or associated activities, which move the DFI towards achieving its stated vision (i.e. impact).

Ownership: Taking responsibility for an idea or problem, in this context the DFI.

Participation: Refers to the meaningful involvement of people with dementia, their carers and families in all stages of the development and management of the DFI. Participation is key to adopting a human rights-based, person-centred approach.

Partner: An individual, group of individuals or an organization that work together to achieve a common vision, impact or interest, including the development of a new DFI, integration of dementia into an existing initiative, monitoring and evaluation of a DFI and/or scaling-up of a DFI, the human rights of people with dementia and/or dementia awareness and understanding.

Physical environment: Refers to the immediate physical surroundings, including built infrastructure and industrial and occupational structures, such as roads, sidewalks, doorways and entryways, businesses, parks, libraries and other public spaces.

Primary focus area: Changes required to create a society that is more inclusive of people living with dementia; in this case refers to changes to the social environment, physical environment or both.

Priority: An issue, or set of issues, that takes precedence over others based on common agreement amongst partners, including people with dementia, their carers and families, and based on evidence.

Private sector: The part of a country’s economy that consists of industries and commercial, for-profit companies that are not owned or controlled by the government.

Quality of life: Individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment.

Rationale: In this context, a stated reason justifying the need for developing a new DFI, integrating dementia into an existing initiative, monitoring and evaluating a DFI and/or scaling-up a DFI, and why action to raise dementia awareness and understanding is required.

Rehabilitation: Refers to regaining skills, abilities or knowledge lost or compromised as a result of acquiring a disability or due to a change in one’s disability or circumstances.

Rehabilitation encompasses a wide range of activities including rehabilitative medical care, physical, psychological, speech, and occupational therapy and support services *(33)(34)*.

Resources: Unless otherwise specified, the human and financial resources required to develop a new DFI, integrate dementia into an existing initiative, monitor and evaluate a DFI and/or scale-up a DFI. Human resources refer to the number of staff needed and the skill mix required. In the context of this toolkit, it may refer to community (care) workers, advocacy, policy, programme, coordination, management and/or support staff, researchers and academics, social and health care providers such as generalist and specialized physicians, nurses, pharmacists, social workers, personal support workers, community health workers, amongst others. Financial resources refer to the funds (money) that are budgeted and allocated to support the development of a new DFI, integration of dementia into an existing initiative, monitoring and evaluation of a DFI and/or scaling-up of a DFI.

Risk: In this context, the result of an activity or group of activities that jeopardize the achievement of the DFI's stated vision.

Social care: Assistance with activities of daily living (such as personal care, maintaining the home); synonym – home and community care.

Social care provider: A professional providing basic nursing and personal care to people due to the effects of ageing, illness, injury, or other physical or mental impairment. They provide health advice to patients and families; monitor patients' conditions; and implement care, treatment and referral plans usually established by medical, nursing and other health professionals. They have completed formal training in nursing at a recognized, university-level school for a diploma or degree, or have acquired extensive on-the-job training.

Social costs: In this context, the direct and indirect costs to a group of individuals, or society as a whole, resulting from the DFI and associated activities.

Social environment: The social environment can be defined as social relationships and cultural contexts within which a person, or group of people, live(s). Components of the social environment include, but are not limited to: social and economic processes, social and health services, social inequality, cultural practices, the arts, religious institutions and practices, beliefs about place and community, wealth, power relations, government and labour markets *(11)*.

Society: An enduring and cooperating social group of people who have developed organized patterns of relationships and behaviours through interaction with one another.

Stereotype: A set idea or image that people have of what someone or something is like, especially an idea that is wrong.

Stigma: A distinguishing mark establishing a demarcation between the stigmatized person and others attributing negative characteristics to this person. The stigma attached to dementia can lead to social exclusion, abuse and discrimination. Stigma can worsen the person's mental and physical health.

Sustainability: In this context, refers to the DFI, an/or its associated activities, having a lasting impact over time, as opposed to only yielding one-time outcomes.

Sustainable Development Goals (SDGs): The 17 goals adopted by world leaders on 15 September 2015 as part of the 2030 Agenda for Sustainable Development. The SDGs came into force on 1 January 2016 and include specific targets to be achieved over the next 15 years *(3)*.

Target groups: The individuals or groups of individuals, targeted by the DFI and its activities. Target groups may involve people with dementia, their carers and/or families, the general population, health and/or social care providers, emergency response providers, government policy-makers and politicians, financial, legal, commercial/retail sectors, and/or transportation staff, schoolchildren, students, teachers and/or volunteers.

Timeframe: The period of time by when an action, project, programme or plan should be completed; in this case, the period of time by when the DFI's vision should be achieved.

Treaty: A formal contract or agreement between two or more political authorities (e.g. countries or sovereigns), formally signed by representatives and confirmed by the lawmaking authority of the state.

Universal design: The design of products, environments, programmes and services usable by all people, to the greatest extent possible, without that need for adaptation or specialized design. Universal design does not exclude assistive devices for particular groups of persons with disabilities where this is needed *(13)*.

United Nations Convention on the Rights of Persons with Disability (UN CRPD): The UN CRPD is a human rights agreement adopted by 82 countries in 2006. It adopts a broad categorization of persons with disabilities and reaffirms that all persons with all types of disabilities, including people with dementia, must enjoy all human rights and fundamental freedoms. It clarifies and qualifies how all categories of rights apply to persons with disabilities, including people with dementia, and identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights and areas where their rights have been violated, and where protection of rights must be reinforced.*(2)*

Vision: A broad, evidence-based statement of a desired future state that will be reached after multiple years of successful implementation.

Executive summary

Dementia affects every aspect of a person's life. In the early stages a person may experience loss of memory that causes them to forget how to perform simple day-to-day tasks, such as cooking or cleaning. As the illness progresses, the person may become more dependent on others.

Yet, as challenging as it may be to live with dementia, stigma and discrimination make it worse. Stigma heightens the already significant psychological, social, emotional and financial impacts that dementia has on individuals, their carers, families and communities. It also exposes people with dementia to potential human rights violations in their own communities. It is not uncommon for people with dementia to experience physical and emotional abuse, social isolation or loss of dignity. Supportive environments and societies are crucial in helping overcome stigma and discrimination against people with dementia.
There is a need to raise public awareness and improve understanding of dementia by engaging communities and helping them assume ownership of this endeavor. This is the first step in combating stigma. Dementia awareness and friendliness feature prominently in the Global Action Plan on the Public Health Response to Dementia 2017-2025, adopted in May 2017 by the Seventieth World Health Assembly. WHO is committed to helping individuals and communities empower people with dementia to remain in, and be a significant part of, society. This is reflected in the global dementia action plan's global target 2.2. which aims to establish at least one dementia-friendly initiative to foster a dementia-inclusive society in 50% of countries by 2025. WHO developed *Towards a dementia-inclusive society: WHO toolkit for dementia-friendly initiatives* to help communities and countries achieve this target. The toolkit will also support the implementation of other initiatives such as the Decade of Healthy Ageing 2020-2030.

A look inside the toolkit

The toolkit supports individuals working in communities who have little to no experience in programme planning, implementation, management, and/or evaluation, to create dementia-inclusive societies. The toolkit is divided into two parts:

- Part I contains introductory information on dementia, and includes a theoretical framework.
- Part II includes four practical modules, each featuring a series of practical steps and exercises, focusing on: starting a new dementia-friendly initiative (DFI), integrating dementia into an existing initiative, monitoring and evaluating a DFI, and scaling-up a DFI. The modules can be used together or separately, and can be adapted to suit local needs and settings.

The exercises included in the toolkit may be most effective when used to facilitate group discussions amongst team members and partners seeking to create dementia-inclusive societies.

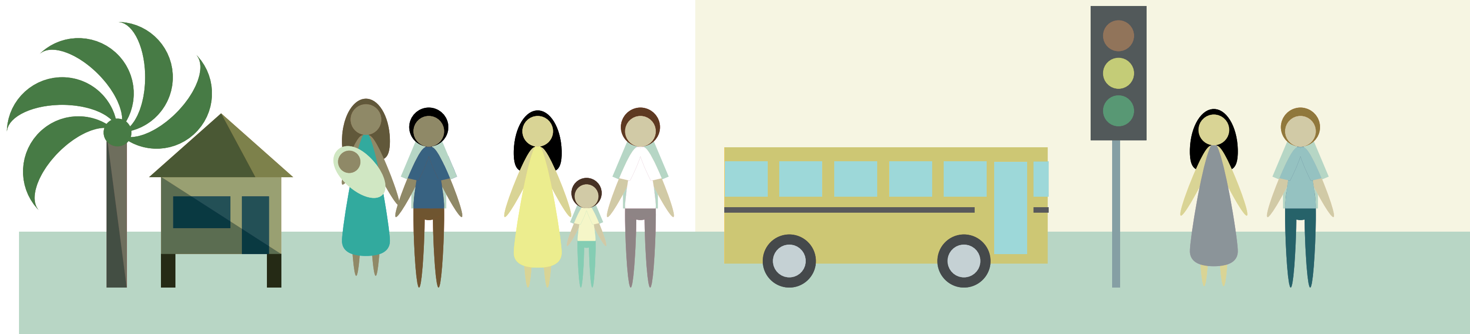
What is dementia inclusiveness and friendliness?

Around the world, local communities are coming together to create more inclusive societies and supportive environments. These are fundamental in fighting stigma and discrimination and ensuring that people with dementia and their families are meaningfully included in society. Different terms have been used to refer to these efforts, including dementia-capable communities, memory-friendly communities, living well with dementia in the community, sustainable environments for people living with dementia, dementia-sensitive living environment, and a society conscientious of, and friendly towards, neurocognitive disease.

For ease of communication in this document we use the term, “dementia-inclusive society” to refer to the kind of society to strive for, where everyone, including people with dementia, has a place. By “dementia-friendly initiatives” we mean the activities being undertaken to make society more inclusive of people with dementia. Examples of DFIs include, but are by no means limited to, showing 45-second educational films about dementia at supermarket queues, establishing mechanisms to enable people with dementia to vote in elections and teaching children about dementia.

The framework

The (see Figure 1) provides a step-by-step template for carrying out, integrating, evaluating and scaling initiatives that are adaptable to local contexts, cultural norms, community practices and population needs. It outlines the different components of the framework and defines key principles and actors such as key partners and target groups. The framework identifies the fundamental process and steps that will guide the implementation, evaluation and/or scaling of DFIs in subsequent sections of the toolkit.



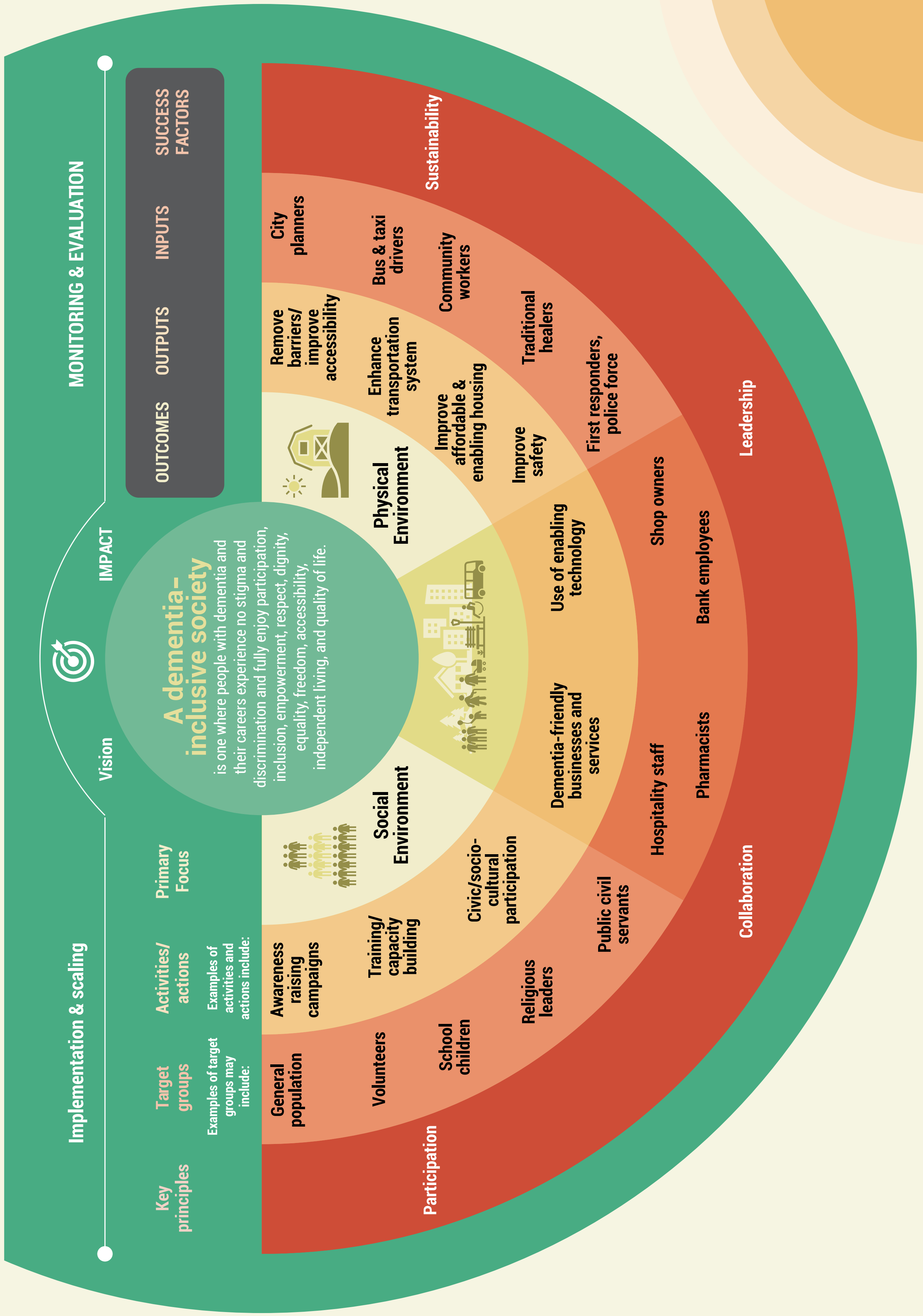


FIGURE 1 WHO’S DEMENTIA-INCLUSIVE SOCIETIES FRAMEWORK

Module A:
developing a new DFI

Module A offers practical guidance and tools to start a new DFI. Firstly, Module A uses a series of guided steps and exercises to help users identify stakeholders and partners, as well as a coordination team that will oversee and manage the initiative. Secondly, it helps users gather the information necessary to identify the most pressing issues that the DFI will address and to define a vision for the initiative. Thirdly, module A provides exercises on how to set goals and outcome, to help users identify focus areas. Lastly, it guides users in translating goals and expected outcomes into specific activities and developing a risk- and resource-management plan.

Module B:
integrating dementia into an existing initiative

Module B offers practical guidance and tools to integrate dementia into an existing, initiative. Working with a series of guided steps and exercises, Module B firstly helps users identify stakeholders and partners, as well as a coordination team to oversee and manage the integration. Secondly, it helps users gather the information necessary to make an inventory of relevant existing initiatives. It also enables users to pick the most pressing issues that they will address by integrating dementia into an existing initiative. Users together with partners and stakeholders can then draw up their vision for the integration. Thirdly, Module B prepares users to jointly define their goals and expected outcomes – in other words their focus areas. Fourthly, users receive guidance to translate their goals and expected outcomes into specific activities so as to achieve the joint vision. Lastly, users learn how to develop a risk- and resource-management plan.

Module C:
monitoring and evaluation (M&E)

M&E ensures that every step of the DFI implementation has been achieved. Module C offers a series of exercises and tools that enable users to decide what type of evaluation best suits their initiatives and then develop a logic model. The logic model illustrates how resources (inputs) make it possible to carry out DFI activities, which in turn produce results (outputs and outcomes) and move the DFI towards achieving its stated vision (impact). Module C also guides users in formulating evaluation questions and indicators. Evaluation questions specify what the evaluation will measure. Evaluation indicators on the other hand specify what information and data to collect so as to answer the evaluation questions.

Module D:
scaling up DFIs

Scaling up an existing DFI is an effective way of spreading good practices and lessons learned from one geographical location or target group to another. With the help of practical tips, checklists and exercises, Module D assists users in selecting a DFI for scale-up, ensuring that it fulfils the four key principles (participation, collaboration, coordination and sustainability) included in the DFI framework. The module also helps users identify the appropriate type of scale-up and develop a vision, focus areas and goals. Finally, Module D helps users plan and implement activities, including expanding DFIs to new locations, to achieve the vision, as well as develop a risk- and resource-management plan.

Conclusion

With its solid theoretical basis, practical guidance and exercises, the toolkit is a valuable resource that will enhance the skills and knowledge of individuals working within communities to build dementia-inclusive societies. By providing M&E guidelines, the toolkit fills a gap and helps build capacity as well as generate new evidence to support the implementation of DFIs. The toolkit is person-centred, rights-based and focused on raising public awareness of dementia. It will support communities in their efforts to achieve the vision of the Global Action Plan on the Public Health Response to Dementia 2017-2025. The specific goal of DFIs is to help bring about lasting changes to the social and/or physical environment. DFIs, therefore, need to work towards a society that includes and empowers people with dementia, as well as older people in general and people with other disabilities, rather than one that segregates them. For this reason, DFIs draw on the strengths of people with dementia, their carers and families, provided that appropriate support is in place to enable them to participate fully in society and the economy.

About this toolkit

Thank you for your interest in WHO's *Towards a dementia-inclusive society: WHO toolkit for dementia-friendly initiatives.* We hope that you find the material in this toolkit useful as you seek to promote dementia inclusiveness and address stigma in your community.

Dementia affects every aspect of a person's life, and stigma and discrimination make it worse. Stigma heightens the already significant psychological, social, emotional and financial impacts that dementia has on individuals, their carers, families and communities. It also exposes people with dementia to potential human rights violations in their own communities. It is not uncommon for people with dementia to experience physical and emotional abuse, social isolation or loss of dignity. There is a need to raise public awareness and improve understanding of dementia by engaging communities and helping them assume ownership of this endeavor. This is the first step in combating stigma and the main purpose of the toolkit.

The development of this toolkit was informed by an international steering group. Additionally, it drew on a synthesis of published and unpublished reports on DFIs and extensive stakeholder consultations. Civil society and government representatives across all six WHO regions and country income levels (high-, middle- and low-income countries) contributed through interviews. In addition, six focus group discussions led by a steering group partner – Dementia Alliance International (DAI) – made it possible to collect information about the needs of people with dementia and their idea of a dementia-inclusive society.

Purpose

The purpose of the toolkit is to promote lasting societal change and full inclusion of people with dementia and their families in society. More specifically, the toolkit:

- presents a common framework that identifies key components of, and partners that need to be involved in creating, dementia inclusiveness;
- provides guidance on how to use the framework to implement and scale up initiatives, as well as integrate dementia into related initiatives, such as age-friendly, healthy and barrier-free cities; and
- outlines steps to monitor progress in the initiatives' implementation and evaluate their impact.

Structure of the toolkit

The toolkit is divided into two broad sections.

Part I contains the theoretical background. It includes information on dementia, human rights and global commitments. It also provides a conceptual framework that can be used to create dementia-inclusive societies and implement dementia-friendly initiatives (DFIs).

Part II contains the practical steps and exercises for developing a new DFI, integrating dementia into an existing initiative, evaluating DFIs, and scaling up DFIs. Individuals working at the community-level can use these practical tools to facilitate conversations related to creating dementia-inclusive societies, including planning and implementing activities to achieve this. Part II of the toolkit is intended to be used as a facilitation tool in group settings, amongst relevant team members and partners.

Audience

The toolkit is geared towards individuals with little to no experience in programme planning, management, implementation and/or evaluation. Intended audiences may include:

- members and/or leaders of local communities, nongovernmental organizations, consumer or patient groups, and other civil society organizations;
- policy makers and planners at local, regional and/or national levels;
- health and social care providers and/or healers;
- researchers and academics;
- the media;
- business owners and/or staff.

PART 1:
Background information

Introduction

> *"While the world waits for a cure for dementia, we need more communities and cities to embrace and engage those living with dementia instead of isolating and excluding them."*
>
> *First WHO Ministerial Conference on Global Action Against Dementia (1)*

Dementia is a global challenge, currently affecting approximately 50 million people around the world (see Figure 2). Dementia affects every aspect of a person's life as well as the lives of their family and social network. Unfortunately, dementia remains shrouded in misconceptions, false beliefs and lack of awareness *(2)*.

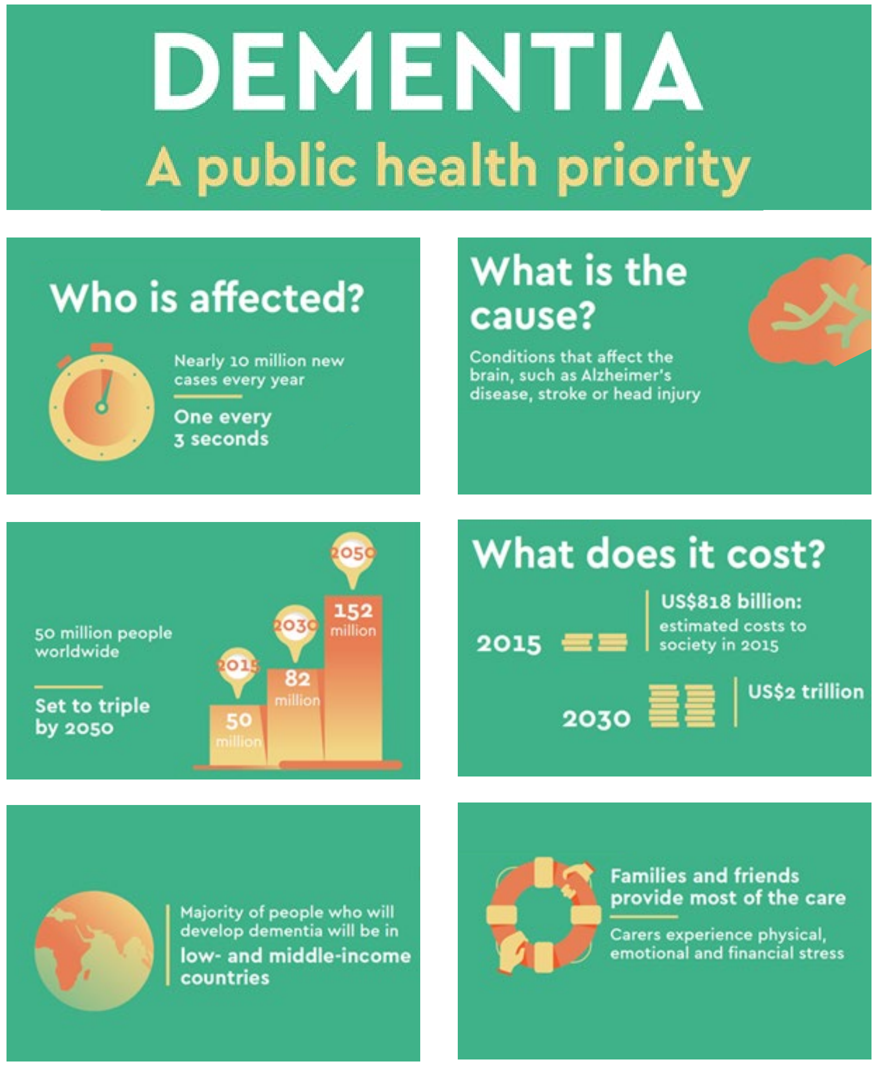


FIGURE 2 GLOBAL DEMENTIA BURDEN IN NUMBERS

WHO mandate and other global commitments

In May 2017, the Seventieth World Health Assembly adopted the Global action plan on the public health response to dementia 2017 – 2025 *(3)*. The global dementia action plan represents an international commitment to improving the lives of people with dementia, their carers and families. At the same time it seeks to lessen the impact of dementia on them, as well as on communities and countries. The global dementia action plan's vision is *"a world in which dementia is prevented and people with dementia and their carers live well and receive the care and support they need to fulfil their potential with dignity, respect, autonomy and equality" (3)*.

The plan calls for an approach to dementia that focuses on human rights and people. There is a need to create, or improve awareness of dementia. This will help educate society to better understand people affected by dementia, as well as their families and carers. This represents a shift from treating dementia as a purely medical condition that leads to impairment and dependence, to understanding it as an acquired progressive, cognitive and psychosocial disability. The shift brings with it the need to empower people with dementia to live their lives in a manner that they choose and value. This does not merely refer to the individual's physical and mental capacity, but also to the physical and social environments that they live in *(4)*.

To accomplish this, the global dementia action plan builds on strategic commitments and initiatives carried out at international and national levels (see Figure 3). This includes, but is in no way limited to, the 2030 Agenda for Sustainable Development and its 17 Sustainable Development Goals, Universal Health Coverage and the Osaka Summit Declaration of the 2019 G20 Summit. Also included are other closely related strategies, plans and initiatives concerning population ageing and endorsed by the World Health Assembly and the UN General Assembly.

FIGURE 3 RELEVANT STRATEGIC COMMITMENTS INITIATIVES

Dementia and human rights

There is a need to dispel myths and stereotypes among the general population, as well as health and social care professionals, concerning dementia. Communicating accurate information about dementia and creating supportive environments help put the emphasis on the person rather than their disability and impairment and are central to combating stigma. Misconceptions about people with dementia include for example perceiving it as a normal part of ageing, a state of "craziness", an act of God or fate, associated with spirits or witchcraft.

Negative stereotypes can lead someone to unfairly judge another person and falsely attribute negative characteristics to them, resulting in stigma. Stigma in turn may cause discrimination and human rights violations against people with dementia. Some examples include coercive or forced treatment or institutionalization, disregard for an individual's legal capacity to make decisions, and depriving them of their dignity and autonomy. Violations of, or indifference to, the rights of a person can have serious health consequences or worsen poor health.

International human rights agreements, also known as human rights treaties or conventions, were developed to protect against human rights violations and discrimination. These agreements affirm that all people are equally entitled to their human rights without discrimination, regardless of nationality, place of residence, sex, national or ethnic origin, skin colour, religion, language, or any other status *(5)*. See the Annex for a list of relevant international human rights treaties.

One instrument that is particularly relevant to people with dementia is the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) *(6)*. The UN CRPD ensures among other things that persons with disabilities, including those with dementia, have the right to:

- equality and non-discrimination
- accessibility (to live independently and participate fully in all aspects of life)
- equal recognition, in terms of liberty and security, before the law
- live independently and be included in the community
- respect for privacy
- health
- habilitation and rehabilitation
- participation in political and cultural life, recreation, leisure and sport
- adequate living conditions and social protection.

The UN CRPD provides the foundation for identifying and eliminating barriers to ensure that people with dementia can live in their own communities and access their environment. The Annex provides information about the role and accountability of countries under the UN CRPD.

Commentary
Human rights and dementia-friendly movement

There are 37 references to human rights and the United Nations Convention on the Rights of Persons with Disabilities in the global action plan on the public health response to dementia 2017 – 2025. This is a welcome recognition by all WHO Member States of the importance of human rights. But only if it translates into a better quality of life and better health services for people with dementia. To achieve this people at all levels – national, regional and local – need to gain a better understanding of what it means to walk in the shoes of people with dementia.

Alzheimer's Disease International (ADI) believes a social movement based on dementia friendliness has the potential to help promote an everyday understanding of the practical means to protect the rights of people with dementia and to assist them to access the services and enjoy the activities we all have a right to, whether through major policy initiatives or local projects.

The dementia friends initiatives in countries such as Japan, the United Kingdom and the Republic of Korea have reached millions of people who now have a better understanding of dementia. In some cases these individuals have gone on to involve themselves in their communities in volunteering or in dementia-friendly initiatives in their workplaces such as hospitals.

The greater power of dementia friendliness is to inspire communities whether small or large and large organisations from health to corporations in key sectors such as banks, retail and insurance to address the issues of most concern to people with dementia and their care partners.

There is no one size fits all in developing dementia-friendly initiatives but there is one immutable rule and that is that people with dementia should be involved from the outset.

Glenn Rees, Chair, ADI

Local grass-root initiatives to address stigma

Around the world, local communities are coming together to raise awareness, create supportive environments, and meaningfully include people with dementia and their families in society. Different terms have been used to refer to these efforts, including dementia-capable communities, memory-friendly communities, living well with dementia in the community, sustainable environments for people living with dementia, dementia-sensitive living environment, and a society conscientious of and friendly toward neurocognitive disease.

For ease of communication in this document we use the term, “dementia-inclusive society” to refer to the kind of society to strive for, where everyone, including people with dementia, has a place. By “dementia-friendly initiatives” we mean the activities being undertaken to make society more inclusive of people with dementia. Examples of DFIs include, but are by no means limited to, showing 45-second educational films about dementia at supermarket queues, establishing mechanisms to enable people with dementia to vote in elections and teaching children about dementia. See Table 1 on p 46-47 for more information.

Local DFIs may vary significantly in format, structure and content. Also likely to vary are the outcomes of each DFI, the partners engaged and population groups targeted by the initiative. Despite their diversity and context-specificity, DFIs highlight a common desire to reduce stigma, raise awareness of dementia and enhance the autonomy, dignity and empowerment of people with dementia at global and community levels.

Case study
Dementia Friendly Spots in Slovenia

In 2016 Spominčica - Alzheimer Slovenija (www.spomincica.si) developed the Dementia Friendly Spots programme. It is a national awareness raising programme connecting service provider organizations in a network of information points about dementia at the local level. The network includes: police and fire stations, shops, libraries, pharmacies, homes for the elderly, the Faculty for Social Work, the Ministry for Social Affairs, the Medical Chamber of Slovenia, community healthcare centres, and the Slovenian Red Cross, amongst others.

The goal of the programme is to train employees about dementia, communication with people with dementia, post-diagnostic support and the rights of people with dementia and their carers. The main objective of Dementia Friendly Spots is to provide information about dementia in local communities and support people with dementia and their families to stay at home as long as possible.

The first Dementia Friendly Spot opened in July 2017 at the Human Rights Ombudsman Office after training the employees. This was a symbolic opening, as it reinforced the message that people with dementia have rights and that the community is there to protect those rights even if the person is not able to protect them anymore. The opening was covered by national media, television, radio and newspapers. A member of the European Working Group of People with Dementia spoke about their life with dementia after the diagnosis and stressed the importance of building a dementia-inclusive society. Since, there has been a growing interest in Dementia Friendly Spots from organizations all around Slovenia and in September 2020 there were more than 220 network members.

The creation of a Dementia Friendly Spot is designed as an awareness raising event with cultural programming, important partners from the local community and media. Each Dementia Friendly Spot is marked with a label of three forget-me-nots, has informative materials about dementia, services and support in a visible place and has its own webpage.

The Dementia Friendly Spots network in Slovenia has demonstrated increased awareness about dementia and recognition of the warning signs. Accessibility to information about services and support is widely spread across the communities. Additionally, more persons receive timely diagnosis and treatment and support for carers. Policymakers increasingly recognize the urgency of properly addressing dementia. Together we are building a dementia-inclusive society.

Alzheimer Slovenija

> *In keeping with the vision of an inclusive society, DFIs should focus on a broad range of partners in order to avoid segregating or isolating people with dementia, for example by creating spaces that are designed only for people with dementia.*

DFI Framework

The DFI framework provides an outline and step-by-step guidance for implementing, integrating, evaluating and scaling initiatives that can be adapted to local contexts, cultural norms, community practices and population needs. The benefit of the DFI framework is that it can be used for both implementation and evaluation.

The framework integrates a common working definition of a dementia-inclusive society and outlines primary focus areas. It provides examples of individual DFIs (or activities) as well as partners and target groups. These, together, can move societies towards greater inclusion of people with dementia and their families. See page 27 for a visual representation of the framework.

What is a dementia-inclusive society?

A dementia-inclusive society is one in which people with dementia and their carers fully participate in society and have a place in it. They enjoy respect, freedom, dignity, equality, accessibility and quality of life. It is one where they are empowered to live independently, free from stigma, discrimination, exploitation, violence or abuse.

Vision and key principles of dementia inclusiveness

> *“We all have a responsibility to work towards a society that is more dementia-friendly and inclusive. The best way to do this is to involve people with dementia and their carers in all issues that affect them.”*
>
> *Dr Tedros Adhanom Ghebreyesus*
> *Director General, World Health Organization*

Vision

The framework’s vision is to make society inclusive of people living with dementia, their carers and families so that they are free to make their own choices and are protected from discrimination. A dementia-inclusive society also provides people with dementia with the same rights as everyone else to belong in society and to be respected. Additionally, it means that people with dementia are entitled to equal opportunities in all aspects of life and equal access to public services and space. This is consistent with the findings of the focus group discussions held by Dementia Alliance International (DAI) and the global dementia action plan. The vision paints a picture of what the initiative should achieve after years of successful implementation. Achieving this vision would safeguard and protect fundamental rights at the community level.

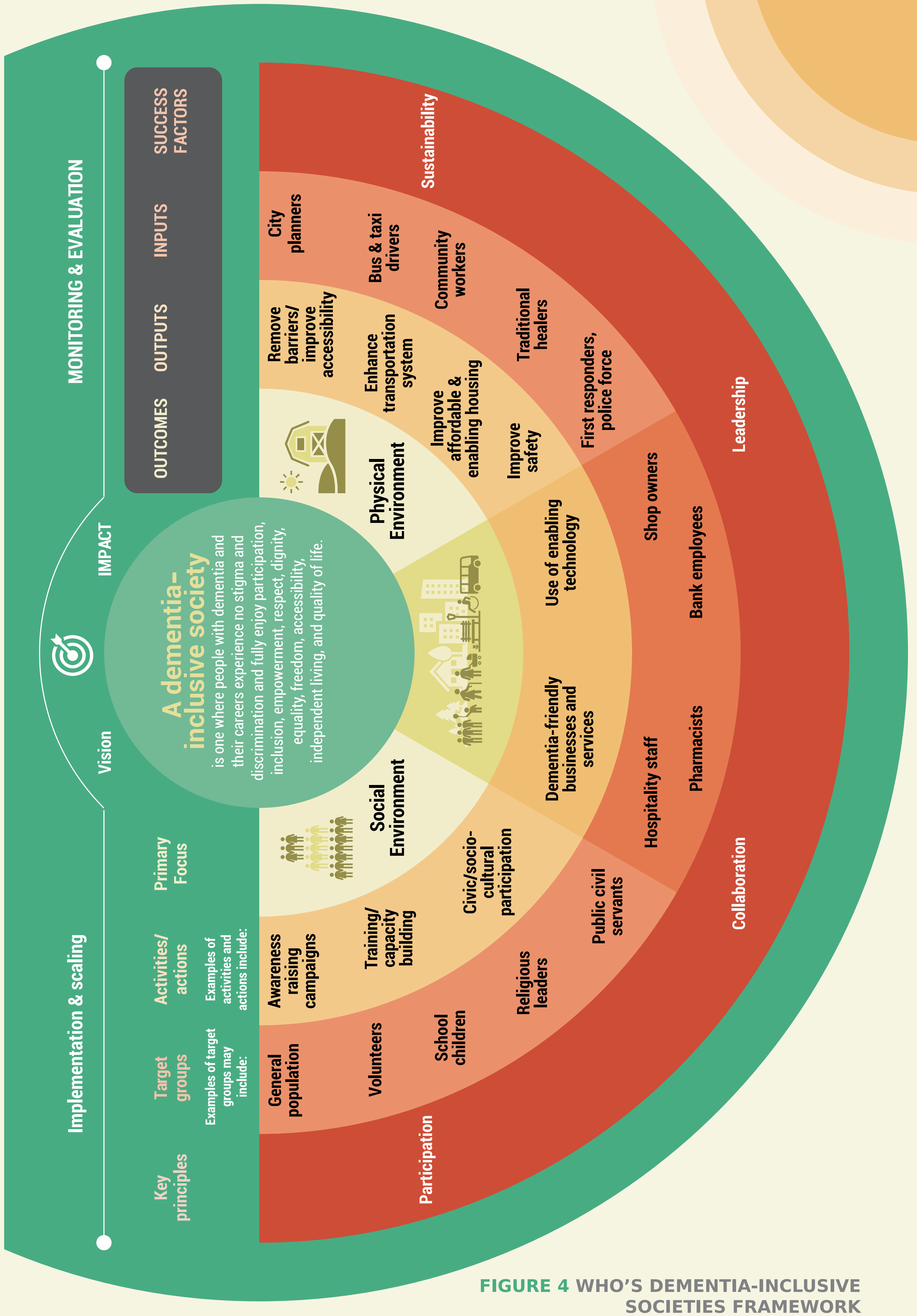


FIGURE 4 WHO’S DEMENTIA-INCLUSIVE SOCIETIES FRAMEWORK

Commentary
Creating inclusive societies for all

The inclusion of dementia in the UN CRPD represents a significant achievement that should not be overlooked. The cornerstone of this convention is accessibility and inclusion of persons with disabilities, including people with dementia, not differential treatment.

With all of the ongoing work in the area of dementia-inclusiveness and awareness, it is important that we do not deviate too far from the essence of the UN CRPD. As a person with dementia, I do not want to be treated differently from others, or identified as being vulnerable, a potential easy target. I simply wish to be enabled and empowered to continue to engage in social, cultural, economic and other activities as all other people do, and as I did before my diagnosis. However, I constantly have to determine the best way of navigating within, and engaging with, my community. If communities understand and are educated about dementia, then this task would be much easier and I would not need to explain what dementia is, or why I sometimes need help.

Creating an inclusive society – for all, alike – is about choice. The choice to identify oneself, or not, as a person living with dementia; the choice to engage, or not, in activities. It is only through education that we can create truly inclusive societies, and where living with dementia does not imply segregation, differential treatment or forced choice. We must educate our communities, governments, health and social care practitioners, teachers and students about dementia and what it means to live with dementia, starting at a young age.

Universally, every person wants to be accepted and valued for who they are. I am the same person as I was 10-12 years ago and do not want to be treated differently, or explicitly identified as vulnerable, simply because of a diagnosis. It is vital that communities and governments keep this in mind as we move towards creating societies that are inclusive of all people. In the end, the onus truly rests on communities in ensuring that all members are accepted, included, valued and able to access their environment.

Helen Rochford-Brennan,
European Working Group of People with Dementia

Key Principles

Participation

Participation is key to adopting a human rights-based, person-centred approach. At the most basic level, it refers to the involvement of people with dementia and their care partners in all stages of the development and management of the DFI (i.e. design, planning, implementation and evaluation). Meaningful participation, however, implies that people with dementia are uniquely positioned and empowered to plan and implement the DFI and related activities. This will ensure that the planned activities and expected outcomes of the DFI accurately reflect the preferences, needs, priorities and choices of people with dementia.

Tips for meaningful engagement of people with dementia

These tips can help to ensure that people with dementia are meaningfully involved in all stages and activities related to the implementation, evaluation and scaling of a DFI.

Project meetings are arranged at times that best suit the person with dementia.

The carer, or another person, is available during the meeting to assist the person with dementia.

The meeting is audio recorded and transcribed; minutes are sent following the meeting.

An appropriate venue is selected, considering seating, lighting, ventilation, acoustics, signage and accessibility.

Stimulus material is on hand to help discuss complex ideas in preparation for, and during, the meeting.

Direct questioning and jargon are avoided.

A meeting agenda and key discussion points are sent out to the person with dementia in advance of the meeting, with someone available to discuss these points and prepare if needed.

Meeting pace and length are suitable to the person with dementia.

The contributions of the person with dementia (and their supporter) are valued and this is emphasized.

The person with dementia (and their supporter) receive remuneration for expenses they incur.

Multisectoral collaboration

Multisectoral collaboration refers to the involvement of multiple sectors, key partners and levels of government to ensure that the DFI reflects the complex needs and choices of people with dementia, their carers and families. At the very least, effective collaboration across different sectors should:

- engage partners beyond the health sector, including from social, education, housing, finance, justice, labour, public safety, transportation, environment and infrastructure areas;
- engage partners across the public, private and not-for-profit sectors;
- integrate the diverse perspectives of key partners in the design, implementation, evaluation and management of the DFI;
- ensure regular communication between all partners; and
- help mobilize resources across sectors.

Key partners are individuals, groups of individuals, or organizations that are involved in planning, integrating, evaluating and/or scaling up the DFI. Examples include, but are not limited to:

- government representatives
- civil society representatives, including national Alzheimer's associations
- academic and technical experts
- community, religious and opinion leaders
- individuals targeted by the DFI (among them school teachers, fire fighters, police officers, business owners, city planners)
- the business community
- national/global donors
- multilateral and international organizations.

Case study
Building dementia-friendly communities

To make Singapore a dementia-friendly nation, the Agency for Integrated Care (AIC), with the support of Ministry of Health (MOH), partners key community stakeholders, to set up Dementia-Friendly Communities (DFCs) in various neighbourhoods across Singapore. In a DFC, the community understands dementia, and persons with dementia and their families feel included and are supported, empowered and enabled to live well in the community.

DFCs are set up based on the “3Es” framework (Engage, Empower and Enable) with activities focusing on dementia prevention and early detection, and providing support for people with dementiaand their caregivers.

Engage - Community members such as residents, businesses and grassroot leaders are engaged by AIC through talks and house visits to raise awareness of dementia so that a supportive network (i.e. Dementia Friends and Champions) is built within the community.

Empower - As a strong network is built amongst community partners, social service agencies, healthcare providers, businesses and faith-based organisations, people with dementia, their caregivers, and the community are empowered with accessible and coordinated care and support.

Go-To Points (GTPs) are set up in the community to serve as a resource centre and to act as a safe return point for people with dementia who are lost. Caregiver Support Network (CSN) are established for dementia caregivers to befriend and support each other.

Enable - people with dementia and their caregivers are enabled to live well in the community via technology and infrastructure enhancements:

- Dementia Friends mobile application was launched to provide helpful resources on dementia and caregiving. Caregivers can tap on the network of Dementia Friends (via the app) to look for loved ones with dementia that are lost.
- Infrastructure in DFCs are enhanced to make the environment safe and easy to navigate for people with dementia.

Presently, there are 10 DFCs in Singapore, and by building more, we hope to create a caring and inclusive society for people with dementia and their caregivers.

Ministry of Health, Singapore

Coordination

Collaboration across different sectors is closely tied to effective coordination. Coordination refers to the guidance and direction provided through a governance mechanism, such as a coordinating team, in implementing, integrating, evaluating and/or scaling a DFI. Strong coordination allows all involved sectors and partners to communicate effectively with one another. Additionally, it ensures clear articulation of roles and responsibilities, and helps mobilize, and effectively manage, financial, human and capital resources across sectors. Coordination helps build buy-in amongst partners and create community ownership. The box below lists tips for selecting an effective coordinating team.

Tips for selecting an effective coordinating team

- The team shares a unified vision of the DFI.
- The team has the skills to train and build the capacity of partner(s).
- The team can provide support over a period of multiple years.
- The team has the relevant strategic, operational and technical skills and experience to carry out the DFI, including monitoring and evaluation capacities.
- The team is able to advocate among policy-makers, politicians, programme managers and donors.
- The team understands the socio-economic, cultural and political environment where the initiative will be implemented, integrated, evaluated or scaled.
- The team has effective and motivated leaders who are perceived as credible by implementing partners, target group(s), local community/ies and people with dementia.
- The team is able to plan for, and mobilize, sufficient financial and human resources.

Case study
The importance of communication in effective coordination

Miles for Memories Help Home T.E.C.H (To Ensure they Come Home) Program involves the use of a personal identification bracelet with a phone number and bar code. With the appropriate consent, the person with dementia is registered in the programme through the Calhoun County Consolidated Dispatch Authority (in Michigan State), a sole public safety answering point for the area that directs essential emergency services when called.

When the bracelet is scanned, information includes name, address, and emergency contact details as a minimum. It can also include photos, video, level of dementia, additional chronic conditions, medications and health care providers. Family members can update the information through a phone app and make it public or private. Documents, such as health advocate information, fingerprints and more, can be uploaded using a further level of security. A phone call to 9-1-1, the national emergency number for the USA, will allow all area police departments to access the information directly in their law enforcement vehicles. Emergency responders, fire fighters and emergency rooms can access emergency information by scanning the bracelet. In just five seconds they can identify the person, read all the relevant information and notify family through the phone number listed.

In the first seven months of the programme, 18 individuals returned home, avoiding unnecessary trips in an ambulance as well as the litany of tests that they would have undergone at the emergency room, saving thousands of dollars in medical expenses. The information on the bracelet can be accessed across the USA. Training continues for emergency responders and others who will use the system. The bracelet improved access to vital information, enhancing the way a person experiences triage in an emergency room.

Carers are now also encouraged to wear the bracelet. A few weeks after a carer registered his wife who lives with dementia on the programme, he experienced a heart attack and was hospitalized for several days. When he was able to communicate again, he immediately asked about his wife, who was home alone. If he had been wearing a bracelet, the emergency room would have been alerted.

There is now a pilot for a Global Positioning System (GPS) bracelet.

Miles for Memories, Battle Creek, Michigan, USA

Sustainability

Sustainability means that the DFI can have a lasting impact over time, as opposed to only yielding one-time outcomes. Sustainability is achieved by ensuring the continuity of a DFI, integrating them into existing initiatives, or extending them to additional geographic areas and/or target groups (see Module D).

At a minimum, the following sustainability factors should be considered:

- Projected and actual costs
- Resource needs and available funding
- The coordinating team's capacity to maintain the DFI over time
- Regular risk assessment and management
- Clear messaging and communication.

Tips for ensuring sustainability

The following considerations will help ensure a DFI's long-term sustainability

The DFI is easy to understand and provides clear benefits to people with dementia and target groups.

The DFI can be integrated into existing initiatives.

The DFI can be scaled across sectors or locations, while remaining context-specific and culturally-acceptable.

Changes in community demographics and the needs of people with dementia are continuously assessed.

Cost estimations are appropriate, including financial, and human resources as well as social costs.

Resources are sufficient for immediate and long-term implementation.

Risk identification and management plans are established.

The coordinating team has sufficient capacity.

Case study

How to make an initiative sustainable by integrating it into existing efforts

The Alzheimer's and Dementia Organization Kenya was established in 2016. Previously, the organization was a support group for caregivers of people with dementia. The organization has very little funds so it decided to start with raising awareness and use the power of volunteering. Dementia literacy is low and it is important for people to stop seeing dementia as a normal part of ageing. The organization looks for affordable strategies and often adds its initiatives to the events of other organizations, particularly religious institutions. Many members belong to a religious community, which makes it easy to access such events.

During World Alzheimer's Month in September 2018, the Alzheimer's and Dementia Organization Kenya ran large media stories on radio and television. One television story that was posted on YouTube received over 17,000 views. Based on comments received, the stories did help people looking after their older loved ones who had shown symptoms similar to those in the video on dementia. It gave them an idea of their loved ones' ailment.

The stigma of dementia comes from fear, especially when the person living with the condition is under 65. It can be frightening owing to the behavioural changes it causes and the fact that its symptoms are difficult to describe in medical terms. Such lack of knowledge and information about dementia causes people to think of it in terms that they understand, including witchcraft.

The organization sells wristbands at different events. It has set up booths in shopping malls to sell the bands so as to raise funds while also creating awareness. Well-wishers give donations to support the organization's activities and raise awareness. Additionally, the organization distributes purple ribbons to help stir curiosity among people and initiate conversations about dementia. This is another way of spreading the word on dementia.

Alzheimer's and Dementia Organization Kenya, Kenya

Primary focus of dementia-inclusive societies

> *"Addressing both the social and physical aspects of the community environment is essential in order to respond well to the needs and preferences of older adults to promote their health and wellbeing"*
>
> *World Health Organization, Measuring the age-friendliness of cities: a guide to using core indicators*

This toolkit supports country efforts to make necessary changes to the social or physical environment to create a society that is more inclusive of people living with dementia. However, there are many links between the social and physical environment, which means that an initiative that starts with a focus on one area might (and in many cases should) eventually also address change in another.

For example, a DFI whose initial aim is to introduce clear signs to help people navigate their way within a public building could later serve to train staff to communicate with people with dementia. The reverse may also apply: communication training might inspire a decision to improve the physical environment (for instance through the use of signs). As such, the subsequent definitions of the social and physical environment have been developed to provide clarity. However, these are neither set in stone nor do they limit a DFI's development and scope.

People with dementia, their carers and families should drive the selection of the DFI's primary focus to ensure that it responds to their needs, priorities, preferences and choices.

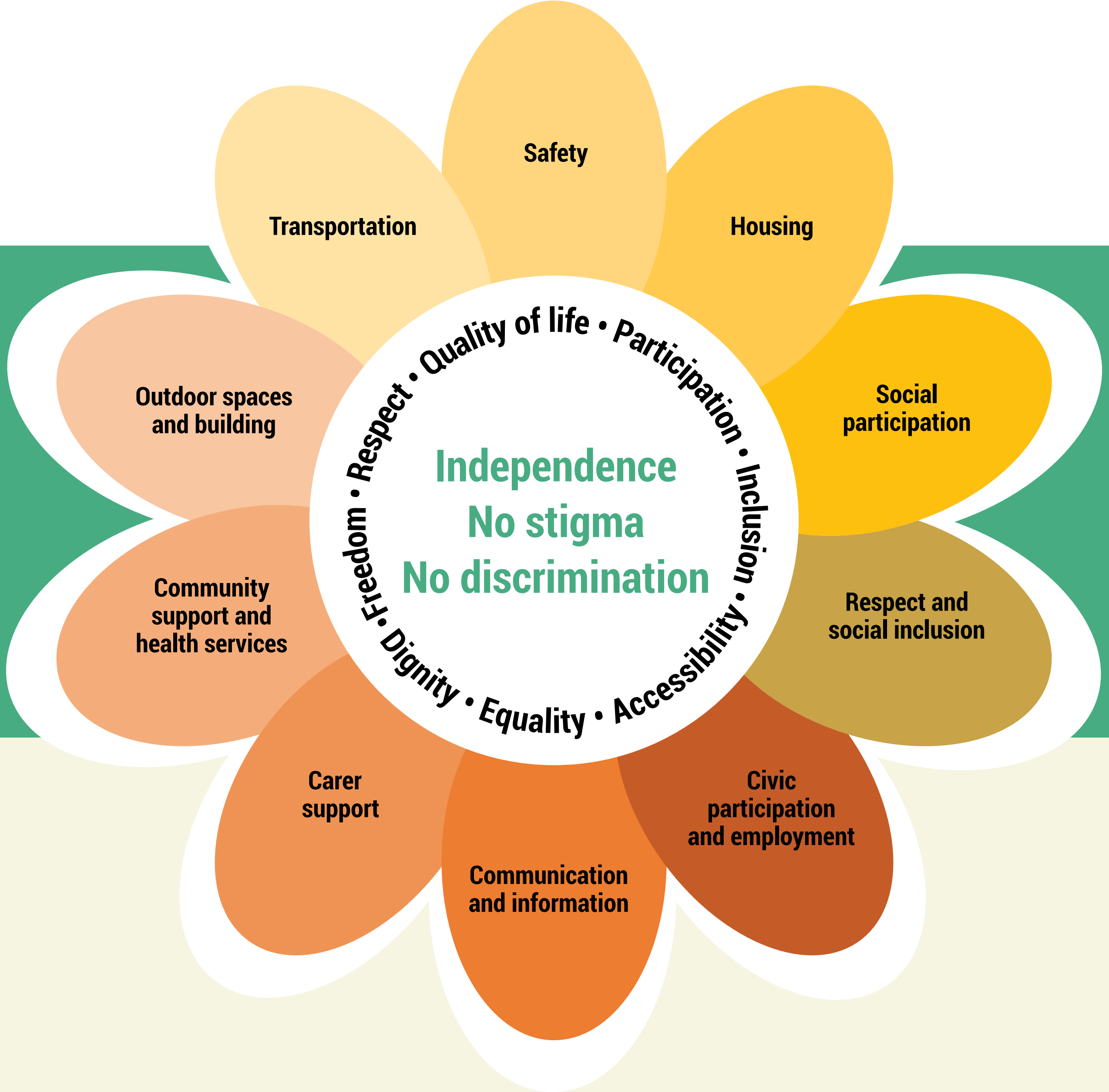


FIGURE 5 INTERACTION BETWEEN SOCIAL AND PHYSICAL ENVIRONMENT (ADAPTED FROM WHO'S AGE-FRIENDLY CITY TOPIC AREAS)

Social environment

The social environment can be defined as social relationships and cultural contexts within which a person, or group of people, live(s). Components of the social environment include, but are not limited to: social and economic processes, social and health services, social inequality, cultural practices, the arts, religious institutions and practices, beliefs about place and community, wealth, power relations, government and labour markets *(7)*. Social environments can be experienced at various scales, including households, social networks, neighbourhoods, towns and cities, and regions *(7)*.

Changes to the social environment may involve enhancing social and community participation, social inclusion, and civic engagement and employment. Examples may include the participation of people with dementia, their carers and families in social, cultural, religious or civic activities (see Table 1 on p. 46-47 for concrete examples). It might also involve engaging people with dementia in health and social care planning and decision-making. The social dimensions of age-friendly environments are important for encouraging people with dementia, and older people more generally, to lead active and healthy lives and for lowering barriers for healthy and active ageing. The concept of Universal Design may be useful when modifying the social environment (see Box on page 43). It helps design and compose the environment to ensure that it is accessible, understandable and easily used by all.

As part of age- and dementia-friendly initiatives, DFIs seeking to create an inclusive social environment may focus on:

- creating positive social attitudes and norms concerning older people in general, and people with dementia specifically
- creating opportunities to engage in volunteer activities
- engaging people with dementia in paid employment, as and when appropriate
- including people with dementia in socio-cultural activities
- enabling people with dementia to participate in relevant decision-making
- making information available in an accessible manner
- ensuring health and social services are appropriate, available and accessible
- fostering economic security.

Case study
Ensuring the right to vote

Alzheimer Nederlands prepared a user-friendly programme for people living with dementia to exercise their right to vote. They did this in the lead-up to two elections: the national election in 2017 and the local elections in 2018, with plans to continue for future elections. Alzheimer Nederlands sent out information about the programme to all political parties and informed their volunteers. They also provided an overview of the programme to case managers, carers, day care centres, nursing homes and palliative care services. Information about the programme was shared on the Alzheimer Nederland website and on social media using the hashtag #dementiafriendly.

Activities in the lead-up to the elections included hosted site visits and invitations to potential new members of parliament to Alzheimer's Cafes to meet people with dementia and their carers. Alzheimer Nederlands shared information about their organization and a paper on their position on dementia-friendly support. Politicians from six different parties accepted the invitation.

For the local election Alzheimer Nederlands produced infographics and a video and wrote blogs. The organization also contacted 380 mayors by mail and provided training on dementia friendliness for volunteers who were to serve at polling stations. Care providers and branches of all organizations in municipalities received information. Alzheimer Nederlands posted on social media in the last four weeks of the campaigning period. The media wrote stories, published seven articles and aired a television show about the programme. As an outcome, the Ministry of the Interior wants to talk about how to support people with dementia at polling stations during all future elections.

Alzheimer Nederland, The Netherlands

Video on how to vote if you have dementia:
https://www.youtube.com/watch?v=VuoEtgBURjU&t=14s

Physical environment

The physical environment includes outdoor environments, transport and mobility, and housing (*8*). It refers to the immediate physical surroundings, including built infrastructure and industrial and occupational structures, such as roads, sidewalks, doorways and entryways, businesses, parks, libraries and other public spaces. The level of maintenance, ambient noise, lighting, indoor air quality and/or the thermal comfort of industrial and occupational structures may also form part of the physical environment *(9)*. The physical environment may change when public spaces, health and social care facilities, transportation systems, retail/commercial spaces or individual homes undergo adaptations (see Table 1 on p. 46-47 for concrete examples). Age- and dementia-friendly physical environments optimize opportunities for people to live healthily and actively across the life-course and encompass different needs and abilities *(10)*. Universal Design may be a useful concept to consider when modifying the physical environment (see Box on page 43).

As part of age- and dementia-friendly initiatives, DFIs seeking to create an accessible and safe physical environment may focus on:

- improving neighborhood walkability
- making public spaces, buildings, and facilities more accessible and safer
- making public transportation vehicles and public transport stops more accessible and safer
- making housing more affordable and safer.

Universal Design

Universal Design is a way of designing and composing the environment to ensure that it can be accessed, understood and used:

- to the greatest possible extent
- in the most independent and natural manner possible
- in the widest possible range of situations
- without the need for adaptation, modification, assistive devices or specialised solutions
- by any persons of any age or size or having any particular physical, sensory, mental health or intellectual ability or disability. *(10)*

With respect to DFIs, Universal Design principles refer to:

- Equitable use: the DFI is useful to people with dementia, their carers and families.
- Flexible in use: the DFI accommodates the wide range of preferences and abilities of people with dementia, their carers and families.
- Simple and intuitive use: the DFI is easy to understand, regardless of the experience, knowledge or language skills of the population it targets.
- Perceptible information: the DFI communicates necessary information effectively, regardless of the surroundings or the user’s sensory abilities.
- Tolerance for error: the DFI minimizes hazards and the adverse effects of accidental or unintended actions.
- Low physical effort: the DFI can be used efficiently and comfortably and causes minimal fatigue.
- Size and space for approach and use: appropriate size and space are provided for approach, reach, manipulation, and use regardless of the user’s body size, posture or mobility *(10)*.

Activities

> *"Dementia-friendly initiatives cannot and should not replace medical, psychological or psychosocial care, treatment, services and/or support for people with dementia and their carers."*
>
> *Paola Barbarino, Alzheimer's Disease International*

For the purpose of this toolkit, a DFI refers to all activities and actions that promote lasting change to the social and/or physical environment to help build dementia-inclusive societies. DFIs may seek to create new outcomes for people with dementia or strengthen the impact of existing activities. Their ultimate aim is to enhance the inclusion, in society, of all individuals, including people with dementia, older people, and/or people with disabilities. DFIs should draw on the strengths of people with dementia, their carers and families. Importantly, DFIs cannot and should not replace care, treatment, services and/or support otherwise provided by trained health and social care professionals through national/sub-national health and/or social systems, whether public or private.

Table 1 on pages 46-47 provides examples of DFIs, classified based on their type of activity, reach, target groups, and key partners.

Target groups

> *"Only by engaging the wider community will we succeed where previous generations have failed in protecting the rights of people with dementia"*
>
> *Glenn Rees AM*
> *Chair, Alzheimer's Disease International*

Depending on the specific context, DFIs vary largely in design. As a result they will engage a varied set of partners, and target different population groups. However, what all DFIs have in common is respect for the four key principles (see pp 31-37).

Target groups refer to individuals or groups of individuals within the community who stand to benefit from the DFI and its activities. The target group is different from the coordinating team, who is responsible for overseeing, managing, implementing and/or evaluating the DFI (see p.34). While DFIs ultimately seek to benefit people with dementia, their carers and/or families, the DFI's activities may target any of the following: the general population, health and/or social care providers, emergency response providers, government policy-makers and politicians, financial, legal, commercial/retail, transportation sectors, schoolchildren, students, teachers and/or volunteers.

The planning, implementation, integration, evaluation or scaling-up of a DFI should reflect the target groups' needs. Representatives of the target groups should participate in all stages of the DFI and in its governance structure.

Case example

Initiatives by people with dementia, for people with dementia

In China, the number of people with cognitive impairment has reached nearly 10 million, yet diagnostic rates and public awareness remain low. To increase public awareness of cognitive impairment, Tencent Video (Chinese version of YouTube), Houghton Street Media and Hanna Pictures jointly launched Forget Me Not Café, the first television show focused on people with cognitive impairments in China.

Forget Me Not Café presented a story about waiters with cognitive disorder aged 68 to 79 years who run a restaurant, together with celebrities. Working in the café was challenging for people with cognitive impairment. Sometimes they served the wrong dishes or forgot to place an order, but they always remained enthusiastic and ensured a delightful mealtime experience for their customers.

The total show had 10 episodes, reached 700 million viewings, was continuously ranked No. 1 on television platforms, and became the top hit on social media. More importantly, the online search on cognitive impairment and dementia increased by 400% per day.

During the participation in Forget Me Not Café, the waiters became more social and showed signs of improved physical and mental health. The audience always shared how impressed they were with the waiters. The general public also paid more attention to cognitive impairment and expressed interest in learning more about risk factors, symptoms and prevention of dementia.

Forget Me Not Café season II is scheduled for release in 2020 on Tencent Video.

Forget Me Not Café TV Show, China

TABLE 1 EXAMPLES OF DFI ACTIVITIES, REACH, TARGET GROUPS AND KEY PARTNERS

ACTIVITY	REACH			TARGET GROUP(S)	KEY PARTNERS
	National level	Community level	Individual level		
Conduct an awareness raising campaign	Television program Forget Me Not Café, China Promoting dementia-inclusive communities: A strategic communication toolkit, WHO WPRO	Wristbands with dementia messages	One-hour individualized education through Dementia Friends programme	General public Volunteers	Broadcasting/media companies Supermarket owners and managers Community leaders Dementia Friends Volunteer groups National Alzheimer's associations
Educate and build capacity	Training of primary care physicians	Kids 4 Dementia in schools	Dementia-friendly gyms / sports hubs	Primary care physicians School children Sport centre staff/sport trainers	Professional medical associations Government School principals and teachers Sport centre owners and managers
Enhance civic, social, cultural and religious participation and inclusion	Voting in elections	Museum-based and arts-based programmes for people with dementia Dementia-friendly church services	Museum-based and arts-based programmes for people with dementia Dementia-friendly church services	Government Electoral and city hall staff Museum staff Religious leaders and congregation members	Government Mayor and city hall staff Religious leaders and organizations Museum managers
Improve accessibility	Barrier-free cities/towns Free and accessible buses	Way-finding Dementia-friendly taxis	Livable housing - home and neighbourhood modifications Individual car modifications	People with dementia City planners Business owners Bus and taxi drivers	Mayors City planners Construction / home building companies People with dementia, their carers and families Transportation department and business Policymakers
Improve safety	Dementia-friendly police			Police force	Government Mayor Chief of police
Make businesses and services inclusive	Dementia-friendly pharmacies	Dementia-friendly/-inclusive banks Dementia-friendly business checklist		Pharmacists Hospitality staff Bank staff Business owners	Professional associations of pharmacists Government Bank, retail and hospitality managers Industry groups
Implement enabling technology			Miles for Memory -GPS tracking	People with dementia Caregivers and families of people with dementia	Family members of people with dementia Emergency service responders Healthcare providers Hospitals

PART 2:

Implementation, monitoring and evaluation

Before you get started

> *"If we focus on the possibilities of people with dementia instead of their limitations, their dementia will disappear behind their talents and not the other way around"*
>
> *Jurn Verschraeger, Center of Expertise on Dementia Flanders*

Implementing a DFI represents a unique opportunity to improve the quality of life and safeguard the rights of people with dementia, their carers and families by enhancing the social and physical environment in which they live. DFIs tend to be highly context-dependent, responding to the needs, and tailored to the customs, of local target groups.

While context-specificity is an important success factor in carrying out any DFI effectively, there is a need to better streamline the implementation process as a whole. A more structured implementation process can ensure that people with dementia, their carers and families participate more systematically and meaningfully. It can also help in measuring, documenting, sustaining and/or replicating impactful initiatives in other settings.

Modules A and B provide you with practical guidance and tools to start a new DFI and integrate dementia into a related initiative, respectively. Module C outlines practical steps and tools to monitor and evaluate a DFI, while Module D will help you determine whether and how to scale a DFI. The basic framework (see Figure 6) is the same for all scenarios but the steps and/or exercises may differ.

It is important to keep in mind that while these modules provide generic guidance for planning, implementing, evaluating and scaling DFIs, you are encouraged to build on the content of this document, applying and adapting the modules that are most relevant to local resource settings and the needs of people with dementia in your community. Before you get started with the modules, however, take some time to complete Exercise 1 on p. 60, to help you identify your partners and coordinating team.

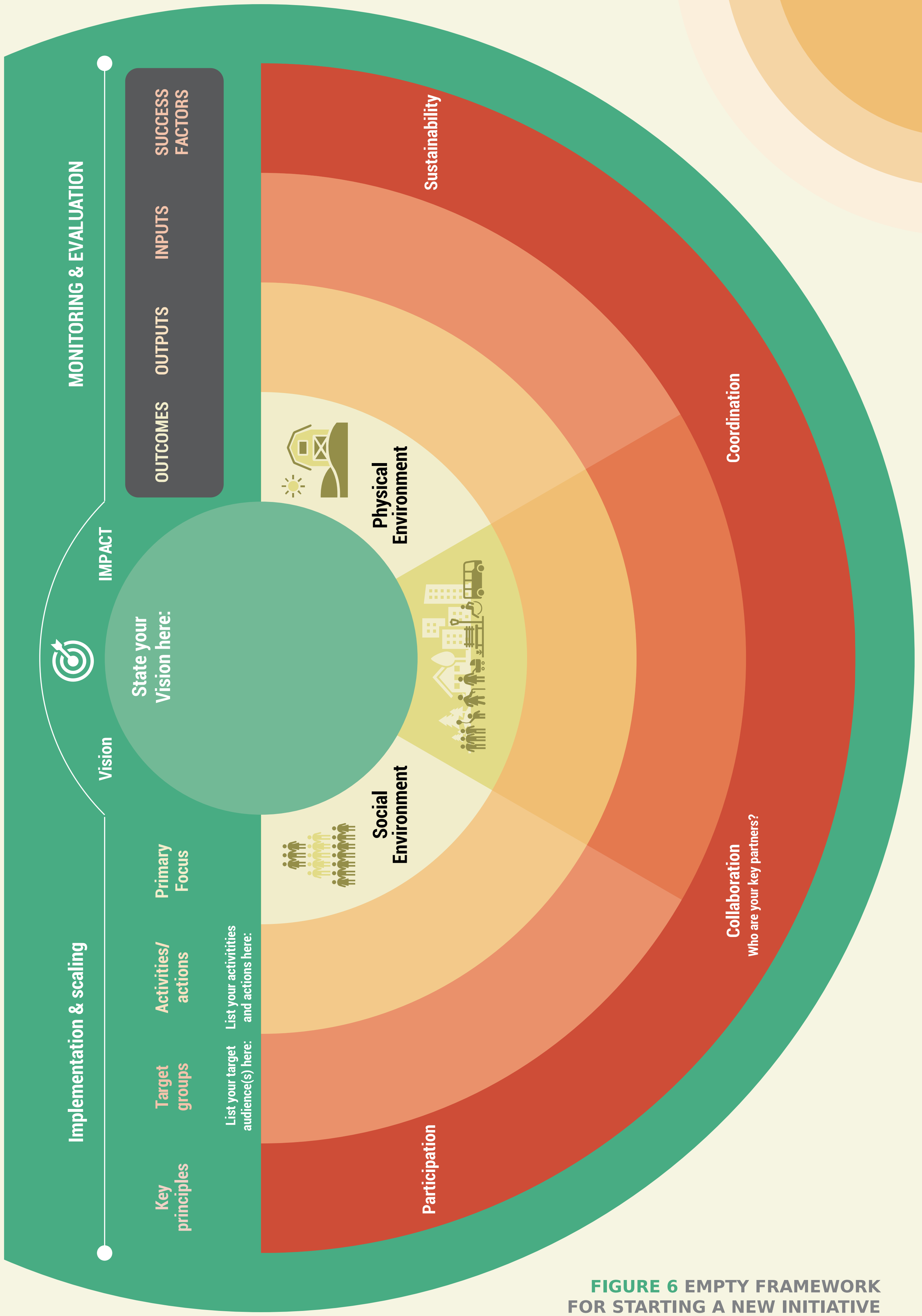


FIGURE 6 EMPTY FRAMEWORK FOR STARTING A NEW INITIATIVE

Module A. Starting a new initiative

> *“We will implement a comprehensive set of policies to address dementia, including promoting risk reduction and sustainable provision of long-term care as well as inclusive societies aiming to improve quality of lives of people with dementia and carers”*
>
> *Article 31,*
> *G20 Osaka Leaders’ Declaration (11)*

Initiating a new DFI is an opportunity to effectively plan the implementation process, incorporating the four key principles: participation, collaboration across sectors, coordination and sustainability. Implementing a new initiative involves four steps: (i) identifying a common vision based on needs, (ii) translating the vision into expected outcomes, (iii) planning and carrying out activities to achieve the vision, and (iv) identifying and managing risks and resource needs.

A.1. Identify a common vision

A common vision among partners is pivotal to ensuring ownership, engagement and impact. The first step in identifying a common vision is to understand what needs to change to make the social and/or physical environment more inclusive of people with dementia. An effective way of gaining this understanding is to engage all the relevant partners, primarily people with dementia, their carers and families.

Exercise 2 helps you gather the information necessary to define your vision. This exercise will allow you to summarize the most pressing issues that your DFI will address and how these impact the lives of people with dementia, their carers and families, as well as other relevant partners. Share a summary of the information gathered with people with dementia, their carers and families, as well as key partners that were consulted. All partners then need to work together to develop a common vision for the DFI (see Exercise 3). Use the DFI framework on page 48 to articulate your vision.

Remember that information should be shared in an accessible and easy-to-read format.

Case study

Identifying the needs of people with dementia and their families

In 2016, the Abbiategrasso community, the first dementia-friendly community in Italy, explored the needs and experiences of people with dementia (i.e. spaces used, habits, places attended, satisfaction about local services offered). They discovered that people with dementia and their families wanted to feel safer. In response to this, a training course for the local police was set up.

Findings suggested that people with dementia spent most of the day out of their homes and reported fear of getting lost and not knowing who to turn to in case of need. Thanks to the participation of the municipal authority, police officers attended two training sessions given by a geriatrician and a psychologist for five hours in total. In the months following this training, police officers helped two people with dementia who had lost their way home during a moment of confusion.

Findings also suggested that people with dementia wanted to be more active. To address this, the Abbiategrasso community set up a physical training course specifically for people with dementia accompanied by family members. They also wanted to establish a network to support people with dementia. The course was extended to a higher number of people with dementia becoming a “gym group” as part of a support network. The trainer was trained by physicians, psychologists and physiotherapists to acquire the skills necessary to better approach people with dementia. This “gym group” was expanded after a successful pilot. They met on a weekly basis to exercise, talk and share experiences.

Federazione Alzheimer Italia, Italy

A.2. Translate the vision into primary focus areas

According to the DFI framework, it is necessary to translate the vision into one or more primary focus areas. As such, the coordinating team and key partners must decide whether to modify the social environment, physical environment, or both, to achieve the common vision. In addition, it is important to identify the expected outcomes of these changes and how they will help achieve the vision. Exercise 4 will help determine your DFI's primary focus area(s)(and expected outcomes.

Your focus area(s) and expected outcomes should reflect the information gathered through previous exercises and concentrate on the most relevant, feasible, sustainable and human rights-based options. In the spirit of greater inclusiveness, it is desirable to also consider outcomes that will support people with disabilities, older people or the population as a whole.

This exercise will naturally vary based on the identified needs and priorities, available resources, local expertise, and the capacity of the coordinating team and local partners. Constraints, be they national/sub-national, political, social, economic or cultural, will also influence the exercise. They can play a role in determining what the DFI addresses, and its limitations.

The principles of participation and multisectoral collaboration are crucial for this step.

Case study
Translating the vision into focus areas

In Bulgaria, the provision of social services and support to people living with dementia and their carers unfortunately still requires a great deal of improvement.

As part of the global Dementia Friends movement, Alzheimer Bulgaria Association's goal is to: a) improve the public policies and attitudes towards dementia; b) disseminate information in order to make the general public informed and aware about the problem of dementia, as well as its societal costs and implications for family members; and, c) conduct training and information sessions.

The Dementia Friends Bulgaria movement was successfully launched in 2018. Following information sessions with undergraduate and Masters students from Psychology and Social work disciplines, as well as professionals from various backgrounds, the following outcomes have been achieved thus far: 1) more than 3 general information sessions with students were held raising awareness on dementia; 2) more than 141 Dementia Friends are created already and 20 of them also completed 6 months of volunteering as dementia befrienders in two nursing homes in Bulgaria.

The Association has already created partnerships with companies, such as Hewlett Packard Europe (HPE) Bulgaria, and organized a charity dementia mini-marathon with another Bulgarian NGO to raise awareness on dementia prevention through sports in October 2019.

Alzheimer Bulgaria Association

Case study

Turning actions into outcomes

Police Officers are frequently confronted with difficult situations when meeting people with dementia and their carers. They often do not know how to reassure a person with dementia when they are wandering and getting lost, or they do not know how to give instructions in such a way that they are well understood and prevent responses like agitation. If police officers are not prepared for effective communication with people with dementia, situations may get out of hand.

The project "Mission Dementia" was initiated by the Austrian M.A.S. Alzheimerhilfe and the Federal Police Academy's E-learning Centre of the Austrian Federal Ministry of the Interior. These two institutions cooperated and designed an internet-based learning program involving persons with dementia, support providers and police Officers. The learning program consists of three teaching modules lasting about 15 minutes each and one evaluation tool, which is implemented into the Austrian-wide Police Intranet. The e-learning tool was evaluated with a questionnaire integrated into the learning tool.

Results show high satisfaction with the interactive tool. As of 2020, 11.000 police officers completed the learning program and 10.915 received a certificate. In addition to the e-learning tool, a certification process for Police Stations was initiated. If 70% of police officers in a Police Station successfully complete the learning tool and the police station can provide a proof of regular interactions with nearby social services such as nursing homes, day care centres, dementia service centres, the station can apply to be certified as a "dementia-friendly police station" by the Danube University Krems. So far, 240 police stations have received this award. A follow up project with other groups of the public administration was initiated in February 2019. A specific e-learning tool was developed and community-based projects integrating persons with dementia and their support providers into community life is encouraged within a certification process.

Danube University Krems, Austria

A.3. Plan and implement activities to achieve the vision

Activities highlight the actions that will operationalize the focus areas, and help achieve the expected outcomes, identified in the previous section. Activities result in outputs, which move you closer to achieving the DFI's vision. Activities may be new or build on existing DFIs, or related initiatives that aim to make society more inclusive. Figure 7 highlights key elements of well-designed activities.

The types of activities will depend on the DFI's target groups. It is therefore important to determine what groups the DFI will target, and their awareness of dementia. It is also necessary to determine how to engage the groups, and anticipate potential challenges to their engagement, as well as solutions. Use Exercise 5 to help identify your target groups and activities.

Well Designed Activities

- Have an associated timeline for implementing, and method to measure the status and progress of, each activity (i.e. Monitoring)
- Identify partners' and stakeholders' roles and responsiblities, as well as a mechanism to coordinate these across sectors
- Estimate resources required to implement each activity and strategies to mobilize and coordinate these
- Address context-specific considerations (e.g. political, social, economic, cultural factors)
- Focus on the specific target group(s) and geographic location(s) in which they are to be carried out
- Address the human rights, identified priorities, needs and preferences of people with dementia, their carers and families
- Involve people with dementia, their carers and families in their planning and implementation

FIGURE 7 KEY ELEMENTS OF WELL-DESIGNED ACTIVITIES

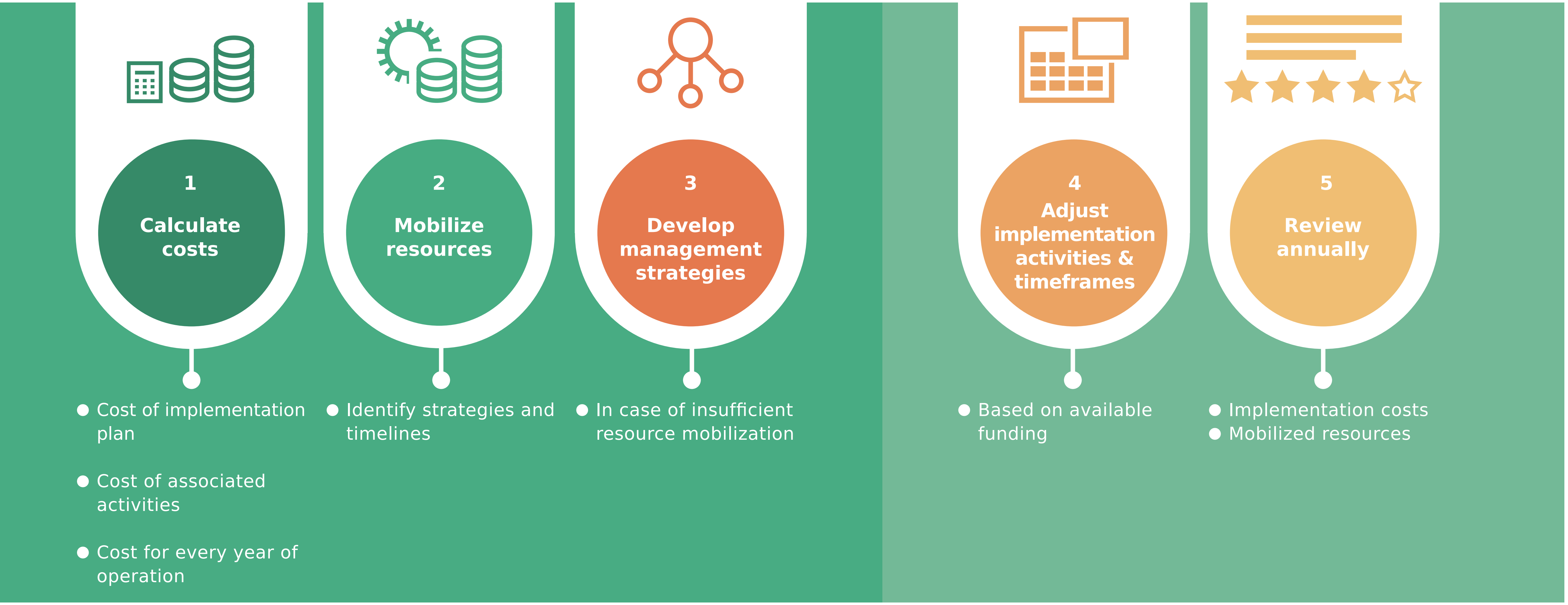
A.4. Identify and manage risks and resource needs

The coordinating team should identify any obstacles to achieving the DFI's vision and the right strategies to minimize risks throughout the DFI planning and implementation process. The coordinating team also needs to determine the resources (financial, human and capital) required to carry out the activities that you identified in the previous section, as well as those associated with monitoring and evaluation (M&E). This estimation of resources should cover any training and/or capacity building required, given that volunteers and community members often represent an important resource pool.

It is important to develop the estimation of resources into a budget and share it with partners. Figure 8 articulates the key steps involved in developing a budget for the implementation of DFIs. The coordinating team will need to identify, who within the team and among partners, is responsible for managing the budget and mobilizing resources. Use Exercise 6 to help you identify and manage risks and resources.

It is important to monitor your progress continuously so as to manage risks effectively and change course if necessary. Beyond assessing progress and managing risk, M&E can help determine whether to mobilize additional resources to ensure sustainable implementation. M&E will help determine the impact that the DFI is having on people with dementia, their carers and families, your partners, as well as society generally. It will also spot any unintended consequences that the DFI may be having and potential spill-over effects. These include increased awareness of dementia in neighbouring municipalities or towns, changes to policy and/or legal frameworks at the national or sub-national level, and so on. More in-depth information is provided on M&E in Module C.

FIGURE 8 DEVELOPING A DFI IMPLEMENTATION BUDGET



1 Calculate costs
- Cost of implementation plan
- Cost of associated activities
- Cost for every year of operation

2 Mobilize resources
- Identify strategies and timelines

3 Develop management strategies
- In case of insufficient resource mobilization

4 Adjust implementation activities & timeframes
- Based on available funding

5 Review annually
- Implementation costs
- Mobilized resources

EXERCISE 1
PARTNER MAPPING

Identify partners and a coordinating team

Who/how?

Alone or with a small group of partners that you have identified, as part of an initial brainstorm workshop or consultation. This includes people with dementia, their carers and/or families.

Resources

Flipcharts, pens and sticky notes

Description

Identify the individuals, or groups of individuals with whom you will form partnerships with and engage. For example, you may wish to include some of the individuals that you identify as members of your coordinating team.

Activity

1. Using sticky notes or paper, brainstorm and write down all of the groups that:
    a. may be interested in/are aligned with your initiative (e.g. advocacy groups for older people);
    b. you will need to engage in order to implement your initiative (e.g. decision-makers, funders).

2. On the flipchart, write in two different columns: partners and coordinating team members. Next, place each of the sticky notes or paper containing an individual, or group of individuals, under one of the two columns, explaining why you feel that this is the right categorization.

3. Now, you will have two lists: one for partners and one for coordinating team members that you identified. For every partner and coordinating team member in each of the two lists identify:
    a what their role and responsibilities will be in implementing the DFI;
    b. what strategies you will use to engage them.

4. Finally, consider whether you foresee any difficulties engaging any of the identified partners and/or coordinating team members, and what strategies you will use to overcome these challenges. Use your flipchart or paper to write this down.

Notes

EXERCISE 2
ISSUE IDENTIFICATION

Identify the most pressing issues that your DFI will address and how they affect people with dementia and other partners.

Who/how?

All concerned partners, as part of a workshop or consultation. This includes people with dementia, their carers and/or families.

Description

This exercise will help you identify the most pressing issues, or barriers, to creating a dementia-inclusive society, and why these issues are important. Together, this information will help inform your DFI's vision, focus areas and activities.

Activity

1. List the most pressing issues that you have identified and would like to address through your DFI. Use sticky notes or paper to brainstorm and write down the issues.

2. Next, go back to the partners that you identified in Exercise 1. Use your flipchart or paper to write down how each of the issues that you identified affects the lives of:
    a. people with dementia
    b. other partners.

Notes

EXERCISE 3
VISION DEFINITION

Define a common vision for the DFI

Who/how?

Your DFI's coordinating team and key partners, as part of a planning meeting or workshop. This includes people with dementia, their carers and/or families.

Resources

Sample DFI framework (see Figure 6).

Description

Based on the information collected in Exercise 2, build your vision. Your vision should be short and clear, and contain an implementation timeframe associated with it.

Ultimately, your vision should reflect the long-term impact of the DFI on people living with dementia, their carers and families. It should be clear and easy to understand. In doing so, consider the examples below.

✓ **Vision:** *a public transportation system that is accessible and easy to navigate for people with dementia.*

And not:

✗ **Vision:** *train bus drivers to make the public transportation system more accessible and easy to navigate for people with dementia.*

Activity

Write down your vision below using the sample DFI framework in Figure 6 or in the space below.

Notes

EXERCISE 4
PRIMARY FOCUS AREAS AND OUTCOME IDENTIFICATION

Identify primary focus areas and expected outcomes

Who/how?

Your DFI's coordinating team and key partners, as part of a planning meeting or workshop. This includes people with dementia, their carers and/or families.

Resources

Flipcharts, pens and sticky notes; sample DFI framework in Figure 6.

Description

This exercise will help you determine how to address the issues that you identified in Exercise 2 (on page 61). In doing so, it will help you translate the vision that you built in Exercise 3 (on page 62) into primary focus areas and expected outcomes.

Activity

1. Go back to the issues that you identified in Exercise 2. Write down whether changes to the social environment, the physical environment, or both will need to be made in order to address the identified issues. This is your primary focus area(s). Write down your primary focus area(s) using the sample DFI framework in Figure 6.

2. Indicate which aspects of the social and/or physical environment you need to change. Consider what evidence exists to support each change. Make note of that as well.

3. Think about the expected outcomes that you seek to achieve by implementing changes to the social and/or physical environment. Write these down on your flipchart or paper.

4. Next, think of the potential challenges that you might encounter in implementing the changes to the social and/or physical environment that you identified. What strategies would you use to overcome these challenges? Use your flipchart or paper to write this down.

Notes

EXERCISE 5
DFI ACTIVITIES

Translate the primary focus areas and expected outcomes into specific activities.

Who/how?

Your DFI’s coordinating team and key partners, as part of a planning meeting or workshop. This includes people with dementia, their carers and/or families.

Resources

Flipcharts, pens and sticky notes; sample DFI framework in Figure 6.

Description

This exercise will help you determine, plan and implement activities for the focus area(s) that you identified in Exercise 4. It will also help you identify the target groups that will be the focus of your activities.

Activity

1. Go back to the focus area(s) and expected outcomes that you identified in Exercise 4 and list these on the flipchart or paper.

2. Using sticky notes or paper, write down which target group(s) you need to focus on in order to reach each of your expected outcomes. In doing so, consider the following questions:
    a. What is each target group’s level of dementia awareness/understanding?
    b. How will you engage each target group in a meaningful way?
    c. What potential challenges do you foresee in engaging each target group?
    d. What strategies will you use to overcome these challenges?

3. Next, write down the activities that you need to implement for each of your target groups, in order to reach each of your expected outcomes.

4. Now, place each activity on the flipchart and explain how it will achieve each of your expected outcomes.

5. For each activity, think about and write down the following:
    a. Who will implement it?
    b. Where will it be implemented?
    c. What is the timeline for implementing it?
    d. What are the costs associated with it?
    e. What outputs will it yield?

6. Write down your final list of activities using the sample DFI framework in Figure 6.

Notes

EXERCISE 6
RISKS AND RESOURCES

Identify and manage risks and resources.

Who/how?

Your DFI’s coordinating team and key partners, as part of a planning meeting or workshop. This includes people with dementia, their carers and/or families.

Resources

Flipcharts, pens and sticky notes.

Description

This exercise will help you identify and manage (i) risks associated with and (ii) resources required to implement each of the activities that you planned in Exercise 5.

Activity

1. Go back to the activities that you identified in Exercise 5 and list these on the flipchart or paper.

2. Write down the risks associated with implementing/not implementing each activity.

3. Next, brainstorm how you can reduce the likelihood and impact of each risk. Write these strategies down as well.

4. Now, estimate the cost associated with implementing each activity, and make a note of this.

5. Calculate the total cost across all activities. This is your resource estimate.

6. Next, write down your current resources. Look at how these map onto your estimated costs. The discrepancy between your existing resources and estimated costs represents the amount of resources that you need to mobilize. Remember to consider both financial and human resources. This is your budget.

7. Using the flipchart or paper, identify strategies to mobilize outstanding funding and indicate the timeline by when this needs to be achieved.

8. Finally, identify strategies in case insufficient resources are mobilized.

Notes

Module B. Integrating dementia into a related initiative

> *"Age-friendly cities and communities are becoming better places in which to grow older. By drawing on this guidance they can be better places to grow older and to live with dementia."*
>
> *Alana Officer,*
> *WHO Global Network for Age-friendly Cities and Communities.*

Over the last decade, various initiatives were launched to improve the quality of life of older people, people with disabilities and city dwellers more generally *(12)(13)(14)(15)*. One such initiative is the UN Decade of Healthy Ageing (2020-2030), which brings together a broad range of stakeholders, including governments, civil society, academia, health and social care professionals and the private sector to improve the lives of older people, their families and communities over the next 10 years *(4)*. Another noteworthy initiative is WHO's Global Network for Age-friendly Cities and Communities (GNAFCC) established in 2010. The GNAFCC supports city and community efforts to develop great places in which to grow older *(15)*.

Age-friendly environments share many goals similar to those envisioned by DFIs. These include: the creation of environments that are free from physical and social barriers; the promotion of health, physical and mental capacity, and independent living, as well as; the opportunity to make decisions and participate in society *(16)*. Creating age-friendly environments also requires the meaningful and sustained engagement of older people and coordinated collaboration across various sectors. Both age-friendly and dementia-friendly initiatives aim to create more inclusive societies.

Where possible, it is important that DFIs work in harmony with initiatives aimed at creating age-friendly cities and communities (AFCC). AFCCs should also strive to comprehensively integrate dementia throughout planning, implementation, monitoring and evaluation, and scale-up. When necessary, it is important to implement DFIs even within the broader context of AFCCs, in order to meet the unique needs of people with dementia, their families and caregivers.

Integrating dementia into an existing age-friendly (or other related) initiative provides an opportunity to leverage and build on impacts already achieved at national, sub-national and/or local levels, as well as on important international commitments. This process involves integrating four key steps within existing processes: (i) identifying a vision based on the needs of people with dementia; (ii) translating the vision into focus areas and expected outcomes; (iii) planning and carrying out activities to achieve the joint vision; and (iv) identifying and managing risks and resources.

Case study
An initiative that can be integrated into existing support pathways

Club Hubs enable people affected by dementia to live well. They do this by harnessing the benefits of sport and physical activity. To this end, they work together with the community, through sports clubs (or centres for sporting/ leisure activity) situated within neighbourhoods.

Club Hubs are places where people affected by dementia can go regularly to relax, have fun, socialize, connect to other services and play games and sports. Attendees are not "patients" or "service users", but club members who help decide priorities, determine what goes on, and influence the development of their club.

The approach is based on Meeting Centres, which are inspired by the adaptation-coping model *(17)*. This employs cognitive, emotional, and social techniques to enable people to adjust to the change dementia brings.

Club Hubs can be integrated into local care and support pathways. This allows coordinated care to link people harmoniously to the services they need. The approach is free from the stigma that accompanies traditional health and care interventions for dementia, because it is based around sport and "club membership".

Experiences of people affected by dementia are the indicators being used to measure impact, and they are generated by a thematic analysis of multiple data sources.

University of Worcester, United Kingdom

B.1. Identify a joint vision based on needs

Dementia- and age-friendly initiatives are complementary. While DFIs focus on the specific requirements of people with dementia, their carers and families, age-friendly initiatives consider the needs of older people more broadly. Therefore, as a first step you should identify and map out relevant initiatives that have been, or are being, implemented at both local and national levels. To identify a joint vision it is necessary to look into other relevant initiatives in place (such as a local age-friendly city initiative or DFI) and find common ground or areas of potential collaboration.

Case study

Integrating dementia into an age-friendly initiative

In Massachusetts, aligning the age- and dementia-friendly frameworks helps to avoid confusion, improve efficiency, strengthen collective work and help initiatives on the community, regional and statewide levels to be more inclusive. Integrating the two movements helps better leverage resources and eliminate redundancy. It also allows the region to build a broader network of support and involvement.

The key idea is being intentional about including stakeholders that can speak to the experience of dementia throughout the process of assessment, action planning, implementation and evaluation. Whether it is a resident living with dementia, a caregiver of someone living with dementia, or a professional that serves and supports people living with dementia.

The essential element in integration is including the voice of people living with dementia within Age-Friendly efforts from the earliest possible point. This could begin with convening a steering or coordination committee, but at the very least should include questions on surveys and within listening sessions that include those residents that can speak to the dementia experience. Even if age-friendly community work started without a dementia-friendly perspective, there are always opportunities to include dementia-friendly stakeholders in action plan implementation. Likewise, communities can begin with dementia-friendly initiatives, which can serve as an excellent foundation for which to add age-friendly efforts.

Massachusetts Healthy Aging Collaborative, United States of America

Use Exercise 7 on p. 73 to map existing initiatives and identify synergies. The more similarities there are, the more entry points, and the greater the likelihood of complementing existing initiatives. Use Exercise 8 on p. 74 to identify the most pressing issues that you will address and Exercise 9 on p. 75 to define your joint vision for integration. Remember to consider how the needs the people with dementia and those of older adults intersect, align or differ.

B.2. Translate the vision into focus areas and expected outcomes

Once you have identified and prioritized relevant initiatives for integration, you need to translate the joint vision into expected outcomes. The first step is to decide whether you will address the needs of people with dementia and their caregivers through an existing age-friendly initiative, or whether a standalone DFI needs to be created as part of a broader age-friendly initiative to focus on modifying the social environment, physical environment, or both in order to achieve your vision. In other words, you need to identify your focus area. It is important to do this together with partners involved in managing and implementing the initiative(s) selected for integration. The coordinating team should have the capacity to identify common ground as well as potential advantages in terms of resources. This is key to developing successful partnerships.

Expected outcomes should be directly related to the identified focus areas, and should help achieve the chosen, joint vision. It is necessary to fully respect the needs and choices of people with dementia, their carers and families as you integrate dementia into existing initiatives. Identifying expected outcomes may involve engaging a wide range of partners across sectors, which presents challenges as well as opportunities. For example, partnership with multiple actors may allow for pooled resources, greater ownership and implementation capacity but will also require stronger coordination and leadership. All relevant partners, including people with dementia, their families and carers, should participate in all stages of, and decisions related to, the integration process. Exercise 10 on p. 76 will help you identify your focus areas,and expected outcomes for integration.

B.3. Plan and implement activities to achieve the joint vision

In the next step you need to plan and implement activities that will help you reach the expected outcomes identified in the previous section. Successfully planning and carrying out activities strongly depends on the quality and effectiveness of the collaboration established with integration partners. The integration of dementia into an existing initiative will involve identifying: (i) new activities that you need to plan to achieve the stated vision and expected outcomes; (ii) how you will implement the activities; (iii) what outputs (or results) the activities will yield; and (iv) how to integrate the activities in a way that reflects policies, programmes, products and/or technologies which apply to the existing initiative. Exercise 11 on p. 77 will help you plan activities that can be implemented in a feasible and sustainable manner.

Planning and implementing activities requires a clear distinction of roles and responsibilities among partners, as well as effective communication and coordination mechanisms. It is important to consider how to jointly monitor and evaluate activities and their outputs, and to set indicators and an evaluation framework that can effectively measure joint outcomes and impact. Additional information related to M&E can be found in Module C of this toolkit.

Case study
Decade of Healthy Ageing 2020-2030

The Decade of Healthy Ageing 2020-2030, endorsed by the World Health Assembly on 3 August 2020, is a global collaboration that brings together diverse sectors and stakeholders including governments, civil society, international organizations, professionals, academic institutions, the media and the private sector to improve the lives of older people, their families and communities.

The Decade of Healthy Ageing focuses on four key action areas, all of which are intended to be country-led. As such, government in partnership with civil society, older adults and inclusive of people with dementia, their family and caregivers. Key actions include:

- changing how we think, feel and act towards age and ageing;
- developing communities in ways that foster the abilities of older people;
- delivering person-centred integrated care and primary health services responsive to older people;
- providing older people who need it with access to long-term care.

Unit for Demographic Change and Healthy Ageing,
World Health Organization

B.4. Identify and manage risks and resources

Once you have planned the activities for integration, identify implementation risks and related risk management strategies. Risk assessment should include direct risks – insufficient financial or human resources, weakened focus on dementia resulting from the integration process – and indirect risks, such as unintended harmful effects on target groups and/or people with dementia, their carers and families. Risk management should be carried out for each of the DFI's individual activities. Exercise 12 on p. 78 can help you identify and manage risks and resources.

Successful integration relies on the ability of the coordinating team and its partners to (i) harness existing resources and work within the budget of the existing initiatives, and (ii) accurately estimate any additional resources required to address dementia as part of the existing initiatives. This process involves mobilizing net new funding and making more efficient use of existing resources *(19)*. It requires a careful analysis of available resources. Mobilizing sufficient resources requires a detailed cost estimate that can be checked against an assessment of existing resources. This applies to the integration process as a whole, and to each individual activity.

The coordinating team should decide who is responsible for resource and risk management, both within the coordinating team and among partners. It is also important to monitor your progress continuously so as to manage risks effectively and change course if necessary. Beyond assessing progress and managing risk, monitoring and evaluation (M&E) can help determine whether to mobilize additional resources to ensure sustainable implementation. M&E will help determine the impact that your initiative is having on older people, people with dementia, their carers and families, your partners, as well as society generally. More in-depth information is provided on M&E in Module C.

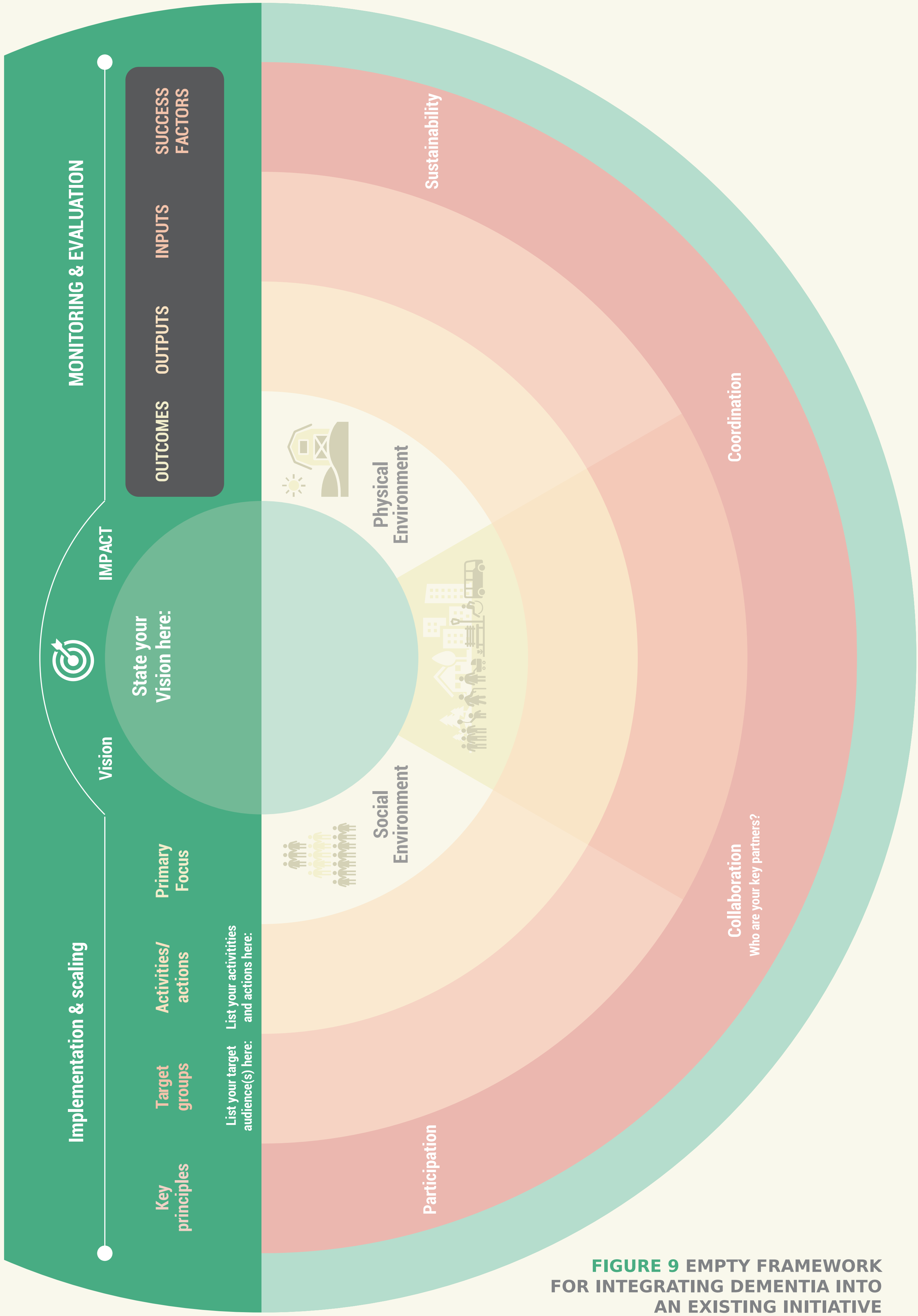


FIGURE 9 EMPTY FRAMEWORK FOR INTEGRATING DEMENTIA INTO AN EXISTING INITIATIVE

EXERCISE 7
INITIATIVE MAPPING

Map existing initiatives into which dementia could be integrated.

Who/how?

All concerned partners, as part of a workshop or consultation. This includes people with dementia, their carers and/or families.

Resources

Flipcharts, pens and sticky notes

Description

This exercise will help you map and identify existing initiatives into which dementia can be integrated.

Activity

1. Using sticky notes or paper, write down existing initiatives that relate to dementia and place these on the flipchart. These could involve initiatives focused on ageing, disability, accessibility, human rights, or other related topics.

2. List the issues that each initiative addresses. Now look for patterns.
    a. Which initiatives already address dementia? Where are these being implemented?
    b. Which dementia-related issues do the existing initiatives address?
    c. Do multiple initiatives address the same dementia-related issue(s)?
    d. What dementia-related issues remain unaddressed?
    e. Which initiatives could easily be modified to address the needs of people with dementia?
    f. Which initiatives have strong political, community and/or financial support?
    g. Which initiatives have a strong coordinating team and partners?

3. Now prioritize the initiatives where integrating dementia seems the most feasible, cost-effective and impactful.

4. Finally, use your prioritized list of initiatives to develop engagement strategies. Start at the top of your prioritized list. Remember to consider potential engagement challenges and solutions to overcome these.

Notes

EXERCISE 8
ISSUE IDENTIFICATION

Identify the most pressing issues that you will address, and how they affect people with dementia and other partners

Who/how?

Your coordinating team and key partners, including those involved in the integration process, as part of a planning meeting or workshop. This includes people with dementia, their carers and/or families.

Resources

Flipcharts, pens and sticky notes

Description

This exercise will help you identify the most pressing issues, or barriers, to creating a dementia-inclusive society, and why these issues are important. Together, this information will help you build a joint vision to integrate dementia into an existing initiative.

Activity

1. List the most pressing issues that you have identified and would like to address by integrating dementia into an existing initiative. Use sticky notes or paper to brainstorm and write the issues down.

2. Next, go back to the partners that you identified in Exercise 1 (under "Before you get started"). Use your flipchart or paper to write down how each of the issues that you identified affects the lives of:
    a. people with dementia
    b. other partners.

Notes

EXERCISE 9
JOINT VISION DEFINITION

Define a joint vision for integrating dementia into an existing initiative.

Who/how?

Your coordinating team and key partners, including those involved in the integration process, as part of a planning meeting or workshop. This includes people with dementia, their carers and/or families.

Resources

Sample DFI framework (see Figure 9)

Description

Based on the information collected in Exercises 7 and 8, build a joint vision. Your vision should be short and clear, and have an implementation timeframe associated with it.

Ultimately, your vision should reflect the expected impact that the DFI will have in the long term on people living with dementia, their carers and families. It should be clear and easy to understand. In doing so, consider the examples below.

✓ **Vision:** *housing that is affordable, accessible and responds to multifaceted needs of both older people and people with dementia.*

And not:

✗ **Vision:** *engage construction companies to build housing options that integrate assisted living devices for older people and people with dementia.*

Activity

Write down your joint vision below using the sample DFI framework in Figure 9.

Notes

EXERCISE 10
JOINT FOCUS AREAS AND OUTCOME IDENTIFICATION

Identify primary focus areas and expected outcomes

Who/how?

Your coordinating team and partners, including those involved in the integration process, as part of a planning meeting or workshop. This includes people with dementia, their carers and/or families.

Resources

Flipcharts, pens and sticky notes; sample DFI framework in Figure 9.

Description

This exercise will help you determine how to address the issues that you identified in Exercise 8. In doing so, it will help you translate the vision that you built in Exercise 9 into focus areas and expected outcomes.

Activity

1. Go back to the issues that you identified in Exercise 8. Write down whether changes to the social environment, the physical environment, or both will need to be made in order to address the identified issues. This is your primary focus area(s). Write down your primary focus area using the sample framework in Figure 9.

2. Indicate which aspects of the social and/or physical environment will need to be changed within the context of integration. Consider what evidence exists to support each change. Make note of that as well.

3. Think about the expected outcomes that you seek to achieve by implementing changes to the social and/or physical environment. Write these down on your flipchart or paper.

4. Next, think of the potential challenges that you might encounter in implementing the changes to the social and/or physical environment that you identified. What strategies would you use to overcome these challenges? Use your flipchart or paper to write this down.

Notes

EXERCISE 11
DFI ACTIVITY PLANNING

Translate the primary focus areas and expected outcomes into specific activities.

Who/how?

Your coordinating team and key partners, including those involved in the integration process, as part of a planning meeting or workshop. This includes people with dementia, their carers and/or families.

Resources

Flipcharts, pens and sticky notes; sample DFI framework in Figure 9.

Description

This exercise will help you plan and implement activities for the focus area(s) that you identified in Exercise 10. It will also help you identify the target groups that will be the focus of your activities, and where these will take place.

Activity

1. Go back to the focus area(s) and expected outcomes that you identified in Exercise 10 and list these on the flipchart or paper.

2. Using sticky notes or paper, write down which target group(s) you need to focus on in order to reach each of your expected outcomes. In doing so, consider the following questions:
    a. What is each target group’s level of dementia awareness/understanding?
    b. How will you engage each target group in a meaningful way?
    c. What potential challenges do you foresee in engaging each target group? What strategies will you use to overcome these challenges?

3. Next, write down the integration activities that need to be implemented for each of your target groups, in order to reach each of your expected outcomes.

4. Now, place each activity on the flipchart and explain how it will achieve each of your expected outcomes.

5. For each activity, think about and write down the following:
    a. Who will implement it?
    b. Where will it be implemented?
    c. What is the timeline for implementing it?
    d. What are the costs associated with it?
    e. What outputs will it yield?

6. Write down your final list of activities using the sample DFI framework in Figure 9.

Notes

EXERCISE 12
RISKS AND RESOURCES

Identify and manage risks and resources.

Who/how?

Your coordinating team and key partners, including those involved in the integration process, as part of a planning meeting or workshop. This includes people with dementia, their carers and/or families.

Resources

Flipcharts, pens and sticky notes.

Description

This exercise will help you identify and manage (i) risks associated with and (ii) resources required to implement each of the activities that you planned in Exercise 11.

Activity

1. Go back to the activities that you identified in Exercise 11 and list these on the flipchart or paper.

2. Write down the risks associated with implementing/not implementing each activity.

3. Next, brainstorm how you can reduce the likelihood and impact of each risk. Write these strategies down as well.

4. Now, estimate the cost associated with implementing each activity, and make a note of this.

5. Calculate the total cost across all activities. This is your resource estimate.

6. Next, write down your current resources. Look at how these map onto your estimated costs. The discrepancy between your existing resources and estimated costs represents the amount of resources that you need to mobilize. Remember to consider both financial and human resources. This is your budget.

7. Using the flipchart or paper, identify strategies to mobilize outstanding funding and indicate the timeline by when this needs to be achieved.

8. Finally, identify strategies in case insufficient resources are mobilized.

Notes

Notes

Module C. Monitoring and evaluation

> *"Careful consideration must be given to the selection of indicators as they have great potential to influence, for better or for worse, how a problem is framed as well as what actions are triggered as a result."*
>
> *Measuring the age-friendliness of cities: a guide to using core indicators" and then in a new line "World Health Organization (20)*

Monitoring & evaluation (M&E) is an ongoing process and ensures that you carry out every step of the DFI framework. It also provides information on (i) whether the DFI activities were implemented as planned, (ii) the outputs and outcomes that the activities achieved, and (iii) the impact that the activities had on people with dementia, their carers and families as well as on the target groups. In other words it establishes whether the DFI achieved its vision. M&E also helps inform whether scale-up is appropriate (see Module D for more information on scaling-up a DFI).

There should be a person or team dedicated to undertaking M&E. Ideally the M&E team is independent from the coordinating team that implemented the DFI (to prevent potential biases). If this is not feasible, the coordinating team may wish to carry out M&E activities. It is important to mobilize sufficient funds to carry out M&E activities (if not secured in advance). Equally important is the need to create an M&E framework that places emphasis on the evaluation type, criteria, questions, indicators, as well as a logic model, timelines and deliverables.

This section is organized into two steps:

(i) identifying the relevant type of evaluation; and

(ii) developing a logic model. The second step also involves identifying evaluation questions and indicators. Each step will be addressed in turn.

C.1. Identify the relevant type of evaluation

Two types of evaluations are particularly relevant to DFIs: an evaluation of the process (i.e. monitoring), and of the impact.

Monitoring helps determine how well the DFI and its activities are being implemented, including whether this is being done as intended and according to timelines and planned resources. This can help identify challenges early on in the implementation and address them in a timely manner. Monitoring occurs throughout the implementation to allow for continuous learning and improvements.

An **evaluation** reveals whether the DFI achieved its vision and expected outcomes effectively and efficiently. It also provides information to determine the impact of activities, following a pre-determined period of time (such as 6 – 12 months), and guides future planning, budgeting and scaling. Which type of evaluation you use should correspond to your DFI framework and the evaluation's goal. Table 2 on page 82 shows three key types of evaluations that may be relevant to DFIs.

TABLE 2 EVALUATION TYPES, GOALS, TIMING AND RATIONALE (21).

	WHAT	WHEN	WHY
Monitoring	● Determine whether DFI activities have been implemented as intended.	● As soon as the DFI begins. ● During the implementation/ integration/scaling of an existing DFI.	● Makes it possible to spot problems related to implementation early. ● Allows for continuous learning and improvements. ● Determines how well the DFI and its activities are working.
Outcome-based evaluation	● Measure the DFI's effects on the target groups by assessing progress towards achieving the expected outcomes of the DFI.	● Once the DFI has reached at least one target group.	● Helps determine whether the DFI is being effective in meeting its expected outcomes.
Economic evaluation	● Identifies the resources being used by the DFI and its activities, and their costs, compared to the outcomes achieved.	● At the beginning of a new DFI. ● During the implementation/ integration/scaling of an existing DFI.	● Provides a means to assess cost relative to outcomes.
Impact evaluation	● Assesses whether the DFI and its activities are producing the anticipated changes to the social and physical environment, and adhering to its vision and focus areas.	● During the implementation/ integration/scaling of an existing DFI. ● Following the implementation/ integration and/or scaling of a DFI.	● Provides evidence for use in policy, service planning and funding decisions.

Case study
Implementing an impact evaluation

The project "Dementia-friendly Community Pharmacy" aims to promote health and wellbeing for families, informal carers and people living with dementia by implementing needs-based, person-centered care. Community pharmacies have been chosen because people living with dementia and their carers are regular users of these services. The project is based on principles of health promotion and palliative care aimed at the participation and empowerment of all actors, fostering dignity, quality of life and reducing stigma.

A team of researchers developed interventions in close cooperation with community pharmacy staff, carers, the self-help group Alzheimer Austria (representing carers), and the Austrian Chamber of Pharmacists. The project involved: a needs assessment with carers and pharmacy staff; training workshops for pharmacy staff focusing on communication, networking and pharmaceutical care; and small-scale projects developed by the participating pharmacies.

Evaluation showed that self-rated competency among pharmacy staff significantly increased during the project. Networks between pharmacies and support organizations were set up and the number of network partners increased. Pharmacies developed a range of initiatives reaching out to the community to de-stigmatize dementia. Carers reported a high level of satisfaction with the project.

Based on the evaluation of a number of actions to increase visibility, a group (a group of pharmacists, carers, a person with dementia, representatives of the self-help group, the Austria Chamber of Pharmacists, and researchers) created a logo. This logo is awarded to all pharmacies that successfully completed the workshops and implemented a small-scale project. This has gradually developed into a label indicating engagement in dementia care.

Interventions, workshops and small-scale projects, should take into account the resources available for pharmacies (e.g. staff working time) and the fact that pharmacies (at least in Austria) are privately owned, profit-oriented businesses. The dementia-friendly pharmacy project explicitly excluded generating profits (e.g. from selling dietary supplements) as a project aim. We aim to include people living with dementia in further projects, and in network meetings. This will be easier, as now there are self-help groups by and for people with dementia in Austria.

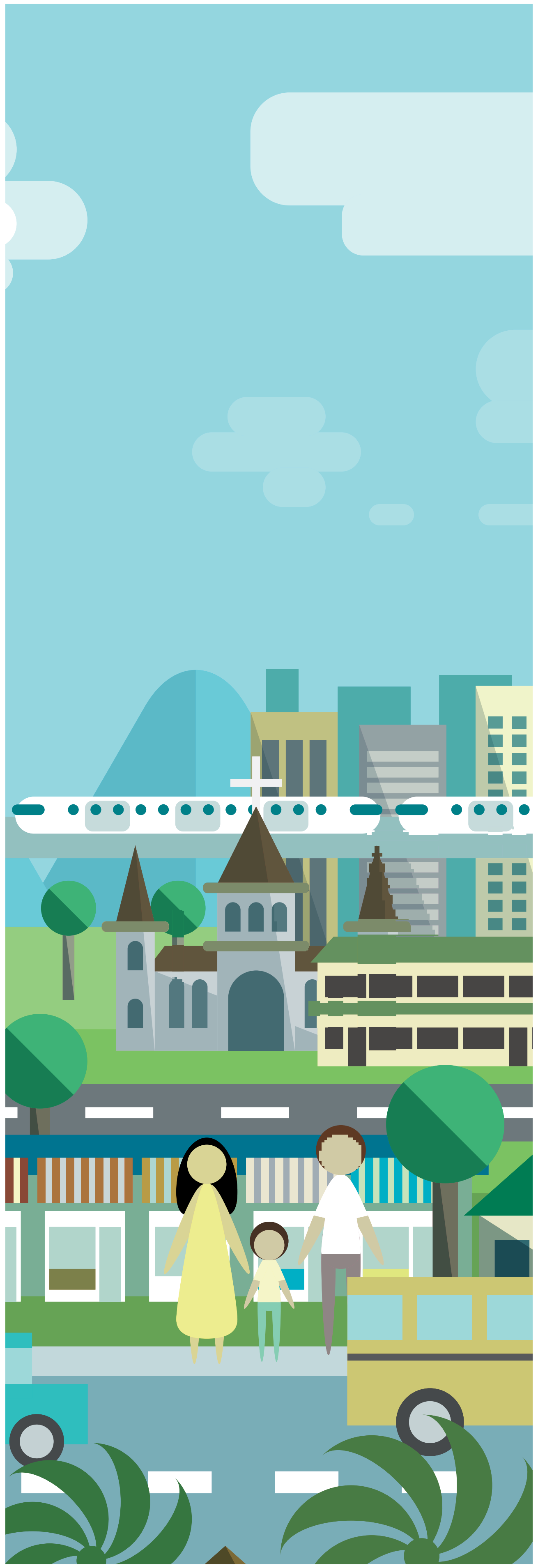
University of Vienna, Institute of Nursing Science, Austria

C.2. Develop a logic model

The next step is to develop a logic model. Based on the DFI framework, a logic model identifies how resources (or inputs) make it possible to carry out DFI activities. These in turn produce a series of results (or outputs and outcomes) and move the DFI towards achieving its stated vision (or impact). A logic model includes indicators that help measure activities, outputs, outcomes and impacts. It may also highlight various constraints and contextual considerations and assumptions, at the national/sub-national level. It is important to view the logic model as a living document, which can and should be regularly updated.

Table 3 on pp 86-87 represents a sample logic model, including sample inputs, outputs, outcomes and impacts on pp 31-37. In Exercise 13 on pp 88-89, you can develop your own logic model. You will need to refer back to your vision, activities and outcomes.

Once you have built your logic model, you need to identify evaluation questions and indicators. **Evaluation questions** specify what will be measured through the evaluation. **Evaluation indicators** help determine what information and data to collect so as to answer the evaluation questions. Evaluation questions and indicators will vary based on the type of evaluation selected. Exercise 14 on pp 90-94 will help you develop your evaluation questions and indicators based on examples. Once you have completed this exercise, consult Module D for information about scaling-up a DFI.



Case study
Measuring the outcomes and impact of activities

In 2018, CHJ-Lezhi, a local multi-disciplinary healthcare team collaborated with the local Chaoxi community in Dongcheng District, Beijing (China) to survey residents aged 60 and above. Findings suggested that the majority of residents had very little knowledge of dementia or dementia-inclusive communities. In response to this, the healthcare team and local residential committee decided to implement a four-phase initiative involving community education, engagement, and collaborative action in creating dementia-inclusive communities.

In order to raise awareness and understanding of dementia, the team set up a dementia awareness program for local residents. Unlike other educational programs, they combined brain exercises with educational lectures, which helped raise awareness of dementia and brain health amongst residents.

Following the success of the dementia awareness program, the team launched a meeting with the residential committee director and other key community members to create a dementia-inclusive community. They then decided to create a volunteer team to promote conversations about dementia to end stigma.

Thanks to the participation of the residential committee director and key members, more and more residents became involved in this volunteer program. In the initial survey, only 56% and 12.5% of the local resident reported that they heard of dementia and dementia-inclusive community, respectively. After four-month training and dissemination, the percentage went up to 72% and 36%, respectively. Meanwhile, their scores on knowledge of dementia, including the risk factors, prevention, symptoms and treatment of dementia, increased from 37.5% to 65%. Considering the success of the initiative, a follow-up volunteer training program is planned.

CHJ-Lezhi, Beijing, China

TABLE 3 SAMPLE LOGIC MODEL FOR DFIS

Inputs	Activities	Outputs	Short-term outcomes	Long-term outcomes	Impact
Financial, human and capital resources	Implement an awareness-raising campaign	National dementia-awareness campaign implemented	Increased understanding of dementia and people with dementia	Reduced stigma	A dementia-friendly and inclusive society where people with dementia and their carers fully enjoy participation, inclusion, respect, freedom, dignity, equality, accessibility and quality of life, are empowered to live independently, and are free from stigma, discrimination, exploitation, violence or abuse.
Training and capacity building	Expand Dementia Friends programme to the national level	Dementia Friends programme scaled from two to seven sub-regions	Communities are better equipped to communicate with, and assist, people with dementia		
Advocacy and information	Develop assessment mechanism to vet dementia-friendly businesses	Business friendly checklist and vetting mechanism implemented	Businesses have the capacity to respond to the needs of people with dementia People with dementia maintain their functional capacity and independence to remain in the community	Dementia-friendly social environments	
Existing, related initiatives	Engage city planners to develop a dementia-friendly city pilot project	Dementia-friendly city pilot established	Increased autonomy of people with dementia	Dementia-friendly physical environments	
International human rights instruments (such as UN CRPD)	Integrate the DFI into age-friendly programmes	Components of DFI activities integrated into age-friendly programmes	Age-friendly programmes address the needs and preferences of people with dementia, their carers and families	Improved quality of life for people with dementia and older people	

EXERCISE 13 DEVELOP A LOGIC MODEL

Inputs	Activities	Outputs	Short-term outcomes	Long-term outcomes	Impact

EXERCISE 14
EVALUATION QUESTIONS AND INDICATORS

Identifying evaluation questions and indicators (22)

Using the table below, identify evaluation questions and indicators to assess your DFI's activities, outputs, outcomes and impact.

	Sample evaluation questions	Sample indicators
Inputs	● How do the allocated resources fit with the resource estimate established prior to implementation/integration/ scale-up?	● Proportion of allocated resources in relation to estimated resources
	● What resources were used to achieve expected outcomes?	● Types of resources used to achieve the expected outcomes ● % of allocated resources utilized to achieve the expected outcomes
	● How do the allocated resources compare with the actual level of needs and operating environment?	● Proportion of required resources in relation to allocated resources
	● Was the DFI amended during the implementation/integration/ scale-up period to provide the best value for money?	● Types of resource and changes made to the programme to optimize cost-effectiveness
	● To what extent were UN CRPD principles incorporated into the planning and implementation of the DFI?	● Proportion of people with dementia who reported that the planning and implementation of the DFI took into account UN CRPD principles
	Your evaluation questions	**Your indicators**
	●	●
	●	●
	●	●
	●	●

	Sample evaluation questions	Sample indicators
Activities	● What particular activities of the DFI led to the successful implementation/ integration/ scale-up?	● Types of activities across implementation/scale-up/ integration sites
	● What activities led to successful alignment with related initiatives?	● Types of activities undertaken to integrate / align the DFI with related initiatives
	Your evaluation questions	**Your indicators**
	●	●
	●	●
	●	●
	●	●

	Sample evaluation questions	Sample indicators
Outputs	● Were objectives achieved on time?	● % objectives achieved according to stated timelines
	● To what extent did the DFI meet the needs and reflect the priorities of people with dementia, their carers and families?	● Proportion of people with dementia participating in the DFI reporting that the DFI met their needs and priorities
	● To what extent did the objectives of the DFI match the target groups' established values, norms and practices?	● Proportion of target groups reporting satisfaction or strong satisfaction with local and cultural adaptation of the DFI
	Your evaluation questions	**Your indicators**
	●	●
	●	●
	●	●
	●	●

	Sample evaluation questions	Sample indicators
Outcomes	● To what extent did the target groups increase their capacity to communicate with, empower and support people with dementia, their carers and families?	● Types of new skills and knowledge learned by target groups as a results of the DFI
	● Did the DFI result in the expected outcomes in the short and medium term? ○ What were the barriers to, and enablers of, success? ○ To what extent did contextual factors help or hinder the implementation/ integration/ scale-up of the DFI?	● Types of short- and medium-term outcomes produced through the DFI ○ Types of barriers to and enablers of success ○ % of people with dementia, target groups, and partners reporting significant positive/negative impact of contextual factors on outcomes of the DFI
	● What were the comparative costs and benefits of participation in the DFI on (i) people with dementia, their carers and families, (ii) the target groups and key partners?	● Types of costs and benefits reported by (i) people with dementia, their carers and families, (ii) the target groups and key partners resulting from participation in the DFI
	Your evaluation questions	**Your indicators**
	●	●
	●	●
	●	●
	●	●

	Sample evaluation questions	Sample indicators
Impact	● What intended and unintended impacts did the DFI produce on (i) people with dementia, their carers and families, (ii) the target groups, (iii) key partners, and (iv) the social and/or physical environment?	● Types of intended/unintended impacts produced by the DFI on (i) people with dementia, their carers and families, (ii) the target groups, (iii) key partners, and (iv) the social and/or physical environment ● % match of actual impacts to the DFI’s intended impacts ● Number of statements of political support (at the sub-national / national level)
	● How did the DFI impact the human rights of people with dementia and their carers?	● Number of public statements by elected officials about the need for strengthened sub-national / national policy or legal frameworks, including human rights clauses, resulting from DFI implementation / scaling ● Number of sub-national / national policy or legal frameworks, including human rights clauses, resulting from DFI implementation / scaling
	Your evaluation questions	**Your indicators**
	●	●
	●	●
	●	●
	●	●

	Sample evaluation questions	Sample indicators
Other (sustain-ability)	• To what extent: ○ is the DFI easy to understand? ○ does the DFI provide clear benefits to the target groups? ○ can the DFI be scaled across sectors, geographic locations or institutionalized at a sub-national or national level while remaining context-specific and culturally acceptable?	• Proportion of people with dementia reporting that the DFI is easy to understand • Proportion of target groups reporting that they benefited from the DFI • Types of benefits reported by the target groups • Proportion of planned scale-up sites implementing the DFI at a sub-national/ national level • Proportion of planned scale-up sites integrating the DFI at a sub-national/ national level
	• What resources are required to sustain the impacts of the DFI at the implementation/integration/ scale-up sites? ○ How does the use of resources compare to similar DFIs? ○ What is the likelihood that resources will be allocated, mobilized or redirected to sustain the intended impact(s)?	• Percentage increase in financial resources secured following pilot testing / proof of concept of DFI • Percentage of implementation/ integration/scale-up budget secured from sub-national / national budget (health or other)
	• Did the DFI help build the capacity of local organizations to ensure the continuity of activities?	• Proportion of core DFI activities maintained across scale-up sites
	• Have impacts been sustained (i) over time, (ii) across implementation/integration/ scale-up sites (follow-up M&E)?	• Proportion of impacts sustained after 1, 3 and 5 years • Proportion of impacts sustained across scale-up sites
	Your evaluation questions	**Your indicators**
	•	•
	•	•
	•	•
	•	•

Module D. Scaling an existing initiative

> *"Together we must work together to create a society in which people of all ages can continue to meaningfully participate and live healthy, active lives with peace of mind."*
>
> *Japanese Prime Minister Shinzo Abe (23)*

Scaling an existing DFI is an effective way of spreading good practices and lessons learned from one geographical location or target group to another. In this document, "scaling up" means to broaden the evaluated impact of an activity, or group of activities, in order to: benefit more people with dementia, their carers and families, and; foster lasting and larger scale changes to the social and/or physical environment (24). See Module C for an overview of evaluation types and how to conduct an evaluation.

This section is organized into five steps: (i) assessing whether the DFI to be scaled-up achieved its stated vision; (ii) identifying the type of scale-up; (iii) identifying a vision, focus areas and expected outcomes for scale-up; (iv) planning and implementing activities to achieve the scale-up vision, and; (v) identifying and managing risks and resources during the scale-up process.

Case study
Evidence-based scale-up

The aim of Kids4Dementia is to proactively create positive dementia attitudes among our young people. Kids4Dementia is a teacher-led multimedia modular education programme for 10 – 13 year olds. Through an engaging animated story, real-life videos and interactive activities, schoolchildren learn how it feels to have dementia or live with someone with dementia. They discover activities they can do with a person who has dementia and how visits to aged care homes can be fun. Students also learn how to keep their brains healthy *(25)*.

Teachers choose the module order and the programme purposefully aligns with local school curricula. It demands minimal preparation or resources, and no prior knowledge from the teacher.

In a waitlist-controlled pilot trial, programme impact was assessed via a validated bespoke measure of children's dementia attitudes *(26)*, and through focus groups with students and teachers. The teachers and students loved the programme, and importantly, the children's attitudes about dementia improved significantly after their participation in Kids4Dementia *(27)*. The students also reported sharing their new knowledge with their parents, presenting the exciting idea that maybe schoolchildren are a novel bottom-up way of increasing dementia literacy in adults.

In a larger trial of impact, Kids4Dementia has been rolled out across 26 Australian schools, comprising a sample of 1,400 students.

University of New South Wales, Australia

D.1. Assess the DFI that is to be scaled

The first step in determining a DFI's potential for sustainable scaling is to conduct an evaluation to determine whether it achieved its stated vision (see Module C). This evaluation will help determine whether the DFI's activities were carried out as planned as well as whether and how the implementation met the expected outcomes. It will also show if the implementation met the needs of people with dementia and of the target groups.

Key considerations for selecting a DFI for scale-up

Perceived need: e.g. people with dementia, their carers and families, the general public or local authorities have expressed their need for the DFI and its scaling-up.

Participation: There is a clear plan to meaningfully engage people with dementia, their carers and families in the scale-up of the DFI.

Strong multisectoral partnerships and collaboration: The DFI has an established, network with different sectors, across planned scale-up sites.

Leadership and coordination: The DFI has effective, stable leadership, coordination and management.

Sustainability: There are sufficient resources to ensure immediate and long-term scale-up of the DFI across locations.

Capacity: The coordinating team has adequate implementation capacity and expertise.

Continuity: The team that is coordinating the scale-up was also involved in the development, implementation and/or evaluation of the DFI. It is important to determine whether the specific environment, people and/or organizational features and values that helped the DFI achieve its favourable results also play a role in a successful scale-up *(28)*.

Strategic links to national/international priorities: The DFI's vision, focus areas and expected outcomes are aligned for example with the UN CRPD and the Sustainable Development Goals.

Alignment with related initiatives: The DFI can be aligned with or integrated into related initiatives, such as age-friendly cities and communities, barrier-free communities, or healthy cities.

Timing: The timing during the political cycle is appropriate (in the case of government) to scale the DFI.

Data gathered through the evaluation can be summarized into recommended actions, which include risks and mitigation strategies. The recommendations will help determine whether the DFI has the potential to be scaled up in a sustainable manner. Use Exercise 15 on p.103 to assess whether you have completed all of the steps required to select a DFI for scale-up.

Case study

Expanding awareness from one country to a global movement

The dementia-friendly approach originated in Japan and was then championed by Alzheimer's Society in England, Wales and Northern Ireland. Dementia Friends tackles the stigma and discrimination people with dementia can face globally through increasing awareness, driving attitude change and action. It centres around five positive key messages aiming to change how people view the condition. Alzheimer's Society's Dementia Friends programme is the United Kingdom's (UK) biggest ever initiative to change people's perceptions of dementia. Dementia Friends is about learning more about the condition in an easy and engaging way as well as the small ways everyone can take action to support those living with the condition.

Alzheimer's Society's Dementia Friends programme was launched in England and Wales in 2013. Its aim was to transform the way the nation thinks, acts and talks about dementia. Dementia Friends are those who have watched a video or attended a session delivered by a Champion where they learn more about dementia and the ways in which they can help. From the outset, data on the number of people participating in the Dementia Friends programme was reported. In 2014, an action card was introduced to collect data on the actions Dementia Friends commit to on joining the programme, which helps to demonstrate the programme's impact and provides data on geographic and demographic reach. Results show that the more engaged Dementia Friends are, the greater the opportunities to get feedback on the initiative.

An evaluation survey for Dementia Friends was launched in 2016. It provides an understanding of motivations for joining the programme, and this information is used to better target new audiences to join based on these drivers. The findings were: 73% feel more confident interacting with people with dementia since becoming a Dementia Friend; 86% feel they have a better understanding of dementia; 84% feel the programme is inspiring communities to take action; and, 80% feel motivated to do more.

Alzheimer's Society commissioned New Philanthropy Capital (NPC) and the University of Hertfordshire to help build an impact measurement framework for ongoing evaluation. This involves: quantitative evaluation to compare awareness levels prior to and after becoming a Dementia Friend; and, in-depth interviews with people affected by dementia to demonstrate how Dementia Friends are helping to change attitudes and improve lives.

There are over 60 Dementia Friends programmes (or national equivalent) launched or in development in more than 50 countries. Under the Global Dementia Friends Network, hosted by Alzheimer's Society, countries were working together to share, support and collaborate for a truly global dementia-friendly movement. Members of the Global Dementia Friends Network have collectively created almost 18 million Dementia Friends worldwide.

Alzheimer's Society, United Kingdom

D.2. Identify the type of scale-up

Once a DFI is selected for scale-up, it is important to carefully select and identify the most appropriate type of scale-up. There are three key types of scale-up: (i) horizontal scale-up; (ii) vertical scale-up, and; (iii) functional scale-up, explained in Table 4 below.

TABLE 4 TYPES OF SCALE-UP (27)

Horizontal scale-up	
Description	- Expansion or replication of the DFI to other geographical sites or target groups - Example: after successful pilot testing, the school programme Kids4Dementia is brought to more schools.
Considerations	- Requires a high level of implementation efficiency and involves tailoring the DFI to each context
Vertical scale-up	
Description	- Also referred to as institutional scale-up - The formal adoption and institutionalization of a DFI, e.g. through national planning mechanisms, policy or legal changes - Example: national policies are developed to ensure that all police officers are trained about dementia.
Considerations	- Frequently undertaken by government - Requires system adaptation - Requires resource rationalization and redistribution at the national or sub-national level
Functional scale-up	
Description	- Also referred to as diversification - New features, activities or interventions are added to an existing DFI - Example: an age-friendly initiative is broadened to include dementia.
Considerations	- Is most effective once the DFI has already achieved a sufficient reach and support, if the scale-up organization and coordinating team have adequate capacity, and if there is a clear rationale indicating why the DFI could benefit from additional activities

The type of scale-up depends on the DFI, its focus areas and activities and the socio-economic, political and cultural environment. To ensure sustainable expansion, both horizontal and vertical scale-up may be pursued simultaneously. Regardless of the type of scale-up, there is a need to assess other DFIs and related initiatives within the planned scale-up sites to find common ground, synergies and potential for collaboration. Use Exercise 16 on p. 104 to help you determine the most appropriate type of scale-up for your DFI.

Case study

Making banks dementia-friendly: An example of horizontal scale-up

The Jinmei Social Service Agency has reached out to financial banks in Pudong, District of Shanghai (China) to make them dementia-friendly. The Bank of Shanghai at Nanquan Street sub-branch is the first cooperative partner in this initiative.

Employees are trained using an interactive format, during which trainers focus on awareness raising, knowledge about dementia, and communication skills with people living with dementia and their carers. Bank employees are asked to share stories when they encountered customers with dementia. For example, one day a customer wanted to withdraw money using a blank piece of paper. The bank employee at first thought this was a prank. After contacting the family, the employee found out that this customer had dementia. The employee felt embarrassed that he had not known how to handle such a situation. After the training, employees learned how to identify persons living with dementia and ways to communicate with them, such as redirecting the client's attention, and inviting them to sit in the private VIP room.

In addition, a policy change has been made to establish a green pathway to facilitate financial business for family members with a relative who lives with dementia. Family members are given a bank issued "Yellow Card", which allows them to receive prompt and priority service so that they can return home quickly to their loved one. This bank also maintains a record of the use of Yellow Card to track the number of families affected by dementia that they serve. These efforts are being extended to another branch of Bank of China Construction in the same district, while exploring other ways to make the bank environment more friendly to people with dementia and their carers.

Jinmei Social Service Agency, Shanghai, China

D.3. Identify a scale-up vision, focus areas and expected outcomes

Based on the information and data gathered through the evaluation (see Module C), you can develop a vision of what the "full scale" DFI will look like. The vision should be shared among all partners involved in the expansion. The first step in selecting a vision for scale-up is to clearly identify and describe the DFI and the impact it has had to date. It will then be important to identify (i) the DFI's vision for scale-up and associated timeline for expansion, (ii) its focus areas and (iii) expected outcomes at scale *(29)(30)*. In identifying the scale-up vision, it is necessary to carefully consider the socio-economic, cultural and political context of the planned scale-up. You can use Exercise 17 on p. 105 to define your vision and Exercise 18 on p. 106 to identify your focus areas and expected outcomes.

D.4. Plan and implement activities to achieve the scale-up vision

Plan and implement activities that directly contribute to the expected outcomes identified in section D.3., and demonstrate how they will help achieve the DFI's vision. Each activity should be accompanied by (i) a clear indication of who (organization and individual) will be responsible for implementing it, (ii) the output of each activity, (iii) a timeline and the amount of resources that will be required for implementation, as well as mechanisms to mobilize these. It is highly recommended to use existing structures, processes, policies and pathways to scale-up the DFI, rather than creating parallel, and potentially duplicative, administrative mechanisms.

The types of activities that are planned depend on the scale-up target groups. As such, it is important to start by determining which groups will serve as the focus of the DFI scale-up, and their level of awareness of dementia. It is also necessary to determine how these groups will be engaged, as well as potential engagement challenges and solutions, what potential challenges to expect in doing so and how to resolve them. It is important to consider how to tailor the DFI's activities to reflect local customs, cultural norms and practices, local leadership structures and social networks of the groups targeted for scale-up *(30)*.

To identify the implementer of each activity there is a need to understand the range of partners, sectors and levels of government that will be involved in scaling up the DFI, both within and beyond government. Finally, it is necessary to choose the locations for the scale-up activities. Use Exercise 19 on p. 109 to define your activities, target groups and scale-up locations.

Case study
Building capacity for scale-up

The *Dementia Friendly America* initiative, launched in 2015, is a national effort to effectively support and serve people across the USA who are living with dementia as well as their care partners and loved ones.

The *Dementia Friendly America* model – pioneered by Minnesota's state-wide successful initiative, ACT on Alzheimer's – helps communities become more dementia-friendly by providing them with a toolkit that gives a step-by-step process, along with hands-on materials. The toolkit includes tools and timelines to:

- coordinate with key partners and develop an action team;
- gather data and analyse community strengths and gaps, and;
- formulate and execute a dementia-friendly action plan.

The *Dementia Friendly America* staff team provide technical assistance and support to communities that join the *Dementia Friendly America* network of communities. Joining the network means that the community is committed to becoming more dementia-friendly, that its leadership includes people living with dementia, and that it has dementia-friendly change goals.

National Association of Area Agencies on Aging, USA

D.5. Identify and manage risks and resource needs

Once activities are planned, you need to identify risks to their implementation and strategies manage these risks. Risk assessments should include direct risks – insufficient financial or human resources, lack of acceptability of the DFI in scale-up locations – and indirect risks, such as unintended (harmful) impacts on target groups and/or people with dementia, their carers and families.

You need to choose who is responsible for resource and risk management, within the coordinating team and among partners. To ensure sustainable scale-up of the DFI, it is recommended that you mobilize resources at the local, national and global levels (if relevant), across the health and social sectors, and a range of partners (such as the government, civil society, private sector, international donors). A clear M&E plan for scaling up the DFI may also help secure funding (see **Module C** for more detailed information about M&E). Exercise 19 will help you assess and manage risks and resources.

EXERCISE 15
CHECKLIST FOR ASSESSING A DFI FOR SCALE-UP

Checklist to ensure that you have taken all the required steps to assess and select an appropriate DFI for scale-up.

Who/how?

Your coordinating team and key partners, as part of a planning meeting or workshop. This includes people with dementia, their carers and/or families.

Resources

Flipcharts, pens and sticky notes.

Description

This exercise will help you ensure that you have taken all the required steps to assess and select a DFI for scale-up.

Overall

☐ An evaluation was carried out, demonstrating that the DFI achieved its expected outcomes and impact (i.e. vision).

Participation

The evaluation demonstrated that:

☐ The DFI's activities and outcomes were relevant to, and compatible with, the needs, priorities and preferences of people with dementia, their carers and families.
☐ The DFI empowers people with dementia through participation in its planning, management, implementation and/or evaluation.
☐ The DFI reflects key human rights principles, by modelling inclusion and participation.
☐ The DFI is supported by people with dementia, their carers and families.
☐ The DFI's activities and outcomes were relevant to, and compatible with, the needs, values, norms and practices of the target group(s) where it was implemented.

Multisectoral collaboration

The evaluation demonstrated that:

☐ The DFI engaged key partners across relevant sectors (e.g. health, social, educational, housing, employment, transportation sectors).
☐ The DFI engaged a range of actors spanning civil society, academia, government and/or private sector.
☐ The DFI engaged multiple levels of government levels.
☐ The DFI is compatible with policies, programmes, services and/or DFIs present in target scale-up locations.

Coordination

The evaluation demonstrated that:

☐ The DFI has a clear coordination structure and division of roles and responsibilities.
☐ The DFI has the potential to have a lasting impact over time, i.e. its activities can be maintained, expanded to additional target groups and/or geographic areas, or integrated into existing initiatives.

Sustainability

The evaluation demonstrated that:

☐ The DFI demonstrates a relative advantage in terms of perceived costs and benefits when compared to the status quo (i.e. existing programmes and/or practices).
☐ The DFI was designed and implemented based on the most up-to-date evidence and data available.
☐ The DFI is easy to understand, implement and/or participate in.
☐ The DFI is supported by, and involves, people with dementia, their carers and families.
☐ The DFI is supported by persons or institutions perceived as legitimate and accountable.
☐ The DFI’s core activities can be replicated without much alteration.
☐ The DFI’s core activities can easily be adapted to local scale-up contexts.
☐ The DFI’s core activities can be replicated using similar resource levels.
☐ The DFI is supported by, and involves, people with dementia, their carers and families.
☐ The DFI is supported by persons or institutions perceived as legitimate and accountable.
☐ The DFI’s core activities can be replicated without much alteration.
☐ The DFI’s core activities can easily be adapted to local scale-up contexts.
☐ The DFI’s core activities can be replicated using similar resource levels.

Notes

EXERCISE 16
SCALE-UP TYPE IDENTIFICATION

Identify the most appropriate type(s) of scale-up

Who/how?

Your coordinating team and key partners, as part of a planning meeting or workshop. This includes people with dementia, their carers and/or families.

Resources

Flipcharts, pens and sticky notes

Description

This exercise will help you identify type(s) of scale-up that are most appropriate for the DFI that you are seeking to expand.

Activity

1. Using a flipchart or paper, identify the key features, focus areas and activities of the DFI that you are seeking to scale, within the context of the types of scale-up explained in Table 4.

2. Next consider the technical expertise of your coordinating team and the level of political buy-in.

3. Then, list the pros and cons of selecting each scale-up type.

4. Finally, assess how the information noted down in points 1 and 2 map onto the constraints, pros and cons of each scale-up type to determine which is most appropriate for scaling your DFI.

Notes

EXERCISE 17
VISION DEFINITION FOR SCALE-UP

Define a vision for scaling up the DFI.

Who/how?

Your coordinating team and key partners, as part of a planning meeting or workshop. This includes people with dementia, their carers and/or families.

Resources

Sample DFI framework (see Figure 10)

Description

Based on the information collected in Exercise 16, build a vision for scale-up. Your vision should be short and clear, and have an implementation timeframe associated with it.

Ultimately, your vision should reflect the expected impact that the DFI will have at full scale on people living with dementia, their carers and families. It should be clear and easy to understand.

Activity

Write down your vision using the sample DFI framework in Figure 10.

Notes

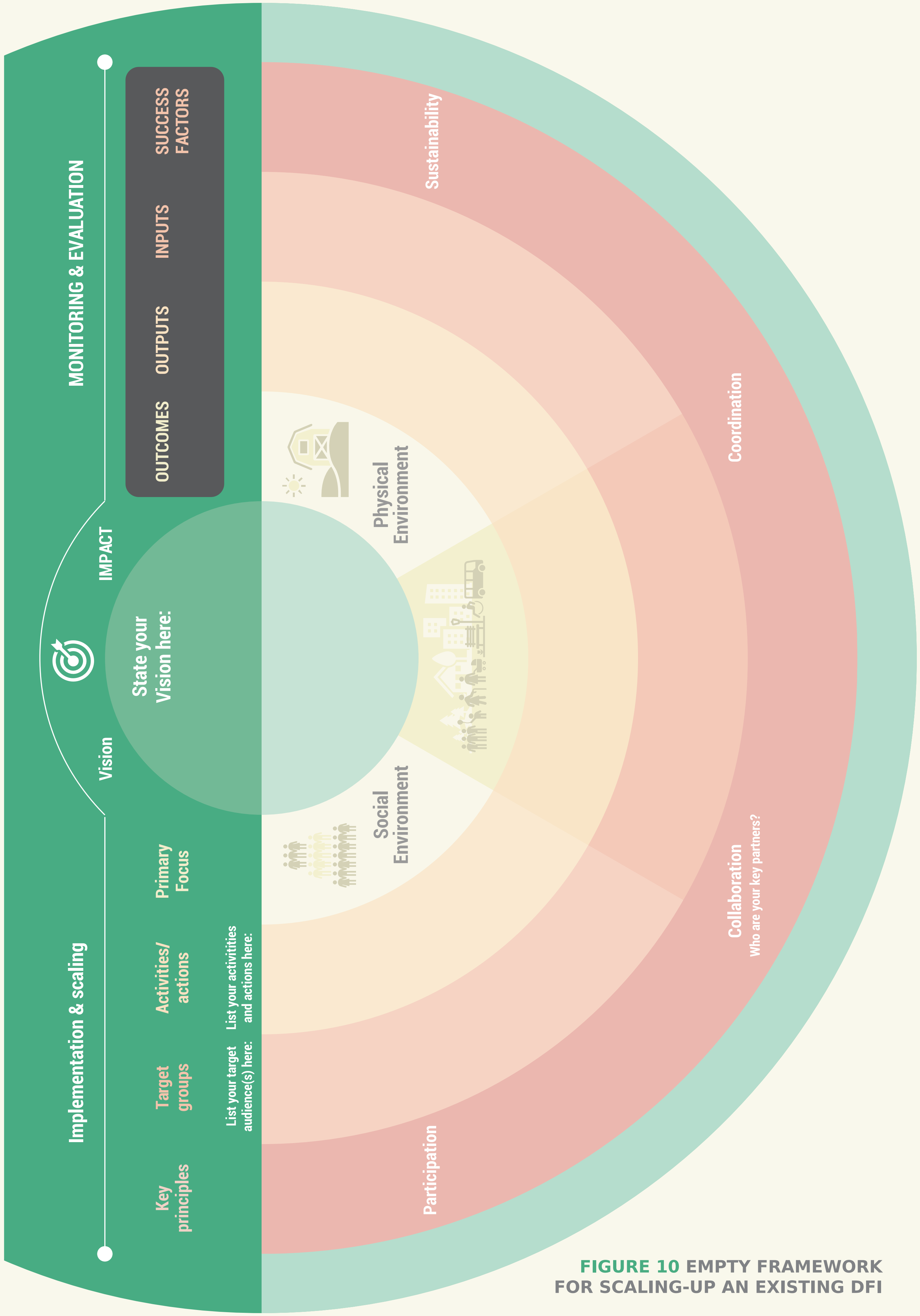


FIGURE 10 EMPTY FRAMEWORK FOR SCALING-UP AN EXISTING DFI

EXERCISE 18
FOCUS AREAS AND EXPECTED OUTCOME IDENTIFICATION

Identify focus areas and expected outcomes for scaling-up the DFI.

Who/how?

Your coordinating team and key partners, as part of a planning meeting or workshop. This includes people with dementia, their carers and/or families.

Resources

Flipcharts, pens and sticky notes; sample DFI framework in Figure 10.

Description

This exercise will help you determine how to translate the scale-up vision that you built in Exercise 17 into focus areas and expected outcomes.

Activity

1. Go back to Exercise 16. Write down whether changes to the social environment, the physical environment, or both will need to be scaled-up. This is your primary focus area(s). Write down your primary focus area using the sample framework in Figure 10.

2. Indicate which aspects of the social and/or physical environment will need to be scaled-up. Consider what evidence exists to support each scale-up. Make note of that as well.

3. Think about the expected outcomes that you seek to achieve by scaling-up changes to the social and/or physical environment. Write these down on your flipchart or paper.

4. Next, think of the potential challenges that you might encounter in scaling-up changes to the social and/or physical environment that you identified. What strategies would you use to overcome these challenges? Use your flipchart or paper to write this down.

Notes

EXERCISE 19
IDENTIFYING ACTIVITIES, TARGET GROUPS AND SCALE-UP LOCATIONS

Translate the expected outcomes of the scale-up that you identified in Exercise 17 into specific activities.

Who/how?

Your coordinating team and key partners, including those involved in the integration process, as part of a planning meeting or workshop. This includes people with dementia, their carers and/or families.

Resources

Flipcharts, pens and sticky notes; sample DFI framework in Figure 10.

Description

This exercise will help you plan and implement scale-up activities for the focus area(s) that you identified in Exercise 17. It will also help you identify the target groups that will be the focus of your activities, and where these will take place.

Activity

1. Go back to the focus area(s) and expected outcomes that you identified in Exercise 17 and list these on the flipchart or paper.

2. Using sticky notes or paper, write down which target group(s) you need to focus on in order to reach each of your expected outcomes. In doing so, consider the following questions:

    a. What is each target group’s level of dementia awareness/understanding?
    b. How will you engage each target group in a meaningful way?
    c. What potential challenges do you foresee in engaging each target group? What strategies will you use to overcome these challenges?

3. Next, write down the scale-up activities that need to be implemented for each of your target groups, in order to reach each of your expected outcomes.

4. Now, place each activity on the flipchart and explain how it will achieve each of your expected outcomes.

5. For each activity, think about and write down the following:
    a. Who will implement it?
    b. Where will it be implemented?
    c. What is the timeline for implementing it?
    d. What are the costs associated with it?
    e. What outputs will it yield?

6. Write down your final list of activities using the sample DFI framework in Figure 10.

Notes

EXERCISE 20
RISKS AND RESOURCES

Identify and manage risks and resources.

Who/how?

Your coordinating team and key partners, as part of a planning meeting or workshop. This includes people with dementia, their carers and/or families.

Resources

Flipcharts, pens and sticky notes.

Description

This exercise will help you identify and manage (i) risks associated with and (ii) resources required to implement each of the activities that you planned in Exercise 18.

Activity

1. Go back to the activities that you identified in Exercise 18 and list them on the flipchart or paper.
2. Write down the risks associated with implementing/not implementing each activity.
3. Next, brainstorm how you can reduce the likelihood and impact of each risk. Write these strategies down as well.
4. Now, estimate the cost associated with implementing each activity, and make a note of this.
5. Calculate the total cost across all activities. This is your resource estimate.
6. Next, write down your current resources. Look at how these map onto your estimated costs. The discrepancy between your existing resources and estimated costs represents the amount of resources that you need to mobilize. Remember to consider both financial and human resources. This is your budget.
7. Using the flipchart or paper, identify strategies to mobilize outstanding funding and indicate the timeline by when this needs to be achieved.
8. Finally, identify strategies in case insufficient resources are mobilized.

Notes

Concluding remarks

Despite ongoing global efforts, a lack of awareness surrounding dementia implies that people with dementia, their carers and families continue to experience stigma and discrimination within the communities that they live in. Dementia-friendly initiatives represent one of many steps required to create dementia-inclusive societies where people with dementia, their carers and families feel respected, valued, empowered and safe.

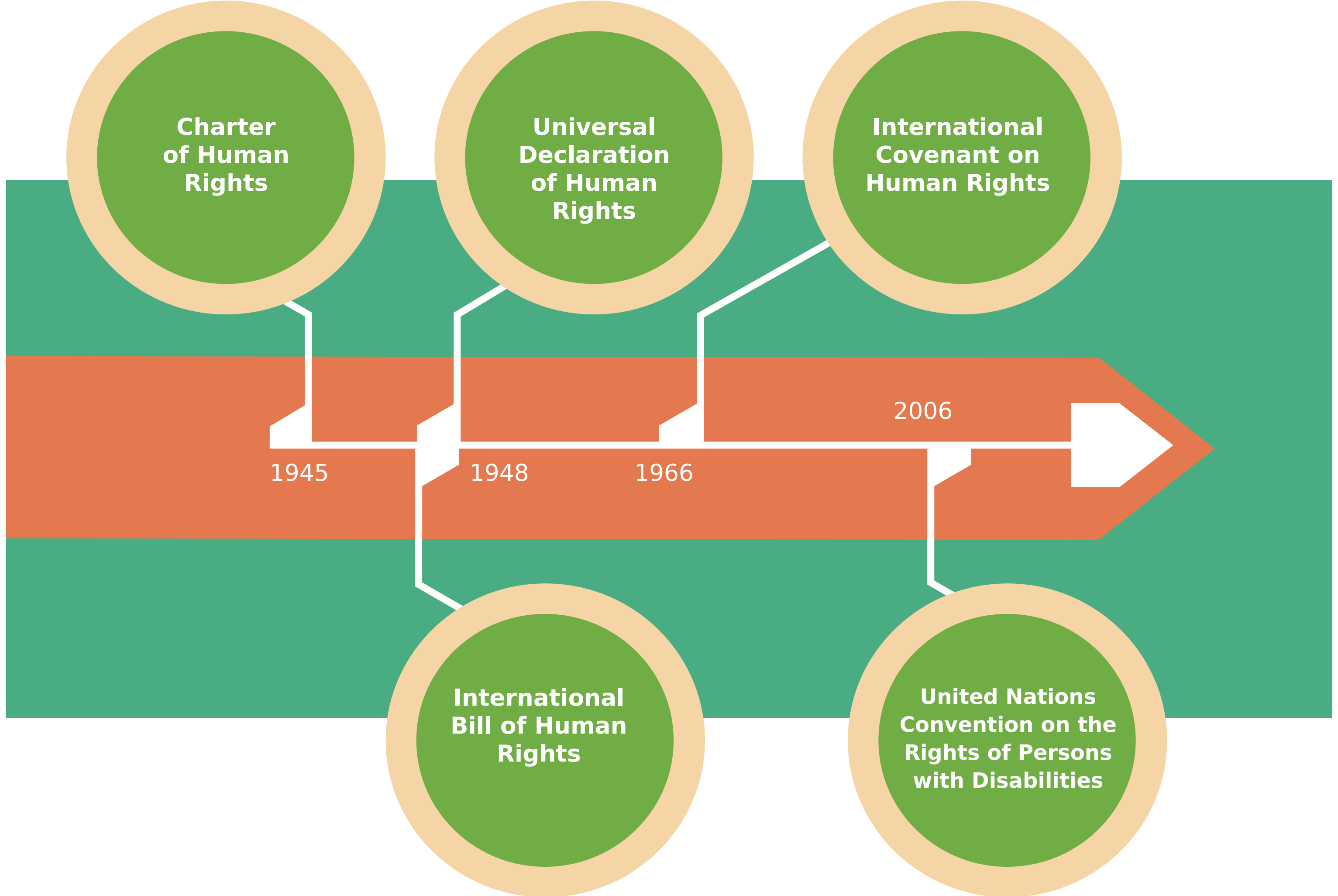
The process of planning, implementing, evaluating and scaling DFIs, or integrating dementia into an existing initiative, requires accounting for the diverse perspectives of multisectoral partners. It also involves defining a vision grounded in evidence, local context and needs, and operationalizing it into sustainable activities in order to reach expected outcomes for people with dementia. Most importantly, however, it demands a rights-based approach, placing people with dementia at the center of the process.

While this toolkit provides generic guidance for planning, implementing, evaluating and scaling DFIs, you are encouraged to build on the content of this document, applying and adapting the sections that are most relevant to local resource settings and the needs of people with dementia in your community and country. It is important to keep in mind that every DFI will likely differ in terms of its focus, target group(s), and activities, implying that it may be difficult to replicate the exact outcomes or impacts generated in a given setting. With this in mind, however, those seeking to support DFIs share a common wish to empower people with dementia, enhance their quality of life and ensure that they can meaningfully and comfortably live in their own communities. For this reason, much can be learned from other, similar, initiatives implemented across and beyond your community or country.

Though DFIs can help raise awareness about dementia and combat stigma, comprehensive actions still need to be taken by political leaders, governments and communities worldwide to ensure that the rights of people with dementia, their carers and families are appropriately safeguarded and human rights violations denounced and condemned. The process of creating dementia-inclusive societies may be slow, and changes may only be achieved following multiple years of collaboration, consultation and funding. However, international commitments such as the UN CRPD and the Global action plan on the public health response to dementia (2017-2025) represent the foundation, and an undeniable rationale, upon which dementia-inclusive societies can, and should, be built to improve the lives of those living with dementia.

Annexes

Annex 1. Timeline of international human rights laws, treaties and conventions



RELEVANT LINKS

Charter of Human Rights: https://www.un.org/en/sections/un-charter/un-charter-full-text/

Universal Declaration of Human Rights: https://www.un.org/en/universal-declaration-human-rights/

International Bill of Human Rights: https://www.ohchr.org/Documents/Publications/FactSheet2Rev.1en.pdf

United Nations Convention on the Rights of Persons with Disabilities: https://www.un.org/development/ desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html#Fulltext

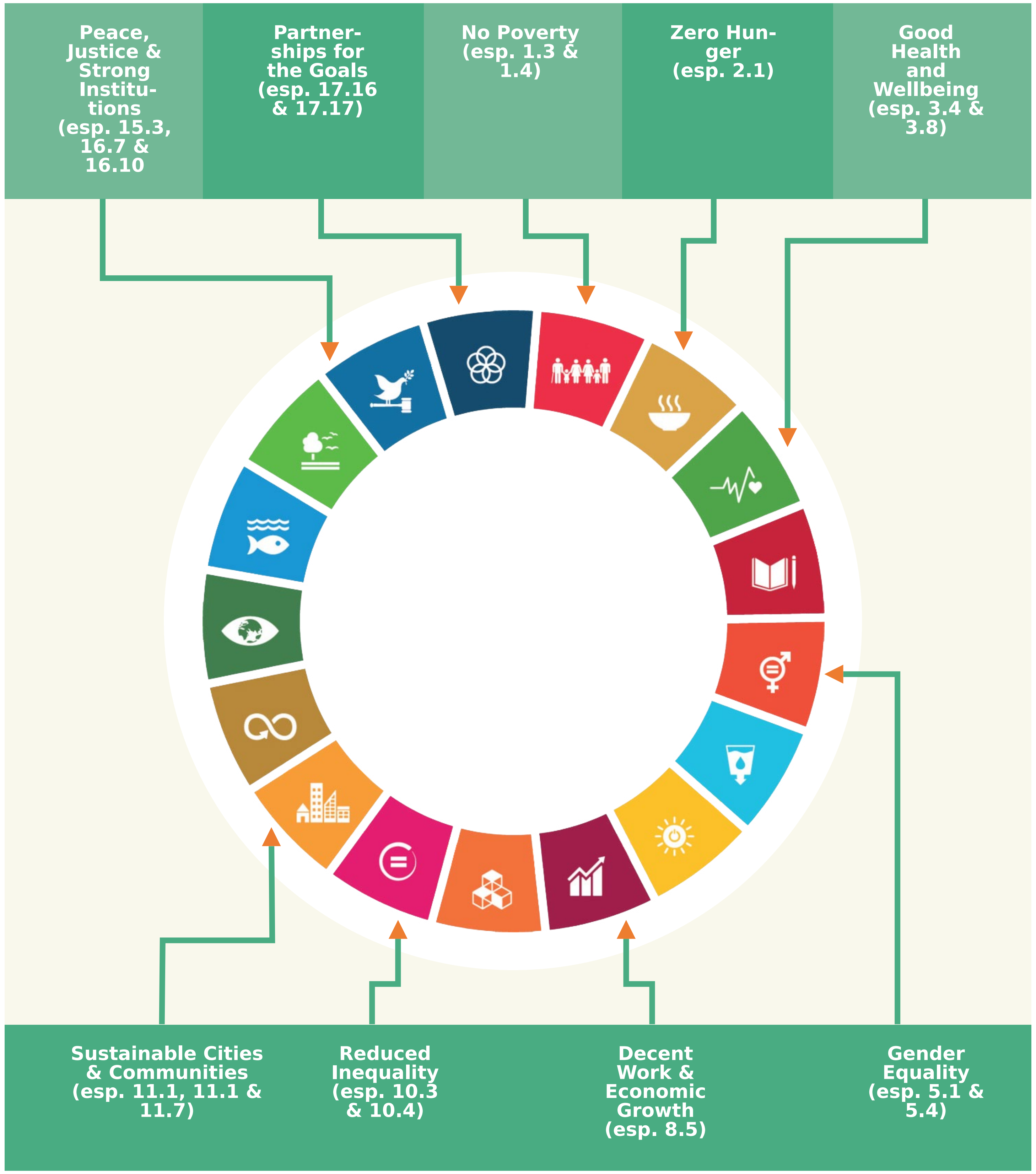
Annex 2. Role of countries under the UN CRPD

The UN CRPD describes what countries should do to ensure that persons with disabilities get equal treatment. These actions include *(31)*:

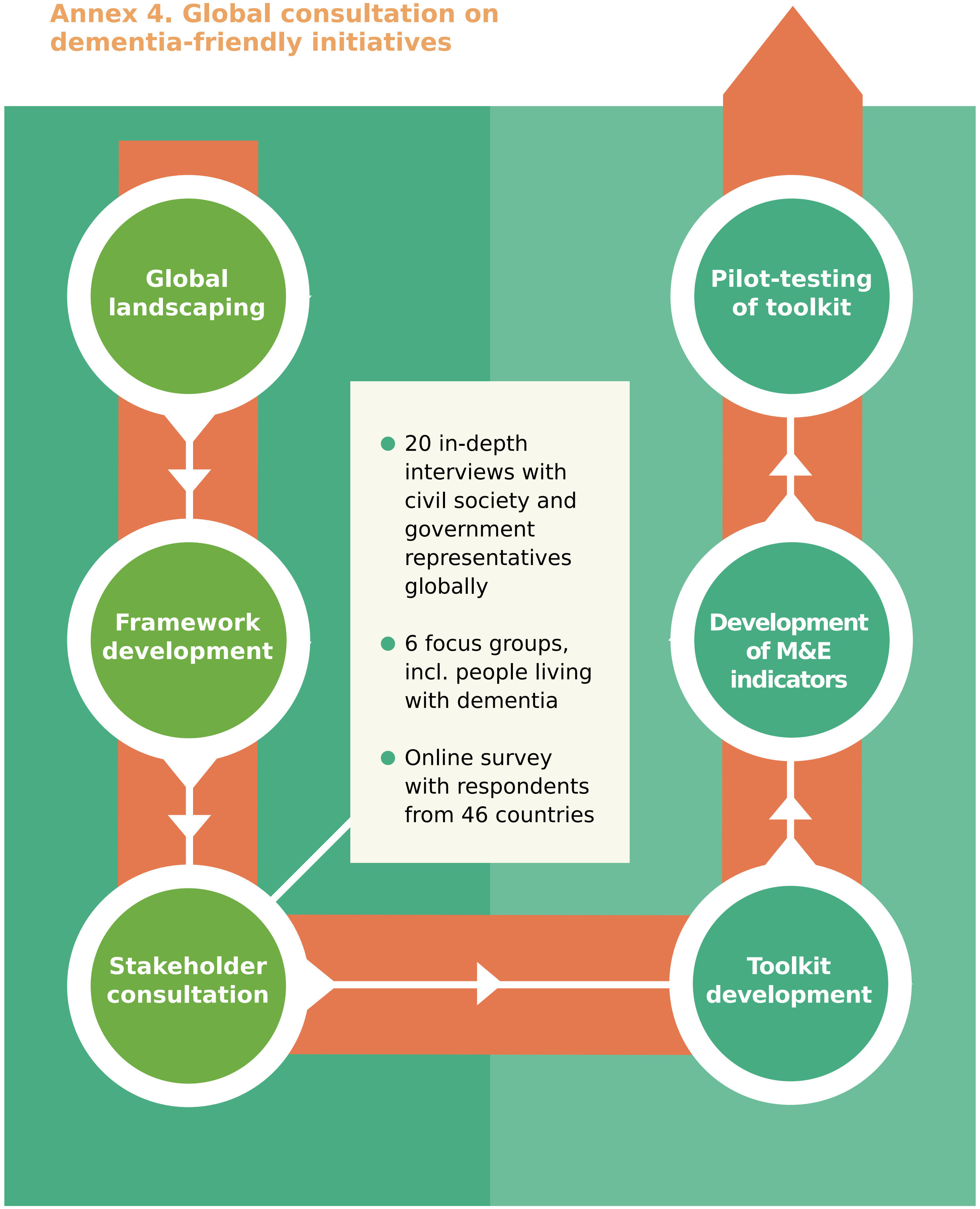
- Making rules and laws to guarantee people with disability their rights, and changing or repealing laws that are not fair;
- Ensuring that all policies include the right to equal treatment;
- Avoiding all actions that violate the UN CRPD;
- Ensuring that government and the authorities implement the UN CRPD;
- Preventing all forms of discrimination against people with disability;
- Ensuring that information is designed for everyone to use, or can be easily changed;
- Using new technology to help people with disability;
- Enabling people with disability to gain access to information on topics that will help them;
- Training and educating people about this agreement;
- Guaranteeing people with disability equal access to housing, social welfare benefits, education, the job market, health care and other vital resources;
- Involving people with disability in making new laws and policies.

Importantly, under the UN CRPD, countries also need to develop mechanisms to guarantee freedom from: torture and cruel, inhumane or degrading treatment or punishment, and; abuse of people with disabilities, including people with dementia (Articles 15, 16, 17) *(6)*.

Annex 3. Sustainable Development Goals (SDGs) with relevance to dementia-friendly initiatives *(3)*



Annex 4. Global consultation on dementia-friendly initiatives

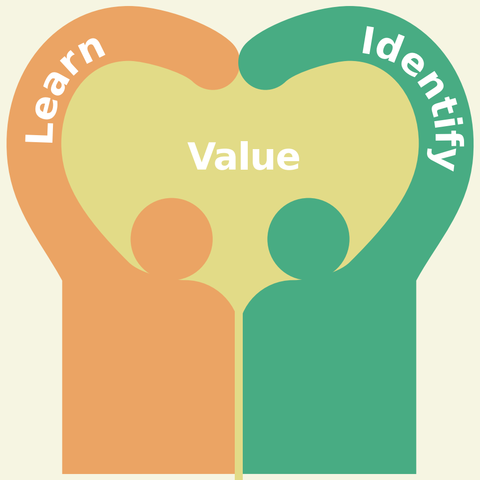


- 20 in-depth interviews with civil society and government representatives globally
- 6 focus groups, incl. people living with dementia
- Online survey with respondents from 46 countries

Annex 5. Promoting dementia-inclusive communities: A strategic communications toolkit (WHO WPRO)

Strategic communication can support the promotion and establishment of dementia-inclusive communities. Communication reinforces bonds within the community and enables action through the exchange of information and the articulation of shared values, goals and aspirations. Communication can also help change behavior, rally support around a cause and promote access to services.

Designed for program managers, health promotion specialists, and community leaders and mobilizers, this toolkit provides guidance and examples of communication interventions that can be implemented at the community level. The L.I.V.E. framework provides a rationale for organizing different activities.



Learn	Identify	Identify
Raising awareness and understanding of the common signs and symptoms of dementia.	Mobilizing leaders, decision makers and partners to support dementia-friendly activities and initiatives.	Promoting appropriate health seeking ehavior for screening and identification of people living with dementia within the community.

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Towards a dementia-inclusive society: WHO toolkit for dementia-friendly initiatives helps countries raise public awareness and understanding of dementia to support people living with dementia to remain in, and be a significant part of, their communities. The toolkit assists people working in communities to plan, implement, evaluate and scale-up dementia-friendly programmes.

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