



# DEMENTIA AND HUMAN RIGHTS

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# OVERVIEW

- ❖ Definition of human rights and human rights violations
- ❖ International human rights commitments and instruments
- ❖ National human rights commitments and instruments
- ❖ Global tools that can be applied at the national level

# HUMAN RIGHTS



“... are rights **inherent to all human beings**, whatever our nationality, place of residence, sex, national or ethnic origin, colour, religion, language, or any other status.

We are **all equally entitled to our human rights** without discrimination.

These rights are all **interrelated, interdependent and indivisible.**”

*United Nations Human Rights Office of the High Commissioner, OHCHR*  
<https://ohchr.org/EN/Issues/Pages/WhatareHumanRights.aspx>

# HUMAN RIGHTS VIOLATIONS

“Violations are not only those that end life or involve extreme abuse [that are recorded]..., but also those that affront human dignity and identity which are unrecorded.”

*“Dementia and Human Rights by Suzanne Cahill”*

Examples include coercive or forced treatment or institutionalization, disregard of an individual’s legal capacity to make decisions, denial of dignity and autonomy.

Violations or lack of attention to human rights can have serious health consequences or exacerbate poor health.



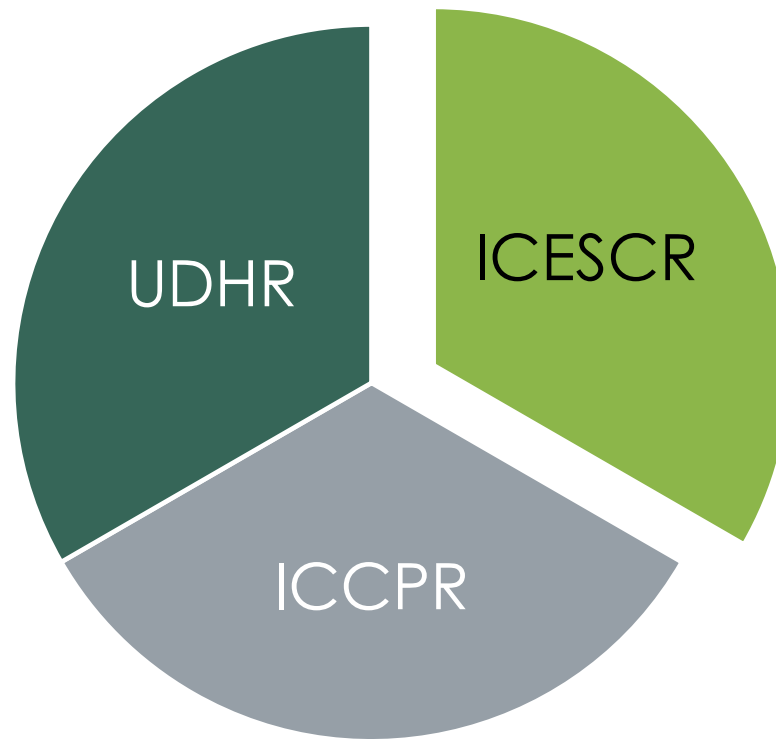
# INTERNATIONAL HUMAN RIGHTS COMMITMENTS AND INSTRUMENTS

# HUMAN RIGHTS & DEMENTIA: RELEVANT INTERNATIONAL COMMITMENTS & DEVELOPMENTS



# INTERNATIONAL BILL OF HUMAN RIGHTS

Universal  
Declaration of  
Human Rights  
(UDHR)



International Covenant  
on Economic, Social and  
Cultural Rights (ICESCR)

International Covenant on Civil and Political Rights  
(ICCPR)

# INTERNATIONAL COVENANT ON ECONOMIC, SOCIAL & CULTURAL RIGHTS (ICESCR)



International Covenant on  
Economic Social and Cultural Rights

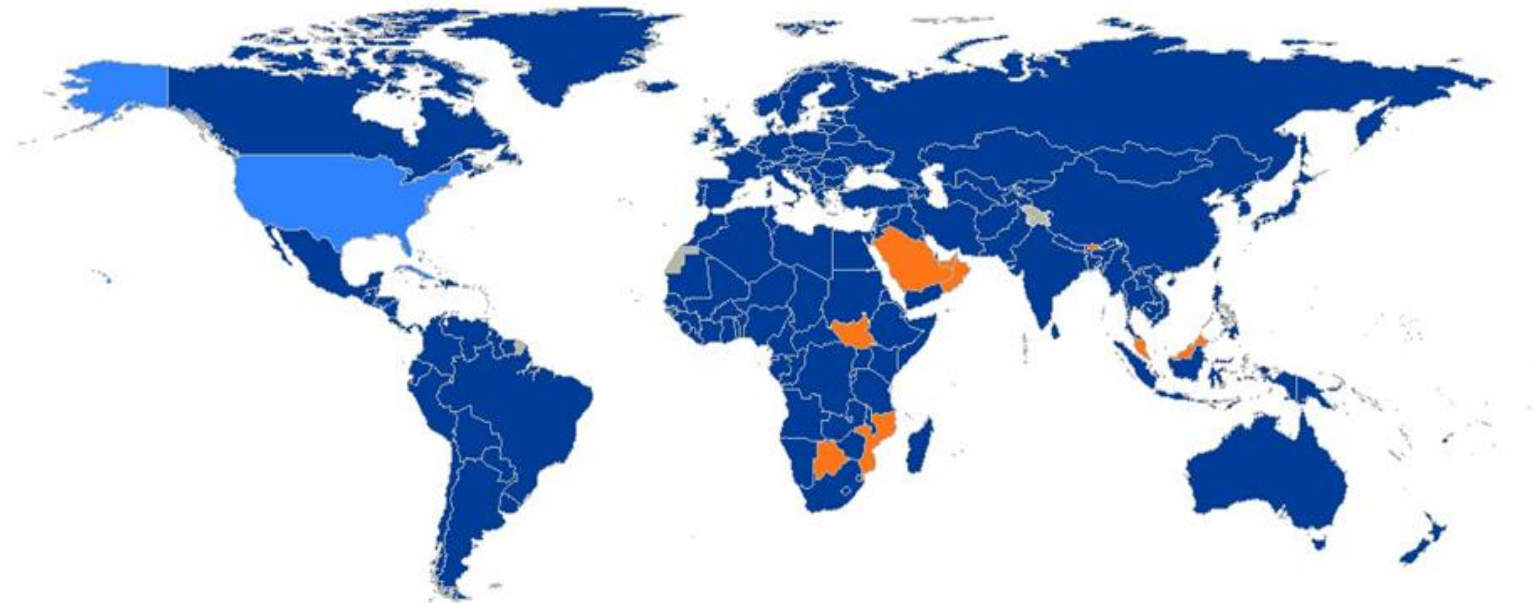
- Multilateral treaty adopted by UN in 1966, came into force in 1976.
- General Comment 14 details the scope and the content of **the Right to Health.**



UNITED NATIONS  
HUMAN RIGHTS  
OFFICE OF THE HIGH COMMISSIONER

International Covenant on Economic, Social and Cultural Rights

Last Updated: 11 Oct 2018



Country Status  
State Party (109) Signatory (4) No Action (24)

English and French version available here:

<https://www.ohchr.org/en/professionalinterest/pages/cescr.aspx>





International Covenant on  
Economic Social and Cultural Rights

## THE RIGHT TO HEALTH...



International Covenant on  
Economic Social and Cultural Rights

- Is **not optional** but a legal obligation (by international human rights standards)
- Is inseparable or '**indivisible**' from **other rights**, incl. the right to food, housing, work, education and non-discrimination; equality; access to information; and participation.
- Includes both **freedoms and entitlements**:
  - Freedoms include the **right to control one's health and body** and to **be free from interference**.
  - Entitlements include the **right to a system of health protection** that gives everyone an equal opportunity to **enjoy the highest attainable level of health**.

# THE RIGHT TO HEALTH REQUIRES HEALTH / SOCIAL CARE SERVICES TO MEET AND MONITOR 4 CRITERIA

## Availability

- A sufficient quantity of functioning public health and health (social) care facilities, goods and services, as well as programmes for all.

## Accessibility

- Health (social care) facilities, goods, and services must be accessible to everyone (non-discrimination; physical accessibility; affordability; information accessibility).

## Acceptability

- Health (social care) facilities, goods, services and programmes are people-centred and cater for the specific needs of diverse population groups and in accordance with international standards of medical ethics for confidentiality and informed consent.

## Quality

- Facilities, goods, and services must be scientifically and medically approved. Quality services should be safe, effective, people-centred, timely, equitable, integrated and efficient

# UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITY (CRPD)



Convention on the Rights of Persons with Disabilities

Last Updated: 11 Oct 2018

- Adopted by the United Nations in 2006, ratified in 2009.
- To promote, protect and ensure the **full and equal enjoyment of human rights** and **fundamental freedoms by all persons with disabilities** and to promote **respect for their inherent dignity**
- **4 broad themes:**
  - Equality
  - Autonomy
  - Participation
  - Solidarity



Country Status  
State Party (177) Signatory (12) No Action (9)

# GENERAL OBLIGATIONS FOR COUNTRIES (ARTICLE 4 CRPD)



- **Protection and promotion** of the human rights of persons with disabilities **in all policies**
- Provision of **accessible information** to people with disabilities about aids, including devices and assistive technology
- **Human rights training of all staff** including professionals working in the field of disability
- **Re-working of inconsistent legislation** and where required, the **adoption of new legislation**
- **Refraining from** any action or **practice inconsistent with the CRPD** and ensuring that public authorities and institutions conform to the Convention.

For French see:

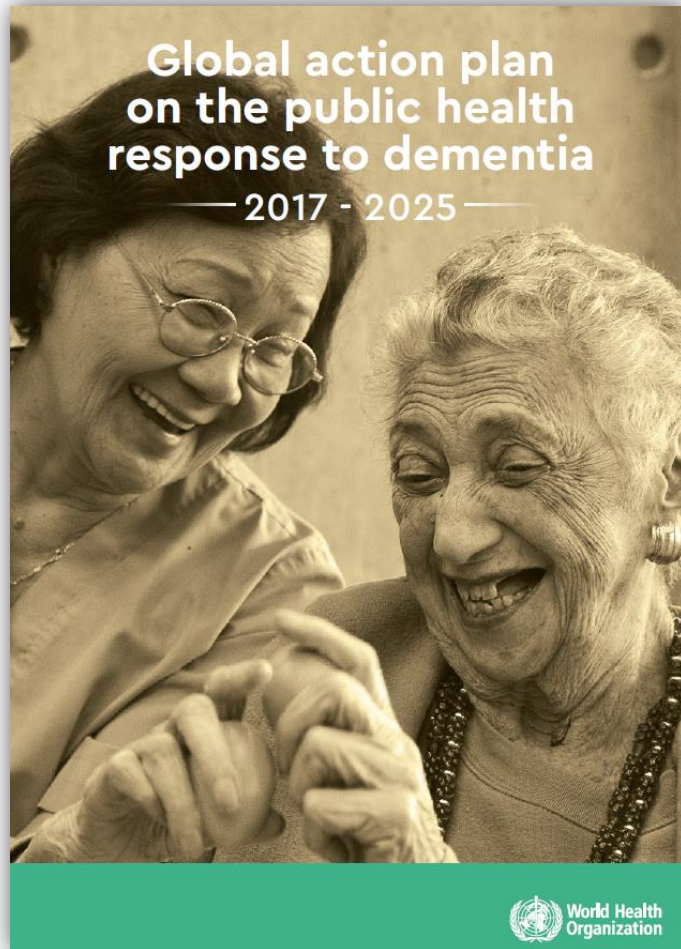
[https://www.ohchr.org/Documents/HRBodies/CRPD/CRPD\\_FR.pdf](https://www.ohchr.org/Documents/HRBodies/CRPD/CRPD_FR.pdf)

# WHO CONSTITUTION

“... The enjoyment of *the highest attainable standard of health is one of the fundamental rights of every human being* without distinction of race, religion, political belief, economic or social condition. ...”



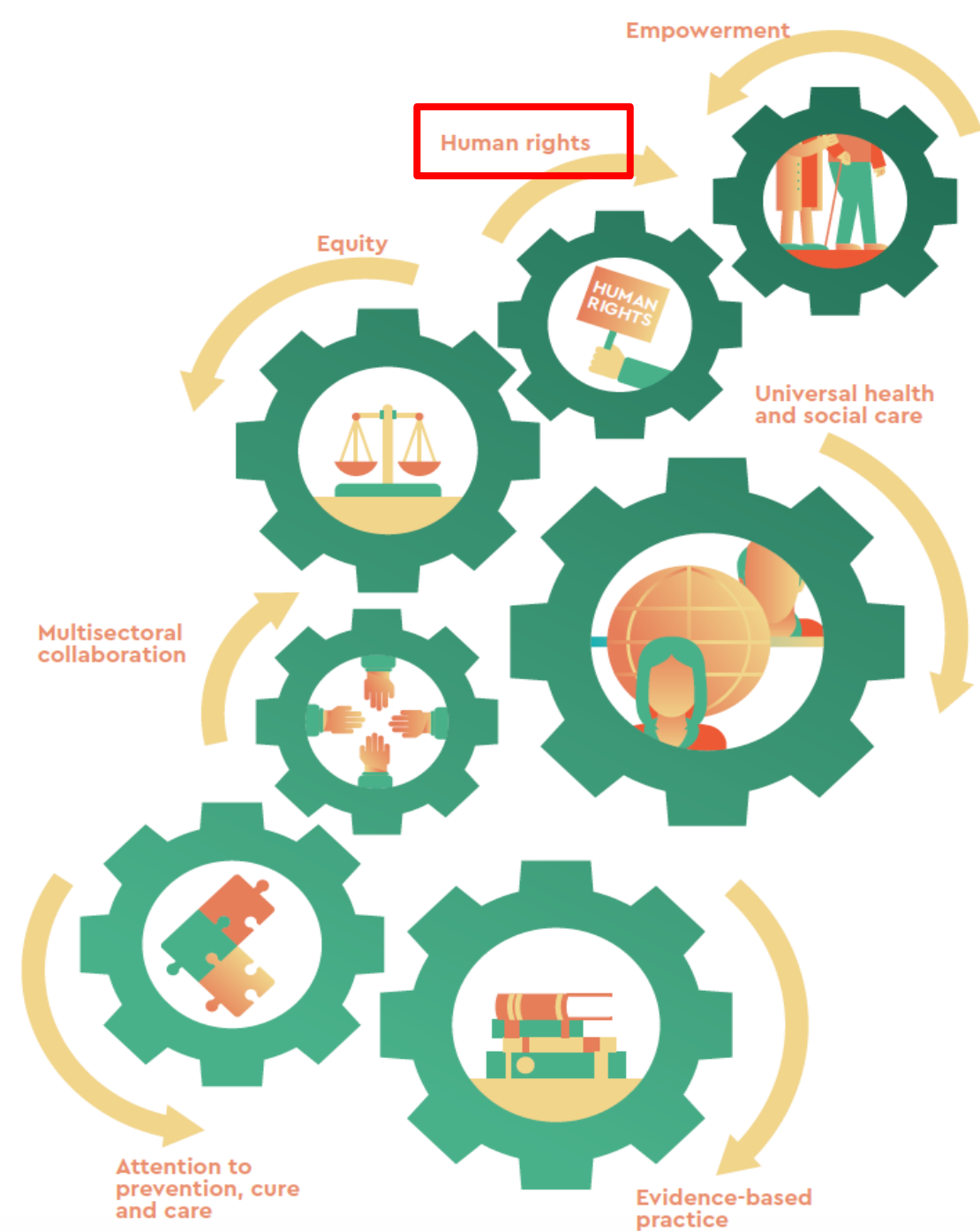
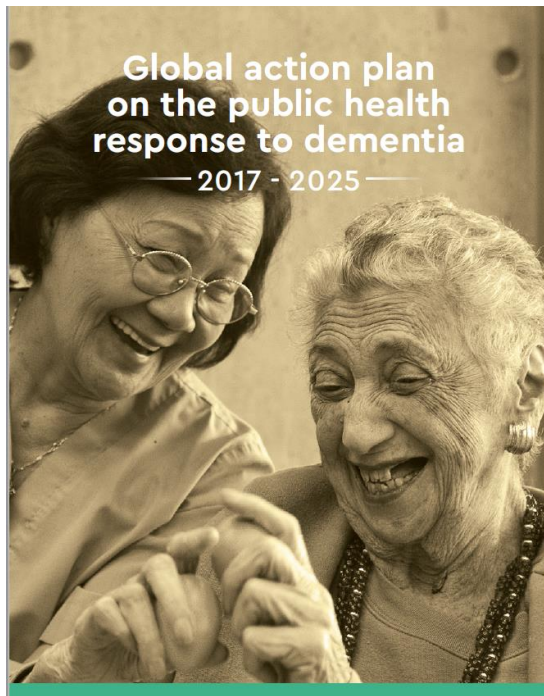
# GLOBAL ACTION PLAN ON THE PUBLIC HEALTH RESPONSE TO DEMENTIA 2017-2025



## Vision

8. The vision of the global action plan on the public health response to dementia 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.

# CROSS-CUTTING PRINCIPLES





# NATIONAL HUMAN RIGHTS COMMITMENTS AND INSTRUMENTS



# CANADIAN CHARTER OF RIGHTS AND FREEDOMS



## EQUALITY RIGHTS

Equality before and under law and equal protection and benefit of law

**15. (1)** Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.


Affirmative action programs

(2) Subsection (1) does not preclude any law, program or activity that has as its object the amelioration of conditions of disadvantaged individuals or groups including those that are disadvantaged because of race, national or ethnic origin, colour, religion, sex, age or mental or physical disability. (84)

# CANADIAN CHARTERS OF RIGHTS

*Alzheimer Society*

## CANADIAN CHARTER OF RIGHTS FOR PEOPLE WITH DEMENTIA



As a person with dementia, I have the same human rights as every Canadian as outlined in the Canadian Charter of Rights and Freedoms. The following charter:

- Makes sure people with dementia know their rights,
- Empowers people with dementia to ensure their rights are protected and respected, and
- Makes sure that people and organizations that support people with dementia know these rights.

As a person with dementia, the following rights are especially important to me. I have the right:

- 1** To be free from discrimination of any kind.
- 2** To benefit from all of Canada's civic and legal rights.
- 3** To participate in developing and implementing policies that affect my life.
- 4** To access support so that I can live as independently as possible and be as engaged as possible in my community. This helps me:
  - Meet my physical, cognitive, social, and spiritual needs,
  - Get involved in community and civic opportunities, and
  - Access opportunities for lifelong learning.
- 5** To get the information and support I need to participate as fully as possible in decisions that affect me, including care decisions from the point of diagnosis to palliative and end-of-life care.
- 6** To expect that professionals involved in my care are:
  - Trained in both dementia and human rights.
  - Held accountable for protecting my human rights including my right to get the support and information I need to make decisions that are right for me.
  - Treating me with respect and dignity.
  - Offering me equal access to appropriate treatment options as I develop health conditions other than my dementia.
- 7** To access effective complaint and appeal procedures when my rights are not protected or respected.

It will take the effort of every Canadian to protect and respect the rights of people with dementia so that we are seen as valuable and vital community members.

Contact your local Alzheimer Society to learn how you can **get involved!**  
1-800-616-8816 | [alzheimer.ca](http://alzheimer.ca)



**1**

To be free from discrimination of any kind.

**2**

To benefit from all of Canada's civic and legal rights.

**3**

To participate in developing and implementing policies that affect my life.

**4**

To access support so that I can live as independently as possible and be as engaged as possible in my community. This helps me:

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**6**

**7**

To access effective complaint and appeal procedures when my rights are not protected or respected.



# A HUMAN RIGHTS-BASED APPROACH



# BIOPSYCHOSOCIAL VS. RIGHTS-BASED APPROACHES TO DEMENTIA

## Biopsychosocial model

Dementia as an acquired disability

Shift from biomedical model of dementia

Address barriers that create the disability

VS.

## Rights-based approach

Targets discriminatory practices & unjust power relations

Prioritize the needs of the most vulnerable

# CORE PRINCIPLES OF A HUMAN RIGHTS-BASED APPROACH TO HEALTH AND SOCIAL CARE

## Participation

- Everyone has the right to participate in decisions that affect their lives; all stakeholders have ownership and control in the assessment, analysis, planning, implementation, monitoring and evaluation of policies and practices

## Accountability

- States and other duty-bearers are answerable for the observance of human rights

## Non-discrimination and equality

- This guarantees that human rights are exercised without discrimination of any kind

## Empowerment

- Individuals and communities should understand their rights and be supported to participate in the development of policies and practices that affect their lives.

## Legality

- All measures related to dementia should be linked to national and international human rights standards (e.g. UDHR, ICESCR, UN CRPD)



# GLOBAL TOOLS THAT CAN BE APPLIED AT THE NATIONAL LEVEL

# MHGAP DEMENTIA MODULE AND OTHER TOOLS

- Evidence-based guidelines for diagnosis, treatment and management of dementia in non-specialist settings

**mhGAP Intervention Guide**  
for mental, neurological and substance use disorders  
in non-specialized health settings  
Version 2.0

**Overview of Priority MNS Conditions**

**DEPRESSION (DEP)**

**PSYCHOSES (PSY)**

**EPILEPSY (EPI)**

**CHILD & ADOLESCENT MENTAL & BEHAVIOUR DISORDERS (CMH)**

**DEMENTIA (DEM)**

**DISORDERS DUE TO SUBSTANCE USE (SUB)**

**SELF-HARM/SUICIDE (SUI)**

**mhGAP operations manual**

**mhGAP training manuals**  
for the mhGAP intervention guide for mental, neurological and substance use disorders in non-specialized health settings – version 2.0  
(for field testing)

World Health Organization

[http://www.who.int/mental\\_health/mhgap/mhGAP\\_intervention\\_guide\\_version\\_2.0/](http://www.who.int/mental_health/mhgap/mhGAP_intervention_guide_version_2.0/)

# MHGAP DEMENTIA MODULE AND OTHER TOOLS (CONT'D.)

## II. Promote Respect and Dignity

Persons with MNS conditions should be treated with respect and dignity in a culturally appropriate manner. As a health care provider, make every effort to respect and promote the will and preference of people with MNS conditions and support and engage them and their carers in the most inclusive way.

Persons with MNS conditions are often more vulnerable to human rights violations. Therefore, it is essential that in the health care setting, providers promote the rights of people with MNS conditions in line with international human rights standards, including the UN Convention on the Rights of Persons with Disability (CRPD)\*.

\*For more information on CRPD: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

### DOs

- » Treat people with MNS conditions with respect and dignity.
- » Protect the confidentiality of people with MNS conditions.
- » Ensure privacy in the clinical setting.
- » Always provide access to information and explain the proposed treatment risks and benefits in writing, if possible.
- » Make sure the person provides consent to treatment.
- » Promote autonomy and independent living in the community.
- » Provide persons with MNS conditions with access to supported decision making options.

### DON'Ts

- » Do not discriminate against people with MNS conditions.
- » Do not ignore the priorities or wishes of people with MNS conditions.
- » Do not make decisions for, on behalf of, or instead of the person with MNS conditions.
- » Do not use overly technical language in explaining proposed treatment.



# MHGAP DEMENTIA MODULE AND OTHER TOOLS (CONT'D.)

## Activity 5: Promoting Respect and Dignity

Promoting human rights, respect and dignity.

How are people with MNS conditions treated in your community?

How are people with epilepsy treated in comparison with people with psychoses or depression?

How are people with substance use disorders treated as compared with people with developmental disorders?

Use these questions to stimulate a discussion and ensure participants think about all the ways people with different MNS conditions are treated.

**Note:** In some societies, it may be necessary to mention that people hearing voices are revered and respected. So, their treatment may not always be negative.

# MHGAP DEMENTIA MODULE AND OTHER TOOLS (CONT'D.)

As health providers we can

- Change our own perception and attitude towards people with MNS disorders.
- **Respect and advocate for the implementation of relevant international conventions, such as the United Nations **Convention on the Rights of Persons with Disabilities**.**
- Reaffirm that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms.
- Play a large part in fulfilling these rights.

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Explain the points on the slide. Ask participants if they think they could implement these changes.




Inform participants that the full convention is available if they wish to see it.

Consider reading aloud the following three examples of articles from the convention:

1. The right to good quality, affordable and accessible mental health services in the community (Art. 25).

2. The right to rehabilitation services in the community (Art. 26).

3. The right to live in the community and participate in community life (Art. 19).

Principle	Description
<p data-bbox="25 107 343 214">Universal health coverage</p> 	<ul data-bbox="522 107 2509 514" style="list-style-type: none"> <li>• In universal health coverage, all people and communities can use the promotive, preventive, curative, rehabilitative and palliative health services they need, and those services are of good quality and do not put people at risk of financial harm.</li> <li>• Any action should benefit the whole of society, regardless of age, sex, socioeconomic status, nationality, race, ethnicity, religion or sexual orientation. People with MNS conditions should be able to access essential health and social services that enable them to achieve the highest attainable standard of health.</li> </ul>
<p data-bbox="25 578 293 621">Human rights</p> 	<ul data-bbox="522 578 2509 1056" style="list-style-type: none"> <li>• People with MNS conditions are particularly vulnerable to violation of their human rights (10).</li> <li>• Providers must promote the rights and uphold the dignity of people with MNS conditions, in line with international human rights standards, including the United Nations Convention on the Rights of Persons with Disabilities (11) and national legislation for people with disabilities (see also Essential care and practice below).</li> <li>• WHO's QualityRights (10) provides practical guidance for improving the quality of care provided by mental health services and for promoting the rights of people with MNS conditions. It offers an approach to care that is rights- based and recovery-oriented.</li> </ul>
<p data-bbox="25 1106 331 1213">Evidence-based practice</p> 	<ul data-bbox="522 1106 2458 1406" style="list-style-type: none"> <li>• Interventions for the prevention, treatment and care of MNS conditions should be based on scientific evidence and/or best practice, taking the context into account.</li> <li>• mhGAP guidelines are the basis of the mhGAP-IG version 2.0 and the mhGAP operations manual, emphasizing the importance of scientific evidence and best practice in planning, preparing and providing integrated mental health services (5).</li> </ul>

# TOWARDS A DEMENTIA PLAN: A WHO GUIDE

- A step-by-step guide to creating a national dementia plan



## Global action area

## Proposed activities

## Implementation considerations

### Dementia as a public health priority

- Develop and implement a dementia plan
- Implement legislation to protect the human rights of people with dementia, their carers and families
- Create mechanisms to monitor the protection of people with dementia regarding their human rights, wishes and preferences
- Identify a focal point, unit or functional division responsible for dementia
- Allocate sustainable financial resources to the dementia plan
- Establish mechanisms for tracking expenditures on dementia across sectors

- Equity, dignity and human rights of people with dementia
- Consult people with dementia and other stakeholders
- Align legislation with the CRPD and other human rights instruments
- Allocate funding based on identified service needs and resource requirements

## Global action area

## Proposed activities

## Implementation considerations

### Dementia diagnosis, treatment, care and support

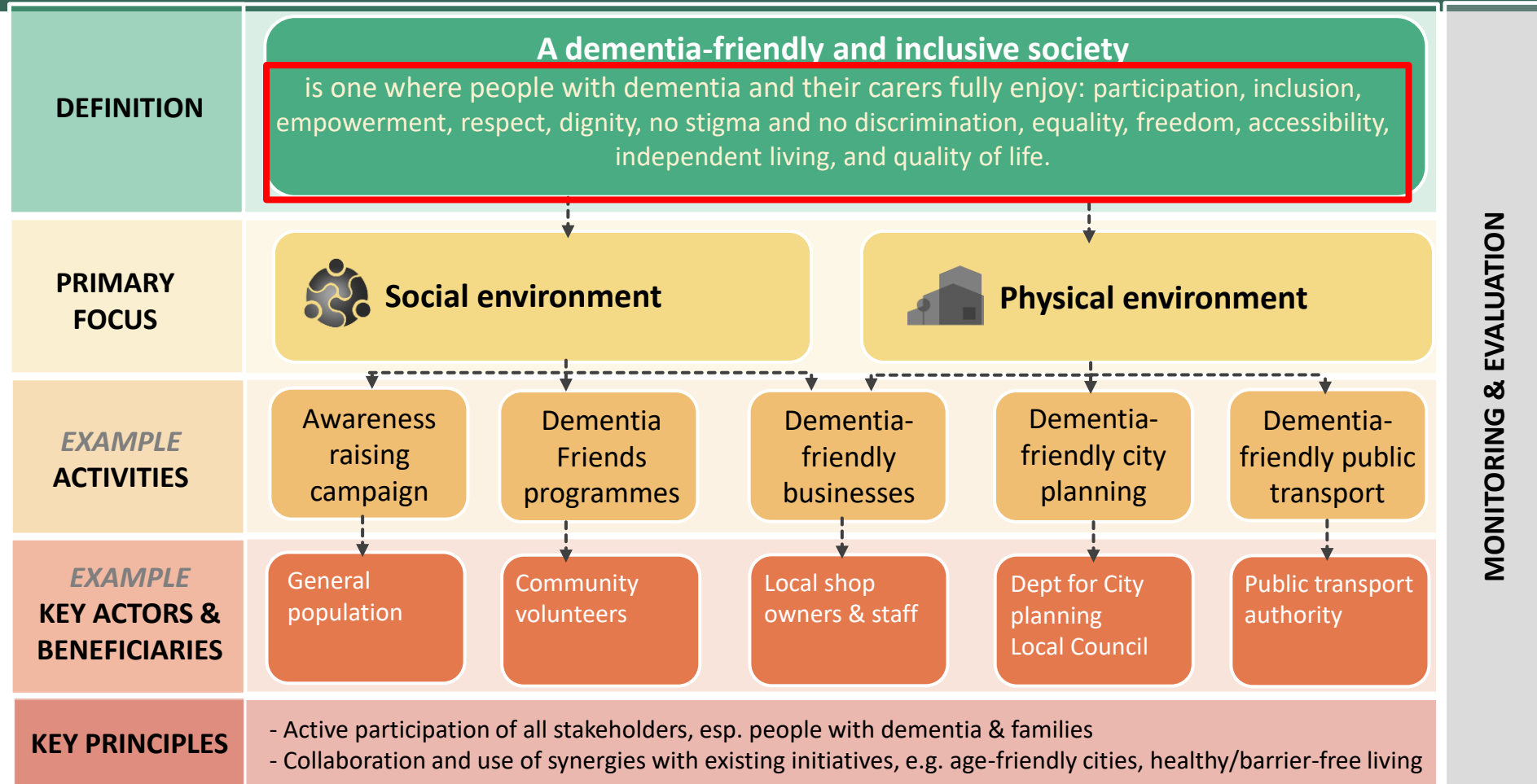
- Develop a coordinated care pathway for people with dementia
- Build health and social care providers' knowledge and skills
- Improve quality of care towards the end of life
- Shift care from hospitals to multidisciplinary, community-based settings
- Enhance access to person-centred, gender-sensitive, culturally appropriate care

- Embed the care pathway within an integrated health and social care system
- Use the care pathway to provide efficient, quality care and integrate multiple services
- Build capacity to deliver evidence-based, culturally appropriate and human rights-oriented care
- Earmark budgets and resources for training
- Improve end of life care by:
  - Recognizing dementia as a condition requiring palliative care
  - Promoting awareness about advance care planning
  - Respecting the values and preferences of people with dementia
  - Training health care providers

# TOWARDS A DEMENTIA-INCLUSIVE SOCIETY: A WHO TOOLKIT

Currently under development

Framework of the toolkit



In collaboration with AlzSoc UK, ADI, DAI, DH UK, MHLW Japan  
 Supported by Department of Health UK

# WHO'S GLOBAL DEMENTIA OBSERVATORY

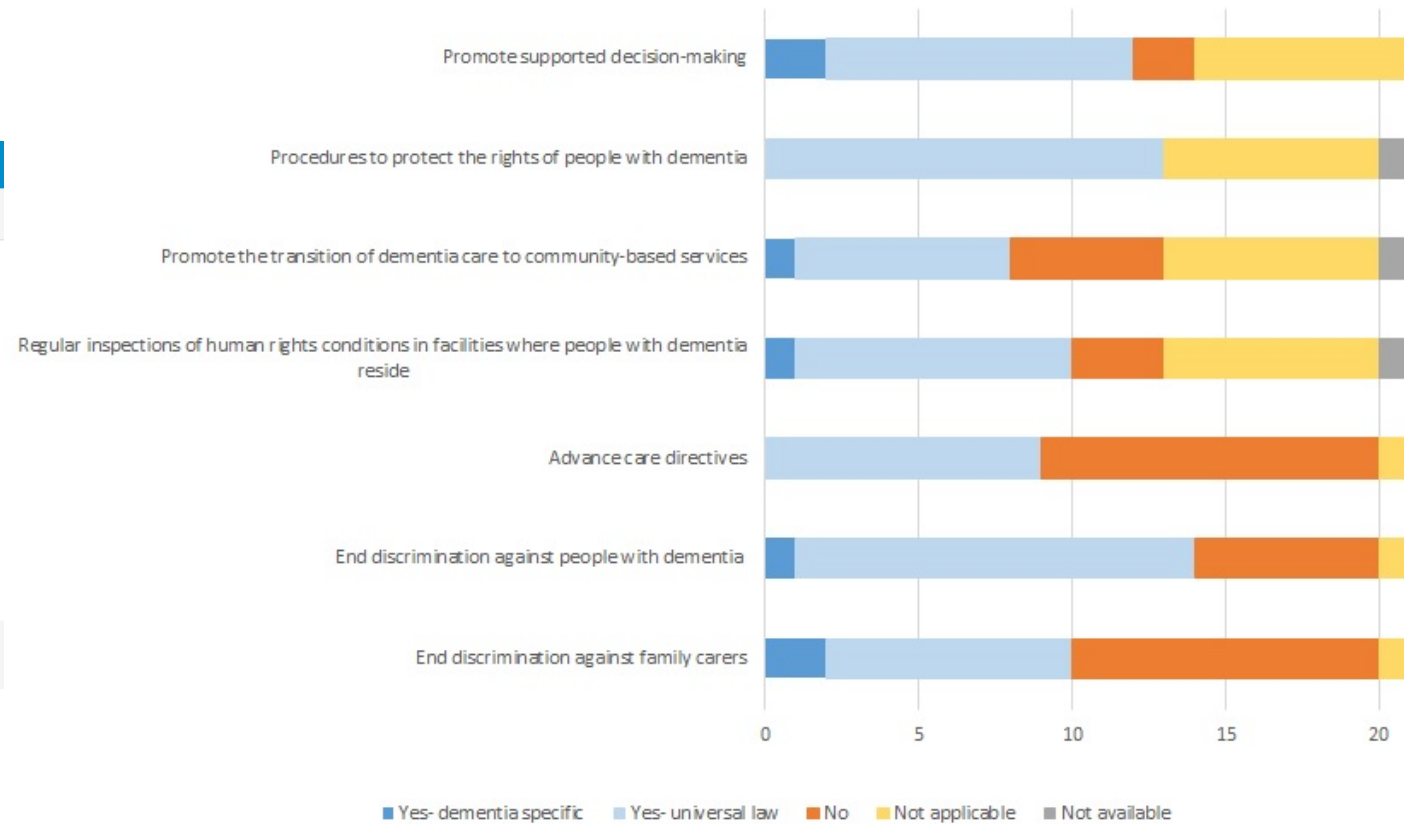
<http://apps.who.int/gho/data/node.dementia>

## Provisions to protect rights and care of people with dementia

Graph

Data

Provisions to protect the rights of people with dementia



### Global Dementia Observatory (GDO)

#### Dementia – A public health priority

What are the symptoms?

- Difficulties with everyday tasks
- Confusion in familiar environments
- Difficulty with words and numbers
- Memory loss
- Changes in mood and behavior

#### The global public health threat

Nearly 30 million new cases every year  
One every 3 seconds

50 million people worldwide  
Set to triple by 2050

Majority of people who will develop dementia will live in low- and middle-income countries

#### Societal cost of dementia

2015: US\$18 billion; estimated costs to society in 2015

2030: US\$2 trillion

100% Direct medical care, 82% Direct social care, 18% Informal care

Read more on the Global Dementia Observatory >

### Browse the full list of indicators

Select an indicator or type some keywords...

Select an indicator or type some keywords...

**PUBLIC HEALTH PRIORITY**

- Dementia plan
- Dementia governance
- Provisions to protect rights and care of people with dementia**
- Dementia standards/ guidelines/ protocols
- Dementia care coordination

**AWARENESS**

- Education of non-health professionals
- Diabetes



# WHO QUALITY RIGHTS GUIDANCE AND TRAINING TOOLS

- Comprehensive package of training and guidance modules.
- Build capacity on how to implement a human rights and recovery approach in the area of mental health in line with the UN CRPD and other international human rights standards.



*For more information, see:*

[http://www.who.int/mental\\_health/policy/quality\\_rights/guidance\\_training\\_tools/en/](http://www.who.int/mental_health/policy/quality_rights/guidance_training_tools/en/)

- Under development: a guidance document and checklist aiming to **assist policy-makers** in aligning their policy and law with the UN CRPD

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