PAHO Action Plan on Dementia: The development of an Action Plan on Dementia at the regional and local level in Latin America.

Luis Miguel Gutiérrez Robledo MD PhD
Director General
Instituto Nacional de Geriatría, Mexico.
Aim

• Provide a general overview of the PAHO Regional Action Plan on Dementia
• Show an specific example: the development of the Mexican National Plan
6.5% to 8.5% of adults over 60 in the Americas have dementia. The number of cases is expected to nearly double in the region over the next 20 years, (7.8 million in 2010 to 14.8 million in 2030).
6,157 USD per capita total cost in Mexico

And a 369% increase is projected 2010-2050
World Context

• **September 2011 United Nations General assembly** “mental and neurological disorders, including Alzheimer’s Disease are an important cause of morbidity and contribute to the global non communicable disease burden, for which there is a need to provide equitable access to effective programs and Health care interventions”.

• **Report : Dementia a Public Health Priority, 2012**

• **PAHO working group begins, July 2013**

• **Costa Rica and Mexico present Action Plans: September 2014**

• **PAHO Regional Action Plan issued September 2015**
Health leaders at PAHO 54th council in September 2015, pledged to take new action to mitigate the impact of a dramatic increase over the next 20 years in dementias in older people in the region.
Kick off Meeting July 2013.

To produce this document, several virtual and face-to-face consultations were held with representatives of health ministries and other ministries in the Region involved in this issue.

• Individual face-to-face consultations were also held with the representatives of the Region who had participated in the First WHO Ministerial Conference on Global Action against Dementia in Geneva.

• Feedback and comments were also received through virtual consultations with groups of experts from diverse academic and research institutes, civil society, collaborating centers, and other international partners.
Main goal:

• To promote universal access to health and universal health coverage with quality interventions for people with or at risk of dementias, in order to help them recover or maintain their functional capacities, prevent or avoid dependence, and improve their quality of life and the well-being of their families and caregivers.
The plan proposes that countries work over the next five years to:

• **Strengthen health services and community-based networks** throughout the region to allow older persons to stay in the right place.

• **Promote the development of long-term health care facilities** for older persons whose dementia is too far advanced for quality care at home.

• **Strengthen the capacity of health systems to promote healthy lifestyles** to prevent health conditions that research has shown can lead to dementias, such as hypertension, diabetes, smoking and obesity.

• **Train health-care professionals** in the care of people with dementias, from the undergraduate level through medical school and continuing education.

• **Ramp up basic, clinical, epidemiological and social research** into the causes of dementias to learn how to better prevent, manage and care for these conditions.

• **Establish legal protections** to protect the human rights of people with dementias, and take action to reduce stigma and stereotypes.
Global LTC coverage deficit due to financial resource gaps, in per cent of the population 65 years and over excluded (Threshold: 1,461.8 PPP$)

- Very high deficit: More than 75% of the population aged 65+
- High deficit: 50 to 75% of the population aged 65+
- Significant deficit: Less than 50% of the population aged 65+
- Above the minimum level: No relative deficit
- No data

Strategic Lines of Action

1. Promote plans, policies, and programs that promote and respect human rights to address risk reduction, prevention, reduction of dependence, and provision of care (including long-term care) associated with dementias.

2. Establish, in health systems and health services networks, interventions for prevention and quality care for persons with or at risk of dementias.

3. Implement a quality long-term care system that addresses the needs of dependent persons, their families, and caregivers, based on a primary health care approach, respect for human rights, gender equality, and equity, within the strategic framework of universal access to health and universal health coverage.

4. Develop or strengthen the necessary human resources training to address health needs of persons with or at risk of dementias.

5. Improve research and surveillance capacity to generate and collect quality information to address the social and health needs of persons with dementias.
Other global and regional program documents and resolutions of relevance to this document.

• Plan of Action on the Health of Older Persons including Active and Healthy Aging [CD49/8];
• Strategy and Plan of Action on Mental Health [CD49/11];
• Plan of Action for the Prevention and Control of Noncommunicable Diseases [CD52/7, Rev. 1];
• Plan of Action on Disabilities and Rehabilitation [CD53/7];
• Plan of Action on Mental Health [CD53/8, Rev. 1].
MEXICO’S ACTION PLAN ON ALZHEIMER’S DISEASE AND OTHER DEMENTIAS
The way towards an Action Plan

1986
FIRST SUPPORT GROUP CREATED IN MEXICO CITY

1988
LEGAL CONSTITUTION OF ASOCIACION MEXICANA DE ALZHEIMER Y ENFERMEDADES SIMILARES A.C. (AMAES)

1988
AMAES JOINS ALZHEIMER’S DISEASE INTERNATIONAL (ADI),

2002
FIRST NATIONAL ASOCIATIONS MEETING FEDERACION MEXICANA DE ALZHEIMER (FEDMA) IS CREATED

2003
MEXICO FOUND MEMBER OF ALZHEIMER IBEROAMERICA

2006
ANUAL MEETING OF THE EXPERT GROUP ON DEMENTIA BEGINS

2011
SEPTEMBER THE MINISTER OF HEALTH ASKS FOR THE DEVELOPMENT OF AN ACTION PLAN BY THE INSTITUTO NACIONAL DE GERIATRIA TOGETHER WITH NGO’S

2012
WHO DECLARES DEMENTIA A PUBLIC HEALTH PRIORITY
National Institute of Geriatrics

• Advisory role on aging and health at the Ministry
• Founded 2008
• Teaching and research divisions, 100 professionals, 20 fulltime researchers.
• Largest research and teaching institute in Latin America specialized on ageing and health.
• Responsible for gathering epidemiologic data on aging and health from different sources: Mexican Health and Aging Longitudinal Survey (N=20,000 15 year follow up) Health and Nutrition Examination Survey (N=50,000 households every 6 years, and the SABE surveys, at the local state level (20 out of 32).

http://www.geriatria.salud.gob.mx
The Mexican Alzheimer Federation (FEDMA founded 2002).

Its main aim is to promote an organized work of the civil society (through their regional associates) for the benefit of the people that suffer any kind of dementia, as well as to give guidance, training and support to their families and caregivers in the whole country.

Nowadays it has registered 21 statewide associations (regional) and 46 formally integrated support groups.
Mexican milestones

- **2011**: Minister of Health asks for the development of an Action Plan
- **2012**: Intention Letter signed to promote the collaboration between the National Institute of Geriatrics and the Mexican Alzheimer’s Federation to proceed with the creation of the Action Plan proposal.
- **2013**: An agreement is signed to collaborate in the development of a specific Alzheimer’s action plan by the representatives of the national health institutes (geriatrics, neurology and psychiatry, as well as the Mexican Alzheimer’s Federation). Declared their intention to fight together and against the negative and devastating consequences of Alzheimer’s disease in Mexico.
- **2014**: The official Alzheimer Action Plan is presented to the Mexican health authorities.
- **2015**: with Mexico’s participation, PAHO adopts a regional action plan.
- **2015**: General Health Law is modified to promote dementia care development.
En México, a partir de los datos de la encuesta ENSANUT 2012 y del grupo de investigación en demencia 10/66, sabemos que actualmente hay aproximadamente 800,000 casos de personas que padecen algún tipo de demencia en nuestro país. La incidencia anual estimada es de 27 casos nuevos por cada mil personas de 65 años o más. De acuerdo a estas cifras, podemos afirmar que para el año 2050 esta cifra se incrementará a tres y medio millones de afectados.

A partir de estas evidencias, podemos afirmar que México necesita urgentemente un abordaje integral y eficiente, basado en el desarrollo de un Plan de Acción Específico, para dar respuesta a las necesidades generadas por esta enfermedad.

México requiere más información dura y de alcance nacional para profundizar en el conocimiento del impacto humano, social y económico que la enfermedad representa para México, la carga que como enfermedad genera esta afeción.
Main Goal

To promote the wellbeing of people with dementia and their caregivers by means of a synergy among health care institutions, academy and NGO’s aiming to strengthen the response of the Mexican Health System to the needs of patients and their families.

7 specific goals: de-stigmatization, public awareness, integrated care development, research, education and prevention aiming to improve well-being of people with the disease and their families.
Strategic Actions

- Prevention and promotion of mental health.
- Allow access to quality services.
- Timely diagnosis and treatment of the people affected with the disease.
- Specific and enough human resources training.
- To promote the human rights of the affected people and their caregivers.
- Develop Long term and palliative care.
- To develop research on dementia.
- To asses the effectiveness of the proposed actions.
In Latin America, only Mexico and Costa Rica have developed action plans

• México has developed several ongoing specific actions as suggested by PAHO:
  • Epidemiologic characterization of dementia (since 2012)
  • Training of professionals (2013 and ongoing)
  • Modification of the General Health Law aiming to service development (September 2015)
Academy and NGO's  
Lobbying and Advocacy training program

First contact with Senator Diaz
How to move forward?

• Using sound research data and evidence
• Training and exchanging information
• Keeping messages clear and straightforward
• Developing realistic requests
• Building coalitions
• Creating a network (triple helix)
  • NGO’s
  • Academia
  • Government
Research and capacity building to face the challenge of dementia
Gathering Knowledge about Epidemiology


Sosa Ortiz AL 10/66 group. Contribution in 36 papers of the group, 5 specifically on Mexico’s situation.
Development of primary care training programs

- **On line Diploma** (160 hours, 6 month) Interdisciplinary care of Alzheimer disease and related disorders (250 trainees in 20 states, 3 generations)

- **On line training program** (1 month) person centered model of care 100 trainees in the first generation

- **MOOC** Alzheimer: what we must know 4,927 registered (released january 2016)
Production of audiovisual materials and a photo-novel addressed to primary caregivers
Development of highly specialized training programs

- **High specialty training in Dementia** (one year National Institute of Neurology Dr Ana Luisa Sosa)
- **High specialty training in Geriatric Neurology** (1 year National Institute of Medical Sciences Dr. Alberto Mimenza)
- **Specialty training in geropsychiatry** (2 years National Institute of Psychiatry, Dr. Oscar Ugalde)
800,000 people affected, underdiagnosis, lack of access to primary care and specialized services. Caregivers lack knowledge and support and suffer an excessive burden.

**Action Plan**
- Awareness: Information, capacity building, research and model of care development
- Fight against stigma: With patients and families, promote Access to Health services and develop an evidence knowledge base
- Aim for patient and caregivers wellbeing: Co-responsibility leads to lower health cost impact
- Privilege: Prevention, health promotion and education aiming to reduce prevalence of predisposing conditions

The Action Plan is feasible with the resources we have.
High impact messages

Presenta México plan de acción para detectar y tratar el Alzheimer

Por Redacción | 19 noviembre, 2012 | En Noticias

El gobierno federal presentó el Plan de Acción Alzheimer, que tiene como objetivo establecer un modelo integral de atención médica para los pacientes que sufran esta demencia y grupos de apoyo para sus familiares.
Key role of NGO’s in advocacy

- FEDMA (National level)
- Alzheimer Mexico (CDMX)

15,000 people in Mexico City’s central plaza
INICIATIVA DE LAS SENADORAS CRISTINA DÍAZ SALAZAR, DIVA GASTÉLUM BAJO, HILDA FLORES ESCALERA, LILIA MERODIO REZA, LETICIA HERRERA ALE, ITZEL RÍOS DE LA MORA Y MARÍA ELENA BARRERA TAPIA, CON PROYECTO DE DECRETO POR EL QUE SE ADICIONA LA FRACCIÓN IV BIS AL ARTÍCULO 73 DE LA LEY GENERAL DE SALUD

PROYECTO DE DECRETO

ÚNICO.- Se adiciona la fracción IV al artículo 73 de la Ley General de Salud, para quedar como sigue:

Artículo 73.
I al III...

IV. Fortalecer la capacidad de respuesta del sistema de salud dirigidos a lograr la atención de calidad para las demencias.
Next steps

• **Economic impact measurement** 10/66 InDep initiative, GBD estimation at municipal level (2017) specific project at the Economic Analysis unit Ministry of Health (funding pending $$)

• **Development of indicators (OECD)** work in progress between NIH’s and Ministry of Health Quality of Care office.
Next steps

Development of a model of care (“tropicalization” financed by a grant from the British Academy: Sara Torres INGER / Azucena Guzman U. Edinburgh)
Next steps

• **Cost/benefit assessment and proposal development for the Seguro Popular** Involving as well the social security

• **Longitudinal surveillance** Introducing in depth cognitive assessment in the MHAS (N=20,000 longitudinal survey since 2001, 15 years)
Research network on aging:

• Biology of neuro-degeneration
  • Neurobiology of Alzheimer (NIH’s, INGER, INNYN, CINVESTAV, UNAM)
  • Dementia and the metabolic syndrome (NIH’s)

• Epidemiology (NIH’s MHAS, ENSANUT, 10/66)

• Model of Care and assessment (NIH’s Social Security research unit)
  • Burden of caregivers
  • Abuse and neglect
  • Psychosocial interventions in dementia care

• Neuropsychology (NIH’s)
Working Group

• Instituto Nacional de Geriatría
  – Dra. Isabel Arrieta
  – Mtra. Gabriela Ríos
  – Mtro. Oscar Rosas
  – Mtra. Sara Torres

• Instituto Nacional de Neurología y Neurocirugía
  – Dr. Isaac Acosta
  – Dra. Ana Luisa Sosa

• Instituto Nacional de Psiquiatría
  • Dr. Oscar Ugalde

• Instituto Nacional de Salud Pública
  – Dra. Betty Manrique
  – Dr. Aaron Salinas
  – Dra. Mara Téllez Rojo

• Instituto Nacional de las Personas Adultas Mayores
  • Dr. Sergio Valdez Rojas

• Federación Mexicana Alzheimer
  • AMAES Rosa Farres
  • Alzheimer México IAP Regina Altena

• PAHO
  • Dr Enrique Vega

Thank you to my partners for making it worth the ride, it has been a long way! ....... And it is not over yet, we have a long way to go
And thank you.....