TOWARDS FULL REALIZATION
AND PROTECTION OF
ALL HUMAN RIGHTS OF
PERSONS WITH DEMENTIA

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ADI 2016 Conference Budapest
1.1. Based upon my expertise

Profession: Sociologist

Work experience: Senior Policy Advisor

Social Advocate: HUMAN RIGHTS DEFENDER

- Workers Rights (40 years)
- Older Persons Rights (10 years)
- Rights Persons with Dementia (7 years)
1.2. MY FUNCTIONS AS CSO REPRESENTATIVE

Meetings of Civil Society Regional & International

- **Secretary SMAF**
  St. Maarten Alzheimer’s Foundation
- **Vice-President SMSPA**
  St. Maarten Seniors & Pensioners Association

Meetings of International Organizations region and world

- **ADI Regional Representative**
  Alzheimer Disease International
- **CORV Ambassador**
  Civil Society Organizations on Aging & Old Age of Latin America & The Caribbean

National

Regional /International
1.3. HUMAN RIGHTS DUE DILIGENCE
OLDER PERSONS WITH DEMENTIA

2014 UN Social Forum On
Rights Older Persons

- Right to Autonomy
  - Older Persons &
  - Older Pers. w/Dementia

2015 - 6th UN Open Ended
Working Group on Aging

- Right to Health
  - diagnosis
  - adequate treatment
  - quality care

MULTIPLE DISCRIMINATION

OHCHR: twice at UN
2.1. STATUS OF HUMAN RIGHTS OF OLDER PERSONS WITH DEMENTIA

- Independent Expert Full Enjoyment Rights Older Persons
  - World Alzheimer’s Day 2014

- Discrimination
- Human Rights Violated
- Abuse And Neglect
- Progressive Deprivation Of Political, Civil, Economic, Social And Cultural Rights as their autonomy decreases
**2.2. CALL FOR A HUMAN RIGHTS BASED APPROACH**

**Member States** should:
- Do more to **protect** older people affected by dementia **from stigmatization, discrimination, victimization and neglect**
- Adopt a **human rights-based approach to protect the rights and dignity** of older persons with dementia

- Ensure that older persons with dementia can still **participate in public life of community and in decisions that affect them**
- Take **appropriate action**: provide **accessible information and needed support** (both human and technical)

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Independent Expert for Full enjoyment Rights Older Persons:

1**st** WHO Global Dementia Conference 2015
3.1. 67 YEARS HUMAN RIGHTS FOR ALL

Moral Obligation:
1. Universal Declaration Human Rights - UDHR
   - 1948
   - 30 basic rights + freedoms

Legal Obligation:
2. Civil Political Rights - ICCPR
3. Economic, Social, Cultural Rights - ICESCR
4. Racially Discriminated - CERD 1965
5. Migrant workers - ICMW 1975
6. Women - CEDAW 1979
7. Tortured - CAT 1984
8. Children - CRC 1989
   - Older Persons ....???

Core Instruments (9)
For All Persons (3)

For Discriminated Persons (6)
3.2. Disability Rights Convention Protects Persons with Dementia?

Only When (CRPD art 1)
Long-term Impairments
- Physical
- Mental
- Intellectual Or
- Sensory

When diagnosed in later stages dementia

Not when impairments are Invisible or visible but not considered a long-term impairment

Not During Lifecycle Development Of Risk Factors for Dementia

Not when Undiagnosed

HIC 6 out of 10
LMIC 9 out of 10

YES

NO
4.1. INTER-AMERICAN CONVENTION ON PROTECTING RIGHTS OLDER PERSONS

- adopted June 15, 2015
  - For older persons
  - 41 articles
  - 15 general principles
  - 28 protected rights
  - Civil Political Rights
  - Econ. Social, Cultural Rights
- More than
  - EU Recommendations
  - AU Protocol
- International Covenant Rights Older Persons ??

- To give free and informed consent on health matters (art 11)
- Receiving long-term care (art 12)
- To property (art 23)
- To housing (art 24)
- To healthy environment (art 25)
- To accessibility, personal mobility (art 26)

- More Protection for OP
- EXTRA Rights for OP and OPWD?
4.2. DEMENTIA STRATEGY AND ACTION PLAN FOR OLDER PERSONS (PAHO 2015-2019)

- PAHO = Pan American Health Organization
- Adopted Oct. 1, 2015 for WHO region of the Americas

Priority Area:
1. promote respect for human rights to address risk factor reduction, prevention, reduction of dependence, provision of care

2. Interventions for prevention and quality care in health systems and health services networks
3. Quality long term care based upon primary health care approach, respect for human rights, gender equality and equity
4. Human resources training in Dementia Care
5. Research + Surveillance

All 30 Basic Human Rights?

Other priority areas
5.1. ALL HUMAN RIGHTS PWD: GLOBAL PERSPECTIVE - LOCAL SOLUTIONS

**Vision:** PWD cured, treated effectively, free from dementia in good health

**Strategies** for adequate quality of life, cure, treatment or care
- Awareness equal rights PWD + caregivers
- Human rights based health & care services
- Social action for inclusion of PWD + caregivers support

To **make dementia a public health priority** & social development rights issue with a good evidence base
- Disaggregate numbers of PWD for age, gender, nationality, etc.
- Life cycle risk factors for dementia and other chronic diseases (NCD’s)
- Promote advances in cure, affordable treatment, care and prevention
5.2. TO RESPECT ALL HR PWD: GLOBAL PERSPECTIVE - LOCAL SOLUTIONS

- Involve + empower PWD + caregivers to speak out
- Promote best practices HR based dementia care
- Address all issues from sexuality to palliative care

Human Rights PWD
- Use all UN conventions not only CRPD

Dementia Friends
- Discuss practical ways to promote awareness & respect for the rights of PWD

RESPECT ALL RIGHTS PWD

WORKSHOPS ON
5.3. TO GUARANTEE ALL HUMAN RIGHTS PERSONS WITH DEMENTIA

HUMAN RIGHTS BASED LIVING FREE FROM OR W/DEMEN'TIA

- Awareness
- Advocacy
- Prevention
- Diagnosis
- Treatment
- Care
- Research & Development
- Prevalence & Incidence
- all age categories

ADDRESS ALL VIOLATIONS HUMAN RIGHTS PWD !!!

MONITOR IMPLEMENTATION & REVIEW All Human Rights Conventions Including:

- International Convention Rights Persons Disabilities
- + Inter-American Convention Protecting Rights Older Persons
- + PAHO Dementia Strategy & Action Plan Older Persons
5.4. HUMAN RIGHTS BASED ADVOCACY WITH STRATEGIC ALLIANCES

- **Brain health & Dementia**: a Public Health AND Right to Development Priority
- **WHO Global Dementia Strategy & Action Plan**
- **UN Additional protocols to protect PWD in all Covenants**
- **UN Intern. Convention on Protecting Rights of Older Persons**

- **DAI** - Dementia Alliance Int.
- **WDC** - World Dementia Council
- **GADA** - Global Alzheimer’s & Dementia Alliance
- **NCD-Alliance**
- **GAWH** - Global Alliance on Women’s Health
- **ITUC** - International Trade Union Confederation
- **CDAAA** - Caribbean Dementia Awareness Advocacy Alliance
- **Faith based organizations**

**HUMAN RIGHTS BASED ADVOCACY**

**STRATEGIC PARTNERS**
5.5. FOR ADI: GLOBAL PERSPECTIVE - LOCAL & REGIONAL SOLUTIONS

Globalization ADI
Human Rights Based Vision: global equality in quality of life for all persons with dementia & caregivers
- ADI Services now by 86 national Alzheimer associations
- PWD in 196 WHO countries

Regionalization ADI
Honoring the HR Non-discrimination principle:
- ADI objective to eliminate unequal development of services and discrepancies in quality of service level among ADI-members
- ADI restructuring of support, human and financial resources to provide to PWD in low, middle & high income countries same level of services

NATIONAL ALZHEIMER ORGANIZATIONS
REGIONAL ALZHEIMER ORGANIZATION