

Towards Full Realization And Protection Of All Human Rights Of Persons With Dementia

drs Raymond Jessurun

ADI 2016 Conference Budapest

INTRODUCTION

It is for me a privilege to have been selected to open the theme of this Parallel Session #2 “ Law, Ethics and the Rights of People with Dementia” . My presentation is based upon local solutions that we have implemented in the Caribbean Country of Sint Maarten to defend the rights of persons with dementia. As these local solutions have the potential to give a perspective to the rights of persons with dementia in the region of the Americas and globally, my presentation fits perfect in the theme of this 31st ADI Conference: “Dementia: Global Perspective – Local Solutions”.

OUTLINE OF THIS PRESENTATION

- 1. My brief assessment of the human rights of Persons with Dementia**
- 2. Assessment of the UN Independent Expert on the Full Realization of the Rights of Older Persons**
- 3. International Protection Instruments of Human Rights of Everyone**
- 4. 1st Region with Protection of Human Rights of Older Persons & Older Persons With Dementia**
- 5. Towards Full Realization of all Human Rights of Persons with Dementia**

Slide 1.1. MY EXPERTISE

I am a Sociologist, with experience as Senior Public Policy Advisor and as an activist for social justice. As a human rights defender I have been defending Workers Rights for 40 years, Older Persons Rights for the last 10 years, and Rights of Persons with Dementia for the past 7 years.

Slide 1.2. MY FUNCTIONS AS REPRESENTATIVE OF CIVIL SOCIETY ORGANIZATIONS

As co-founder and board member of the St. Maarten Alzheimer’s Foundation and the St. Maarten Seniors & Pensioners Association, I have been sharing our local experience with the struggle for equal rights of older persons and persons with dementia in particular, in meetings of civil society organizations held in Latin America and the Caribbean. Before I came to Sint Maarten I represented the civil servants union and seniors organizations from the Netherlands Antilles locally and abroad.

Two international civil society organizations, Alzheimer Disease International (ADI) and the Regional Coordination of Civil Society Organizations on Aging and Old Age of Latin America and the Caribbean

(CORV) have appointed me to represent them as their ambassador to international organizations. In this capacity I have been lobbying and advocating with government officials and representatives of civil society at meetings of the United Nations (UN)¹, the Caribbean Community (CARICOM), the World Health Organization (WHO) and the Pan-American Health Organization (PAHO) for the protection of the rights of older persons and of persons with dementia

Slide 1.3. HUMAN RIGHTS DUE DILIGENCE OLDER PERSONS WITH DEMENTIA 2014 + 2015

For two events the past two years I have received an invitation from the UN Office of the High Commissioner on Human Rights to address as human rights expert of the Latin America & Caribbean region at the UN, the challenges in the realization of human rights of older persons with dementia.

In 2014 at the Social Forum On the Rights of Older Persons of the United Nations Human Rights Council held in Geneva in April 2014 I addressed the difficulty of realization of one of the Older Persons Principles adopted by the United Nations, the Right to Autonomy of Older Persons and of Older Persons with dementia in particular in low and middle income countries.

Last year at the 6th Session of the United Nations Open Ended Working Group on Aging in New York, I addressed the challenges in the realization of the Right to Health for persons with dementia in Sint Marten and the Caribbean as low and middle income countries. The differences in realization of the right to get a timely and proper diagnosis, an adequate treatment, or appropriate and affordable care between older persons with dementia in low and middle income countries vs those in high income countries I denounced as multiple discrimination and as geo-political violations of human rights of older persons and of persons with dementia!

ASSESSMENT INDEPENDENT EXPERT FULL REALIZATION RIGHTS OLDER PERSONS -ROSA KORNFELD-MATTE

Slide 2.1. STATUS OF HUMAN RIGHTS OF OLDER PERSONS WITH DEMENTIA

The United Nations Independent Expert for the Full Enjoyment of all the Rights of Older Persons on World Alzheimer's Day 2014 gave her first statement on the status of the rights of older persons with dementia. She concluded that Older Persons with dementia experience just as older persons discrimination, violations of their human rights, abuse and neglect, and a progressive deprivation of political, civil, economic, social and cultural rights as their autonomy decreases.

¹ (such as the United Nations Committee for Social Development (UN/CSD), the United Nations Open Ended Working Group on Aging (UN/OEWGA), the United Nations Social Forum on the Rights of Older Persons, as well at Intergovernmental and Ministerial meetings of the United Nations Economic Committee for Latin America and the Caribbean (UN/ECLAC),

Slide 2.2. 2015 CALL FOR A HUMAN RIGHTS BASED APPROACH

Last year at the First Global Ministerial Meeting on Dementia of the World Health Organization (WHO) in Geneva, the Independent Expert for the Full enjoyment of the Rights of Older Persons stated, that Member States should do more to protect older people affected by dementia from stigmatization, discrimination, victimization and neglect. After analyzing the national dementia plans of different countries, she concluded that a human rights-based approach to protect the rights and dignity of older persons with dementia was lacking in all the plans. Furthermore she reminded the governments, that older persons with dementia can still participate in public life of the community and in decisions that affect them, and that governments should take appropriate action by providing these older persons with accessible information and the needed support (both human and technical).

SINCE 1948 INTERNATIONAL PROTECTION HUMAN RIGHTS FOR EVERYONE: ALSO PWD

Slide 3.1. 67 YEARS HUMAN RIGHTS FOR ALL PERSONS WITH DEMENTIA.

In 1948, 67 years ago, the United Nations adopted and signed the Universal Declaration on Human Rights (UDHR). 30 basic human rights and freedoms for everyone have become a moral obligation for all states to implement. In 1966 the United Nations adopted two legally binding human rights instruments, which included these 30 basic and fundamental human rights for all: the International Covenants on Civil & Political Rights (ICCPR) and the International Covenant on Economic, Social, Cultural Rights (ICESCR). These three international public law instruments are to protect everyone, which means therefore also the persons with dementia.

In addition to these three human rights instruments, the United Nations have adopted six more core binding conventions, but this was for specific categories of discriminated persons, such as children, women, migrant workers, the last one adopted was for persons with disabilities.² If persons of these specific categories develop dementia their discrimination ought to be protected by the three general core documents, and one or more of the core human rights documents for specific categories of discriminated persons!

To protect the rights of older persons the UN Open Ended Working Group on Aging got a mandate from the UN General Assembly to look at the possibility of an international convention. In October last year the Organization of American States reached to a consensus on an Inter-American Convention to Protect the Rights of Older Persons, which convention might be used as draft for negotiations to reach consensus on an International Convention to Protect the Rights of Older Persons.

² These international covenants protect the rights of persons to eradicate all forms of racial discrimination (CERD 1965), the rights of migrant workers and their families (ICMW 1975), the covenant against all forms of discrimination of the rights of women (CEDAW 1979), the covenant against all forms of torture and degrading or dehumanizing treatment (CAT 1984), covenant on rights of the child (CRC 1989), and the last one adopted to protect the rights of persons with disabilities (CRPD 2006).

Slide 3.2, DISABILITY RIGHTS CONVENTION PROTECTS PERSONS WITH DEMENTIA?

The board of ADI and the ADI Council meeting of yesterday, have decided to evaluate the realization of human rights of persons with dementia and to specifically check if persons with dementia are adequately protected by the Convention for Persons with Disabilities. Based upon article 1 of the Disability Convention, only when persons with dementia have a diagnosed long-term physical, mental, intellectual or sensory impairment, only then they can claim rights detailed in the disability convention. These impairments manifest usually in the advanced stages of dementia. Where are the rights of a person with undiagnosed dementia protected? The overwhelming majority of persons with dementia have not gotten a diagnosis. ADI reported based on research, that in High Income Countries 6 out of 10 persons have not been diagnosed, and in Lower and Middle Income Countries 9 out of 10 persons is not diagnosed! In other words the disabilities convention excludes most persons with dementia, especially if they are undiagnosed and if they have an early stage of dementia. Knowing that risk factors for non-communicable diseases such as dementia develop already in an early stage of the lifecycle, all these persons at risk of developing dementia, who have the same rights as all other persons in society, are not protected by the disabilities convention. Take for instance their right to health (the right to a timely diagnosis, right to adequate treatment, right to appropriate care). Persons with dementia should not have to wait until a visible long-term impairment has developed to claim the right to health under the disability convention. Can they claim their right to health successfully under one or more of the 9 core human rights documents? Based upon my analyses we have to propose amendments to these conventions to effectively protect the rights of persons with dementia.

FIRST REGION IN THE WORLD TO PROTECT HUMAN RIGHTS OLDER PERSONS WITH DEMENTIA

Slide 4.1. INTER-AMERICAN CONVENTION ON PROTECTING RIGHTS OLDER PERSONS

Two very promising developments were concluded last year in the Americas. One was on World Elderly Abuse Awareness Day, June 15th, when the Organization of American States adopted a resolution, to accept an Inter-American Convention to Protect the Rights of Older Persons. This is the first human rights convention for older persons to guarantee them more protection of their human rights. The European Union and the African Union have both developed morally human rights instruments for older persons, which does not have the legal implications of a human rights convention. In the Inter-American convention older persons and by extension older persons with a dementia condition, are getting more explicit rights such as for instance

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

Slide 4.2. DEMENTIA STRATEGY AND ACTION PLAN FOR OLDER PERSONS (PAHO;2015-2019)

The other promising development for older persons with dementia took place on the International Day of Older Persons last year. The Plenary Session of the Pan American Health Organization adopted the first Regional Dementia Strategy and Action Plan of the world for Older Persons with dementia.

Younger persons (under 60) with dementia are excluded from these historic documents and thus from the protection arranged in the Inter-American Convention on the rights of older persons as well as by the PAHO Dementia Strategy and Action Plan.

Analyzing the document the PAHO Dementia Strategy and Action Plan though, as first area of priority is mentioned to promote respect for human rights to address risk factor reduction, prevention, reduction of dependence, provision of care. Respect for Human rights is also explicitly mentioned in the 3rd priority area: -Quality long term care based upon primary health care approach, respect for human rights, gender equality and equity

The other three priority areas do not mention human rights realization: 2-Interventions for prevention and quality care in health systems and health services networks, 4-Human resources training in Dementia Care, 5-Research+ Surveillance. However, if States start to implement the human rights based approach promoted by the Independent Expert of the Full Enjoyment of the Rights of Older Persons, than not only the right to health, but all other of the 30 basic human rights and freedoms can be promoted under this 5 year strategy and action plan. To prevent that the health and wellbeing of the older person with dementia are being affected, because one or more human rights are violated, it is important to implement all human rights in this strategy and action plan for the older persons with dementia in the Americas.

5. TOWARDS FULL REALIZATION ALL HUMAN RIGHTS PERSONS WITH DEMENTIA

5.1. ALL HUMAN RIGHTS PWD: GLOBAL PERSPECTIVE –LOCAL SOLUTIONS

If our Vision is that Persons With Dementia must be either cured or being treated effectively, to be free from dementia and have good (brain)health. What should be the Strategies to achieve this as well as an adequate quality of life, a cure, a proper treatment or care for persons with dementia? I suggest a few :

- ⊙ AWARENESS about equal rights Persons With Dementia and caregivers have
- ⊙ human rights based HEALTH & CARE SERVICES
- ⊙ SOCIAL ACTION FOR INCLUSION of Persons With Dementia and caregivers support
- ⊙ PUBLIC ADVOCACY To make dementia a public health priority & a social development human rights issue with a good evidence base
- ⊙ Disaggregate NUMBERS of Persons With Dementia 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

Slide 5.2. TO RESPECT ALL HR PWD : GLOBAL PERSPECTIVE – LOCAL SOLUTIONS

To respect all rights of persons with Dementia, I suggest to inform them about all their human rights, and to empower them and their caregivers to speak out for the realization of their rights, and to promote best practices in Human Rights based dementia care, and address with them all real life issues, such as sexuality and palliative care topics also to be addressed in this conference.

I commend ADI for the WORKSHOPS ON Human Rights of Persons with dementia and recommend not only to use the Convention for the Rights of Persons with Disabilities, but all UN conventions. I also applaud the Workshop on Dementia Friendly communities, to discuss practical ways to promote awareness & respect for the rights of Persons With Dementia. But just think about this: if people do not know all the 30 basic human rights and freedoms they are entitled to or they do not know the content of the covenants that protect all their human rights, their respect for human rights will be limited to only some of the rights, is not it?

Slide 5.3. TO GUARANTEE ALL HUMAN RIGHTS PERSONS WITH DEMENTIA

I suggest therefore HUMAN RIGHTS BASED POLICIES, which have to aim to realize HUMAN RIGHTS BASED LIVING FREE FROM DEMENTIA OR WITH DEMENTIA but then with less discomfort possible. All the following policies therefore must be reviewed to make them human rights compliant: Awareness , Advocacy, Prevention, Diagnosis , Treatment, Care , Research & Development, Prevalence & Incidence, and that not only for older persons with dementia!

I also suggest to ADDRESS ALL VIOLATIONS OF HUMAN RIGHTS of Persons with dementia, and MONITOR IMPLEMENTATION & REVIEW of All Human Rights Conventions Including the International Convention Rights Persons Disabilities. I also suggest to review the two older persons adopted documents of the Americas on human rights for older persons and of those with dementia in particular.³

Slide 5.4. HUMAN RIGHTS BASED ADVOCACY WITH STRATEGIC ALLIANCES

To advance the human rights cause of the persons with dementia and their codification, I suggest for us to advocate for governments to make Brain health & Dementia: a Public Health AND Right to Development Priority. I propose to advocate at the WHO to review and adjust the PAHO Strategy and Action Plan and promote consensus under governments to adopt a WHO Global Dementia Strategy & Action Plan. At the UN level we have to advocate for Additional protocols to protect Persons With Dementia in all Covenants. At the UN we have to advocate to use the Inter American Convention of the Rights of Older Persons as the draft to discuss and reach to a consensus document for an International Convention on Protecting Rights of Older Persons. Not we alone have to advocate for

³ Inter-American Convention Protecting Rights Older Persons, PAHO Dementia Strategy & Action Plan Older Persons

the above with governments and international agencies. We must develop strategic partnerships such as with the following entities both on the global, and regional level, as we did at the local and regional level in Sint Maarten and the Non-Latin Caribbean, with Rotary District 7020 and Lions District 60A and 60B, and the Indian Merchant Association in the Caribbean Dementia Awareness Alliance.⁴

Slide 5.5. FOR ADI : GLOBAL PERSPECTIVE – LOCAL & REGIONAL SOLUTIONS

ADI as the global voice on dementia should pick up again its Globalization policy based upon a Human Rights Based Vision: for all persons with dementia & caregivers to have global equality in quality of life. ADI Services are now provided by only 86 key national Alzheimer associations affiliated to ADI.. How to reach the Persons With Dementia in the other 110 WHO countries and territories? These numbers also have the same human right to be served on an equal footing.

Human Rights Based Mission: develop 196 ADI member organizations to provide same quality of service globally to each PWD

ADI should adjust its Regionalization policy and must honor the Human Right Non-discrimination principle. ADI's objective should be to eliminate unequal development of services and discrepancies in quality of service level among ADI-members, and to restructure the support, human and financial resources within the ADI family, to provide to Persons With Dementia in low, middle & high income countries the same level of services.

How many more years we want to continue the unequal implementation of the human rights of person with dementia in the world and in particular in low and middle income countries?

⁴ STRATEGIC PARTNERS: 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