

HUMAN  
RIGHTS  
BELONG  
to EVERY-  
ONE

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**Alzheimer's Disease  
International**

*The global voice on dementia*



**DEMENTIA  
ALLIANCE  
INTERNATIONAL**

*The global voice of dementia*

**JOIN US**

for a DAI and ADI webinar

***Dementia & rights; from  
principles to practice***

**27 February 2020**

**06:00 EST | 11:00 GMT | 12:00 CET  
21:30 Adelaide | 22:00 Sydney**

# Welcome and introductions



**Paola Barbarino**  
Chief Executive, ADI

# Speakers

- **Kate Swaffer**
- **Suzanne Cahill**
- **Silvia Perel-Levin**
- **Mary Beth Wighton**
- **Jim Pearson**
- **LiYu Tang**

# Kate Swaffer

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Chair, CEO and co-founder, Dementia Alliance International;

Elected Board member of Alzheimer's Disease International;

PhD Candidate, University of South Australia;

Honorary Associate Fellow, Faculty of Science, Medicine and Health, University of Wollongong



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# ADI/DAI Materials

- The Human Rights of People Living with Dementia – from Rhetoric to Reality
- Access to Convention on the Rights of People with Disabilities (CRPD)
- A brief for Alzheimer associations

# The UN CRPD and other Conventions

**Kate Swaffer**

Chair, CEO & Co-founder, Dementia Alliance International  
Board member, Alzheimer's Disease International  
Activist, Academic, Author, Speaker

[info@infodai.org](mailto:info@infodai.org) [www.infodai.org](http://www.infodai.org)

@KateSwaffer @DementiaAllianc



# An Insider's view

- Diagnosed with younger onset dementia aged 49
- Why I co founded Dementia Alliance international (DAI)
- DAI and the quest for human rights
- The lack of Universal Health Coverage
- Reframing Dementia as a disability

Support and Advocacy, of, by and for people with dementia



# Human Rights and Dementia

"It is widely recognized that people living with dementia are frequently denied their human rights both in the community and in care homes. In many countries people living with dementia are often physically and chemically restrained, even when regulations are in place to uphold their rights. Furthermore, people living with dementia can also be victims of abuse. For example, they may be beaten for being "stubborn" or exhibiting challenging behavior. Third parties may also use a diagnosis of dementia to their own benefit, such as using deceit to acquire a person's assets. This reflects the ethical challenges inherent in the support and protection of people living with dementia, and legislation alone will not be sufficient to ensure the protection of their rights."

(World Health Organisation, 2015)

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# DAI's three key demands at the WHO First Ministerial Conference in Dementia in 2015



1. We have human right to a more ethical pathway of care, including our pre and post-diagnostic care, including rehabilitation.
2. Being treated with the same human rights as all others, under the Disability Discrimination Acts and UN Convention on the Rights of Persons with Disabilities.
3. That research does not only focus on a cure, but also on care.

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# However...

1. We are still being told to go home and die, and there is nothing you or we can do.
2. We are not provided with rehabilitation or other enabling post diagnostic care that supports independence.
3. We are not provided with the same **disability** support as every other person with an acquired disability.
4. It is still too often "about us without us";
  - tokenistic inclusion is no longer an option.

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# Dementia is a Disability



*"Dementia is one of the major causes of disability and dependency among older people worldwide."*

World Health Organisation, Dementia: Key Facts, <https://www.who.int/news-room/fact-sheets/detail/dementia>, retrieved 27 February 2020.

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# The Declaration of Human Rights and the CRPD

1. The 1948 UN Universal Declaration of Human Rights protects every citizen in the world, including people with dementia who live with disabilities.
2. The UN Convention on the Rights of Persons with Disabilities was adopted in 2006 but is only now beginning to be used by the dementia community, although mostly by advocates, and not organisations or policy makers.

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# Human Rights Violations

**Human Rights breach 1: Denial of health care and support** - Article 25: Health; Article 26: Habilitation and rehabilitation

**Human Rights breach 2: Denial of social participation** - Article 19: Living independently and being included in the community; Article 29: Participation in political and public life; Article 30: Participation in cultural life, recreation, leisure and sport

**Human Rights breach 3: Denial of employment and reasonable accommodations** - CRPD Article 5: Equality and non-discrimination; Article 17: Work and employment; Article 29: Participation in political and public life and Article 30 Participation in cultural life, recreation, leisure and sport

**Human Rights breach 4: Denial of rehabilitation** - Article 26: Habilitation and rehabilitation

**Human Rights breach 5: Denial of health care** - Article 25: Health

**Human Rights breach 6: Denial of disability support to live independently** - Article 19 – Living independently and being included in the community

**General Human Rights breaches:** Denial of equality and non-discrimination

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# Harnessing the CRPD:

1. Lobby to ensure that regional, national and local dementia policies and future plans reflect CRPD Principles and Articles.
2. Insist on the rights of people with dementia to participate as equals in the development of policy and in the implementation of the CRPD (Art. 33.3).
3. Using these rights to submit parallel reports when their country is reporting to the CRPD Committee.
4. Publicise the Committee's Concluding Observations to advocate for the implementation of its Recommendations.

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# The Optional Protocol to the Convention Against Torture

1. The Optional Protocol to the Convention Against Torture (OPCAT) is of particular relevance to residential aged care and secure dementia units.
2. Nursing homes and secure dementia units are places of dementia.

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# Article 19: Inclusion



If you do not have dementia, and you are invited to speak at any event or meeting about dementia, please ensure the organisers also ask people with dementia as invited speakers - and - that they are announced at the same time as all other speakers.

**This is one small, but very tangible step you can take, to uphold the rights of all people with dementia.**

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# Questions to consider:

1. To what extent are your policies based on human rights?
2. How closely do you work with other disability organisations in your country or region?
3. Do you know how they have used CRPD?
4. Would you join them to ensure that people with dementia are included?
5. Do you accept dementia is the major cause of disability and dependence in older persons?
6. Do your policies reflect dementia as a condition causing disability?
7. Are your programs focused on disability support, or still Prescribing Disengagement®?

Support and Advocacy, of, by and for people with dementia

# Suzanne Cahill

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Adjunct Professor of Social Work and  
Social Policy, Trinity College Dublin;

Honorary Professor of Dementia Care,  
NUI Galway;

Affiliated Professor of Health and  
Welfare, Institute of Gerontology,  
University of Jonkoping, Sweden;

Author of 'Dementia and Human Rights'



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# Silvia Perel-Levin

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Chair of the NGO Committee on Ageing,  
Geneva;

Representative of the International  
Network for the Prevention of Elder  
Abuse (INPEA) to the UN;

Independent consultant on ageing,  
health and communication



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# Silvia Perel-Levin

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## Links

- Ayalon L, Tesch-Römer C (eds.), Contemporary Perspectives on Ageism, International Perspectives on Aging volume 19, open access : <https://doi.org/10.1007/978-3-319-73820-8>
- Global Alliance for the rights of older people (GAROP) <https://www.rightsofoldpeople.org>
- UN Open-ended Working Group on Ageing <https://social.un.org/ageing-working-group/>
- WHO Decade of Healthy Ageing <https://www.who.int/ageing/decade-of-healthy-ageing>



# Mary Beth Wighton

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Founding member and Co-Chair of  
Dementia Advocacy Canada;

Founding member and Chair of the  
Ontario Dementia Advisory Group;

Member of Canadian Federal Ministerial  
Advisory Group on Dementia



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# Dementia & Rights From Principle to Practice ADI & DAI

Mary Beth Wighton - Co-chair Dementia Advocacy  
Canada (DAC)

Feb. 28<sup>th</sup> 2020



Dementia  
Advocacy  
Canada

*Voices of Lived Experience*





## Articles of Focus

- 9 - Accessibility - Transportation
- 12 - Equal recognition before the law
- 19 - Participation in political & public life
- 19 - Living independently and being included in the community
- 20 - Personal mobility
- 25 - Health
- 26 - Habilitation and rehabilitation
- 29 - Participation in political and public life

*"Finally, the committee was reminded that the United Nations Convention on the Rights of Persons with Disabilities ensures that persons with dementia, as with other disabilities, are entitled to participate as equals in discussions about the programs and services that affect them."*

## Achievements

- ✓ Key stakeholder in Ontario Dementia Provincial Strategy plan
- ✓ Witness to the Canadian Senate on its study of Dementia in Canada
- ✓ ODAG Board Member Phyllis Fehr- presents in Geneva at the 17th Session of the CRPD Committee
- ✓ Partner with Federal Ministry of Health on development of National Dementia Strategy conference agenda
- ✓ First organization of its kind in Canada
- ✓ Recognized internationally for its work

## Articles of Focus

- 12 - Equal recognition before the law
- 19 - Participation in political & public life
- 19 - Living independently and being included in the community
- 25 - Health
- 26 - Habilitation and rehabilitation
- 29 - Participation in political and public life

## Frustrations

- Hard to recruit advocacy members
- *Not enough advocacy member for the amount of projects and works*
- *Goals of National Dementia Plan, are not tied to Articles of CRPD*

## Achievements

- ✓ Group is a key outcome from the National Dementia Conference
- ✓ Host of All Party Political webinar
- ✓ **Host of numerous webinars on pressing issues**
- ✓ Quickly developed key strategic relationships across sectors
- ✓ First organization of its kind in Canada
- ✓ Recognized internationally for its work
- ✓ MB Wighton - member of Ministerial Advisory Board



# Rights in the new Canadian plan

- **Respect human rights:** Actions taken under the strategy respect the human rights of those living with dementia and reflect and reinforce Canada's domestic and international commitments to human rights.
- **Human rights lens:** A person-centred approach that focuses on respecting and preserving an individual's rights, autonomy and dignity in alignment with Canada's human rights commitments.
- **Inclusion:** Steps are taken to enable the participation of people living with dementia.
- **Respects choice:** The rights of individuals living with dementia to make their own decisions are broadly understood and facilitated.
- **Hears the voices of those living with dementia:** Actively including and consulting those living with dementia on matters that affect their quality of life.
- **Caregiver perspectives:** Consideration is given to the needs of the family and friends who care for people living with dementia.



# What's Next for Canada?

- National Dementia Strategy must be quickly implemented and with an application of a human rights lens, and the integration of principles of equity, diversity and inclusion throughout.
- The government of Canada has not prioritized dementia as a national crisis.
- Agencies, organizations, researchers, etc. must use the CRPD as a tool to push for the rights of persons with dementia to be met.



Thank you.

# Jim Pearson

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Director of Policy and Research,  
Alzheimer's Scotland;

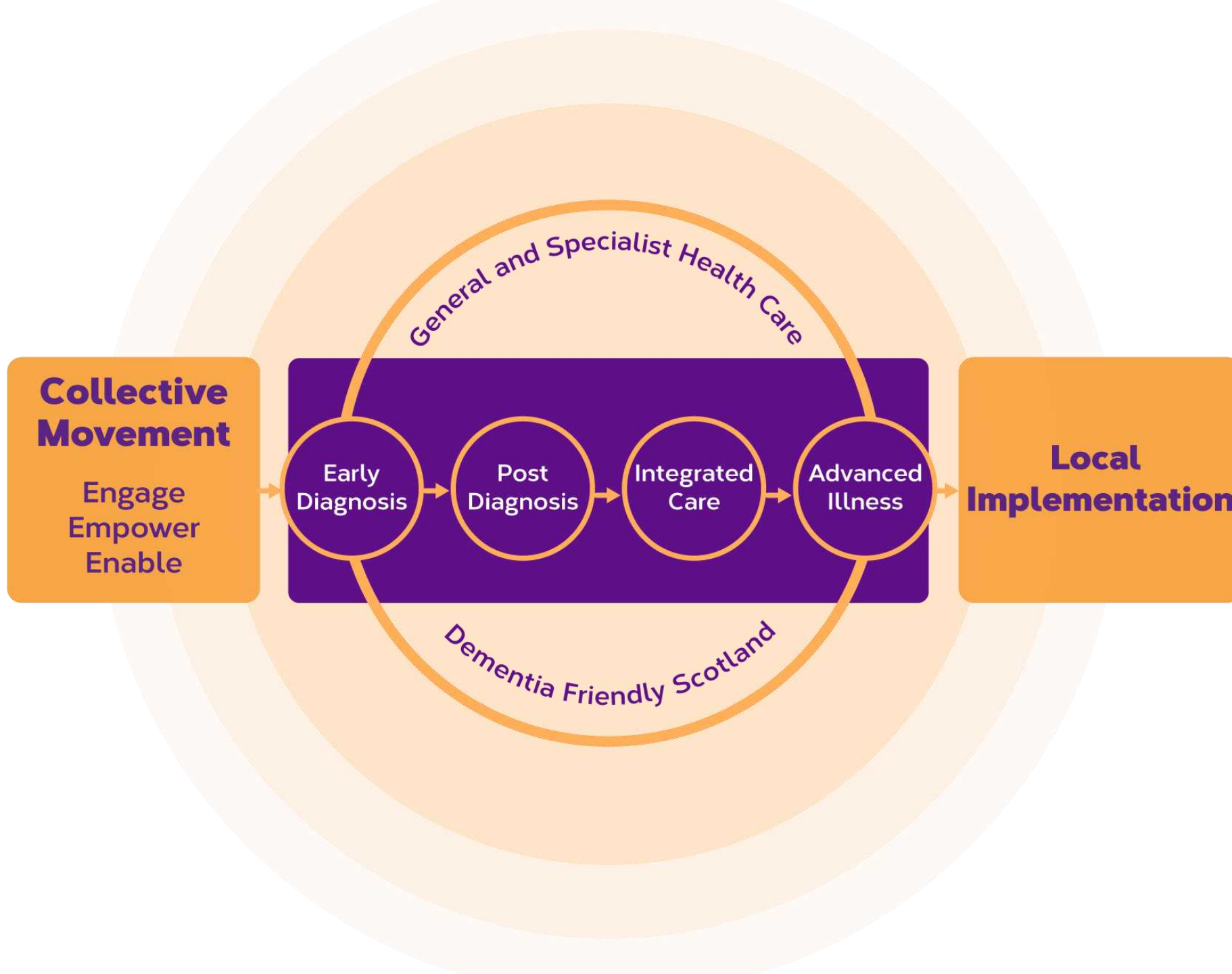
Member of the Alzheimer Europe  
Board of Directors



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# Transforming Dementia Policy and Practice from a Human Rights Perspective

**Henry Simmons, Alzheimer Scotland**







2009 – Charter of Rights endorsed by Scottish Parliament

# Why a charter of rights was needed

## Barriers to rights

- Nature of the illness, disempowerment and lack of voice
- Medical model dominant paradigm
- Negative perception that nothing can be done
- Long standing discrimination
- High levels of stigma
- Numerous reported care and system failings

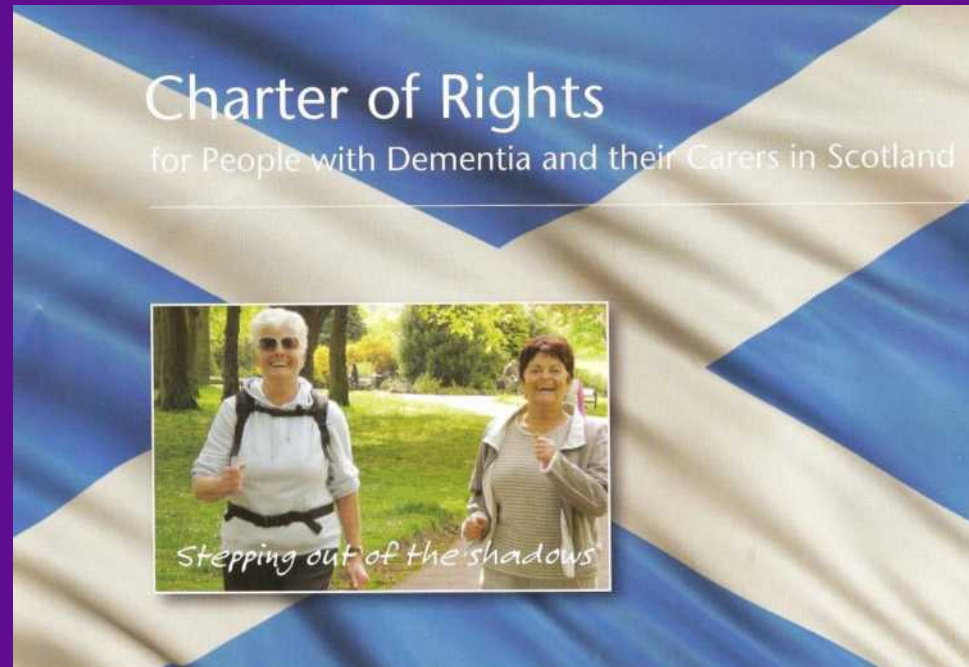
## The Charter of Rights aimed to;

- Empower people with dementia and their carers to assert their rights in any and in every part of their daily lives wherever they live
- Give people power, choice and control to live well with dementia
- Shift the paradigm from medical model to person centred rights based model
- Ensure that those who provide health, social care and other services understand and respect the rights of people with dementia and their carers



# Charter of Rights: Human Rights principles and values

- Participation
- Accountability
- Non Discrimination
- Empowerment
- Legality



- It promotes the respect, protection and fulfilment of all existing human rights of people with dementia and their carers, as guaranteed in;
  - European Convention of Human Rights
  - Universal Declaration of Human Rights
  - International Covenants on Economic, Social and Cultural Rights and Civil and Political Rights, and the Convention on the Rights of Persons with Disabilities

# Scotland's National Dementia Strategies 2010, 2013 and 2016



- The Charter of Rights is front and centre of the strategies and is the driving principle behind the development and implementation of each of the three national Dementia Strategies
- All policies developed from the strategy are founded on the principles of a human rights based approach
- The expert voice of people living with dementia and their carers drives the shape and content of the strategies
- New standards of care are developed using a rights based model
- New knowledge and skills framework; Promoting Excellence developed using same approach



## What next

- Consultation for Scotland's 4<sup>th</sup> national dementia strategy begins in March 2020
- We are seeking to ensure that human rights remain front and centre.
- Runs alongside
  - Review of Adult Social Care
  - Review of current legal framework for Mental Health, Adults with Incapacity, and Adults Support and Protection
- Key focus for Alzheimer Scotland is ensuring that the voice of people with dementia and those who care for them set the priorities in the development, implementation and monitoring

# LiYu Tang

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Secretary General, Taiwan  
Alzheimer's Disease Association  
(TADA);

Full member of the World  
Dementia Council

Board member of Taiwan Family  
Caregiver Association



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# Alzheimer's Disease International Webinar

## The Human Rights of People with Dementia in Taiwan

**LiYu Tang**  
**Taiwan Alzheimer's Disease Association**  
**27<sup>th</sup> Feb 2020**



## Article 4.3

## Participation in decision-making

## Article 21

## Freedom of expression and opinion, and access to information



### Dementia advisory group

#### Issues discussed

Dementia friendly bank, library, bus, metro-system..

World Alzheimer's Month, Financial security, Palliative care, Covid-19 etc.

## Article 4.3

## Participation in decision-making



Meeting of national dementia plan



Meeting of Taipei action plans

Participated in the development of national dementia plan and local action plans



## Article 5

## Equality and non-discrimination

## Article 8

## Awareness-raising



Break  
the  
myth



打破

迷思

Minister of Health and Welfare



Famous actor in Taiwan



## Article 5

## Equality and non-discrimination

## Article 8

## Awareness-raising





## Article 19

# Living independently and being included in the community

5 World Alzheimer's Month Exhibitions in 4 cities in Taiwan  
To honor the talent of people with dementia







## People with dementia shared experience in the training of the masters of MRT stations



Article 9

Accessibility

- Guideline of dementia care responding to Covid-19 – in Mandarin

### 失智者防疫指引—專業人員篇

社團法人台灣失智症協會

2020/02/20 版

#### 一、疫情說明

因應嚴重特殊傳染性肺炎（COVID-19，簡稱武漢肺炎）疫情，世界衛生組織（WHO）已提供疫情訊息與相關指引。聯合國的機構間常設委員會（Inter Agency Standing Committee, IASC）更指出，在疫情爆發期間，仍須確保足夠的心理健康與社會心理支持（mental health and psychosocial support, MHPSS）。因此，各國須確保以下核心原則：不傷害、促進人權與平等、使用參與管道、建立在現有資源和能力上、採取多層介入措施，並與整合性支持系統合作等。因此，衛生福利部疾病管制署也加強提供醫療、長期照護、社會福利機構等單位之相關指引，確保

Article 13

Access to Justice

Article 12

Equal recognition before the law

## Legal Consultation Trainings (>300 Lawyers) 2018-2019





## Article 16

## Freedom from exploitation, violence and abuse



Task force of financial security of People with Dementia

Dementia and property loss case investigation

2019 Taiwan Dementia Conference

“Human Rights of People with Dementia:  
Freedom from Financial Exploitation”

## Article 27

## Work and employment



Dementia Friendly Workplace Projects to raise awareness and support people with dementia to work

Including bank, technology company, insurance companies etc. More than 25 talks, 1500 participants.

Young Café – 9 young people with dementia working in Café



Dementia and Driving Decision Aid (DDDA)  
Collaborate with University of Wollongong

DDDA Trainings for care managers



87 x Integrated Dementia Care Center (IDCC)

434 x Support Center for People with Dementia and their Families (SPDF)

1 x Service center for young onset dementia



## Article 29

## Participation in political and public life



Raised awareness of the right to vote and the support service in the election of Taiwan president



# Hurdles

#Difficult to involve people with dementia to join DAG / Stigma

#Only one DAG in Taiwan

#Human rights approach is not the mindset of professionals and carers

➔ Learn to wear the eyeglasses of human rights of people with dementia

**Abundant learning**

# Thank You!

# Question and answer



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**@DementiaAllianc**  
**#Dementiarights**





**Singapore**  
**2020**

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**10-12 December**

[www.adi2020.org](http://www.adi2020.org)