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UN Convention on the Rights of Persons with Disabilities (CRPD):

What does it have to offer people living with dementia?

Taiwan, 2017/9/30



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

Dementia Alliance International

- A global advocacy and support group, of, by and exclusively for people with dementia, advocating for the global voice and needs of people with dementia.
- In collaboration with Alzheimer's Disease International, Dementia Alliance International is the peak body for people with dementia, and **the global voice of people with dementia.**
- DAI has over 4000 members, representing 43 countries
- DAI Members age from 18 – 93 years old

Key facts about dementia

- Dementia is a syndrome in which there is deterioration in memory, thinking, behaviour and the ability to perform everyday activities, usually of a chronic or progressive nature severe enough to effect reduce a person's ability to work or to perform everyday activities beyond what might be expected from normal ageing.
- Although dementia mainly affects older people, it is not a normal part of ageing.
- Worldwide, an estimated 50 million people have dementia, and there are nearly 10 million new cases every year.
- Alzheimer's disease is the most common cause of dementia
- **Dementia is one of the major causes of disability** and dependency among older people worldwide.
- Dementia has physical, psychological, social, and economical impact on care partners, families and society.

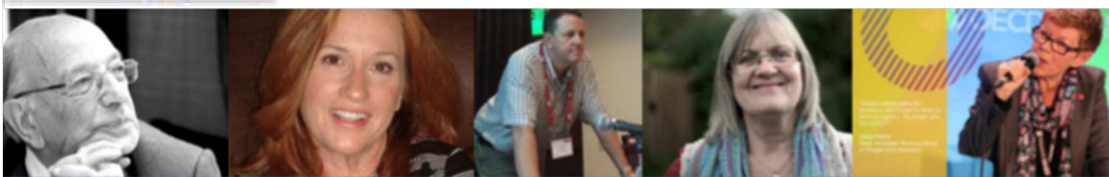
Global Dementia Statistics

- > 50 million people in the world diagnosed (WHO, 2017)
- 1 new diagnosis globally every 3.2 seconds (WHO, 2015)
- 253,511 people diagnosed with dementia in Taiwan, meaning 1/13 Taiwanese over 65 have dementia (Taipei Times, 2017)
- >12,000 people with younger onset dementia in Taiwan
- > 130 types or causes of dementia
- Alzheimer's Disease makes up 50-70% of all dementias
- Dementia is a terminal, progressive chronic illness
- No cure, no disease modifying drugs
- Medical model of care no longer appropriate

Prevalence of Younger Onset Dementia (YOD)

This refers to people diagnosed with dementia under the age of 65.

- More often the rarer forms of dementia
- >12,000 people in Taiwan with YOD
- >26,000 people in Australia with YOD
- >42,000 people in the UK with YOD
- >200,000 people in the USA with YOD



The Human Rights of People Living with Dementia: from Rhetoric to Reality



DAI launched this landmark publication, as a direct result of our advocacy, and demand for a human rights based approach including access to the CRPD, now adopted by ADI and in the Global Action Plan.

What matters to us now is that people living with dementia should be empowered to use their undisputed right of access to this and to other relevant UN Human Rights Conventions, including the CRPD and a future Convention on the Rights of Older Persons.



A Dementia Alliance International publication
to coincide with the adoption by Alzheimer's Disease International
of a Human Rights based approach,
and to coincide with Dementia Awareness Week UK 2016

16 May 2016 (first edition)

Definition of disability

- The Convention adopts a **social model of disability**, but does not offer a specific definition.
- The Convention's preamble (e) explains that the Convention recognises:
- *"...that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others,"*
- **Dementia is one of the major causes of disability** and dependency among older people worldwide.

Core provisions of the CRPD

- Principle of "reasonable accommodation"
- Prevention of discrimination
- Accessibility
- Situations of risk and humanitarian emergency
- Recognition before the law and legal capacity
- Access to justice
- Right to education
- Right to health
- Protecting the integrity of the person
- Respect for the family
- Habilitation and rehabilitation
- Participation rights
- Work and employment
- Adequate standard of living and social protection
- Right to vote

General CRPD Principles

- Respect for dignity, autonomy, freedom to make choices, independence
- Non-discrimination (e.g. age, gender, disability)
- Full participation & inclusion in society
- Respect for difference; acceptance of disability as part of human diversity
- Equality of opportunity
- Accessibility
- Equality between men and women

Global Dementia Charter

I CAN LIVE WELL WITH DEMENTIA

Therefore, people with dementia should have:

- Access to health care (Articles 19, 25, 26)
 - Timely diagnosis of dementia
 - Access to human rights based post diagnostic support
 - Medicine and treatment
 - Rehabilitation and disability support
 - High quality care that's right for me
- A say in the care and support we receive (Articles 21,25,26)
- Support to live independently for as long as possible (Article 19)
- Treated as individuals with dignity and respect
- Respected for who we are (Article 3a,d)
- End of life wishes discussed while able to do so



Global estimates of numbers of people with dementia

The WHO Global Action Plan: A Public Health Response to Dementia (2017) set the stage.

Governments, in partnership with civil society, people with dementia and their families must start now by preparing national dementia plans in their own countries, which includes a human rights approach to dementia.

www.alz.co.uk/dementia-plans/



World Health
Organization

Global Action Plan on the Public Health Response to Dementia

— 2017 - 2025 —

Vision

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.

Goal

To improve the lives of people with dementia, their carers and families, while decreasing the impact of dementia on them as well as on communities and countries.

7 cross cutting principles in the Global Action Plan for dementia

1. **Human rights of people with dementia**
2. **Empowerment and engagement of people with dementia and their carers.**
3. Evidence-based practice for dementia risk reduction and care.
4. Multisectoral collaboration on the public health response to dementia.
5. **Universal health and social care coverage for dementia.**
6. **Equity.**
7. Appropriate attention to dementia prevention, cure and care.

How can the CRPD be used by Governments, Alzheimer Associations and Civil Society?

- Lobbying to ensure that regional, national and local dementia policies and future plans reflect CRPD Principles and Articles
- Insisting on the right of people with dementia to participate as equals in the development of policy and in the implementation of the CRPD (Art. 33.3)
- Using their right to submit parallel reports when their country is reporting to the CRPD Committee
- Publicising the Committee's Concluding Observations to advocate for the implementation of its Recommendations.

Impact on Governments

- The 174 countries that have RATIFIED the Convention have made a commitment in international law to implement each of its Principles and Articles
- Each country must submit a detailed report on progress in implementing all Principles and Articles after 2 years and then every 4 years to the UN Disability Committee - 17 of its 18 elected members are themselves disabled
- Any civil society NGO or an individual has the right to submit a parallel report
- The Committee's Concluding Observations are on the website and can be used by civil society in advocating for change, <http://www.ohchr.org>
- I believe Taiwan is in a unique position to lead the world

Article 19: LIVING INDEPENDENTLY IN THE COMMUNITY

- 19a: Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement
- 19b: Persons with disabilities have access to a range of in-home, residential and other community services, including personal assistance necessary to support living and inclusion in the community in their own home, and to prevent isolation or segregation from the community
- 19c: Community services and facilities for the general population are available on an equal basis and are responsive to their needs.

Article 25: HEALTH

CRPD Article 25: THE RIGHT TO HEALTH specifies that "persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability."

- Same range, quality and standard of free, affordable health care
- Disability-relevant services:
 - early detection & intervention
 - services to minimise further disabilities
 - including older persons.
- LIVE AT HOME OR AS CLOSE TO HOME AS POSSIBLE
- No discrimination in health insurance, denial of health care, food or fluids on the basis of disability

Article 26: REHABILITATION

- Based on early multi-disciplinary assessment of individual needs & strengths
- Use of assistive devices and technologies designed for persons with disabilities
- Promote initial and continuing training for professionals and staff

WHO Global Disability Action Plan 2014-2021

This plan is fully based on CRPD Principles and Articles. It has good indicators for assessing progress.

**THIS ALSO MEANS CRPD MUST BE REFLECTED
IN REGIONAL AND NATIONAL DEMENTIA
STRATEGIES**

Community Based Rehabilitation (CBR)

The aim of **community-based rehabilitation** is to help people with disabilities, by establishing **community-based** programs for social integration, equalization of opportunities, and physical therapy **rehabilitation** programs for people with any type of disability.

DAI's Next Steps

- Working with countries and civil society to ensure human rights and implementation of CRPD, SGD's and CBR
- Supporting Alzheimer's societies in developing HR policies & plans
- Submitting parallel reports to the UN and the WHO
- Promote human rights approach at all conferences and events
- Raising our concerns about human rights of persons with dementia in WHO Disability Policy, CBR and regional and national dementia strategies
- Working with disability organisations, e.g. IDA and IDDC

New pathway of disAbility support to live with, not only die from dementia

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- Timely Diagnosis
- Focus on well being/QoL
- **Acquired Brain Injury rehabilitation post Dx**
 - Speech pathology
 - Neuroplasticity
 - Occupational Therapy
 - Neurophysiotherapist
 - Risk reduction strategies – e.g. life style changes (as we do for other chronic diseases)
- **disAbility assessment and support , immediately post dx**
 - Webster packs
 - Technology
 - Laminated instruction sheets
 - Support and manage risk rather than eliminate it
- Grief and Loss counselling
- Peer to peer support groups
 - People with dementia
 - Care partners and families
 - Children
- **Support to maintain pre dx lifestyle**
- Support to continue working if YOD (and is a personal choice)
- Support to continue usual activities, socialising, sport, recreation, community engagement, etc
- Inclusive and accessible communities (not just dementia friendly)

Transformation of the Criminal Justice System

- Raising awareness of dementia in Taiwan judicial system
- Reviewing and making report of dementia related crime
- Developing protocol for intervention of dementia related crime
- Providing training for frontline police officers, lawyers, court workers etc.
- Dementia friendly courts and justice system

Dementia and the criminal justice system

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- People with dementia still have legal capacity
- They may need decision making support as capacity changes
- Criminal justice system must support this
- Reasonable Accommodations need to be made for people with dementia

People with dementia must be supported in the justice system

- Case study 1
 - DAI member in the USA
- Case study 2
 - Personal experience
- Case study 3
 - LiYu

Thank you

謝謝！

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