Human rights for people with dementia

Kate Swaffer

Chair, CEO & Co-founder, Dementia Alliance International
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Masers of Science in Dementia Care (2014), Retired nurse
There is a systemic and gross **UNDERESTIMATION** of the capacity of people with dementia, even in the later stages of the disease.

(Kate Swaffer 2016)

SEE THE PERSON NOT THE DEMENTIA
I am one of more than 50 million people in the world with dementia (WHO 2015).

We are individually and collectively demanding a human rights based approach to dementia.
Acknowledging those advocates with dementia who led the way...

Although they may not have used the language of human rights or the CRPD, they were demanding full inclusion in civil society...

**Article 19 of the CRPD:** Living independently and being included in the community
People with dementia are becoming very active

2000: DASNI
2002: SDWG
2006: AAUSAEO-DAG
2012: EWGPWD
2013: AADAC
2013: IDWG
2013: JDWG’s
2014: SDAG (recognised in 2016 by the WHO)
2014: ODAG
2015: HDWG
2016: DEEP Think Tank
2016: DAAT
Kiama Dementia Friendly Project project wins WHO award

BRENDAN CRABB
31 Aug 2016, 4:42 p.m.

Kiama councillor Kathy Rice (second from left) with the award at the WHO conference.

The World Health Organisation (WHO) has recognised the efforts of Kiama council’s Health Plan and in particular the Kiama Dementia Friendly Project.
A brief history and overview of Dementia Alliance International and our collective advocacy.
Dementia Alliance International

• Established on January 1, 2014 DAI is a global advocacy and support group, of, by and for people with dementia, and the global voice of people with dementia.

• DAI now represents > 3500 members in 39 countries. It is a registered charity in the USA.

• DAI is in a strategic but autonomous partnership with Alzheimer’s Disease International, also our major sponsor.
DAI Founding Members
2015: DAI-ADI
DAI Vision: A person with dementia is valued and included

ADI Vision: Prevention, care and inclusion today; cure tomorrow

DAI Global Charter: Living beyond dementia

ADI Global Charter: I can live well with dementia
We believe the only way to ensure people with dementia can live beyond dementia is through a **human rights** based approach...

*Supporting us to live with dementia, not only to die from it is a basic human right.*
2015: Demand for a Human Rights approach to dementia

1. We have human right to a more ethical pre and post diagnosis pathway, including rehabilitation.

2. Being treated with the same human rights as everyone else, under the Disability Discrimination Acts and UN Convention on the Rights of Persons with Disabilities

3. Research that focus on care as much as a cure.
The need for a human rights-based approach (2015)

“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.”
2016: World Dementia Council includes 2 people with dementia
DAI and ADI worked collaboratively on a briefing paper for ADI to present to it’s Council Members at their meeting in Budapest prior to the ADI conference in 2016.
April - May 2016

• April: ADI Council members voted unanimously for a human rights based approach to dementia
• Professor Peter Mittler, then DAI’s Human Rights Advisor gave a leading edge keynote presentation on the importance of this and ADI ran a Human Rights Workshop

• May: DAI publishes *The Human Rights Of People Living With Dementia: From Rhetoric To Reality* (Available in a number of languages including Japanese)

• 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. (Peter Mittler)
The Human Rights of People Living with Dementia: from Rhetoric to Reality
DAI’s work had only just begun!

- **June**: DAI attends the annual United Nations Conference Of States Parties (COSP) o the CRPD in new York
- **August**: DAI-ADI joint position paper presented at the WHO *ACCESS TO CRPD and SDG’s BY PERSON WITH DEMENTIA*
- **September**: DAI virtual attendance at the 2nd CBR World Congress, Kuala Lumpur, Malaysia: *EXTENDING CBR TO OLDER PERSONS A GLOBAL IMPERATIVE*
- **September**: DAI received Observer Member status with IDA
- **October**: DAI formally responds to the WHO *Draft Zero of the Global Action Plan*
- **October**: DAI attends the UN Human Rights Council – Social Forum for the 10th Anniversary of the Convention on the Rights of Persons with Disabilities (CRPD)
- **October**: DAI attends the mhGAP Forum at the WHO
And it continues...

- **October 16-February 17**: DAI contributes to the WHO Quality Rights Training Modules
- **February**: DAI attends REHABILITATION 2030: A Call For Action in Geneva
- **February**: International Women's Day event in London
- **March**: DAI attends the 17th session of the CRPD Committee in Geneva
- **April**: ADI and DAI Joint paper presented to the ADI Council members in Kyoto – *There is a briefing session for Alzheimer Associations: Accessing the CRPD, Saturday 07:30*
- **May**: DAI will attend the World Health Assembly
- **June**: COSP in New York
- **October**: mhGAP Forum in Geneva
Many others have worked hard on human rights too...
Long before DAI and continuing on after us....
You may be wondering...

Why have people with dementia felt the need to work so hard for a human rights based approach to dementia?
Human rights

On December 10, 1948 the UNIVERSAL DECLARATION OF HUMAN RIGHTS was adopted by the General Assembly of the United Nations
The **1948** Convention was (and still is) meant to protect every single member of civil society in the world...

Including people diagnosed with any type of a dementia, and who have disabilities caused by the symptoms of their dementia.
67 years later...

In 2015, The Organisation for Economic Co-operation and Development (OECD) report *Addressing Dementia: The OECD Response* concluded:
“Dementia receives the worst care in the developed world.”

(OECD, 2015)
We are excited to know that countries are working towards human rights becoming a reality for people with dementia. Scotland and Canada are leading the way, and ADI, DAI, and many of the local or national Dementia Working Groups are actively supporting their own countries in this work.

Prescribed Disengagement®

What is it?

• “Go home, get your end of life affairs in order, and get acquainted with aged care.”

Dementia is the only illness I know where people are told to go home and prepare to die and not fight for their lives!

What’s the cost?

• Hopelessness for those diagnosed and our families
• Person with dementia often assumes victimhood, and becomes disempowered
• It promotes learned helplessness in those diagnosed
• Care partner takes over, further disabling and disempowering the person diagnosed
Why are we still being Prescribed Disengagement®?

• 1970’s – diagnosis usually later in the disease process, therefore late stage post diagnostic treatment and management appropriate.

• 2000’s – diagnosis is occurring much earlier in the disease process, but health and care professionals are still applying late stage disease management.
We must stop promoting dependence...

For now let’s forget the human cost...

From an economic perspective, society cannot afford to keep providing a pathway that promotes dependence from the time of diagnosis onto families, and then health care, service providers and governments.
Treat the symptoms of dementia as disAbilities

There is a new Communication Access symbol (SCOPE, 2016)

We also need a uniform symbol for Invisible disabilities
Relative Disqualification and Absolute Disqualification

• Driving License and Medical Conditions in Japan
• Relative Disqualification: In some cases, people are disqualified and/or have driver’s licenses revoked.
  – Most of those who’ve had a stroke and who have mental illnesses fall within this category.
• Absolute Disqualification: Driver’s license is not granted. If they already have a license, it will be taken away.
• There is absolutely no regard for the progress of the person’s illness or their recovery efforts.

(Mizuno Yutaka)
If Diagnosed with Dementia in Japan

• In Japan, driver’s licenses are denied or revoked for people who have been diagnosed with Alzheimer’s disease, vascular dementia, fronto-temporal dementia, dementia with Lewy bodies.
• Blanket measures offer no consideration for individual differences, abilities or personalities.
  – Someone who has a cautious personality
  – Some people with dementia have very poor memories in general, but remember traffic regulations and traffic control signs well.
• In countries such as Australia, Canada, Singapore, the UK, and Norway, people with dementia are assessed and their driving ability is determined on a case by case basis

(Mizuno Yutaka)
Lack of Knowledge about Dementia is the root of prejudice

- Vague fears about dementia
- One assumption: “People with dementia do crazy things.”
- For these reasons, the general public in Japan may not see the problem with this provision.
- Furthermore, it passes on stigmas and assumptions to the next generation: “People with dementia do dangerous things.”

(Mizuno Yutaka)
A Support & Advocacy group, of by and for people with dementia

- Exclusive and FREE membership and FREE services
- Weekly online support groups
- 24/7 chat rooms
- Monthly online cafes
- Monthly webinars
- Master classes
- http://www.infodai.org
- http://www.joindai.org
Diagnosed with dementia: What Next?

DAI WORKSHOP: 2 - 3:30pm today – Room D – 1st Floor
DAI will continue to:

• Engage with the United Nations Committee on the Rights of Persons with Disabilities, including through its policy making processes
• Seek to further develop productive relationships with the global network of National Human Rights Institutions, and other organisations
• Prepare and disseminate information from IDA, and on the UN (CRPD) and other Conventions – in partnership with ADI when relevant to do so
• Encourage and support national and regional Alzheimer’s organisations to participate in the examinations by the United Nations Committee on the Rights of Persons with Disabilities of their own states.
• Timely diagnosis

• **Human rights based approach** to diagnosis of dementia AND care
  – Including proactive rehabilitation and disAbility support to improve resilience, hope, quality of life and independence for longer, support for families, and when required, palliative care

• Balanced research
  – Risk reduction, care and disease modifying drugs and a cure

• **Education, Education, Education**
Thanks to my UK publisher Jessica Kingsley Publishers and my Japanese Publisher, my book is available at the conference in English and Japanese at the Creates Kamogawas Booth in the Exhibition hall.

I’LL BE AT THEIR BOOTH AT 1PM TODAY.
Thank you

OUR LIVES BEGIN TO END THE DAY WE BECOME SILENT ABOUT THINGS THAT MATTER

Martin Luther King Jr.

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