



Conference of
States Parties to the
Convention on the
**Rights of
Persons with
Disabilities**

United Nations Headquarters, New York

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Dementia: the leading cause of disability

Thursday June 13 at 9:45am in Conference Room C.11



In 2019, the Dementia Alliance International (DAI) is celebrating 5 years of existence, and at this Side Event, we recognise the progress that has been made by people with dementia in the advancement of the rights of persons with dementia, as persons living with acquired cognitive disabilities.

Through the side-event, DAI shares the progress made towards claiming their rights as persons with cognitive disabilities over the past 5+ years, aiming to highlight dementia as a disability, and identify areas of further collaboration between the members of DAI and its international partners and all relevant stakeholders, including United Nations agencies.

The overarching theme is of social inclusion and health, which are two of the determinants of well-being, both of which are being systematically denied to people with dementia all around the world, including in the developed countries. We will hear from an eminent list of speakers, on the rights of persons with any type of disability, including dementia, to full and equal access to the CRPD, and specifically on the right to rehabilitation and to Universal Health Care.

Background and history of DAI

Dementia Alliance International (DAI) is a 501(c)3 registered charity, and is the world's leading organisation exclusively for people diagnosed with any type of dementia. It is an advocacy and support group of, by and for people with dementia, and the the global voice of dementia. DAI's vision is "A world where people with dementia are valued and included". DAI represents the 50 million people currently living with dementia, and the projected 82 million in 2030 and 152 million in 2050. Our membership is currently represented in 49 countries around the world, including many members living in the Low and Middle Income Countries (LMIC's).

From grassroots advocacy to global activism, DAI seeks to claim the human rights of people with dementia and ensure that our rights as disabled persons are secure. Dedicated to empowering all people to live a better life with dementia, DAI believes in the power of energy, creativity, human connections and joy as the shared inheritance of every human on earth. Our members advocate and educate locally, nationally and internationally. We speak at professional conferences and lead vast online communities of people. We work to reduce stigma and discrimination, bringing awareness to the truth that life can be well-lived beyond any diagnosis or disability, including dementia.

Concluded by the OECD in 2015, "people with dementia receive the worst care of any disease in the developed world" and indeed, DAI members report, anywhere in the world.

While it is challenging to fix serious problems that are global in scale, we have done it before. As a species, we have eradicated smallpox and polio. We have increased global life expectancy and we have reduced global childhood mortality rates.

The challenges we face are big, but this will not drive us to inaction and hopelessness, for we each carry the burden of making things better in our own chosen sphere.

We didn't choose to have dementia, but we do choose to work towards a world where we have

equal social inclusion as all others, and full and equal access to universal health care, including rehabilitation, and proactive disability assessment and support immediately after a diagnosis.

At Dementia Alliance International, we believe it is imperative to change misconceptions about dementia, address stigmas associated with it, discourage psychological and physical abuse of all disabled people, and demand that the voices of people with dementia be included in decisions directly affecting us. The stigma and discrimination experienced by people with dementia – and their families – is very real and incredibly disabling. Countering the myth that people with dementia go from the point of diagnosis, immediately to the end-stages of the disease, is extremely important.

Currently, people with dementia are disenfranchised upon diagnosis. Our legal and social status is immediately reduced, and our human rights are stripped away. We are excluded from equal and full inclusion in public spaces and activities and even viewed by some as “less than human”. Much of our work centers on reducing stigma and discrimination, bringing awareness to the truth that life can be well lived beyond any diagnosis, including dementia. Disability rights are another important arena. Like other disabled persons, we have the right to equal and full inclusion in public spaces and activities. And with appropriate disability support, we can continue to live meaningful and positive lives.

The misguided under-estimations of the potential of people with dementia continue to create oppressive and humiliating barriers to our full and equal engagement in society, and the continuing major breaches of our human rights through the systemic and endemic overuse of chemical and physical restraints, and though segregation and institutionalisation continue.

Hence DAI members individually and collectively advocate for rights, and educate locally, nationally and internationally, at professional conferences, and in the vast online communities they have built, so that we are not reduced in legal or social status. DAI is dedicated to empowering all people live a better life with dementia. It advocates for the right to equal and full inclusion in public spaces and activities.

DAI Chair, Kate Swaffer was an invited keynote speaker at the WHO First Ministerial Conference on Dementia in March 2015, and made rights and access to Universal Health Coverage the focus of her presentation. DAI's global focus has been on human rights and disability rights, and we continue to work with organisations such as the World Health Organisation (WHO), the United Nations and others, to ensure that since the WHO Global action plan on the public health response to dementia 2017 – 2025, was adopted, national, regional or local dementia plans will include human rights, and people with dementia have full and equal access to the CRPD.

DAI is working hard towards ensuring dementia is not left behind in the 2030 Agenda, and its Sustainable Development Goals' are not only achieved, but that dementia is also realised as a condition causing cognitive disabilities in its own right.



Dementia 50 million

Approximately 50 million people worldwide have dementia.

One new diagnosis every 3 seconds.



Dementia cost \$818 billion

The majority of care is provided by family carers.



Mortality 7th

Dementia is now the 7th leading cause of death.

http://www.who.int/mental_health/neurology/dementia/en/
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The World Health Organisation (WHO) estimates worldwide, there are 50 million people living with dementia, and even in developed countries, often only 50% of people are formally diagnosed. In the low and middle-income countries, this formal diagnosis figure is usually much lower. There is one new diagnosis globally every 3.2 seconds (WHO, 2015)(i), and there are many types or causes of dementia, Alzheimer's Disease (AD) making up 50-70% of all dementias; it is a terminal, chronic progressive chronic illness.

There is still no cure, although there are some treatments for some types of AD that may slow down the symptoms, but are not disease modifying drugs, and it has become clear the medical model of care alone, is no longer appropriate for early stage dementia, but we need a pathway that also includes social support and disability.

Although the WHO states, "Dementia is one of the major causes of disability and dependency among older people worldwide", currently, no country or organisation that we know of provides disability assessment, support or services to anyone diagnosed with dementia.

People with dementia who are living with acquired cognitive disabilities, are therefore being denied adequate support. DAI's goal is to claim our rights under the CRPD and other Conventions as disabled persons.

However, dementia is too often not recognised as a condition causing acquired disabilities, and consequently, people with dementia are denied many human rights and the undeniable rights to access to the Convention on the Rights of Persons with Disabilities (CRPD).

DAI's vision is **"A world where people with dementia are valued and included"**.

DAI started instinctively, after many years of discussions with organizations and then others diagnosed with dementia, and is still for the purpose of self-advocacy; when our founding members were each diagnosed with dementia, they individually experienced

“the degenerating sense of ‘nobodiness’” that civil rights leader, Martin Luther King, Jr. had already recognized in another disenfranchised group, the mid-20th century African-Americans.

From day one of the organisation, DAI believed the Margaret Meade’s quote, and they continue to work hard to prove this to be true:

Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it’s the only thing that ever has.

DAI’s work on claiming the Human Rights for all people with dementia means people with dementia are legally entitled to be included, and not just consulted, or represented by others. They are also entitled to the appropriate disability support, including funding to ensure inclusion, that any other persons or groups of disabled people are afforded.

Our global focus has been on human rights and disability rights, and we continue to work with organisations such as the World Health Organisation (WHO), the United Nations, the Conventions Of State Parties and others, to ensure that since the *WHO Global action plan on the public health response to dementia 2017 – 2025(ii)*, was adopted, national, regional or local dementia plans will include human rights.

All persons with dementia must have their human rights upheld . Both dementia and disability are frequently associated with stigma, isolation and discrimination, and whilst individuals may not wish to identify as having dementia or acquired disabilities, dementia must now be recognised not only as a pathway to deficits and death, but as a condition causing an acquired cognitive disabilities and therefore is covered under the UN’s Convention on the Rights of Persons with Disabilities. For further explanation on this, please read, *Access to CRPD and SDGs by Person’s With Dementia (iii)* jointly produced by Alzheimer’s Disease International and Dementia Alliance International .

This is also why we continue to advocate at the grass roots level, and have become activists in the global space, for better care, to work towards our goal to change the reality we face daily.

Dementia and the CRPD

We include a number of reflections on human rights and the CRPD, and which generally, are being ignored in dementia and aged care.

Awareness-raising:

The Convention requires that Member States take action, including at the family level, to foster respect for the human rights of persons with disabilities. This includes action to combat stereotypes, prejudices and harmful practices including those based on age and to promote awareness of the capabilities and contributions of persons with disabilities.

This is particularly relevant to addressing the stigma and social isolation that is still a very common experience of many persons with dementia and which acts as a major barrier to

their participation in society and in achieving the social change necessary to secure their inclusion and wellbeing, including in RACF's.

Equality and non-discrimination, including the obligation to provide 'reasonable accommodation':

The Convention requires that Member States ensure that persons with disabilities enjoy equality before the law and to guarantee legal protection against all forms of discrimination.

This may include unlawful discrimination by healthcare and other service providers, driving license authorities, insurance companies and employers.

Discrimination includes the failure to provide 'reasonable accommodations', that is, modifications and adjustments that enable persons with disabilities to enjoy or exercise their human rights on an equal basis with others.

This might include assistance when shopping or with personal banking, or support (including financial support) to participate in civil society or political life.

It does also include the reasonable accommodation of our disabilities being fully supported financially to participate equally and fully in civil society, including within RACF's.

Equal recognition before the law:

The Convention requires Member States to repeal guardianship laws and to replace 'substitute decision-making' with 'supported decision making' in order to protect and promote the legal personhood and autonomy of people otherwise deemed to lack capacity.

This is particularly relevant to persons with dementia who commonly find their autonomy automatically undermined or removed following diagnosis or who do not presently enjoy access to independent advocacy for support with major decisions, such in relation to health, financial matters or their fitness to drive or travel.

Living independently and being included in the community:

The Convention requires Member States to ensure that persons with disabilities can choose where and with whom to live on an equal basis with others.

To achieve this States are required to make available living and support options that prevent segregation and isolation from the wider community, such as can be created through placement in residential care or long-term institutionalisation.

Personalized post-diagnostic support to enable persons with dementia to remain in their own home and to prevent the isolation that they frequently experience is a top priority in public opinion surveys of the views of people with dementia. The isolation experienced following a diagnosis is high this increases when someone moves into residential care.

Participation in public and political life:

The Convention requires member States to take steps to ensure that all persons with disabilities can vote, be provided with modifications and adjustments to voting procedures and even stand for election.

This point is relevant to the topic of participation in civil society, and why so few people with dementia are included on the boards of dementia advocacy members. Including people with dementia on the boards of aged care facilities potentially would also improve practice and outcomes for residents and their families or advocates.

Liberty and security of the person:

The Convention says that 'the existence of a disability shall in no case justify a deprivation of liberty.'

The Committee on the Convention of the Rights of Persons with Disabilities has issued a statement which clarified its view that 'legislation...including mental health laws, still provide instances in which persons may be detained on the grounds of their diagnosis or actual or perceived disability, provided there are other reasons for their detention, including that they are dangerous to themselves or to others.

This practice is incompatible with Article 14 as interpreted by...the CRPD committee.'

Freedom from torture, inhumane or degrading treatment:

The Convention reaffirms the rights of persons with disabilities to live free from torture, inhuman or degrading treatment.

Other UN Treaty Bodies have also interpreted this to include the disproportionate use of anti-psychotic drugs, physical restraint and being detained in psychiatric institutions and care facilities without possibility of returning to the community.

Freedom from exploitation, violence and abuse:

The Convention requires Member States to take action to protect persons with disabilities from all forms of exploitation, violence and abuse, both inside and outside the home. This includes providing assistance to individuals, families and care partners to recognise, avoid and report such behaviours and for States to ensure the effective regulation of facilities and services for persons with disabilities.

Membership of Dementia Alliance International is free, and is open and exclusive to anyone with a medical diagnosis of any type of dementia (MCI is not a dementia). Inquiries about membership: <https://www.dementiaallianceinternational.org/membership/>

i) World Health Organisation, (2018) Dementia: Fact sheets, <https://www.who.int/news-room/fact-sheets/detail/dementia>

ii) World Health Organisation, (2017) Global Action Plan for a Public Health Approach to Dementia 2017-2025, https://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/

iii) Alzheimer's Disease International and Dementia Alliance International (2016) Access to CRPD and SDGs by Persons with Dementia. London; ADI <https://www.alz.co.uk/sites/default/files/pdfs/access-crpd-dementia.pdf>

List of Speakers:



**Mrs. Catalina Devandas Aguilar,
UN Special Rapporteur on the rights of persons with disabilities**

Ms. Catalina Devandas Aguilar (Costa Rica) is a lawyer by training and a human rights advocate. She worked extensively on disability rights and inclusive development for the past 20 years, including with the World Bank, the UN Department for Economic and Social Affairs, and international donor organizations supporting the work of organizations of persons with disabilities in promoting the implementation of the CRPD. Her work priorities include socioeconomic inclusion, the promotion of full citizenship of persons with disabilities, and embracing diversity and the understanding that persons with disabilities are part of human diversity. She is married with three daughters, and has spina bifida.



Kate Swaffer

Kate Swaffer is the current Chair and Chief Executive Officer, and a co founding member of DAI, has a Masters of Science (Dementia Care, 2014), BPsych, BA, former Chef, Graduate Diploma in Grief counseling, and is a retired nurse. She was a member of the World Dementia Council, and is a current board member of Alzheimer's Disease International. She is a Humanitarian and activist for people with dementia, and those in aged care, and has made a human rights based approach to dementia, to reduce stigma, and improve the quality of life for the estimated 50 million people living with dementia globally. Kate was diagnosed with younger onset dementia 11 years ago, aged 49.

Kate is a highly published academic, author and an International speaker including at the WHO First Ministerial Conference on Dementia in March 2015, she has been key to the global advocacy of people living with dementia. She has worked with the WHO on a number of projects, and is very active in ensuring support through policy change towards claiming the rights of persons with disabilities, including from dementia.



Christine Thelker

Christine Thelker is from Vernon, British Columbia, Canada and at 59 says, her sense of humour has grown, since her diagnosis of dementia. She is a Board member of Dementia Alliance International, and previously worked for the Interior Health Authority for 13 years in various sites, including in dementia care and of life care. She advocates for families and patients and for better training for workers in dementia care. She also advocated for better working environments for the employees.

Christine designed and taught a program to nursing students at the local colleges on end of life care and dementia care, and designed a program on unattended sorrow, which was in relation to all the deaths workers saw and the cumulative effects. She believes it has many similar effects on people diagnosed with dementia and doing more work around that. Widowed at 47 and then diagnosed with Vascular dementia at 56, Christine is still advocating, using her voice to help others. She loves working with Dementia Alliance International (DAI) and believes whole-heartedly that it helps keep her living well with her dementia. Her motto since being diagnosed is "I'm not done yet".



Bethany Brown

Bethany Brown researches older people's rights at Human Rights Watch. Before joining Human Rights Watch she worked on policy and advocacy for older people with HelpAge International and HelpAge USA, where she guided research, training and work at the UN. Her work has taken her to Kyrgyzstan, Chile, Haiti, and Iraqi Kurdistan. She has co-authored a book as well as articles and chapters on older people's human rights. Bethany holds a bachelor's degree from Barnard College and a law degree from American University Washington College of Law.



Arlene A. Pietranton, PhD

Arlene A. Pietranton, PhD, CAE serves as Chief Executive Officer of the American Speech-Language-Hearing Association (ASHA), the professional scientific, and credentialing association for over 204,000: audiologists; speech-language pathologists; speech, language, and hearing scientists; and student, international and support personnel affiliates. ASHA's staff of 300 individuals are based in the association's Gold LEED certified national office located in Rockville, MD. She is an ASHA Fellow and past president of the District of Columbia Speech-Language-Hearing Association.

Arlene is an active member of the American Society of Association Executives (ASAE) and has collaborated with association executives throughout North America, Europe, Australia and Asia on association management and governance. She is an ASAE Fellow and a past Chairperson of the ASAE Board of Directors. Arlene earned a Bachelor of Arts in biology, Master of Arts in speech-language pathology, and PhD in psychology from the George Washington University.



Antony Duttine

Antony Duttine is the advisor on disability and rehabilitation at the Pan American Health Organisation/World Health Organization (PAHO /WHO). A major focus of his work centres around health equity for persons with disabilities. Prior to his work at PAHO, Antony was employed by Humanity and Inclusion, undertaking roles in Afghanistan, France and Washington DC. He also acted as chair of the International Disability and Development Consortium's Inclusive Health Task Group. Antony is a physiotherapist by profession, is currently finalizing a doctorate in public health at the London School of Hygiene and Tropical Medicine and holds a master's in development management.



Jan A. Monsbakken

Jan A. Monsbakken is Immediate Past President in Rehabilitation International (RI Global). He was President in RI Global from 2012- 2016. He is also President of RI Norway. He was Deputy Vice President of RI Europe from 2008 – 2011. He is an EC Member of RI Global. He has also been Chair of the RI Foundation from 2013-17, and is now a Board member. He is Treasurer of the Global Rehabilitation Alliance since 2018 when this organization was formally established.

Jans was Chairman of the Norwegian Federation of Disability Organization from 1999 – 2001. He was a Board member of European Disability Forum from 1998 – 2005. He was also a member of the Finance Committee. He has also served as a President for the Nordic Disability Organization. He has also been working as a teacher in Nursing Education for several years. He has been a member of a large number of different Boards and Project committees both on a National and International level. Including a Board member (Treasurer) of International Federation of Psoriasis Associations from 1999 – 2007, and leader of the Committee for World Psoriasis Day.



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