

Dementia: the leading cause of disability

Dementia Alliance International (DAI) attended the 12th Session of the Conference Of State Parties (COSP12) on the Convention on the Rights of Persons with Disabilities (CRPD) in New York, including hosting a Side Event on **Dementia: the leading cause of disability**, which will have far reaching benefits for all people with dementia, now and into the future. Watch [the live recording¹](#) of the DAI Side Event, or download the [DAI Concept note²](#) and the [DAI Handout³ provided on the day³](#).

We also wish to thank the United Nations and the World Health Organisation for supporting our event, and acknowledge our co sponsors, the Australian Government, the International Disability Alliance, Alzheimer's Disease International, Human Rights Watch, the Global Rehabilitation Alliance and the World Hospice and Palliative Care Alliance. We also thank our two sponsors, Alzheimer's Disease International and Boehringer Ingelheim. We especially thank Ms Catalina Devandas Aguilar, the UN Special Rapporteur on the rights of persons with disabilities for her opening remarks. It was a rich discussion on dementia as a disability, on people with dementia as rights bearers, and of the rights of all, including people with dementia to rehabilitation and other services, and to full and equal access to the CRPD

The overarching theme was social inclusion and health, two determinants of well-being, both of which are being systematically denied to people with dementia all around the world. Dementia had never been represented formally in a Side Event ever before at the COSP, hence why DAI felt it was so important. Our disabilities may be more invisible than many others, but we are still, even in 2019, being stigmatised and discriminated against on a daily basis, and we hope this event will be the start of change for the more than 50 million people currently living with dementia, and every person being newly diagnosed every 3.2 seconds.

As an organisation DAI intends to continue to campaign towards others understanding dementia is a condition causing acquired cognitive and other disabilities, and for full and equal access to the CRPD and other Conventions, so that no one is left behind, including people with dementia. Rehabilitation, and all other health and disability services and support are essential for maintaining independence and dignity, for longer, and whilst dementia is a terminal condition, we should not all be 'dying at diagnosis'.

Chair: **Kate Swaffer**, Introduction and overview of the event and introduction of speakers

Speakers:

Ms Catalina Devandas Aguilar, UN Special Rapporteur on the rights of persons with disabilities: Opening remarks

Christine Thelker, DAI Board Member: "Dementia as a disability"

Bethany Brown, Researcher, Older People's Rights, Disability Rights Division, Human Rights Watch: "Violations of the rights of older people with dementia"

Arlene Pietranton, American Speech-Language-Hearing Association: "Rehabilitation for dementia and aphasia"

Mr Antony Duttine, Regional Advisor in disabilities and rehabilitation, Pan American Health Organization/World Health Organisation (PAHO/WHO): "QualityRights"

Jan Monsbakken, Global Rehabilitation Alliance: "The Rights to Rehabilitation for All"

Kate Swaffer, DAI, Chair/CEO: Closing remarks



1 <http://webtv.un.org/search/the-leading-cause-of-disability-cosp12-side-event/6047924231001/?term=&lan=english&page=1>

2 <https://www.dementiaallianceinternational.org/wp-content/uploads/2019/06/DAI-COSP12-Concept-Note-1-1.pdf>

3 <https://www.dementiaallianceinternational.org/wp-content/uploads/2019/06/DAI-COSP12-Side-Event-Handout.pdf>

