

DEMENTIA IN EUROPE

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Plenary 3 “Intersectionality in dementia”

A presentation on “Achieving Cultural Inclusivity in Dementia Care” was delivered by Karan Jutlla, Head of Health Research Centre & Dementia Lead for the University of Wolverhampton. Dr Jutlla discussed ways for improving cultural inclusion to reduce inequalities in dementia and to ensure that widespread accessibility to care becomes a reality. As evidenced in her latest report, co-production is integral to achieving equitable access to support services for people with dementia and their family members and carers. She also highlighted the importance of co-production and invited the audience to consider how culturally-inclusive care can be achieved via a person-centred approach: “In order to achieve cultural inclusivity in dementia care, we must recognise the importance of intersectionality and practice person centred dementia care”, she said.

Dr Alain Dekker from Alliage Care Group and University of Groningen/UMCG (Netherlands) discussed “Dementia in people

with intellectual disabilities: introduction to both Down syndrome and severely disabled populations”. He began by stating that a diagnosis of dementia in people with intellectual disabilities is important for understanding changes and making informed choices about support, treatment and organisation of care. People with Down syndrome, he noted, are at extremely high genetic risk to develop dementia due to Alzheimer’s disease. In people with severe/profound intellectual disabilities, whom he said are until now a largely neglected group when it concerns dementia, the observability of dementia symptoms is different and diagnosing dementia therefore requires closer observation of small changes, in specific daily contexts. He said this depends on acquired skills at baseline and requires a newly-developed diagnostic aid.

Linn Sandberg, Associate Professor Gender Studies, Södertörn University (Sweden) presented “Are they here, are they queer? LGBTQ People with Dementia and the limits

of person-centred care”. She reminded delegates of the importance of challenging heteronormativity in dementia care. Dementia care staff in her current research often stated that they ‘treated everyone the same’ and that sexual and gender identities were very rarely discussed. But, she said that this results in a continuous invisibility and lack of recognition of lesbian, gay, bisexual, trans and queer (LGBTQ) people living with dementia. “Having to repeatedly ‘come out’, to navigate heteronormative care, and to advocate for one’s rights puts undue stress on LGBTQ people living with dementia and on their partners”, she said, stressing that dementia illnesses, as well as the organisation of dementia care, poses particular challenges for LGBTQ people to communicate their life histories, maintain relationships and connections to communities that have been significant to them.

Päivi Topo, Ombudsman for Older People in Finland, discussed “How to better support people living with dementia from socio-economically disadvantaged groups”. She highlighted several virtual health promotion activities, including web-based activities that require no digital skills, since digital skills are rarer among older adults in lower socioeconomic groups than other older adults. She said, “people with dementia living alone with no social network are at high risk of not receiving the support, services and care they need across all socioeconomic groups”. It was most important, from her perspective, that older adults find the activities on offer to be both interesting and beneficial. Group activities are particularly helpful in this respect as they help create social contacts, she noted. Two national programmes promoting health and exercise for older adults exist in Finland, with emphasis being put on better access to care of older adults in socially disadvantaged groups, but improvements are needed in several areas.



Plenary 3 moderators and speakers (left to right): Jean Georges, Karan Jutlla, Päivi Topo, Alain Dekker, Linn Sandberg and Kim Coppes



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