

A Symposium on Dementia and Human Rights

Long Room Hub

Trinity College Dublin

November 8th

The theme of this symposium is “Dementia and Human Rights”. The theme has been chosen carefully as conventionally dementia is seen as a syndrome caused by a disease and not as a disability or a disability/human rights issue. While the disease framing of dementia compels us to think about plaques and tangles, brain scans, drugs, passivity and tragedy, the human rights framework is based on human dignity, autonomy, citizenship, participation and personhood. It requires governments to treat all people fairly and never to discriminate: the goal is to promote human flourishing and a good quality of life.

Ireland’s ratification of the UN Convention on the Rights of Persons with Disabilities is admirable but how can the Convention be used by people living with dementia and their families to enjoy a better quality of life? Have people with this condition a right to home care services or should they be expected to pay for such services? To what extent does the Irish National Dementia Strategy underpinned by a person-centered philosophy promote the citizenship and autonomy rights of the individual? Are newly evolving policies on dementia being cross-checked to ensure compliance with human rights principles?

This Symposium brings together national and international experts and aims to explore these along with other dementia-related issues in more depth. The Symposium will be directly relevant to the learning needs of health and social care professionals working in the field of dementia care in Ireland along with policy makers, researchers and family members affected by Alzheimer’s disease and the related dementias.

Speakers Bios and Abstracts

Keynote Speaker Professor Steve Sabat

Steven R. Sabat is Professor Emeritus of Psychology at Georgetown University. His research has focused on the intact cognitive and social abilities, the subjective experience and selfhood of people with moderate to severe dementia, as well as enhancing communication between people with dementia and their carers. He is the author of numerous articles in scientific journals and chapters in books. As well, he is author of *The Experience of Alzheimer’s Disease: Life through a Tangled Veil* (2001), *Alzheimer’s Disease and Dementia: What Everyone Needs to Know* (2018) and co-editor of *Dementia: Mind, Meaning, and the Person* (2006).

In this keynote address, Professor Sabat will address the topic of the ‘disability of dementia’ suggesting that dementia is more than a pathology’. He will argue that the behavior and performance of the individual diagnosed with dementia can never be solely explained in terms of neurodegenerative decline but rather must be explained as a combination of biological (organic/somatic) psychological and social factors. Steve will also show, that despite the dysfunctions that people diagnosed experience due to brain injury there is a host of important abilities that still remain and need to be honored. These are abilities shared by us all and so whatever it is about us that endows us with human rights, those endowments are possessed as well by people diagnosed with dementia.



Dr Helen Rochford Brennan

Helen Rochford-Brennan is from Tubbercurry in County Sligo, Ireland. For many years, Helen was employed in the tourism and disability sectors and has also devoted tireless years to community activism, working at board level in several organisations. In July 2012, Helen was diagnosed with early onset Alzheimer's disease. Since then she has been Chair of the Irish Dementia Working Group, an advocacy group resourced by The Alzheimer Society of Ireland and as Chair has used her time very efficiently to raise awareness of dementia and raise the profile of human rights for people with dementia. Since 2016, she has been Chair of the European Working Group for People with Dementia.



In this presentation Dr Helen Rochford Brennan will address the topic of 'dementia as a disability rights and human rights' concern. She will draw on her own personal experience and journey through dementia to date to highlight some of the structural and attitudinal barriers people diagnosed with this condition continue to encounter. As Chair of the European Working Group on Dementia she will also highlight examples of best practice observed in other European countries.

Professor Suzanne Cahill

Suzanne Cahill is former National Director of the Dementia Services Information and Development Centre in Ireland and is currently an Adjunct Professor in Social Work and Social Policy at Trinity College Dublin and Honorary Professor of Dementia Care at the Centre for Economic and Social Research in Dementia in NUI Galway She is recognized nationally and internationally as a commentator and expert on dementia matters. Suzanne has published extensively in peer-reviewed journals and in 2018 wrote a book titled Dementia and Human Rights that has generated much interest. She currently serves on the Expert Advisory Group of Alzheimer Europe, on the Irish National Dementia Strategy Monitoring and Evaluation Committee, on the Editorial Board of Dementia and the International Journal of Social Research and Practice. She was co-founder of Ireland's first Alzheimer Café.



Suzanne will introduce the topic and chair the morning's proceedings

John Costello

John is a practicing consultant Solicitor and has had close to 40 years experience advising clients in relation to wills, administration of estates, tax planning, wards of court, powers of attorney and other legal issues concerning the elderly. He also specialises in advising on charity law and family law. He is a Past President of the Law Society of Ireland and a former Chairperson of the Society's Law Reform Committee and the Guidance and Ethics Committee, during which time he was involved in the production of The Charity Law Report. John is the author of a best-selling book titled 'Law & Finance in Retirement' updated in November 2016. He is a former director of St. Michael's House and he has spent a number of years lecturing to members of organisations who assist persons with an intellectual disability. For many years John has given legal assistance to the Alzheimer Society of Ireland. John is currently the Chairman of the Parole Board where he has earnestly set about endeavouring to improve procedures and efficiency.



Article 12 of the UN Convention on the rights of Persons with Disabilities, which Ireland ratified in March 2018, recognizes that where people with Dementia can no longer exercise their legal capacity, assistance must be provided to support their decision-making. This support must respect their rights will and preferences. The Assisted Decision-Making (Capacity) Act 2015 follows these principles by providing for Decision-Making Assistance Agreements, Advance Health Care Directives, Enduring Powers of Attorney and a Court appointed Decision-Making Representative. All these alternative decision-making mechanisms will be analysed from a Human Rights and dementia perspective and in the context of this new Irish Act that has only been very partially implemented to date.

Tadhg Daly

For the last fifteen years, Tadhg has been the Chief Executive Officer of Nursing Homes Ireland and prior to this was employed as the National Development Officer for the Irish Society for the Prevention of Cruelty to Children. Nursing Homes Ireland is the representative organisation for the private and voluntary nursing homes sector in Ireland and this sector along with the care its members provide are key parts of the Irish health services. In his role as CEO, Tadhg is a powerful advocat for older people’s rights in long term residential care, including the rights of people diagnosed with dementia. He is also a well known commentator frequently participating in radio and TV inteviews focusing on this topic.

At this Symposium Tadhg will participate in the afternoon panel discussion focusing on human rights and dementia.

**Colette Kelleher**

Colette is an Irish [independent](#) politician who has served as a [Senator](#) since May 2016, after being [nominated by the Taoiseach](#). She previously served as the [CEO](#) of the [Alzheimer's Society of Ireland](#), during which time the Society published its first Charter on Human Rights and Dementia. Colette holds a MBA, comes from [Macroom](#) and she formerly worked as a social worker in [Dublin](#) where she undertook her Social Work under-graduate training in University College Dublin. Colette’s presentation will focus on the politics of dementia care where, drawing on the Irish Charter of Human Rights and Dementia, she will highlight some of the critical connections between personal experiences and larger social and political structures.

**Pat McLoughlin**

Pat McLoughlin worked as a management consultant prior to becoming Chief Executive of The Alzheimer Society of Ireland in 2016. He served on the management teams of four health boards and was Chief Executive of the South Eastern Health Board and Eastern Health Board. He was the first National Director of the National Hospitals office and Deputy CEO of the HSE. He has assisted Government, on a pro bono basis, in reviews of public expenditure, local government, childcare, health insurance and the Dept of Justice. He has served as Chairman and a member of a number of voluntary organisations. He holds a B.A. and an L.L.B. from N.U.I. Galway and an M.B.A. from Strathclyde Business School.

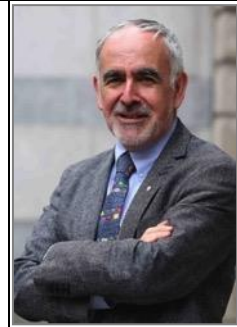
At this Symposium Pat will participate in the afternoon panel discussion focusing on human rights and dementia.



Professor Des O'Neill

Desmond (Des) O'Neill, a specialist in geriatric and stroke medicine is also a writer and commentator in national media. Based in Tallaght Hospital and Trinity College Dublin, his practice and research are focussed on ageing and the neurosciences, and how they interact with the humanities. His particular interest in the longevity dividend - the many ways in which we have gained from our increase in life span - has contributed to national and international initiatives in many aspects of ageing. In 2010 he was awarded the All Ireland Inspirational Life Award for his work on behalf of older people.

Professor O'Neill will chair the afternoon panel discussion on human rights autonomy and dementia.

**Professor Eamon O'Shea**

Eamon O'Shea is a Personal Professor in the School of Business & Economics and was inaugural Director of the Irish Centre for Social Gerontology (ICSG) at the National University of Ireland, Galway. He is currently Director of the Centre for Economic and Social Research on Dementia at NUI Galway. He holds an MA from University College Dublin, an MSc. from the University of York and a PhD from the University of Leicester. He has published over 100 scientific papers in refereed journals, including publications in top-ranked journals. Professor O'Shea has authored/co-authored 15 books and monographs, mainly in the field of ageing, dementia and social policy. His work has been highly influential in setting the agenda for the reform of services and policies for people with dementia in Ireland. He was Chair of the National Economic and Social Forum Expert Group on Care of the Elderly in 2005/06 and co-authored the influential Creating Excellence in Dementia Care report in 2012. He is currently a member of the Implementation Group for the Irish National Dementia Strategy.

The Irish National Dementia Strategy published in 2014 is underpinned by guiding principles of citizenship and personhood but what exactly do these principles mean to the majority of Irish people diagnosed with dementia and their caregivers? How are principles of citizenship and personhood being operationalized in the implementation of the National Strategy and how can Irish health and social care services be reconfigured to address the needs of people living with dementia and their caregivers in a way that is responsive and flexible. These along with other policy-related issues will be discussed in Professor O'Shea's presentation.

**Susan Scally**

Susan Scally has been working in the Department of Health since 2011 and is currently head of Social Care Integration Unit, a new unit established in the Social Care Division of the Department of Health earlier this year. Social Care Integration Unit is responsible for developing policy and providing oversight of the provision of health and personal social services for people with dementia, adults and children with palliative care needs and family carers, as well as regulatory issues related to designated centres for older people and people with a disability. Susan has held various roles at Principal Officer level in the Department of Health, including in the Scheduled and Unscheduled Care Performance Unit and the Drugs Policy and Social Inclusion Unit. Prior to joining the Department of Health, Susan worked on community, rural and local development issues in the Department of Community, Rural and Gaeltacht Affairs and is a former director of the National Advisory Committee on Drugs. Susan spent the early part of her career in the Department of Social Protection.



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