



School of Law
Scoil an Dlí

SHAPING A **JUST SOCIETY**
SINCE 1849

Drilling Deep into the Assisted Decision Making (Capacity) Act 2015- Considerations for Health and Social Care Practice

29th November 2019

**Brookfield Health Sciences Building,
University College Cork**



**seirbhís tacaíochta
cinnteoireachta**

decision support service



Building a
Better Health
Service

Seirbhís Sláinte
Níos Fearr
á Forbairt





National Quality Improvement Team

Agenda

Time	Speaker and Topic
8.00am	Registration
9.00am	Opening address and welcome Professor Mary Donnelly, School of Law, University College Cork (UCC) and Chair of the HSE Assisted Decision Making Steering Group
9.10am	Plenary Address Ms. Aine Flynn, Director, Decision Support Service-Mental Health Commission
9.30am	Session one: Relevant person- a recalibration for the centrality of rights or just more semantics? Chair and opening address Dr. Joan McCarthy, Senior Lecturer in Healthcare Ethics, School of Nursing and Midwifery, UCC Collaborators: Mr. Mervyn Taylor, on behalf of the National Patient Forum Ms. Judy Ryan, Director, Nursing and Midwifery Planning and Development, HSE South East Dr. Fiona McElligott, Consultant in Paediatric Palliative Medicine, Children’s Health Ireland at Temple Street
10.30am	Question and Answer Session Chaired by Dr. Joan McCarthy
10.45am	Break
11.15am	Session Two: Getting to the core of the Act- Will and preference, support, unwise decisions, risk and liability- reflections on practice Chair and opening address: Professor Mary Donnelly, School of Law, UCC Collaborators: Ms. Louise Loughlin, National Manager, National Advocacy Service for People with Disabilities, Professor Shaun O’Keeffe, Consultant Gerontologist, University College Hospital Galway (UCHG), Ms. Elaine Teague, Director of Quality Improvement and Safety Development, Ms. Caroline Howorth, Head of Speech and Language Therapy, & Ms. Niamh Holland, Senior Clinical Psychologist, St. Michael’s House.
12.15pm	Question and Answer Session Chaired by Professor Mary Donnelly
12.30pm	LUNCH
1.30pm	Opening address Mr. John Farrelly, CEO of Mental Health Commission

Time	Speaker and Topic
1.40pm	<p>Session Three: Preserving the centrality of the voice of the person - practice issues and conundrums</p> <p>Chair and opening address Mr. Alex Ruck Keene, Barrister, Writer and Educator specialising in Mental Capacity Law, England and Wales</p> <p>Collaborators Dr. Fiona Morrissey, Disability Law Researcher Dr. Brendan O’Shea, General Practitioner and Assistant Adjuvant Professor at Trinity College Dublin Dr. Helen Rochford Brennan, Chair, European Working Group of People with Dementia</p>
2.40pm	<p>Question and Answer Session Chaired by Mr. Alex Ruck Keene</p>
2.55pm	<p>Session Four: The functional assessment of capacity - transforming reductive capacity assessments?</p> <p>Chair and opening address: Professor Brendan Kelly, Consultant Psychiatrist, Tallaght University Hospital and Trinity College, Dublin</p> <p>Collaborators: Professor Shaun O’Keeffe, Consultant Gerontologist, UCHG Mr. Alex Ruck Keene, Barrister, Writer and Educator specialising in Mental Capacity Law, England and Wales Dr. Patricia Rickard Clarke, Chair, Safeguarding Ireland and Sage Advocacy</p>
3.55pm	<p>Question and Answer Session Chaired by Professor Brendan Kelly</p>
4.10pm	<p>Closing Address Ms. Caoimhe Gleeson, National Programme Lead, HSE National Assisted Decision Making and Consent Office</p>
4.20pm	<p>Close</p>

Biographies

<p>Professor Mary Donnelly</p> 	<p>Professor Mary Donnelly is a Professor and Vice Dean of the School of Law at University College Cork. She researches in the fields of mental capacity/mental health/health law. Her books include <i>Healthcare Decision-Making and the Law: Autonomy, Capacity and the Limits of Liberalism</i> (Cambridge: Cambridge University Press, 2010) and she is co-author of <i>End-of-Life Care: Ethics and Law</i> (Cork University Press, 2011) and co-editor of <i>Ethical and Legal Debates in Irish Healthcare: Confronting Complexities</i> (Manchester University Press, 2016). She was a member of the Expert Group to review the Mental Health Act 2001 (2013-2015) and is a member of the Mental Health Commission Legislation Committee. She was Chair of the Technical Expert Group to develop Codes of Practice under the Assisted Decision-Making (Capacity) Act 2015. She is the joint chair of the HSE National Consent Advisory Group. She is Chair of the HSE Assisted Decision Making Steering Group and Chair of the Advance Healthcare Directives Multidisciplinary Working Group.</p>
<p>Ms. Áine Flynn</p> 	<p>Ms. Áine Flynn graduated from Trinity College Dublin with a law degree and M.Litt. by research. She was admitted as a solicitor in 1999 and from 2012-2017 was a senior partner in KOD Lyons, a firm specialising in public interest law, including disability and equality law. She was on the panel of legal representatives of the Mental Health Commission and the Mental Health (Criminal Law) Review Board from their inception in 2006 and also represented Wards of Court instructed by the General Solicitor. She has written and lectured on Human Rights and has been a member of the Human Rights Committee of the Law Society since 2012. Prior to her present appointment, she was a member of the Law Society's Mental Health and Decision-Making Capacity Task Force. In October 2017, Áine commenced in post as inaugural Director of the Decision Support Service within the Mental Health Commission.</p>
<p>Dr. Joan McCarthy</p> 	<p>Dr. Joan McCarthy is a Senior Lecturer in Healthcare Ethics in the School of Nursing and Midwifery, University College Cork, and a Visiting Professor in the Faculty of Health and Medical Sciences, University of Surrey, UK. Her research interests include: ethics at the beginning and end of life; nursing and midwifery ethics, and; feminist perspectives on bioethics. She has led, and collaborated on, a number of national and international research projects funded by, e.g., the Irish Hospice Foundation, Wellcome Trust, and the Irish Research Council. Her publications include: <i>End-of-Life Care: Ethics and Law</i>, 2011, Cork: Cork University Press (with M. Donnelly, D. Dooley, L. Campbell and D. Smith) and <i>Nursing Ethics, Irish Cases and Concerns</i>, 2012, Dublin: Gill and MacMillan (with D. Dooley). See http://publish.ucc.ie/profiles/C014/jmccarthy for her complete profile.</p>
<p>Mr. Mervyn Taylor</p> 	<p>Prior to joining Sage, Mervyn was Director of M.S. Ireland, CEO of the MS Care Foundation, Manager of Planning & Organisation with the National Social Service Board (now Citizens Information Board), and European Development Manager for a consortium of IT companies. From 2006 - 2012, Mervyn was Manager of the Hospice Friendly Hospitals (HFH) Programme and from 2009 was Project Manager for the Forum on End of Life and of its flagship project 'Think Ahead'. He also managed the pilot project for the HFH Programme at Our Lady of Lourdes Hospital in Drogheda, from 2004-2006, which won a Taoiseach's Public Service Excellence Award. He is currently a member of the Council of the Forum on End of Life and a Director of the Fourth Age Trust. Mervyn holds a BA and MSc (Community Health) from Trinity College Dublin, has studied Creativity & Innovation with the Open University and Leadership with Cranfield University School of Management.</p>

Ms. Judy Ryan



Ms. Judy Ryan RNID, PGDip, Dip., MSc. Judy trained as a Registered Nurse in Intellectual Disability (RNID) spending time in both Scotland and the UK before returning to work in Intellectual Disability services in Ireland. With a career extending across services, practice development and managerial posts, Judy is the Director of the Nursing and Midwifery Planning and Development Unit (NMPDU) South East where her role involves strategically supporting the professions development of nursing and midwifery.

Dr. Fiona McElligott



Dr. Fiona McElligott is a newly appointed Consultant in Paediatric Palliative Medicine (PPM) to Children's Health Ireland at Temple Street, with liaison in reach to The Rotunda Hospital. A graduate of University College Cork, she is a fellow of The Royal College of Paediatrics and Child Health, UK and The Royal College of Physicians of Ireland. She completed a diploma in paediatric palliative care in 2012, prior to pursuing sub-speciality GRID training in PPM in Yorkshire, UK. During this time she was the trainee representative on the PPM College Specialty Advisory Committee (CSAC). Prior to returning to Ireland, Fiona worked as a consultant in PPM in the National Health Service (UK) in Leeds and in Sheffield and was an executive member of the Yorkshire and Humber Children's Palliative Care Network as well as chair of its Education Subgroup. She was an honorary lecturer for Leeds and Sheffield Universities. Fiona is a member of the National Development Committee on Children's Palliative Care, and a board member of LauraLynn Ireland's Children's Hospice.

Ms. Louise Loughlin



Ms. Louise Loughlin is the National Manager of NAS. Louise has worked with NAS since 2011, and has been national manager since 2016. Louise is a Qualified Solicitor in Scots law and has expertise in the areas of advocacy and the rights of people with disabilities across three jurisdictions. Louise has a particular interest in capacity issues and safeguarding. Louise is a member of the National Safeguarding Committee and the HSE Safeguarding Vulnerable Adults Policy Review Group. She is also a member of the NDA Expert Group on Codes of Practice for the Assisted Decision Making (Capacity) Act 2015, the oversight from for the National Patient Experience Survey and the advisory committee for the Decision Support Service.

Professor Shaun O'Keeffe



Professor Shaun O'Keeffe MD FRCPI graduated from University College Dublin and St Vincent's Hospital, Dublin. He trained in Internal and Geriatric Medicine in Galway, Dublin, Boston and Liverpool. He was Consultant Physician in St Michael's and Vincent's Hospitals in Dublin before becoming Consultant Geriatrician in Galway University Hospitals in 2000 and subsequently an Honorary Personal Professor of Medicine at NUI Galway. He is a member of the HSE and Department of Health working groups on implementing the Assisted Decision Making (Capacity) Act, including advance healthcare directives. He is Co-Chair of the HSE National Consent Steering Group. Research interests include cognitive impairment, sleep disturbance and ethical issues in the care of older people.

Ms. Elaine Teague



Ms. Elaine Teague joined St. Michael's House in 1994 and has worked across a wide range of services including frontline services for children and adults with an intellectual disability. Elaine has also worked as a service manager and in the training department. Her work experience includes working in Mental Health services and in Education settings for third level social care students. Elaine has an honours degree in Social Care, a post graduate qualification in Training and Education from DCU, A Corporate Governance qualification from DCU Ryan Academy. Elaine also has a qualification in Quality Management and is a graduate from Trinity College with a postgraduate certificate in Implementation Science. Elaine was appointed to the role of Director of Quality Improvement and Safety Development in November 2018. This was a new role to St. Michael's House and St. Michael' House now has a well-established and integrated Quality and Safety Department. The department supports the continuous quality improvement of the services provided in St. Michael's House.

Ms. Caroline Howorth



Ms. Caroline Howorth is Speech and Language Therapy Manager in St. Michael's House, Dublin (Service for People with an Intellectual Disability). She graduated with a BSc. in Clinical Speech and Language Studies from Trinity College Dublin. She has also obtained a MSc. in Disability and Rehabilitation Studies from University College Dublin. Caroline has worked with children and adults across Primary Care and Disability Settings. At a national level, Caroline is a member of CORU's Appeals Committee and is the HSCP Representative on the HSE's National Consent Policy Advisory Group. She has had presentations at national and international conferences including CPOOL, RCSLT, IASLT and IASSID. Her main research interests relate to promoting communication opportunities for children and adults with complex needs within everyday settings and involving service user feedback in healthcare design.

Ms. Niamh Holland



Ms. Niamh Holland graduated from UCD with a M.A in psychology in 1988. She started working in St. Michael's House the following year 1989. Initially worked frontline in a number of residential houses before moving into a management role within residential services. In 2001 Niamh returned to complete her training in clinical psychology. Since qualifying has worked as a member of the psychology department in St. Michael's House and work primarily with adults across a number of settings. Her role as a Clinical psychologist involves working with all stakeholders involved in a service user's life to ensure the best quality of life is achieved for the individual. She works at an individual and a systemic level, working closely with service users, staff and families and also provides training to staff in PBS sexuality and understanding dementia. One of her roles within the organisation is to chair a committee with overall responsibility for the organisational performance and progress regarding the promotion, implementation, compliance and oversight of St. Michael's House Policy on Identity, Relationships and Sexuality. In 2017/18 she was involved in revising the organisations sexuality policy in line with current legislation with particular reference to the ADM (Capacity Act 2015). In 2018-2019 Niamh completed a Postgraduate Certificate in Sexuality and Relationships for people with Intellectual disabilities.

Mr. John Farrelly



Mr. John Farrelly was educated at Royal College of Surgeons, Honourable Society of King's Inns, Harvard, Smurfit Business School, UCD and the London School of Economics & Politics. John's professional goal is to develop efficient/effective organisations which deliver optimum impact for the public through skilled, determined and compassionate people who apply the law without fear or favour. John has a passion for all sports, most particularly Gaelic Football.

Mr. Alex Ruck Keene



Mr. Alex Ruck Keene is an experienced English barrister, writer and educator. His practice (at 39 Essex Chambers in London) is focused on mental capacity law (broadly defined). He has appeared in cases involving the Mental Capacity Act 2005 at all levels up to and including the United Kingdom Supreme Court and the European Court of Human Rights. He also writes extensively in the field, editing and contributing to leading textbooks and (amongst many other publications) the 39 Essex Chambers Mental Capacity Law Report, the ‘bible’ for solicitors (and others) working in the area.

Alex is the creator of the website www.mentalcapacitylawandpolicy.org.uk, providing resources and expert commentary on some of the most difficult mental capacity issues. Alex is a Visiting Senior Lecturer at the Institute of Psychiatry, Psychology and Neuroscience at King’s College London, a Visiting Lecturer at the College’s Dickson Poon School of Law, and a Wellcome Trust Research Fellow there, working on the collaborative Mental Health and Justice project for the period 2017-2022. He spent from November 2016 to March 2017 on secondment to the Law Commission of England & Wales as a consultant to their Mental Capacity and Deprivation of Liberty Project, and 2018 as legal adviser to the Independent Review of the Mental Health Act 1983 in England & Wales. Alex has a particular interest in comparative mental capacity law, co-editing *The International Protection of Adults* (OUP, 2015), contributing to a forthcoming textbook on assessment of mental capacity in New Zealand, and – closer to home – providing input into law reform processes in the Republic of Ireland, Northern Ireland and Scotland.

Dr. Fiona Morrissey



Dr. Fiona Morrissey completed a PhD in disability law at the Centre for Disability Law and Policy at NUI, Galway in 2014, which focused on the implementation of a legal framework for advance healthcare directives in Ireland. She is particularly interested in affecting cultural change towards human rights-based approaches which focus on the ‘voice’ of the person in healthcare and related services. Her research has been published in international journals and books including the *European Journal of Health Law* and the *Journal of Ethics, Medicine and Public Health*. As part of her research, Fiona spent a period in the State of Virginia in the United States examining the effective implementation of advance healthcare directives in the healthcare system. Fiona has been actively involved in capacity law reform in Ireland and internationally since 2009. She was involved in the campaign leading to the enactment of the Assisted Decision-Making (Capacity) Act 2015 (ADMA), and prepared legislative submissions to the Department of Health on behalf of the Irish Mental Health Commission and other bodies. Fiona is a member of the national working group, which was established to develop Codes of Practice for advance healthcare directives under the Assisted Decision-Making (Capacity) Act 2015. She is currently involved in delivering a new WHO based training programme for health professionals, which promotes human rights standards in healthcare and disability related services internationally.

Dr. Brendan O’Shea






Dr Brendan O’ Shea, MD FRCGP MICGP is a GP & Principal in Practice in Co Kildare, on Council at The Irish College of General Practitioners, and Assistant Adjuvant Professor at Trinity College Dublin. Professional interests include improving care for people with multimorbidities, end of life planning and overweight. He presently chairs The Clinical Advisory Group at the RCPI on Obesity, and is on Board of Directors at The Irish Hospice Foundation. He has previously acted as Irish Representative on Council at EURACT, and also as Director PRC at the ICGP. Non withstanding somewhat intractable difficulties within the Irish Health System, he practices being a committed rational optimist, and frequently and casually but systematically avails of inspiration and energy from people attending for care, and from students.

Dr. Helen Rochford Brennan



Dr. Helen Rochford-Brennan is the current Chairperson of the European Working Group of People with Dementia and is the group’s nominee to the Board of Alzheimer Europe; she is former Chair of the Irish Dementia Working Group. Helen is on the Monitoring Committee of Ireland’s first National Dementia Strategy and a Global Dementia Ambassador. Throughout her time with these organisations she has campaigned to raise awareness of dementia through a Rights based approach, to the media, speaking at international conference’s, engaging with pharma, scientists, clinicians, educators, students and many research projects from developing evidence –based diagnosis to palliative care. Helen was diagnosed after a five year struggle with Early Onset Alzheimer’s at the age of 62 and has since written very personally about living with Alzheimer type of dementia. She hopes her participation in research will one day help find a cure. Despite her pain of coping with short term memory on a daily basis she continues to volunteer with support trying to make the

	<p>change she wants to see in the world. Throughout Helen’s life she has been a Rights and Social Justice Campaigner and today advocates for the Rights of People with Dementia in particular Alzheimer’s disease. Helen has received awards for her advocacy work and last year was awarded an Honorary Doctor of Laws degree from the National University of Ireland Galway.</p> <p>She has contributed to books: Dementia and Human Rights: Suzanne Cahill. Global Perspectives on Legal Capacity Reform Our Voices Our Stories: Centre for Disability and Law NUI Galway. Hear/say Global Stories of Aging and Connections: Global Brain Health UCSF/Trinity College. Helen is currently collaborating on books with Salford and Hull Universities and a documentary film for GBHI on life with Dementia. Creating awareness of Dementia in her community and throughout Ireland plus enjoyment with her family and friends is her greatest joy.</p>
<p>Professor Brendan Kelly</p> 	<p>Professor Brendan Kelly is Professor of Psychiatry at Trinity College Dublin, Consultant Psychiatrist at Tallaght University Hospital, Dublin, and UCD Visiting Full Clinical Professor at University College Dublin School of Medicine and Medical Sciences. In addition to his medical degree (MB BCh BAO), he holds masters degrees in epidemiology (MSc), healthcare management (MA) and Buddhist studies (MA); and doctorates in medicine (MD), history (PhD), governance (DGov) and law (PhD). He has authored and co-authored over 250 publications in peer-reviewed journals, over 500 non-peer-reviewed publications, 13 book chapters and contributions, and 11 books (eight as sole author). His recent books include ‘Hearing Voices: The History of Psychiatry in Ireland’ (2016), ‘Mental Illness, Human Rights and the Law’ (2016) and ‘The Doctor Who Sat For A Year’ (2019). He is a Fellow of the Royal College of Psychiatrists, the Royal College of Physicians of Ireland, and Trinity College Dublin. In 2017, he became Editor-in-Chief of the <i>International Journal of Law and Psychiatry</i>.</p>
<p>Dr. Patricia Rickard Clarke</p> 	<p>Dr. Patricia Rickard-Clarke is a solicitor and former Commissioner of the Law Reform Commission. She is the Independent Chair of the Safeguarding Ireland, Chair of SAGE Advocacy clg, a Board Member of Third Age Foundation clg. She is a member of the HSE’s National Assisted Decision-Making (Capacity) Act Steering Group preparing for the implementation of the <i>Assisted Decision-Making (Capacity) Act 2015</i>, a member of the Multi-Disciplinary Group appointed by the Minister for Health to draft a code of practice for Advance Healthcare Directives and was a member of the National Disability Authority’s Expert Group that developed the non-health care codes of practice for the 2015 Act. She has contributed to a number of publication including the Irish section of the publication on the <i>International Protection of Adults</i> published by Oxford University Press.</p>
<p>Ms. Caoimhe Gleeson</p> 	<p>Ms. Caoimhe Gleeson is the National Programme Lead for Assisted Decision Making in the HSE and has overseen the drafting of the Healthcare Codes of Practice on the Assisted Decision Making (Capacity) Act 2015 on behalf of the Decision Support Service and the Minister for Health. She is a member of the National Disability Authority Technical Group who drafted the non-healthcare Codes of Practice on the 2015 Act on behalf of the Department of Justice. She is also HSE National Specialist in Accessibility and has worked in the area of equality and human rights advocacy, service user partnership, policy and service development for a number of years in Ireland in relation to people with disabilities, the LGBTI Community and other diverse groups.</p> <p>Before joining the H.S.E. she worked in Community Development with NUI, Galway in partnership with a wide variety of agencies and non-governmental organisations in the North West region of the Republic of Ireland and in Northern Ireland. She has worked and volunteered on programmes relating to gender equality, youth work, intercultural education, conflict transformation and mediation, development of civil society and citizenship rights in El Salvador, Ghana, United States, Mongolia, Croatia and Bosnia-Herzegovina.</p> <p>She holds a Master’s Degree in Community Development, a Professional Diploma in Equality and Human Rights, is an accredited mediator and qualified psychotherapist. She is currently studying for an LLB.</p>