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# UCC

**University College Cork, Ireland**  
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# The Assisted Decision-Making (Capacity) Act 2015: Personal and Professional Reflections

Edited by Mary Donnelly and Caoimhe Gleeson

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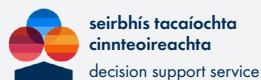




# The Assisted Decision-Making (Capacity) Act 2015: Personal and Professional Reflections

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This book is dedicated to everyone who has advocated for changes in legislation in this area, especially those who are no longer with us.

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## **Disclaimer:**

This book contains a number of personal and professional reflections on the Assisted Decision-Making (Capacity) Act 2015. Unless specifically stated otherwise, all opinions here are those of the authors and do not represent the views of the organisations in which the authors work.

While every attempt has been made to ensure accuracy, the content in the book should not be relied upon as legal advice or opinion.

The characters described in the case studies used in this book do not represent any single individual but are representative narratives which have been assembled based on the authors' professional experiences. Any resemblance to any individual living or dead is entirely coincidental.

THE ASSISTED DECISION-MAKING (CAPACITY) ACT 2015:  
PERSONAL AND PROFESSIONAL REFLECTIONS

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# Foreword

*Aine Flynn — Director of the Decision Support Service*

On 30 December 2015, President Higgins signed into law the Assisted Decision-Making (Capacity) Act 2015.

According to its long title, it is:

‘An Act to provide for the reform of the law relating to persons who require or may require assistance in exercising their decision-making capacity, whether immediately or in the future...’

The signing of the 2015 Act came about after a protracted legislative process and extensive consultation and it has been broadly, if not unreservedly, welcomed as reforming, human rights-based legislation. It has been described as ‘a seismic cultural shift away from a paternalistic and ‘best interests’ approach...to a right-based approach of choice, control and consent’ (Inclusion Ireland).

Although fully enacted, the 2015 Act is largely not yet operational. At time of writing, intensive work is ongoing to prepare for its commencement and, more than five years on, stakeholders are rightly impatient to know when an Act that promised so much will finally deliver. According to early departmental estimates, over 200,000 adults living in Ireland could have decision-making capacity difficulties and may benefit from the new supports provided. This figure is based on numbers of adults with established diagnoses of intellectual disability, acquired brain injury, enduring mental health difficulties and age-related cognitive impairment. It would be wrong, however, to presume that any one of those 200,000 people will necessarily come within the ambit of the Act. That will depend on their individual circumstances. Equally, it would be a mistake to think that this legislation is targeted at or belongs to a particular cohort of people. Any of us could experience difficulties with our decision-making capacity in the future due to illness or injury. Therefore, this really is an Act for everyone.

When fully commenced, the Act will abolish the Victorian wards of court system, which continues to operate at present under the Lunacy Regulation (Ireland) Act of 1871. On admission to wardship, a person is declared ‘of unsound mind and incapable of managing his or her person or property’. The Supreme Court has acknowledged the ‘over-broad’ and ‘disproportionate’ impact of wardship, stating:

‘An order making a person a ward of court has real consequences. It can deprive a person of the power to make many of the choices which are fundamental and integral to day-to-day life. Orders can be over-broad in their effect and disproportionate in their scope’ (*AM v HSE*, 2019: para. 8).

The Act also repeals the Marriage of Lunatics Act of 1811, from the reign of George III. This section came into effect on 1 February 2021, so that wards of court are no longer prohibited from marrying by virtue only of being wards. Significantly, these antique acts are the only two pieces of legislation which the 2015 Act repeals. There is nothing else to repeal. The 2015 Act introduces structure and regulation to the area of decision-making and capacity, where currently we often operate in a grey area founded on custom and practice. In particular, there is a tenacious but unfounded idea that the ‘next of kin’ enjoys some legal status as a substitute decision-maker and is authorised to supply consent on behalf of another adult.

The main reforms introduced under the Act include:

- a statutory definition of capacity based on a functional, time-specific and issue-specific assessment;
- a regulated three-tier framework for decision-making;
- detailed guiding principles, including a statutory presumption of capacity and the replacement of a ‘best interests’ standard with the requirement to give effect to a person’s will and preferences;
- enhanced tools for advance planning by way of enduring powers of attorney and advance healthcare directives;
- the establishment of the Decision Support Service within the Mental Health Commission, with numerous functions to promote and regulate the new framework.

One advantage of not reforming our system for almost 150 years is that we can learn from lengthy experience elsewhere. I have met with providers of comparable services in other jurisdictions and all have commented on the scope and the ambition of the Assisted Decision-Making (Capacity) Act. I am aware that we are being watched with interest. The evolution of the Act and many of its key reforms are in large measure due to the expert input of civil society groups during the consultation process. In its earliest iteration, the proposed title of the Act was the ‘Mental Capacity’ Act. In the final version, the term ‘mental capacity’ does not appear at all and capacity is not linked with a medical diagnosis. The title of the Act, with ‘capacity’ in parentheses, reflects the fact that, rather than merely introducing new tools for assessing capacity or accessing consent, the primary focus of the 2015 Act is on supporting a person as far as possible to exercise their decision-making autonomy. Also in earlier drafts, the Decision Support Service was going to be called the Office of Public Guardian. It was successfully argued that guardianship carries connotations of paternalism contrary to the ethos and purpose of the Act.

Our thinking in relation to how we support people with capacity difficulties has evolved over time and so too have our obligations. The full commencement of the 2015 Act has been identified as essential to compliance with the United Nations Convention on the Rights of Persons with Disabilities, which Ireland ratified in 2018. It has been argued by some respected commentators that the 2015 Act fails to achieve full compliance with the Convention in that it retains as a last resort a form of substitute decision-making at the uppermost tier of the framework and applies a functional test of capacity to determine access to appropriate supports.

Certainly, the 2015 Act is not without its flaws. It is complex, not especially readable, densely worded legislation and, despite being already 146 sections long, it is incomplete. At present in 2021, an amending bill is being progressed. Some amendments will be procedural and technical, and others will be more substantive. It is expected that one significant change will improve the position of current adult wards of court and their access to the court, to representation and to periodic review. It is my own view that the Act is imperfect but deeply principled legislation. The drafters have done their best to reflect a range of expert views, to negotiate the requirements of the UN Convention and to translate important human rights ideals into workable structures and processes

The impacts of the reforms will be felt across multiple sectors. Since coming into post as Director of the Decision Support Service, I have met with diverse stakeholders, including lawyers, bankers, regulators, financial planners, academics, activists and advocates, family carers, the Legal Aid Board, Citizens' Information, the Courts Service, the Central Bank and An Garda Síochána. Notably at every event at which I have spoken, although participants have been there in their professional capacity, I have been approached by someone saying 'This affects me and my family: my elderly father, my aunt, my adult child'. Probably the sector I have engaged with most, and arguably the sector likely to be most affected by the changes, is health and social care.

It was with this in mind that the Decision Support Service and Mental Health Commission colleagues collaborated with the HSE National Office for Human Rights and Equality Policy and UCC Law School to deliver three days of events in late 2019, focusing on the implications of the Act for health and social care professionals and what they can do to prepare. Those events have led to this publication, in which professionals and experts by experience offer their diverse perspectives on what we can expect from the Assisted Decision-Making (Capacity) Act, its nuances and potential pitfalls and how to get ready for commencement. I believe that this book will make a valuable contribution to our shared understanding of supported decision-making and what it should look like in practice.

The 2015 Act undoubtedly presents challenges. At present, this country is living through an extraordinary global pandemic. Much expert commentary has noted that the experiences of some of those who suffered the worst effects of COVID-19 in Ireland could have been

different if the 2015 Act had already been commenced. They point to the difference it could have made to a person to have a trusted decision supporter or a statutory advance healthcare directive in place at this time. Access to the supports under the 2015 Act will have to become a new feature of care. Healthcare workers will have to become used to interacting with the new decision support arrangements. Planning, policy development, education and training will be required. The Decision Support Service has a duty to promote organisational change and will be available to supply information and guidance. It is intended that the codes of practice to be published under the Act will also provide a resource, with codes directed at the healthcare sector in particular.

Practical matters aside, there is also the much talked-about paradigm shift. The Act endorses the recognition of all persons as the holders of rights, with the entitlement to be at the centre of the decisions that affect them. However, I think it is important not to overstate the newness of this. As was apparent from the presentations at our events in 2019 and from the contributions to this book, the concept of rights-based, person-centred care is already well established. The presumption of capacity, the rejection of a status model of incapacity and support for participatory decision-making are already part of expected standards. The letter of the 2015 Act is new and there is undoubtedly much to be done to prepare, but the spirit of the Act is already widely evident in health and social care.

I must commend the expert team at the HSE's National Office for Human Rights and Equality Policy for the work they have done to start the conversation, to promote the 2015 Act and to build confidence in their sector. My thanks are also due to Professor Mary Donnelly of UCC Law School who has been an authoritative voice on capacity and supported decision-making since the earliest stages of the 2015 Act. I thank both joint collaborators for their partnership and for bringing this book to fruition.

Finally, I must acknowledge all of the contributors who have written the chapters that follow. If I may, I wish to thank in particular the experts by experience who have generously shared their powerful personal accounts. Theirs are the voices that we need to hear to and keep hearing when the Act commences, so that we are alert to what we should revisit and do better. The Assisted Decision-Making (Capacity) Act 2015 may be imperfect and it may struggle to deliver fully as the 'Act of Emancipation', joyfully predicted by one of our contributors, but it is undoubtedly better to begin in hope.

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# Editorial

*Mary Donnelly and Caoimhe Gleeson*

The idea for this collection of essays emerged from a conference held in University College Cork in November 2019, which was jointly organised by the Decision Support Service; the HSE National Office for Human Rights and Equality; and the Law School at UCC. The conference was intended to draw attention to the ongoing delays in commencing the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act). At that time, there was no clear line to commencement and a growing concern that there was no political imperative to take the steps needed to bring the 2015 Act into force. We wanted to provide a reminder of the unsustainability of the current legal structures, the importance of the 2015 Act and why political procrastination had to stop.

Almost 18 months later, the world has changed in many ways. The COVID-19 pandemic has impacted on all our lives, but it has had an especially devastating impact on older people and people with disabilities, in particular those who live (and have died) in nursing homes and residential care settings. At the time of writing almost one-third of the people who died from COVID-19 in Ireland were nursing home residents and there are important questions still to be answered about whether this could have been avoided. Alongside these shocking mortality statistics, people living in congregated settings have been subject to an unprecedented level of restrictions on their liberty and freedom of movement and on access to their family and friends and to the wider world. For people with cognitive or psychosocial disabilities living outside of congregated settings, the pandemic has also been deeply damaging: resources have been restricted; programmes have been reduced; and the human element of care has been diminished (in spite of the extraordinary efforts of so many individuals working in health and social care to keep the essence of person-centred care alive).

If we are to learn only one thing from this aspect of the pandemic, it is that respect for human rights must underpin policy and practice for people whose decision-making capacity is limited or impaired. In this, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) is centrally important. Many of the essays in this collection refer to the CRPD, which Ireland signed in 2007 and ratified in 2018. The CRPD provides a roadmap for the delivery of equal rights for persons with disabilities. It requires States to respect the ‘inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons’ (art. 3) and it recognises the equal right to legal capacity of all persons with disabilities (art. 12(1)) and requires States to take appropriate measures to provide people with disabilities with the support they need in order to exercise their legal capacity (art. 12(3)). Delivering on these obligations and on the many others in the CRPD requires long-term political commitment and ongoing advocacy by disability rights activists. The 2015 Act is but a first step on this ongoing journey.

Whether because of the lessons of the pandemic or because Ireland is shortly required to present its first country report under the CRPD, the political commitment needed to bring the 2015 Act into force has finally emerged. We now have a clear ‘launch date’ of June 2022. There has also been slow, but steady, progress towards the culture change needed to deliver the 2015 Act. We can see a discernible shift in approach in the way the roll-out of the COVID-19 vaccination programme was handled. Respect for the will and preferences of people lacking capacity (and their benefit) was made the legal standard for vaccination where consent was not possible (SI No. 698 of 2020) and, in operationalising the vaccination programme, the HSE firmly rebutted the long-discredited fallacy of next-of-kin consent and emphasised the importance of support.

This book has been expanded to reflect this new context. It retains a focus on the 2015 Act as a progressive measure that can significantly improve the lives of people with capacity difficulties. This is underpinned by the powerful personal accounts by contributors for whom the 2015 Act holds the direct promise of greater control over their lives. At the same time, the collection reflects limitations and uncertainties in the 2015 Act and the undoubted challenges in operationalising the new structures.

A good deal of the potential of the 2015 Act relies on people choosing to use the decision-making mechanisms introduced, whether through appointing a decision-making supporter (a decision-making assistant or a co-decision-maker) or making an advance healthcare decision or appointing someone as an enduring power of attorney. It will take time for people to become familiar with and comfortable using these mechanisms. The work of the Decision Support Service is crucial in ensuring public trust in the new legal framework and, in this interregnum before commencement, a great deal of work has been undertaken by the Director and her team to establish the structures to ensure a smooth and straightforward transition to the 2015 Act. The approach of the courts (and of the lawyers who argue before them) will be important too as gaps in the legal framework are resolved. Given that, in one form or another, wardship has been part of the law since the fourteenth century, it is almost inevitable that there will be bumps on the road. We believe that progress is made by articulating the challenges and looking for ways to resolve them, working always with reference to the human rights foundations for the 2015 Act.

In putting together this book, we asked contributors to keep their essays to 2,000 words so we could include as many voices and perspectives as possible. We recognise that while some readers may read this as a collection, others will focus on individual elements and so we have approached editing so that each chapter can be read on its own. The book is divided into six parts. It begins with a series of personal reflections setting out the different reasons why the 2015 Act matters to each of the writers. We chose to begin with these stories because they establish from the outset what is at stake here. Part 2 addresses the legal context for 2015 Act, looking at aspects of the current legal framework (i.e. prior to the 2015 Act coming into force) and identifying gaps that will remain even after the 2015 Act has



become operational. In Part 3, we turn to the ‘relevant person’. The title of this Part reflects the terminology of the 2015 Act. The essays here engage critically with the 2015 Act, asking whether it can achieve the goal of making the relevant person truly relevant and offering a range of perspectives on what the Act can deliver. Part 4 turns to delivery in practice. The essays here provide concrete and practical accounts by experienced practitioners, showing how people can be supported to make decisions in accordance with their will and preferences. The essays in Part 5 explore the potential of advance decision-making as a way to preserve autonomy and control in times of incapacity. Personal, professional and poetic reflections are intermingled to make a powerful case for advance care planning and to show the importance of legally enforceable advance directives. Part 6 draws on the experiences of a wide variety of professionals for whom the 2015 Act will require structural and other changes in professional practices. These thoughtful reflections are drawn from wide experience and reflect, in varying proportions, optimism and caution. Read together, these essays present a rich, multi-faceted picture of legal capacity in Ireland in mid-2021, as we look forward to the commencement of the 2015 Act. We hope to redraw this picture in the future, bringing together a similar body of contributors to look back and evaluate where the 2015 Act has brought us.

We have many people to thank for their support in bringing this book to completion. We begin with the essay contributors for their thoughtful, engaging, honest and often moving responses to the 2015 Act as well as for their courtesy, enduring commitment and endless patience. We are very grateful to Áine Flynn, the Director of the Decision Support Service who has provided the foreword to the book, for her ongoing support and that of the DSS, and in particular of Siobhán Bigley, in the development of the book. The book would not have been possible without the commitment of the team at the HSE National Office for Human Rights and Equality Policy and we thank Orlaith Branagan, Elaine McCaughley, Marie Tighe and most especially Jacqueline Grogan for their support. We are also grateful to Dr Philip Crowley for his support with the book and for ensuring that the 2015 Act has remained a central concern with senior leadership in the HSE. Thank you, too, to Jane O’Faherty for proofing the manuscript and (again) for endless patience. Finally, we are especially fortunate to have a bespoke artwork for the cover of this book; we thank Delaney Davis for creating this beautiful image to symbolise transformation and the emergence of a brighter future.

## Notes on Contributors

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**FIONA ANDERSON** holds a Bachelor of Arts Degree in Sociology, Political and Legal Science and a Masters' Degree in International Comparative Disability Law and Public Policy from NUI Galway. Fiona is to commence full-time the final year of the LLB (Bachelor of Law) programme in September 2021 at NUI Galway. Fiona's primary interests revolve around medical and mental health law and the provision of legal representation for persons with disabilities including psychosocial disability.

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**BARBARA BRENNAN** has over 12 years' experience in changing the culture of mental health at all levels of society. A regular contributor to national mainstream and social media, Barbara is at home speaking to local community groups, CEOs or senior leaders in the public and corporate world. She has lectured at Dublin City University, Trinity College Dublin, and University College Cork inspiring people to think differently about mental health and wellbeing and is the Programme Coordinator for See Change; the National Stigma Reduction Partnership Ireland.

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**SUZY BYRNE** is a disabled woman who has been involved in community work and campaigns on disability and equality issues for 30 years. She is a regional manager for the National Advocacy Service for People with Disabilities which provides professional representative advocacy for disabled individuals who may need support in decision making and accessing rights. Suzy is also a Director of Iarnród Éireann and a board member of the Irish Council of Civil Liberties and an external advisor to the Rethinking Ireland Equality Fund.

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**MARY CONDELL** is a practicing solicitor and mediator and is in-house legal advisor to Sage Advocacy, a support and advocacy service for vulnerable adults, older people and healthcare patients. Before joining Sage advocacy in 2015 she spent many years in private practice advising vulnerable adults. She is co-founder and former chair of Solicitors for the Elderly in Ireland and a member of the NDA expert group preparing draft Codes for the Decision Support Service. She is also a member of the Disability Lawyers Rights Network.

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**JOANNE CONDON** has been a Regional Manager with the National Advocacy Service for people with disabilities (NAS) since 2014. Having completed a degree in Social Science and a Masters in Youth & Community work at UCC, Joanne went on over the next twenty years to work in a wide variety of roles across the social care sector. She acted as a Service Manager with regional oversight for a number of residential services prior to joining the National Advocacy Service as Regional Manager (Southern Region) in 2014. Joanne is also a guest lecturer at University College Cork.

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**FIONA COYLE** joined Mental Health Reform (MHR) in 2020 as Chief Executive Officer. With over 75 member organisations and thousands of individual supporters, MHR provides a unified voice to Government, its agencies, the Oireachtas and the general public on mental health issues. Before this, Fiona spent 2 years as Director of END FGM Europe. Fiona has extensive experience working on upholding human rights in national and international organisations including IPPF, Irish Aid, Dóchas and UNDP.

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**LORRAINE CRAWLEY** has held the position of Senior Clinical Psychologist with Acquired Brain Injury Ireland for the past seven years, having previously worked in the HSE. She is a member of the Psychological Society of Ireland and the British Psychological Society. Lorraine is the current Chair of the Acquired Brain Injury Ireland Research Ethics Committee and a member of the service's Research Prioritisation project.

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**PHILIP CROWLEY** is the National Director for Strategy and Research in the Health Services Executive. In his previous national health service roles over the last 10 years, he was National Lead for Quality and Patient Safety and National Lead for Quality Improvement. He leads on Strategic planning, Research, Population Health and Wellbeing, Global Health, Human Rights and Performance reporting to the HSE Board. He is a doctor who works part-time as a General Practitioner.

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**CAROLINE DALTON** is a lecturer in the School of Nursing in University College Cork. She is a registered intellectual disability nurse whose research interests relate to supporting individuals with an intellectual disability, dementia and acquired brain injury. Dr Dalton is a member of the College of Medicine and Health Inclusion Health Research group and is an active member of the Healthcare Ethics and End of Life Care research cluster.

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**MARY DONNELLY** is a Professor of the School of Law at University College Cork. She researches in the fields of mental capacity/mental health/health law. She is the joint chair of the HSE National Consent Advisory Group and the HSE Assisted Decision-Making Commencement Group and was Chair of the Multidisciplinary Working Group on Advance Healthcare Directives.

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**SARAH DONNELLY** is an Assistant Professor of Social Work in the School of Social Policy, Social Work and Social Justice, University College Dublin, and co-convenor of the European Network for Gerontological Social Work (ENGSW). Sarah's research interests include ageing and dementia, adult safeguarding and capacity and decision-making. She is a Geary Fellow and member of UCD Centre for Interdisciplinary Research Education and Innovation in Health Systems. Sarah is a registered social worker and an active member of the Irish Association of Social Workers (IASW).

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**KAREN DOYLE** is the Services Standards Officer in Focus Ireland Housing and Homeless Charity. She has worked in Focus Ireland for the past 16 years and has held the post of Services Standards officer for the past three years and is integral in the roll out of new legislation and the internal policies which guide Focus Ireland’s practice. Karen has a particular interest in safeguarding.

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**CLARE DUFFY** has been Policy and Public Affairs Manager with Family Carers Ireland since 2008 and manages the organisations policy, public affairs and research functions. Clare is responsible for drafting Family Carers Ireland policy positions across a range of issues with a focus on rights and entitlements, homecare and legislation. Clare has led the National Carers Strategy Monitoring Group since 2014 and represents carers on a number of national committees including the Community and Voluntary Pillar of Social Partnership, the HSE’s National Patient Forum and the National DCA Oversight Committee. She is also a member of the Homecare Coalition and represents Irish carers on the European Eurocarers Policy Committee.

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**ÁINE FLYNN** is a solicitor and former senior partner in KOD Lyons. 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 represented clients in wardship. She has been a member of the Human Rights Committee of the Law Society since 2012. In October 2017, she was appointed inaugural Director of the Decision Support Service under the Assisted Decision-Making (Capacity) Act 2015.

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**EILIONÓIR FLYNN** is an Established Professor of Law and Director of the Centre for Disability Law and Policy at the National University of Ireland Galway. Her research focuses on disability and social justice, with a particular emphasis on legal capacity, advocacy and reproductive justice. She is the Scientific Co-ordinator of the Disability Advocacy Research in Europe Marie Curie Training Network, and has held awards from the European Research Council, Health Research Board, and Wellcome Trust.

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**LEIGH GATH** is the Confidential Recipient for the HSE. She is a wife, mother, author, disability advocate and activist, and a person with a disability. Leigh has worked in disability rights since she was 17 years old – first in Northern Ireland, then in Texas for many years and finally in Ireland. Leigh has been in her present role since 2014, and is passionate about people with disabilities having a voice, as well as the same rights as any other citizen.

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**CAOIMHE GLEESON** is National Programme Manager for the National Office for Human Rights and Equality Policy at the Health Service Executive (HSE). Caoimhe is the HSE representative on the Inter-departmental Steering Board for the commencement of the Assisted Decision-Making (Capacity) Act 2015. Caoimhe has responsibility for the oversight of HSE National Consent Policy and oversight of the implementation of the Assisted Decision-Making (Capacity) Act 2015 in the HSE and works to progress equality, human rights advocacy and policy issues for people with disabilities and other diverse groups in Ireland.

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**JACQUELINE GROGAN** is a Project Manager for the HSE National Office for Human Rights and Equality Policy. She is responsible for policy oversight in relation to the Assisted Decision-Making (Capacity) Act 2015, Wardship, Public Sector Duty, Transgender and Intersex issues, and Universal Access. Prior to joining the HSE in 2016, she worked in disability services both in Scotland and Ireland, including Sense Scotland, Momentum Scotland, the Rehab Group, Headway Ireland and the Disability Federation of Ireland, in the areas of service delivery, research, communications, governance and service development.

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**TIM HANLY** worked as a social worker in Glasgow between 1991 and 1995 as part of a Community Care Team. Since returning to Ireland in 1995, Tim has occupied various management positions within Child Care services. He commenced as Principal Social Worker in HSE National Safeguarding Office in September 2015 and is currently General Manager of the Office. He played a key role in the review of the HSE Safeguarding Vulnerable Persons at Risk of Abuse policy and in the implementation plan for the revised HSE Adult Safeguarding Policy.

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**ADAM HARRIS** is the Founder and CEO of AsIAm, Ireland's National Autism Charity. Adam founded the organisation based on his own experiences growing up on the autism spectrum. A Social Entrepreneurs Ireland Awardee, Adam is a frequent contributor to media and conferences in Ireland and overseas. He has also sat and advised on many government consultative and policy committees on disability rights and inclusion. From Greystones in Co Wicklow, Adam was appointed to the Irish Human Rights and Equality Commission in July 2020.

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**CLAIRE HENDRICK** grew up in Beaumont with her parents and 2 brothers. Claire was in a special class throughout school but was not made aware she had an intellectual disability until she turned 23 years old. On Christmas Eve 2010 she became a ward of court. With the support of her aunt and cousin, Claire engaged a solicitor to fight the ward of court order and was released from Wardship on 30th August 2012. She will always have her disability and is proud of who she is, Wardship did not consider her as a person at any stage. Claire now lives a happy life.

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**NIAMH HOLLAND** is a clinical psychologist who has been working in St. Michael's House since 1989. 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 is to chair a committee with overall responsibility for the organisational performance and progress regarding St. Michael's House Policy on Identity, Relationships and Sexuality.

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**CAROLINE HOWORTH** is Speech and Language Therapy Manager in St. Michael's House, Dublin (Service for People with an Intellectual Disability). 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 made presentations at national and international conferences including CPLOL, 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.

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**CORONA JOYCE** was Senior Policy Officer with Age Action from 2018-2021 where she led on the development of policy and research across priority areas, ensuring that they were shaped by the lived experiences of older people in Ireland. She previously worked in policy, research and project management roles for the Irish Red Cross, the Economic and Social Research Institute and the United Nations, and is currently Senior Policy Officer with Fianna Fáil.

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**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).

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**NIAMH KELLY** works a Senior Occupational Therapist (OT). She has gained a broad range of experience from 15 years working as an OT in London, Dublin and the West of Ireland. As an OT, she has a keen interest in helping people live their life, their way.

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**REBECCA LLOYD** is the Public Engagement Officer for Irish Hospice Foundation. Rebecca has a Master of Science which concentrated on talking with non-medical professionals' experiences when managing the dying and bereaved. She believes we have not yet scratched the surface of what people can do to help and support each other. Rebecca hosts café conversations, workshops, and talks around the country to encourage people to talk a little more openly about dying, death, loss, and bereavement in a safe space.

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**MICHAEL JOHN NORTON** is the National Engagement and Recovery Lead and an advanced level Wellness Recovery Action Plan (WRAP) facilitator. He has spent the last few years being an advocate for mental health and is involved in numerous working groups nationally looking at areas such as WRAP, family recovery and trauma. He also is an early career researcher whose research interests include co-production, mental health and recovery.

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**PATRICIA O'BYRNE** is Pádraig Schäler's mother and since Pádraig's accident, she has been his full-time carer.

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**DAMIEN O'DONOVAN** has been a health club assistant at the Westlodge Hotel, Bantry since 2002. He is very involved in his local GAA club, he loves his social life and likes getting involved in community activities. Last year he won most popular actor award in the Oskaars, a fundraiser run by his local GAA club. He is a gold medal winner for swimming for the World Games which were held in Dublin in 2003. He holds a Gold, Silver and Bronze Medal in the Gaisce Awards. He lives at home with his Mum Mary in Bantry with a number of his siblings.

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**MARY O'DONOVAN** is Damien's Mum and is the proud mum of 7 grown up children (Damien is the second eldest), living in wonderful West Cork. Damien has demonstrated to Mary the importance and value of living a life embedded in one's community and also inspired a passion for self-advocacy and personal empowerment. She is passionate about Damien's right to live his own life in his own community and direct his own life. Mary is a member of the Inclusive Living Network. Mary holds a Higher Certificate in Advocacy from Sligo IT.

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**JOHN O'BRIEN** has been a GP for nearly 40 years, working in West Dublin. He has been a GP teacher and trainer of undergraduate and postgraduate students for many of those years. He has been the GP in attendance to the Daughters of Charity intellectual disability service at St Joseph's Centre Clonsilla. He has a deep interest in the rights and autonomy of those with an intellectual disability and also in excellence in the end of life care. He is a past president of the Irish College of General Practice.

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**SHAUN O'KEEFFE** is a Consultant Geriatrician and Physician in the University Hospital Galway and an Honorary Personal Professor of Medicine at NUI Galway. He trained in Internal and Geriatric Medicine in Galway, Dublin, Boston and Liverpool. He is a member of the HSE and Multidisciplinary working groups on implementing the Assisted Decision-Making (Capacity) Act, including advance healthcare directives. He is Co-Chair of the HSE National Consent Advisory Group. Research interests include cognitive impairment, sleep disturbance and ethical issues in the care of older people.

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**BRENDAN O'SHEA** is a GP and Principal in Practice in Co Kildare. He is a member of the Council at The Irish College of General Practitioners, and Assistant Adjuvant Professor at Trinity College Dublin. He presently chairs The Clinical Advisory Group at the RCPI on Obesity, and is on Board of Directors at The Irish Hospice Foundation. Notwithstanding somewhat intractable difficulties within the Irish Health System, he practices being a committed rational optimist, and frequently, casually but systematically avails of inspiration and energy from people attending for care, and from students.

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**PATRICK QUINN** is the Principal Dental Surgeon for Co. Kerry and is also an Adjunct Senior Lecturer at the College of Medicine and Health, University College Cork where he teaches healthcare ethics and law on the dental programmes. The majority of his clinical career has been devoted to the care of people with disabilities. He has undergraduate and postgraduate degrees in both dentistry and law and is particularly interested in public health ethics and legal and ethical issues relating to the care of people with disabilities.

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**PATRICIA RICKARD-CLARKE** is a solicitor and former Commissioner of the Law Reform Commission. She is the Independent Chair of the Safeguarding Ireland and Deputy Chair of SAGE Advocacy. She is a member of the HSE's National Assisted Decision-Making (Capacity) Act Steering Group, 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.

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**HELEN ROCHFORD-BRENNAN** is Chairperson of the European Working Group of People with Dementia and the group's nominee to the Board of Alzheimer Europe; former Chair of the Irish Dementia Working Group and is on the Monitoring Committee of Ireland's first National Dementia Strategy and a Global Dementia Ambassador. 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. Creating awareness of Dementia in her community and throughout Ireland plus enjoyment with her family and friends is her greatest joy.

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**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. Alex is also 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.

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**JUDY RYAN** 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. 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. Judy has a particular interest in self-advocacy and led a pilot programme to appreciate how people with an intellectual disability could be supported to engage with the Assisted Decision-Making (Capacity) Act 2015.

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**PÁDRAIG SCHÄLER** finished his degree in History and Irish at TCD in 2013 and decided to go on a J1 visa to the US. He was a national champion swimmer, had spent a year swimming in the first division for the University of Kentucky, became the Reachtaire of the Cumann Gaelach at TCD, had published a book, did a regular Irish language podcast, and ran his own Irish language radio shows. Four weeks into his stay in Cape Cod he was struck by a van trying to overtake him as he cycled to work. He has two sisters and lives at home in Dublin with his parents, Pat and Reinhard.

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**REINHARD SCHÄLER** is Pádraig's father and the CEO of the An Saol Foundation which was established after Pádraig's accident. Pádraig is the inspiration behind and provided the name and logo for the HSE supported An Saol Foundation's Neuro Rehabilitation Day Centre in Santry.

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**DEIRDRE SHANAGHER:** Prior to taking up her current position as Strategic Clinical Nurse Expert with Regulatory Compliance with Nursing Homes Ireland, Ms. Deirdre Shanagher was National Development Manager, Palliative and End of Life Care with Irish Hospice Foundation, where she led the Palliative Care for All and Primary Palliative Care Programmes that focused on palliative care for people with illnesses other than cancer, advance care planning and advance healthcare directives. Deirdre is a registered general nurse who has worked as a nurse and nurse manager and holds an MSc in Gerontological Nursing.

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**MARGARET SWEENEY** is a founder member of the Involvement Centre in Carlow, a place for people to meet and get involved in recovery. She plays an active role in the development of recovery in mental health services and is a Recovery Consultant, Recovery Principle and Practice trainer, WRAP and EOLAS facilitator. Margaret is experienced in delivering talks, presentations and workshops in the area of recovery and co-production. Margaret has recently been employed as a recovery education facilitator with the recovery college southeast.

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**ELAINE TEAGUE** is the Director of Quality and Safety in St. Michael's House. She has worked across a wide range of services supporting children and adults with an intellectual disability as a frontline staff, a service manager, a compliance officer and in staff education and training. Her work experience also includes working in Mental Health services and in Education settings for third level social care students. Elaine has an honours degree in Social Care, and post graduate qualifications in Training and Education, Corporate Governance, Quality Management and is a graduate from Trinity College with a postgraduate certificate in Implementation Science.

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**MICHAEL WALSH** is programme manager for the HSE National Clinical Programme for People with Disability. Mike has 25 years clinical, teaching, research and senior management experience in the Irish public health sector, mainly in services for people with disability. Mike has a track record of conducting and leading out on clinical research of conditions which contribute to creating disability, delivering education as well as developing and reforming specialist services for people with disabilities. He is currently a Director of Health Research Charities Ireland (HRCI), a national umbrella organisation for charities active in medical and health research.

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**MARGARET WILLIAMS** is a Registered General Nurse since 2002. She worked in acute care services in various leadership roles. During this time Mags was dedicated to optimal service provision to improve the quality of patient care delivery in an ever-changing and unpredictable environment. She was a strong advocate for person-centred care and individual autonomy and decision making. She is currently working as a Leadership Advisor in the National Clinical Leadership Centre for Nursing and Midwifery in the HSE.

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**ROSY WILSON** worked as an Open University tutor/counsellor and as a lecturer and working mainly with adult learners on Access to Higher Education courses. Rosy has a MA Women's Studies from UCD. Rosy worked as a volunteer at Glenree Centre for Peace and Reconciliation. She was an active Amnesty member and her group partook in Amnesty's Mental Health campaign. In 2012 Amnesty invited Rosy to take part in a Citizen's Jury where 14 'Experts by Experience' teased out many aspects of the Mental Health Service measured against UNCRPD. Rosy has also published 8 poetry collections with Boland Press and Lapwing Publications.

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# 1 Why the Assisted Decision-Making (Capacity) Act 2015 Matters to Me

## 1.1 It's My Life

*Damien and Mary O'Donovan*

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### DAMIEN

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My name is Damien O'Donovan. I live in Bantry, West Cork. I love West Cork, it is the best place to live. I live with my family in Tír na nÓg, in Bantry. I went to school in Bantry, I did my Junior Cert in St. Gobans in Bantry. I work at the Westlodge Hotel, Bantry. I am a pool attendant. I have been working at the Westlodge for 17 years with the team. Westlodge Hotel is the best hotel ever.

I did my bronze, silver and gold Gaisce. I raised six thousand euro for charity in my gold Gaisce walk from Killarney to Bantry. I am involved with Box of Frogs cafe in Bantry with my brother Barry and the team. It is the best cafe in Ireland.

I am involved with Bantry Blues GAA for a very long time. I am involved with coaching under 11s this year we will be under 12s next year. Mary asked me if I have a good life and I said no, I have the best life. I always make my own choices.

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### MARY

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I am always uncomfortable when asked to talk 'about' Damien, I have six other children, I often talk about them, but I would not be speaking about them in the same way as I will do in this piece about Damien. I need to acknowledge this at the beginning and I hope the reasons why I am talking 'about' Damien will become clear, as the writing unfolds.

Damien was born in 1980, there were no services available in our area at that time and I had zero knowledge of Down Syndrome. The first few months of Damien's life were a bit chaotic, whilst I tried to understand what the future might hold for this child who was 'different', until I came to the conclusion

when he was about three months old that he was in fact very much ‘the same’ as everyone else. The only thing that was ‘off key’ was that everyone else was not the same as him, which is what created the difference, in himself he was perfect. Armed with this understanding we proceeded to live life, taking our lead from Damien and trying to ensure he had the skills he would need to try and be as independent as possible for his own life. Damien developed his own personality and I believe one of the attributes that is so powerful for Damien with his decision-making is that he knows himself really, really well. Countless books are written about how to discover your true self, some of us lose ourselves in the course of life’s journey, I often find myself trying to unpeel layers to find out what I really want! Damien has developed a very strong sense of self which is a powerful weapon in decision-making!

We never focused on ‘decision-making’ per se with Damien, but I became aware through the wider world of how easy it was for other people to make decisions for someone like Damien, which I found both surprising and troublesome. We had taken Damien’s autonomy for granted; however I am aware how easy it was for other people to take the lead from Damien and respect his autonomy without any great difficulty. In his early teens, Damien had surgery on his leg and experienced a short hospital stay. I distinctly recall the day after the surgery when the consultant came to do his rounds and began the conversation by directing his questions to me. I would turn to Damien each time he asked me a question and Damien would answer him directly. Very quickly, the consultant shifted and engaged directly with Damien. No big fuss, no offence at all meant by the surgeon, but personal autonomy was established. I certainly would not have been able to articulate at the time that this was ‘empowering’, I didn’t know what empowering was, but I had a sense that it was very important that Damien was expected to speak for himself and be seen as fully present as any of my other children.

Damien makes numerous daily practical and personal decisions with no difficulty. Many years ago, he assumed responsibility for buying the milk for the house, probably because I forgot to on a number of occasions! He will check the fridge each morning and do his own mental calculation on what needs to be bought, this can vary depending on how many people are in the house, but we never run out of milk! Damien does this, and many other countless daily tasks, in the same way as the rest of us, without any great thought. I once heard someone describe decision-making as a muscle; it must be exercised to be fit for purpose. It appears to me in retrospect that making small decisions builds capacity for making larger decisions.

Before talking a little about bigger decisions, I would like to share a big lesson I learned about Damien’s decision making many years ago. He was given an opportunity to travel to the Czech Republic for a swimming event when he was in his early twenties. He immediately said he did not want to travel. I felt at the time that this was a great opportunity for him and, to my shame, I persisted in encouraging him to go long after I should have ‘heard’ his no, and he eventually agreed to go. Unfortunately, Damien became very unwell on the trip. Whether

this was a coincidence or not, it was a lesson I have never forgotten. It takes an awful lot of courage and strength to say no to someone when you know you are in some way reliant on that person. Whilst trying to encourage Damien to engage outside his comfort zone is a good thing, this must be balanced with 'hearing' the answer. This balancing has become easier as the years progressed, as Damien became more confident in who he is and we have learnt to respect his decisions...the first time!

When it comes to making decisions other than the normal daily routine decisions, Damien developed an excellent strategy many years ago: 'I'll think about that'. I have read countless self-help books that try and tell me to stop and think before trying to please others; Damien achieves this with one short phrase. He will very rarely, in fact I think never, give a decision to a 'big' question on the spot. Would he like to go on holiday? Would he like to buy a new suit? Who would he like as trustees for him? Our strategy is to lay out the information as clearly as possible, sometimes in writing depending on the decision, and to make sure as much time as possible is given for the decision. It is sometimes challenging to be completely impartial with the information. With the best of intentions, it can be difficult not to weight the kind of information we provide towards the answer we want, sometimes even by tone of voice.

Most decisions can take days, sometimes weeks, but we have learned this is Damien's process –time, time, time! He does not always give the answer I would like, but I always trust the decision Damien makes is the right choice for him, it is communicated with conviction and comes from deep within his own sense of Damien. As I write this I experience a sickening feeling that someone may someday make a decision for Damien that would offend his sense of who he is and that he would be unable to over-ride that decision, and his 'Damieness' be ignored. I lay my trust in my family and the Assisted Decision-Making (Capacity) Act 2015 to ensure that this will never happen. I believe the 2015 Act alone cannot guarantee this, the trust will lay with the people who guard the 2015 Act, that they will apply the time, attention and humility necessary to ensure that each person's autonomy is respected.

Damien and I have spoken about how he would make a very big decision; the example I used was what if he was told he had a disease in his leg and it had to be cut off to save his life. He immediately pulled back and said 'that's a huge decision'. We talked about how the doctors would have all the information and they would be able to explain everything to him so he could make the decision. It became clear to me as we discussed this issue that this was a very good example of where I would probably have been asked up to now to make that decision for Damien, or put in the position of having to try and explain it all to him. The 2015 Act now puts the onus on the medical profession and others to explain to Damien, in a way that he can understand (plus plenty of time of course!) so that he can make his own decision.

I am excited about the 2015 Act and the change it can bring about for people who are seen as having impaired decision-making capacity. I find it shocking that up to now people were deemed guilty and had to prove their innocence (i.e. had to prove they had capacity, rather

than the reverse). I personally refer to the legislation as the Act of Emancipation! It will be challenging for us all to change our thinking in so many ways. Damien lives at home, he has his own 'apartment' in the house, but I constantly reflect on whether this is what he wants. Whenever we ask him, he says this is where he wants to live. On reading some of the documentation, I came to the decision that we should apply some of the strategies around the assisted decision-making framework and set about getting someone to support Damien to reflect on this decision independently, I fell at the first hurdle!! I decided I knew who the right person was to support Damien 'independently', completely missing the point that Damien should be the person who selects the person to support him!!

I have no research or science to bring to this subject other than my experience with Damien. I have learned it is all too easy to exert influence, even with the best of intentions, and chip away at a person's capacity. The capacity for expressing autonomy is within Damien, he just needs the information, space, time and respect to be able to find his own answers and then he clearly communicates his choices. I know Damien really well, I think I know him really well, but I do not know the inner Damien, I do not feel what he feels, but I have a real trust that he knows himself really well, which is why he has the capacity to be able to make the right choices and decisions for himself. Damien does not live a perfect life, (although he himself says he lives 'the best life'), but we do believe that he feels he is in control of his life.

I get excited when I hear words like autonomy, empowerment, dignity, integrity, etc., but I lack the capacity to clearly articulate why these words trigger such emotion within me. When preparing for the UCC conference, I trawled through the internet to try and find some statement or quote that would help me to communicate to people why I feel it is so important that Damien makes his own decisions, how important it is that Damien lives his own life, on his terms; I kept coming back to Damien's own words. Many years ago, I was doing a project on decision-making as part of a disability course. As part of the project, I asked Damien what it would be like if people made decisions for him. He looked at me as if I had gone completely bonkers, with a shocked and puzzled expression; he said: 'They can't do that' and when I asked him why they can't do that he replied: 'It's my life'.

Damien is a man of few words, he might struggle to explain why this Act is important to him, but he is crystal clear that he has the right to make his own choices and lives his life every day in a way that honours the 2015 Act. I fully acknowledge these are my feelings 'about' Damien, not Damien's words. On reflection, perhaps Damien does not struggle to explain why the 2015 Act is important to him, it has taken me almost two thousand words to try and explain what Damien says in three: 'It's my life'.



## 1.2 Preserving My Voice

*Helen Rochford-Brennan*

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### INTRODUCTION

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To start, let me tell you a little about who I am. I am married to Sean and mother to Martin. I come from a family of nine. In my mid-fifties I started experiencing memory problems. After struggling for five years, I finally received my diagnosis – I had Alzheimer's. It was a slow realization that a creeping fog had descended on my life and was there for good. I was forgetting words, stopping mid-sentence, wondering what I was about to say. My slowed thinking was so difficult to deal with. I could see the words but was unable to reach them. I can still feel the burning silence and see the look on people's faces at a meeting when I forgot words. Dementia had crept in and robbed my short-term memory. Family life became difficult – I was forgetting everyday things like recipes or something important Sean or Martin had told me.

On the day I received my diagnosis, it was a long lonely road home from Galway to Sligo. I was distraught. All I could think was how was I going to tell my family that in an unknown amount of time I would not recognise them or any of the great memories we shared throughout our life.

How I wish someone had been there to support me, and to support and advise Sean and Martin who resorted to Google. It is not a life sentence. I wish someone had told me that. Stigma played a major part in the lack of local support. Nobody talked about it. Sometimes it's easier to cross the street than speak to a person with dementia.

The problems our families face are immense. They live with the pain of watching their loved one change and the relationship dynamic change. When we are diagnosed, our loved ones and our life partners go into carer mode, when what we need is support to do all the things we did every day. For me, having spent my adult life campaigning for human rights, this was inconceivable. I couldn't believe that because of a diagnosis, I would be ignored – worse still, refused help and services. But I didn't have the strength or will to fight it. I retreated. I felt helpless for the first time in my life – no plan, no ideas and no strategies.

Finally, I reached out. On the advice of a nurse, I decided to get involved in research. I got in touch with Trinity College, who were doing research with the Alzheimer Society of Ireland and the newly formed Irish Dementia Working Group, which subsequently led me to the European Working Group of People with Dementia and Alzheimer Europe.

Dementia has been a taboo topic in Irish society and the word dementia or Alzheimer's disease was seldom heard or spoken about except in clinical or medical settings. We were, in a sense, pariahs, non-persons, locked away, because the public were largely afraid of and embarrassed by our dementia and did not know how to relate to us. Up until recently, the voice of people like me has been silenced in Irish society. Nobody with dementia was represented on the Working Group set up by the Department of Health to inform the development of the Irish National Dementia Strategy. Up until 2014, nobody with dementia in Ireland ever participated in, or indeed contributed, to any large conference or seminar on dementia. So, the notion of preserving our voice is, in my view, somewhat preposterous, since until recently we have had no voice out there to preserve!!!

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#### REFLECTIONS ON THE PAST

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And at this point it is important to reflect back a little on the past. For, in the past, the notion of autonomy in Ireland was heavily embedded in considerations about mental capacity, an approach which greatly disadvantaged people like myself and others, since law and medicine supported a binary notion of capacity: people either had full capacity to engage in decision-making or else they had no capacity, but sadly there was little in-between.

Capacity was generally assessed in GP's surgeries or at hospital out-patient departments or Memory Clinics where the person often felt ill at ease and disempowered. Tools were used that contained tricky questions not always relevant to our current lives. These tools captured some but not all of our capacities, and if caught on a bad day (and most of you know that the symptoms of dementia vary considerably day to day) we would fail on tests like the MMSE or the CamCog. We were then deemed to lack capacity and it was not unusual for all our decision-making to be removed and authority was handed over to a third party to make these decisions in our 'best interests'. So, a diagnosis of dementia tended to be equated with the erosion of mental capacity and this automatically removed all our decision-making rights.

The outcome of this approach meant that we were often excluded from participation in any dialogue. This included important conversations about how we might plan our own future care: we were denied opportunities to agree or disagree to post-diagnostic services and, in short, we were robbed of our personhood or what makes us all unique as human beings. It was not uncommon for anti-dementia drugs to be prescribed to us without our ever being told our diagnosis and later for anti-psychotic drugs to be administered without our consenting to such treatments – a practice that is, in my view, both unethical and illegal.

Likewise, in hospitals or care settings, a type of paternalism tended to occur where family members were routinely seen as proxy or substitute decision-makers and asked to sign consent forms to enable staff to proceed with treatments or interventions including surgical procedures, without any attempt first being made to obtain the consent of the individual or to assess that person's capacity to make that particular decision. Although such approaches were strictly speaking not lawful, they were the status quo and were seldom contested.

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### AND BACK TO THE PRESENT

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Thankfully, all of this is past history now as this new forward-thinking legislation aims to adopt a much more nuanced understanding of capacity – promoting individual autonomy and protecting those of us whose decision-making abilities may be threatened by illnesses such as dementia. I believe that the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) gives us a right to exercise autonomy, even those of us who may be deemed to lack decision-making capacity. The 2015 Act, therefore, has meant a radical change in how we think and talk about capacity and for this reason has important ramifications for people diagnosed with dementia.

The 2015 Act has introduced standardised approaches to support capacity. These new legislative changes have greatly strengthened the rights of people with dementia to participate in decision-making and to exercise their remaining capacities for choice, consistent with their values, wishes and will.

So, how can the 2015 Act help a person like me – now several years on in my journey through dementia? And what are some of the conundrums I currently face in relation to this 2015 Act? Let's start with the positives.

One great merit is that the enduring power of attorney component of the Act now enables me to appoint a trusted person (like my husband Sean or my son Martin) to not only make financial decisions for me, taking into account my will and preferences, but also to make all sorts of other decisions such as those relating to my welfare, our property and other affairs. Under the old system, an enduring power of attorney was based on decisions being made in my best interest and not on my will and preference. This distinction between best interest and will and preferences is important, as it essentially delegates power and control back to me, the individual, to decide what I want to do with my life and what I believe is best for me, and not what others think is in my best interests.

The 2015 Act also enables me to make an advance healthcare directive, which for me is a further welcome aspect. This means that I now have the right to plan my future healthcare and, in particular, decide to refuse a particular treatment I do not want. A case at point here is the introduction of artificial hydration or nutrition where scientific evidence shows that

for people with end-stage dementia, these interventions will not prolong life expectancy and will do nothing to improve quality of life. Yet in the absence of making this directive, I might be subjected to such treatment. Another example is when I die, I want to die peacefully and do not want anyone to come along jumping up and down on my poor body trying to resuscitate me. The 2015 Act allows me make provision for this.

However, a conundrum of the 2015 Act that is very important to me is that it does not allow me to insist on receiving certain treatments, which I know may benefit me but which sadly may be denied because I have dementia. There is UK-based research showing that people with a cognitive disability can be discriminated against in hospitals and denied medical procedures because of misguided assumptions that no benefits can accrue to that person because of their dementia. But if I have a fall in a nursing home and fracture my hip or if a cancer is discovered and I need a colostomy bag, I would like to have all the entitlements to medical, surgical and rehabilitative procedures that others will.

Those of you who know me or who have heard me speak publicly know that rightly or wrongly I have a fear of nursing homes and want to continue living in my home for as long as possible, surrounded by all that is familiar to me including my husband, friends, garden and my community. And so, another conundrum of the 2015 Act is that it will not allow me in my advance healthcare directive to create a legally binding statement ensuring that I will always be permitted to stay in my own home, no matter how severe my dementia. This is somewhat ironic given that the State affords me an entitlement to move into a nursing home, but no entitlement to live at home and be supported by those who may want to care for me but need support in doing so.

Advance healthcare directives and enduring powers of attorney enable people living with dementia to take control of their lives, but a real caveat of the 2015 Act is that these protections can only be drawn up legally when a person still has capacity. One of the difficulties with a dementia like mine, young onset, is that it can take many years for a final diagnosis to be made, by which time the person may no longer have capacity and will not be able to make an advance healthcare directive or an enduring power of attorney.

And even when a person living with dementia still has capacity, our ability to engage in future care planning requires doctors to be honest with us, communicating to us (and not to others) the news of our diagnosis, our prognosis and the meaning this has for our current and future lives. It also requires doctors to be familiar with the 2015 Act and to be aware that time is the main currency with which a person with dementia deals. We need to get our affairs in order on time – not when it is too late.

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## CONCLUSION

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This 2015 Act opens up new zones of freedom to people like myself because it inherently recognises that despite having dementia, people can continue to exercise choice, be valued, listened to and fully included as active citizens and participants in society. Once in force, the 2015 Act will have a positive effect on the lives of thousands of people with dementia and their families as it will promote autonomy, dignity and human rights. I welcome this legislation and see it as a giant step in the right direction.

In finishing, I would like to quote President Mary Robinson: ‘The fight for human rights is about speaking truth to power.’ Readers, you are the power – please ensure the rights of people with dementia are upheld...remember tomorrow it will be your friend, your loved one or maybe you.

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## ACKNOWLEDGEMENTS

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I would like to thank to Professor Eilionóir Flynn and Professor Suzanne Cahill for their encouragement over the years, and the Alzheimer Society of Ireland and Alzheimer Europe for ensuring that we keep this very important topic on the agenda.

## 1.3 Decision-Making, Consciousness, and Civil Rights: The Categorical Imperative for Self-Determination. A Personal Account.

*Pádraig Schäler, Patricia O'Byrne and Reinhard Schäler*

*'However careful we are, and however slim the odds, a severe brain injury is something that can happen to anyone, and any family, at any time.'*

The consequences of a severe Acquired Brain Injury (sABI) for the injured and their family are devastating. In one second, life changes so dramatically, it becomes unrecognisable.

Until it becomes the new reality. With huge, nearly unbearable, challenges.

A sABI is a brain injury that involves a long period of unconsciousness (coma) and a prolonged disorder of consciousness (PDOC). Persons with a sABI are very highly dependent, are often non- or minimally-verbal, and require, in most cases, life-long support with basic activities of daily living (ADL) as well as life-long rehabilitation.

Those injured are generally not given much hope for the future. Their 'treatment' is often reduced to a basic maintenance programme, hydration, nutrition and medication, where the end always seems to lurk just around the corner.

In Ireland, any decisions for those adults with a sABI are ultimately taken by healthcare professionals and the HSE. Current law does not provide for a role for the family in any decision-making for the injured, 'incapacitated', person (The Assisted Decision-Making (Capacity) Act 2015 will eventually repeal the Lunacy Act of 1871 and existing case law).

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### PERSONAL EXPERIENCE

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Pádraig, our son, then 23 years old, suffered a devastating brain injury in 2013, when he was hit by a 4.3-ton van in 2013 as he cycled to work one bright morning on Cape Cod, where he had planned to spend the summer on a J1 visa. Nobody was ever prosecuted for the accident.

On the Cape, doctors suggested organ donation to his best friend and, after our arrival, to the family. After about a week, when Pádraig was still in an artificial coma, we, his parents, were repeatedly asked whether we really wanted an 'intolerable life' for Pádraig as he had not been showing signs of consciousness. Back in Ireland, in Beaumont Hospital at his bedside, we were asked which nursing home Pádraig was going to go to. That was the day we reassured him that he was going to live at home. There was a waiting time of at least one year for a transfer to one of the three suitable beds in the National Rehabilitation Hospital (NRH),

the only such facility in the country; even then his stay was going to be for just about three months, the time required by the NRH to assess him and plan for his future care.

Our family is Irish-German. Pádraig has dual citizenship. We decided to move with him to Germany. Pádraig had gone to the local primary Gael Scoil, Scoil Mobhí. His secondary school was Coláiste Eoin. He had studied Irish and History in Trinity College Dublin (TCD). He loved living in Ireland. Moving to Germany was not by choice. Uprooting and breaking up the family, leaving his two sisters behind was heart-breaking. But none of us saw a tolerable alternative.

In Germany, we were made legal guardians ('Betreuer') of Pádraig by the courts, following a lengthy process of independent medical and legal reviews and including a court hearing at his bedside. When asked, the judge explained that one important lesson from Germany's history was that patients had to be protected. Doctors had the power to put patients into any state of reduced consciousness, the judge said. Thorough checks had to ensure that history would not repeat itself.

Our being appointed guardians by the court meant that we could now legally assist Pádraig making decisions about his medical treatment, his residence and his financial affairs.

A few years later, and back in Ireland, we learnt that this was far from common practice. The doctors in the hospital where Pádraig was assessed for a home care package told us that they would decide on his medical treatment. HSE representatives told us that agency carers would, if they felt it necessary, call an ambulance and transfer Pádraig to the A&E of the nearest hospital, without consent or consultation. We were handed a copy of the corresponding HSE guidelines. Banks would not provide us with any information on his account as this information was not requested by Pádraig himself.

When we pointed to our status as legal guardians appointed by a German court, we were told that, according to the legal advice received by the HSE, this court order had no validity in Ireland.

This is when Reinhard rang the German Embassy in Dublin to enquire about their potential reaction to Pádraig looking for protection from the Irish authorities in the extreme case of the full rigour of the Lunacy Act being applied. Thankfully, the situation never escalated to that point.

Pádraig made a significant recovery from his injuries. His tracheostomy, suprapubic catheter and artificial feeding tube (PEG) had been removed. He began to make pronounced, very clear voluntary movements. And while he was still non-verbal and completely dependent for all activities of daily life, he had come off all medication. Above all, we had established that he could hear, see, read and understand everything – in Irish, English, Spanish and German.

Most importantly, he could communicate with tongue, hand and foot movements, and by using a switch ('bleeper') introduced to him by an outstanding therapist in the NRH who had sourced it from the Royal Hospital for Neuro-disability, in Putney, South West London.

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### CIVIL RIGHTS IN ACTION

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Professor Fins, in his highly acclaimed book on sABI, *Rights come to Mind-Brain Injury, Ethics, and the Struggle for Consciousness*, reminds us that not too long ago everybody had a right to vote, except if they were women; everybody had a right to education, except if they were black. We might add that everybody had a right to marry, except if they were a member of the LGBT community. Today's civil rights issue, Professor Fins says, is that of the right to rehabilitation for those with a severe brain injury – for those still left behind.

There are humble beginnings – beginnings that merit the full support of lawmakers, health professionals and society as a whole. Ireland signing the United Nations Convention on the Rights of Persons with Disabilities (CRPD) is one of those, although Ireland has still not signed the Protocol to that Convention which would allow people with disabilities to make an individual complaint to the Committee. The Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act), is another step in the right direction of following the Categorical Imperative for Self-Determination especially for those who, because of the gravity of their injuries, still need a substantial step to be taken by society and lawmakers *Towards a New Frontier for Human Rights*.

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### COMMON SENSE IN ACTION

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In the meantime, a good portion of ingenuity, humanity and a strong dose of common sense are required to by-pass the dreadful exclusive restrictions imposed by the Lunacy Regulation (Ireland) Act 1871 – an Act that even pre-dates the foundation of the State; an Act that we agree has no place in our modern civilised society proudly promoting equality, integration, participation, equal rights, and self-determination as its core values.

After his accident, we had tried on several occasions to get a statement for Pádraig's bank account, which he had used to manage his financial affairs – consisting mainly of regular pocket money income and some once-off gifts from his family. There was no way the bank would issue that statement without Pádraig himself requesting it – or us going through highly complicated, far-reaching proceedings. (We had always explained when in contact with the bank why we were making the call and not Pádraig himself.)

One bright summer morning, Pat and Pádraig went to the bank where his account was held, equipped with the bleeper used by Pádraig to communicate: one bleep for 'yes'; two bleeps for 'no'; three bleeps for 'maybe' or 'I don't know'.



Pádraig arrived at the bank with a bright smile on his face, as suggested to him by Pat, ready to let the bank clerk know with a determined bleep that he was indeed looking for his bank statement. Pat explained what Pádraig was looking for and that she interpreted for him because he was non-verbal. Pádraig continued to smile. Without further ado, the bank clerk happily complied and issued that long-awaited statement.

In a similar fashion, Pádraig has voted in several elections since his accident, from local to national to European elections. He takes his duty as a citizen very seriously.

With our assistance, he set up Cúram Phádraig Cuideachta Faoi Theorainn Ráthaíochta, employing his own carers.

Pádraig is also the man behind the An Saol Foundation CLG, which is running a three year HSE-supported pilot demonstrator project in Santry, Dublin, the An Saol Rehabilitation Day Centre. It is the first such centre in the history of the State, offering state-of-the-art day rehabilitation facilities in the community including physiotherapy, occupational therapy, speech and language therapy, robotic gait therapy, and social rehabilitation activities to those with a severe brain injury and their families, to those who up to very recently had been left behind and without a voice.

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### SPREADING SMILES

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During a recent visit to the supermarket, a friendly, well-meaning assistant came up to Pádraig and Pat. She smiled at Pádraig and said, looking over to Pat, ‘He is a great little helper, isn’t he?’ Pat, although appreciating the intended kindness, was more conscious of Pádraig’s dignity and the need to protect him from pity, answered, ‘Sure, he is of no help to me at all here in the shop. But, you see, his wheelchair is great for hanging heavy shopping bags.’ She did not mention that nor was there anything ‘little’ about him at 6’7”. With that, Pádraig showed his great infectious smile, causing the lady to smile too.

Pádraig’s ability to preserve his sense of humour, to non-verbally communicate and share that humour, to spread happiness is uplifting and inspiring for all who meet him. While he is fully aware of the restrictions imposed by his devastating accident, he does not perceive his life as ‘intolerable’, contrary to the belief of some of the professionals who strongly and repeatedly suggested very far-reaching decisions should be made for him.

With the help of one of his sisters, he discovered the pleasure of connecting with his friends through regular Zoom calls adhering to the COVID-19 social distancing guidelines – on most occasions from a sunny spot in the back garden.

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## THE CATEGORIAL IMPERATIVE

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In addition to the physical injury, deep trauma affects the injured themselves and those close to them. Its impact is rarely acknowledged, never mind addressed appropriately. Its significant effects on their mental health cannot be overstated, often bringing with it family breakdown, economic hardship and worse.

Life with a severe brain injury is incredibly hard, for those directly affected and for their families. It is possibly even harder if that brain injury happens to a young adult with their life and dreams ahead of them: dreams of finding love, a partner and, perhaps, establishing a family.

Those with a sABI not only deserve every help we can give them to realise their ability to the fullest, they have a *right* to receive that support.

Above all, the voiceless have to be given a voice and with it the power to inspire, drive and define developments that will make equality and self-determination real for them.

Decision-Making, Consciousness, and Civil Rights are connected by the Categorical Imperative for Self-Determination. The 2015 Act is a long overdue step to the realisation of the right of self-determination.

Pádraig, Pat and Reinhard, for one, are very clear that there will be 'No Decision about Pádraig without Pádraig'.

## 1.4 I Have Always Been Myself

*Barbara Brennan*

At times when I have been unwell and have displayed the symptoms of severe mental illness, I have still been myself. My preferences in general did not change. For example, the things I like to eat – or not. I also know that my preference will always be to be treated kindly, and to be included in conversations about things that will affect my life.

Even at times when somebody may not fully understand the consequences, or the impact of their decisions, to be treated kindly and to be included in the conversation is a very different experience than having decisions made for you and being excluded. We only have one life. Being excluded from your own life is a very difficult, painful and upsetting thing. We all have the capacity to be kinder. Even in times when we do not understand or cannot imagine where another person is in their mind, that does not mean that we should treat them any less well. Most often, when we treat somebody with kindness and respect, they respond in a much better way.

That kindness and respect should not change because we make assumptions on what that person understands. If anything, if we believe that somebody has diminished capacity, surely then we should treat them with twice as much care, kindness and respect?

It has been my absolute privilege to work in the area of mental health for the last 10 years to help people have easier conversations about the topic and understand that we all have mental health. Only with this understanding can we start getting any idea of how it might be for somebody with severe and enduring mental illness.

When you consider capacity, what exactly is it that you are considering? And in those moments when you decide that somebody does not have capacity, what other things do they have capacity for that maybe you are deciding they don't? At what point is it possible to realise that their capacity has returned, and that they are able to make decisions for themselves?

We need to listen more. Sometimes, we don't realise that the way we have explained something doesn't make sense to the person. Maybe explaining it in a different way is all that's needed. In my journey of the last 12 years of wellness, I have found that a little bit of time and a little bit of compassion goes a very

long way – and can make a huge difference. For somebody who is really struggling with their mental health, you don't know how many people they have spoken to that week, or what those interactions were like. In the moments when we are with somebody who is struggling, we should always assume that they need our kindest selves to be present. Some people do not see that kindness is one of the biggest and most impactful tools that we have. It can have immediate and lasting effect.

I was that person who had diminished capacity at times. Earlier in my life, my future was written off. I was never going to have a job, own a house or do many of the things that most people take for granted. I would live a sheltered life, on heavy medications and living by other people's decisions. Now? Not only do I work full-time, but I manage our national stigma reduction partnership, which is a great privilege. I own my own house. I have been off medication for 12 years and have wellness and vitality in my life.

I am one of the lucky ones. Yes, I have worked incredibly hard to rebuild my life and make it a meaningful one, but I have also had incredible advocates and supporters along the way. People who believed in me regardless of what my history of illness said.

I am lucky that I have found my passion in helping people understand not only what it is like for those who struggle deeply with mental illness – and whose voices are often unheard – but also for those who live with, love and care for somebody who has a severe mental illness.

We still have so much to learn about mental health and illness. We still have so much to learn about what it is to be human. We still have so much to learn about how much people can still give, even when their lives have been written off.

Let's realise our humanity and help each other to be human, to give all we can and to afford each other the kindness and respect that we all deserve regardless of the state of our mental health.

At times when I have been deeply unwell, I was still always aware of how people treated me. When people ignored me, were unkind, mistreated me or excluded me from decisions about my life I WAS aware that these things were happening. I was also aware when I was shown a kindness, when somebody went above and beyond for me, when I was included in conversations and decisions about what was best for me, when time was taken to explain things in ways I understood...All of those times, all it took was for one person to remember that I was still a human being behind all the symptoms. The gestures were small but the impact has echoed long into my future.

Even though I have worked in the area of mental health and stigma reduction for a decade now, I still see every conversation as a privilege. I certainly never thought I would be having conversations about mental health capacity law, and definitely not with people who were in a position to make positive change in this area. I feel blessed to live in a progressive country where I have been afforded a voice and the space to have an opinion. I have also been honoured to work with amazing people in this area looking to make the voice of lived experience part of the process for creating change for the future of mental health and decision-making. As long as we are focused on the human in the middle of it all, as long as we keep asking ourselves WHY we are doing the things we do, as long as we continue to check-in and re-evaluate the situation, we have the opportunity to help the person in the centre feel heard and respected.

That's all most of us want in life.

## 1.5 **Exiting Wardship: How the Assisted Decision-Making (Capacity) Act 2015 Can Change Your Life**

*Claire Hendrick*

I grew on the northside of Dublin, Ireland. I lived with my two brothers and mum and dad. My mum and dad separated when I was 11 years old. I was in a special class in school, and I never knew why. I was unaware that I had an intellectual disability until I was 23 years old. I found medical reports when I had to go through my mum's things when she had died. I was shocked but not surprised, I always knew I was different from others but I didn't think I had a disability. I don't see myself as having a disability.

When I finished school, I became my mum's full-time carer. She had a chronic illness. I was her carer for five years until she passed away in 2006. The day mum died my whole life changed. My mum's house had to be sold. My mum never signed her will. I was left homeless. It took two to three years for the house to sell. My solicitor made me a Ward of Court. He thought it was the best thing for me at the time.

I had to go see a psychiatrist and psychologist about being assessed for being made a Ward of Court. They check your mental abilities and said I was unable to look after my own affairs as I was vulnerable and still grieving for my mum. I was deemed incapable of looking after my own affairs. A lunatic in the eyes of the law.

On Christmas Eve 2010, I became a Ward of Court. I wasn't told until January. I rang my solicitor for an update; he told me I had been made a Ward of Court the month before. All decisions about my life were going to be made by the Ward of Court office. After a while, my aunt and cousin were allowed to make some decisions for me and they made up the committee. At first, all decisions were made by court office workers who didn't know anything about me, only from what they read in the reports.

I couldn't have a relationship, go to the doctor or make decisions for myself. I didn't have access to my own money. I had my own personal bank account for day-to-day spending. I wasn't allowed access to my money that I had inherited from the sale of my mum's house. For my birthday, I wanted to buy a phone, so I had to send the details of the phone, the price, etc. to the court and they took three weeks to reply to me. If I wanted to go to the doctor, I had to let them know even though I did have a medical card and I wasn't asking them to pay for it. I still needed the permission of the court office before receiving any treatment. If I had an accident and needed to see a doctor straight away, I'm not sure what I would have done. You must tell them everything in advance and they might not always get back to you in time.

The court is very strict about relationships. They carried out a full criminal background check on everyone I went out with. But how can you say to someone that you really like 'Oh, by the way, I can't be in a relationship with you because the law won't allow me.'

During this time, I lived in Sophia Housing on Cork Street on the south side of Dublin. This is a supported housing service for people with alcohol and drug issues. I lived there for a year and half. I wasn't sleeping or eating properly. All I wanted was my own home on the north side of the city where my family and friends are. I was very unhappy and with the help of my aunty and cousin, I went to the court office to ask if I could buy my home with my money. I was told I couldn't because I was a Ward of Court. They said I could move out of Sophia Housing and could move into a rented accommodation. This was not easy by any means; how do you tell your new landlord that you will be getting a rent cheque from the High Court? It didn't make sense when it was my money and I couldn't access it.

We decided to challenge the court office because I wanted to buy my own house. I wanted to stay in wardship and buy my own house because I was vulnerable and I have a disability. I wanted to make sure I was protected if anything went wrong, but the court office wouldn't agree to this. In May 2012, I decided to leave wardship.

I had to go get a solicitor to get out of wardship and I had to go back to the same psychologist and psychiatrist to be reassessed to make sure I was self-sufficient and no longer vulnerable. They both said as long as I had legal support and help from my reliable family members, I could leave the Ward of Court system. I will never forget the day my solicitor rang me to say I was released from wardship in August 2012.

On 30th August 2012, my life changed for the better. I was able to go look for my forever home. But being a Ward of Court came with hidden costs, which I didn't know about until I got my money back. It was a lot less than I thought it was, which made it hard to find a house which was suitable.

After a lot of looking around, I finally found a house which was on the northside and wasn't too far away from my family and friends. I went to see the house first on my own – I wanted to prove to myself and everyone that yes, I can find my home by myself. I got my cousin to come with me the second time. We bargained the estate agent down and got a good price. I like nothing more than a good bargain.

I never said once that I had disability, it was never an issue. Because I was paying cash, the sale of the house was straightforward. My cousin and aunty came with me to get the keys and sign the deeds of the house on Valentine's Day 2013 – seven years after my mother had passed away.

Yes, I do have a disability and I am able to live as independent member of society with a little help from my family.

I think wardship is mental torture. I was lucky enough that I had a great family to support me and was able to fight the court system back and come out the other side.

I am now a human being and I am not a 'lunatic' anymore.

## 1.6 The Assisted Decision-Making (Capacity) Act 2015 and Mental Healthcare

*Fiona Anderson*

1.

Looking retrospectively from my experience of the admission procedures and interviews under the Mental Treatment Act 1945, the concept of consent was largely unknown. Admission interviews were, for all intents and purposes, informal capacity tests mixed with subtle coercion to consent to voluntary admission as at the time an involuntary patient did not have the protection and right of an independent psychiatrist's report and tribunal hearing relating to their detention. The admission interview questions were designed to determine the lucidity, concentration, memory and thought processes of the person. Hovering overhead was the prospect of involuntary detainment and, at the time, consultant psychiatrists had a broad range of powers and authority under the legislation and at their whim could wield their authority. Psychiatrists were not required to provide explanations and no questions were asked. Although having been admitted as a voluntary patient and retaining the capacity to make decisions and consent to medical treatment, there was no discussion around the proposed medication regime, its benefits, side-effects and withdrawal symptoms and, upon seeking information about the medication and its properties, all that was said was 'It's non-addictive'. Having consented to be a voluntary patient, I questioned the practice of removing all of my day clothes and it was a humiliating, embarrassing, degrading and dehumanising practice. There appeared to be an underlying belief that I would abscond despite being a voluntary patient.

2.

I had become accustomed to the admission interview procedures and questions. They consisted of four main questions.

- i. What is the price of the Irish Independent?
- ii. Count back from a hundred in sevens.
- iii. Given a name and address and asked to recall it in about ten minutes and
- iv. Is anyone putting thoughts into your head?

I, at this point, could reel off the appropriate responses. In my first admission interview in March 1989, the fourth question and my response sewed me up. Admittedly, I had some rather irrational thoughts; however, being faced with seven individuals in a confined office, I would have said anything to get out of the room. There were three doctors facing



me and four nurses standing against the wall. My response to the second question was more due to my inadequate mathematical ability to subtract accurately, making several mistakes, rather than a lack of concentration issue. I was able to give the price of the newspaper and I was able to recall the name and address given. This is the informal capacity test I referred to at the beginning. I had undergone this admission interview technique several times and during my admission towards the end of July 1994, when I participated in a video training interview.

### 3.

Moving on from that comes my experience of lithium therapy and the process of commencing the treatment. I was a capable adult of 25 years of age when a source thought that this was the ideal treatment for Bipolar Affective Disorder. Discussions took place with a healthcare professional and the source focused on my diagnosis. However, I was not party to these discussions and wasn't even invited to attend and was left sitting in an alcove of the acute psychiatric unit. After the first discussion, I was brought in to the medic. I stated clearly that I did not desire for my illness to be discussed with anyone else, particularly if I was not present and this is noted in the file. This was clearly a breach of my privacy and confidentiality and, interestingly, the content of the previous discussion and the second discussion with the source is not recorded in the file. My request to cease the discussions was not heeded. This upset me a lot and, rather than acknowledging my reasonable reaction to this breach, my medication was inappropriately increased. Although I was given six months to consider the treatment, I felt pressurised into commencing it. I felt I had been lumbered with this diagnosis and label and lobbed into a box with others and not seen or treated as an individual. I question the source of origin of my mood swings and have a battle with psychiatry to recognise that the mood swings are caused by my hormonal imbalance associated with PCOS (Polycystic Ovarian Syndrome) and endometriosis and are symptomatically akin to bipolar. It is of interest in the file of March 1989 that I brought the problems with my menses to their attention; however, there were no follow-up hormonal tests.

Had they done some hormonal profile tests at that time, it would have led to an earlier diagnosis. This leaves me to query whether lithium was the most suitable treatment available to me. I was given the label of bipolar prior to the diagnosis of PCOS and endometriosis at the age of 35 and 39 respectively. I had hormonal profile tests taken whilst in the throes of mood swing episodes and they always come back exhibiting that they were awry and all over the place so hence: was lithium the correct treatment for me? I commenced the lithium treatment in March 1991, having been admitted to the acute psychiatric unit for preliminary tests and a urine collection sample over twenty-four hours. At the time I was not having a mood swing episode. Despite my misgivings about the treatment, I followed my medication regime and had my regular serum level tests. I remembered as an inpatient and outpatient in 1994/1995 that I had several kidney infections and this is noted in the file. I also discovered in the file eleven years later that, on three occasions prior to ECT in July 1995, traces of blood were

found in my urine, which should have raised concerns about my renal function but no action was taken. I continued to have recurring kidney infections and lithium toxicity a number of times, so when I discovered the chronic kidney disease, I immediately set about having the substance removed. A consultant, whose speciality it wasn't, assisted me by conducting a 24-hour urine collection in January 2006 and I was advised due to the results not to wait to deal with my kidney function problems. In April 2007, two allied healthcare professionals concluded to remove the lithium as my kidney function was decreasing and in the hope the progression of the disease could be managed but my kidneys were irreparably damaged. My function hovers around 24% and will continue to decrease as I get older and currently is managed by diet. The cut off point for dialysis treatment is 20%, which is a daunting prospect ahead. The lithium treatment has left a very bitter aftertaste.

4.

My more recent involvement with the mental health services in the last ten years in relation to my treatment plans have been in complete contrast to my experience in the past. It was suggested to me to try Epilim as a mood stabiliser; however, I was given the time and opportunity to research this medication in 2011 and 2016 and make my own informed decision. Despite my age, I was advised of the effect Epilim could have on a foetus, which I appreciated. As I had a litany of medical problems already, having researched the treatment and also reacted to two previous epileptic drugs – one as a mood stabiliser and the second for my chronic pain – I decided I could not take the risk of adding liver damage too. My decision was accepted and respected without having a functional capacity test applied and there was no pressure or influence exerted to change my mind. There were no issues around obtaining consent as I was credited with the intelligence and capacity to make the decision. I have noted that the mental health services have implemented a lithium policy in recent years, which consists of a detailed consent form and the benefits, side-effects, withdrawal symptoms are to be advised and understood by the patient prior to consenting and commencing treatment. This consent form is to be signed by both the consultant psychiatrist and the patient, and a booklet is provided to the patient for reference on lithium. There is also a diary to be brought to appointments to record the various tests that must be signed by the consultant and a small record card to fit in a wallet or purse in an emergency that records the patient is on Lithium. All of these measures should reduce the incidence of chronic kidney disease and thyroid issues. There is also an Epilim policy for women of childbearing age. Epilim has an effect on a foetus leading to disabilities like a cleft palate and other serious disabilities. With the introduction of more modern technology, the childbearing age for a woman has increased. Both policies are recommended.

5.

I will now turn my focus to experience under the Mental Health Act 2001 (the 2001 Act) as an involuntary patient in 2011. Whilst the 2001 Act may have several drawbacks, the establishment of the Mental Health Commission was necessary to provide involuntary

patients with protection of their human rights from arbitrary procedures. The 2001 Act provides involuntary patients with an independent psychiatrist report and tribunal hearing to review their detention within 21 days. At this point, having had the experience, it is important that, despite a person being admitted involuntarily, it does not automatically follow that they lack legal capacity to make decisions about their treatment. Where capacity is compromised is where the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) will come into play. The three-tier hierarchy should be applied in this respect. A person should have the right to appoint a person or people that they trust to assist them at any point in their detention. It is a requirement of the Mental Health Act 2001 that the treating consultant psychiatrist explains in an understandable method and language to the involuntary detainee the benefits, side-effects and withdrawal symptoms of any proposed medication or ECT treatment. Another area that needs to be addressed is the implementation of advance healthcare directives in mental healthcare. Currently, under the 2015 Act, advance medical directives in mental healthcare as an involuntary detainee are not legally binding as they are in general medical services. Instead, the 2001 Act applies. If the patient is unable to consent, this provides a three-month window of opportunity to coerce treatment and the objective of this is providing time for a patient to recover sufficiently so they will be more likely to cooperate with the treatment. However, the 2001 Act also provides in order for the treatment to continue after three months, consent must be obtained in writing from the patient. The patient can decide to cease the treatment and this must be respected, regardless of how unwise it may seem to others.

## 6.

If capacity is somewhat compromised, the involuntary detainee should be permitted to appoint a person, people or an advocate to assist them in either of the following ways:

- i. To assist them to understand the proposed medication regime or ECT treatment and enable them to make an informed decision of their own choice with reference to their wills and preferences and whether other options of treatment are available to them.
- ii. To help them understand and make a joint decision regarding medication or ECT treatment proposed and taking their will and preferences into account. To permit the Court to appoint a Decision-Making Representative, preferably someone close and trusted to the person, to make all decisions on the person's behalf, taking their will and preferences into consideration when making any decisions and, in this case, as any involuntary patient treatment decisions.
- iii. Advance healthcare directives—This is a method of planning ahead that permits you to write down your desires for medical and healthcare treatment decisions in case you become unable to make these decisions at some future point. You can appoint a person or people whom you know and trust to become your

designated healthcare representative(s) to ensure your advance healthcare directives are enforced.

iv. Enduring power of attorney—If your capacity is not currently compromised and, looking ahead, you can apply to make an enduring power of attorney and appoint a person or people you trust to act as your attorney. The role of the attorney is to make certain decisions on your behalf should you become unable to in the future. The attorney does not have to be a lawyer.

7.

Equally, voluntary patients should be encouraged to adopt one of the above measures should they become legally incapacitated at some point in the future or regraded as an involuntary patient.

Finally, I turn my attention to the United Nations Convention on The Rights of Persons With Disabilities (CRPD) and specifically Article 12: Legal Capacity. Ireland has ratified the CRPD; however implementation of the CRPD has yet to be fully realised in many respects. There have been attempts to place reservations on this Article, particularly in relation to mental healthcare. Hopefully, the 2015 Act will work in tandem with the CRPD.

## 2 A Changing Legal Framework

### 2.1 The Making of the Assisted Decision-Making (Capacity) Act 2015

*Jacqueline Grogan*

The Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) was signed into law by President Michael D. Higgins on 30 December 2015. It only took a few seconds for the President to sign his name on the Act, but it has been a long road to get to this point. The 2015 Act will bring Ireland's human rights obligations in relation to capacity and decision-making into the 21st century, and will be a large step in Ireland's compliance with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). It will abolish the current wardship system and will introduce a flexible structure to support people to make decisions.

Ireland's legislation in this area is outdated and the current Wards of Court system is based on the Victorian Lunacy Regulation (Ireland) Act 1871. This legislation defines a Ward as 'a person who has been declared to be of unsound mind and incapable of managing his person or property.' The 1871 Act refers to people as 'lunatics' and 'idiots'. While these terms are not used in Court today when proceedings are taken under the 1871 Act, their continued existence in statute remains.

Disability rights activists have been campaigning for reform of the wardship system since the early 2000s. In 2003, Inclusion Ireland (then known as NAMHI) published *Who Decides and How* (Inclusion Ireland, 2003). This discussion document looked at decision-making and capacity for people with intellectual disabilities and examined the adequacy of the current law in this area. The document also highlighted that even though family members, carers and services have no legal authority to make decisions on behalf of people with intellectual disabilities, the absence of any formal system of decision-making outside of wardship effectively left families and services in a kind of limbo when decisions needed to be made, but no-one had authority to make them.

The discussion document highlighted the need for reform to the legislation in this area, with the focus on supporting people with intellectual disabilities to make decisions and to provide arrangements for a person if they lacked decision-making capacity for a particular decision. This document was followed by a subsequent one specifically looking at making medical decisions (Inclusion Ireland, 2005), and the importance of protecting a person's autonomy when decisions about medical treatment are being made.

In the same year, the Law Reform Commission published their Consultation Paper on the Law and the Elderly, 2003. This Consultation Paper looked to start the discussion on the existing legislation in respect of the elderly in Ireland. It looked at what legal mechanisms and responses would be required to protect the elderly, while emphasising that health and social care services play a part in the protection of vulnerable older people as it cannot be guaranteed by legal mechanisms alone. The Consultation Paper recommended that the Wards of Court system should be abolished and that a new system should be put in place to protect vulnerable older people.

A second Consultation Paper was published by the Law Reform Commission in 2005, addressing the area of Vulnerable Adults and the Law and a Report on this topic was published in 2006. This Report concentrated on legal capacity issues for all adults who require support with decision-making, not just older adults. It focused on a number of key areas of decision-making, including capacity to enter a contract, capacity to enter relationships and capacity to make healthcare decisions. A number of key recommendations in the reform of the law in this area were suggested, some of which are highlighted below:

- The law should reflect an emphasis on capacity rather than lack of capacity;
- The law should be enabling rather than restrictive in nature;
- A functional approach to capacity should be taken, focusing on the person's ability to understand the nature and the consequences of the decision in the context of the available choices at that time;
- Capacity should be presumed in every adult, unless the contrary is demonstrated;
- Appropriate terminology should be used to refer to persons who lack legal capacity, and that phrases like 'idiot', 'lunatic' and 'person of unsound mind' should not be included in any part of the reforming legislation;
- A guardianship system should be established to replace the Wards of Court system.

In 2007, the Irish Government approved proposals for the Mental Capacity and Guardianship Bill. The Bill was written to facilitate the process of ratifying the UNCRPD, signed by Ireland in March 2007. This meant that Ireland needed to amend its existing legal framework on capacity to provide appropriate and effective safeguards.

The Mental Capacity and Guardianship Bill was drafted so that Ireland could meet its obligations in the area of legal capacity issues and ratify the UNCRPD as quickly as possible. The Bill lapsed with the dissolution of the Oireachtas in July 2007 and was resurrected in the new Dáil as the Mental Capacity and Guardianship Bill 2008.

While both draft Bills were broadly welcomed, advocates and civil society raised concerns about the 2008 Bill during the public consultation in 2011, instigated by the Joint Committee on Justice, Defence and Equality. The Committee also hosted public hearings on the Bill and a conference in 2009 to get as much knowledge and good practice as possible to feed into the process of developing the Bill.

The 2008 Bill was largely silent in relation to supporting people to make decisions. Supporting people to make their own decisions is important when considering incapacity in line with Article 12(3) of the UNCRPD, which places an obligation on States Parties to ‘take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity’. The 2008 Bill stated that ‘a person shall not be treated as unable to make a decision unless all practicable steps to help him or her to do so have been taken without success’, however it did not set out a framework of support to assist people to make decisions. Instead, the focus of the Bill was on substitute decision-making through the mechanisms of informal decision-making, court-appointed guardians and enduring powers of attorney. This was concerning to a lot of campaigners, as substitute decision-makers may not make the same decisions that the person would have made. Concerns were also expressed about the minimal safeguards in the Bill when it came to informal decision-making, mainly by family members.

There were also concerns about the use of the term ‘best interests’. Article 12 of the UNCRPD focuses on the will and preferences of the person as the determining factor in decisions about their life. This would mean a move away from the best interests approach, currently embedded in healthcare practice, which can bring a significant risk of paternalism. This would require a significant change of approach for the Bill, which stated that all acts and decisions on behalf of someone who lacks capacity should be done or made in their best interests.

The Mental Capacity and Guardianship Bill 2008 lapsed with the dissolution of the Oireachtas in 2011. The new Government revised the proposed legislation and published the Assisted Decision-Making (Capacity) Bill 2013. This Bill was one of the most debated pieces of legislation in Ireland, with fourteen debates taking place in the Dáil, the Seanad and at Committee Stage, with multiple revised schemes of the Bill being published.

Kathleen Lynch, Minister of State at the Department of Health, introduced the Bill to the Seanad in the first debate in December 2013:

‘The Assisted Decision-Making (Capacity) Bill proposes a fundamental reform of Ireland’s laws on capacity. It has been framed to meet Ireland’s obligations under the UN Convention on the Rights of Persons with Disabilities which requires State parties to eliminate barriers preventing people with disabilities from enjoying their human rights and fundamental freedoms. Accordingly, the existing wardship system, which supplanted the person’s decision-making capacity, is being abolished. It will be replaced by a significantly less intrusive system which is focused on supporting decision-making capacity rather than on supplanting it.’ (Seanad Éireann debate, 2013)

A consultation symposium, hosted by the Department of Justice, Equality and Defence took place in September 2013, and a national consultation was undertaken in 2014 to obtain as much feedback and input into the development of the Bill by key stakeholders.

The Bill moved from having an Office of the Public Guardian in its first iteration to the Decision Support Service by the time the Bill was signed into law. Minister Lynch, in response to the concerns raised in the consultation, stated during the debates:

‘The Bill provides for the establishment of the Office of the Public Guardian in the Courts Service as the body designated to undertake the functions arising from the Bill. I have responded to criticism that the name of the body was overly paternalistic by proposing that it will be called the Decision Support Service. The name change is designed to reflect the purpose of the body which will be to provide services to people with capacity difficulties, to those taking decisions for them and to those interacting with them in a professional capacity.’ (Seanad Éireann debate, 2015)

Provision for informal decision-making was removed as the Bill worked its way through the Oireachtas, due to concerns that it would have allowed informal decision-makers to circumvent the safeguards that were built into the legislation. In relation to its removal, Minister Lynch stated:

‘Although it was never the intention to create a new category of informal decision-makers, the feedback on the Bill as published indicated that stakeholders were concerned we were creating such a category and were giving too many rights to that group, thus potentially undermining the impetus for a person to take on a formal decision-making role under the Bill, with all the consequent obligations.’ (Select Committee on Justice, Defence and Equality, 2015)



The removal of informal decision-making from the Bill was supported by Senators, Deputies, NGOs and civil society.

Provision for advance healthcare directives was included in the amended Bill, allowing a person with capacity to state their will and preferences concerning healthcare treatment decisions that may arise if they subsequently lack capacity. Advance healthcare directives will provide health and social care professionals with important information about a person's healthcare treatment choices. In relation to their inclusion in the Bill, Senator Maurice Cummins stated:

‘The Bill also provides for advance health care directives allowing a person to state his or her will and preferences regarding treatment decisions that may arise in the future when he or she lacks the capacity to provide consent or refuse treatment...This is why this legislation is so important in helping to address the key barriers that affect people who have difficulty in making decisions for themselves.’ (Seanad Éireann debate, 2015)

The Act was passed by both houses of the Oireachtas on 17 December 2015 following the final debate in the Seanad and was signed into law by the President on 31 December 2015.

After enactment, the focus moved to preparation for full commencement of the Act. The Statutory Instrument to allow the establishment of the Decision Support Service was signed by Minister for Justice Frances Fitzgerald on 18 October 2016, and Áine Flynn was appointed Director of the Decision Support Service in October 2017. Since Ms Flynn's appointment, intensive work has taken place to establish the Decision Support Service. At the time of writing, a senior management team has been appointed and a project with multiple work-streams is underway.

On the same date, Minister for Health Simon Harris signed an additional Statutory Instrument into law allowing for the establishment of a multidisciplinary working group on advance healthcare directives. The role of this group was to draft Codes of Practice on Part 8 of the Act, in relation to advance healthcare directives. This group commenced their work in November 2017 and submitted the final codes to the Decision Support Service for consideration in 2018.

A number of other codes of practice were also drafted on the Act. The National Disability Authority established a technical group in 2017 to draft 11 codes of practice on the Act. The HSE Assisted Decision-Making Steering Group drafted a Code of Practice for Health and Social Care Professionals in 2019. These codes of practice will play a key role in the implementation of the 2015 Act. At the time of writing, the codes of practice are being considered by the Decision Support Service prior to them being issued for a public consultation.

Ireland ratified the UNCRPD in 2018 – the final country in Europe to do so, three years after the 2015 Act was signed into law. The significance of the ratification is that Ireland now has obligations to submit reports to the UN Committee on the Rights of Persons with Disabilities on the implementation of the Convention.

Following enactment, there were concerns within civil society that commencement of the 2015 Act was going to be protracted. Amendments to the 2015 Act that were essential for commencement were included in the Disability (Miscellaneous Provisions) Bill 2016, however the Bill didn't progress past committee stage in early 2019.

Addressing these concerns, Minister for Justice Charlie Flanagan affirmed the Government's commitment to the 2015 Act at the launch of the Mental Health Commission Annual Report 2018 in June 2019:

'So what about the Act?...And in relation to it, I want to assure you of two things. Firstly, that key preparations for its commencement are being put in place within my Department. And secondly, that Government is fully committed to its implementation. This Act provides a modern statutory framework to support decision-making by adults with capacity difficulties. It has been framed to meet Ireland's obligations under the UN Convention on the Rights of Persons with Disabilities. The Government's approach to meeting the terms of the Convention is one of sustained and on-going improvement, and work is continuing on the reforms needed for an optimum level of compliance with the requirements of the Convention. In that context, the Assisted Decision-Making (Capacity) Act is a significant piece of reforming human rights legislation.' (Flanagan, 2019)

Following this commitment, the Assisted Decision-Making (Capacity) Amendment Bill 2019 was drafted and debated in July 2019 and October 2019, however the Bill lapsed with the dissolution of the Oireachtas in 2020.

In the current Programme for Government Our Shared Future (Government of Ireland, 2020), there is a firm commitment from the Government to commence the 2015 Act. The responsibility for the Act has moved to the Department of Children, Equality, Disability, Integration and Youth. An interdepartmental steering group has been established, chaired by this Department, with membership from the Decision Support Service, the Mental Health Commission, the Department of Health, the Department of Justice, the HSE and the Courts Service, to oversee the process for commencement of the Act.

In April 2021, the Decision Support Service hosted a webinar, which included an interview with Minister of State for Disability Anne Rabbitte. During the webinar, she stated:

‘It is the will and preference of me as Minister to drive it, to deliver it to June 2022, to ensure that we actually have, when we open the doors, we have a fully functioning operational DSS that can meet the needs of...approximately and growing 220,000 people.’ (Rabbitte, 2021)

The Decision Support Service presented to the Joint Committee on Disability Matters in May 2021. A number of Deputies raised concerns about the length of time it has taken since the Act was enacted for it to be commenced. Deputy Violet-Anne Wynne stated:

‘I want to use my time to relay the frustrations of the people who have been impacted by the fact that the Assisted Decision-Making (Capacity) Act has been delayed in its commencement and the implications a delay has on individuals. The time that lapses between the introduction of legislation and its commencement can be years, which is hugely unfortunate...We need commencement, implementation, resources and regulation.’ (Joint Committee on Disability Matters, 2021)

There has been a firm commitment across Government that commencement will take place in June 2022 before Ireland presents to the UN Committee on the Rights of Persons with Disabilities in July 2022. All of the signs are now indicating that this Act, and the efforts of all of those who have worked towards commencement, will finally come into fruition. This remains to be realised.

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## 2.2 Assessing the Need for the Decision-Making Supports under the Assisted Decision-Making (Capacity) Act 2015 in Irish Hospitals

*Brendan D. Kelly*

Consent to treatment lies at the heart of health and social care, and decision-making capacity lies at the heart of valid consent.

In Irish health and social care, issues of consent are governed by the Health Service Executive's (HSE) 'National Consent Policy' (National Consent Advisory Group, 2013 as amended). In relation to patients who may lack decision-making capacity, the policy states that 'no other person such as a family member, friend or carer and no organisation can give or refuse consent to a health or social care service on behalf of an adult service user who lacks capacity to consent unless they have specific legal authority to do so'. Such legal authority might include the patient being a Ward of Court or the subject of a relevant enduring power of attorney. In emergency situations, where a service user is deemed to lack decision-making capacity, 'consent is not necessary'.

The HSE policy points out that 'Irish case law, national and international guidelines suggest that in making decisions for those who lack capacity, the health and social care professional should determine what is in their best interests, which is decided by reference to their values and preferences if known'. When making such a decision, 'the health and social care professional should: consider whether the service user's lack of capacity is temporary or permanent' (obtaining consent during lucid periods if possible); 'consider which options for treatment would provide overall clinical benefit'; 'consider which option, including the option not to treat, would be least restrictive of the service user's future choices'; 'support and encourage service users to be involved'; 'seek any evidence of the service user's previously expressed preferences' (e.g. previous wishes and beliefs, advance statements); 'consider the views of anyone the service user asks you to consult'; 'consider the views of people who have a close, ongoing, personal relationship with the service user'; and 'consider involving an advocate to support the service user'. The policy emphasises that 'even in the presence of incapacity, the expressed view of the service user carries great weight'.

This HSE policy, which is currently being revised, is consistent with the ‘Guide to Professional Conduct and Ethics for Registered Medical Practitioners’ published by the Medical Council (2019). The Medical Council emphasises that ‘every adult patient is presumed to have the capacity to make decisions about their own health care’. A person lacks decision-making capacity ‘if they are unable to understand, retain, use or weigh up the information needed to make the decision, or if they are unable to communicate their decision, even if helped’. People who lack decision-making capacity ‘are entitled to the same respect for their dignity and personal integrity as anyone with full capacity’.

If nobody else has the ‘legal authority to make decisions on the patient’s behalf’, the Medical Council advises that ‘you [the doctor] will have to decide what is in the patient’s best interests. In doing so, you should consider: which treatment option would give the best clinical benefit to the patient; the patient’s past and present wishes, if they are known; whether the patient is likely to regain capacity to make the decision; the views of other people close to the patient who may be familiar with the patient’s preferences, beliefs and values; and the views of other health professionals involved in the patient’s care’.

This means that if a patient lacks the decision-making capacity to provide valid consent for a given intervention, and nobody else is explicitly legally empowered to decide for the patient, it is up to the doctor to decide what is in the patient’s best interests and proceed accordingly. This position is set to be revised by the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) when it is fully implemented.

The 2015 Act places the ‘will and preferences’ of people with impaired decision-making capacity at the heart of decision-making about ‘personal welfare’ (including healthcare) and ‘property and affairs’. Decision-making capacity must be ‘construed functionally’. This means that while a person might lack decision-making capacity in relation to one area (e.g. finance), they might still have decision-making capacity in relation to another (e.g. healthcare). And while a person might lack decision-making capacity at one time, they might regain it at another.

All interventions under the 2015 Act must be made ‘in good faith and for the benefit of the relevant person’. The legislation presents a set of principles that includes a presumption of decision-making capacity, provision of information and assistance, identifying clear necessity for any intervention, minimisation of restriction, dignity, bodily integrity, privacy and autonomy. Making ‘an unwise decision’ will not indicate lack of decision-making capacity.

The 2015 Act will introduce three levels of supported decision-making for people with impaired decision-making capacity: a ‘decision-making assistant’ will be someone who helps with information and discussions, but will not actually make a decision for someone else; a ‘co-decision-maker’ will be a joint decision-maker; and a ‘decision-making representative’

will be a substitute decision-maker. Arranging some of these supports will involve the Circuit Court. The legislation will also introduce new and revised procedures for ‘advance healthcare directives’ (to direct future care) and ‘enduring powers of attorney’.

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### WHAT PROPORTION OF HOSPITAL INPATIENTS LACK DECISION-MAKING CAPACITY?

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Estimates of the prevalence of decision-making incapacity among medical and surgical hospital inpatients vary across countries, from up to 40% of medical inpatients lacking decision-making capacity in the UK (Raymont et al, 2004; Owen et al, 2013) to 50.7% of patients in the internal medicine ward of a general hospital in Arta in Greece (Bilanakis et al, 2014).

To clarify the situation in Ireland, our research group assessed decision-making capacity in 300 randomly selected inpatients in two general hospitals in Dublin and Portlaoise (Murphy et al, 2018). We found that over one quarter of medical and surgical inpatients (27.7%) lacked decision-making capacity for treatment decisions; 1.7% had partial capacity; and 70.7% had full capacity. Lack of decision-making capacity was associated with older age, having never married, not working outside the home, being a medical rather than surgical inpatient and having a greater number of diagnoses. Given that Ireland has 650,900 acute public hospital discharges per year, this reflects a considerable challenge for the decision-making supports in the 2015 Act (Healthcare Pricing Office, 2019).

As is the case with medical and surgical inpatients, estimates of the rates of decision-making incapacity among psychiatry inpatients vary significantly, with studies suggesting that between 29% and 45% of psychiatry inpatients lack decision-making capacity (Okai et al, 2007; Lepping et al, 2015).

To clarify the situation in Ireland, our research group assessed decision-making capacity for treatment decisions in 215 psychiatry inpatients in four psychiatry admission units (Curley et al, 2019a; 2019b). We found that 1.9% of psychiatry inpatients lacked decision-making capacity for treatment decisions; 50.7% had partial capacity; and 47.4% had full capacity. Among voluntary inpatients, 2.3% lacked decision-making capacity; 39.8% had partial capacity; and 58.0% had full capacity. Among involuntary inpatients, 100% had partial capacity. Lack of decision-making capacity was associated with involuntary status, non-Irish ethnicity, not being employed and greater age. For all groups, assessments of decision-making capacity using research tools accorded closely with assessments using the criteria in the 2015 Act (Murphy et al, 2019; Curley et al, 2019c).

Given that Ireland has 17,000 psychiatry admissions per year, of which 2,225 are involuntary (Daly and Craig, 2019), these findings indicate that a substantial number of psychiatry inpatients will potentially benefit from the decision-making supports in the 2015 Act.

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## CONCLUSION

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Our research findings are subject to a number of limitations. We assessed decision-making capacity at one time-point (as opposed to returning to each patient at another time); there may have been residual selection bias in our samples (despite our inclusion of more than one hospital in each study and random selection of patients); and our study is subject to the limitations of the research tools we used (especially their emphasis on ‘cognition’ in decision-making, rather than other factors such as emotion).

Despite these issues, our studies are the first detailed examinations of this topic in Ireland and we show that lack of decision-making capacity for treatment decisions is common. Our findings emphasise the need for decision-making supports and endorse the definition of decision-making incapacity in the 2015 Act.

Legislation and policy, however, no matter how nuanced they are, can only go a certain distance in shaping the circumstances in which consent is provided. Beyond that point, it is the therapeutic relationship between the health or social care provider and service user that determines the nuanced contours of decision-making (Kong, 2017). People are intrinsically embedded, interdependent creatures, so, when we become ill, health and social care professionals are an inevitable part of the relational landscape in which we make decisions and in which our capacity to make them is shaped. Myriad non-legal factors are relevant: cognitive function, emotion, relationships and circumstances.

Supported decision-making can significantly enhance this landscape, albeit with limitations (Donnelly, 2019). With this in mind, the decision-making supports in Ireland’s 2015 Act are urgently required for both the many patients whom we found to lack decision-making capacity and those who might not lack such capacity but would still appreciate support. There is also a need for further research on this theme, especially in relation to the effectiveness of decision-making supports when they are introduced.

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## 2.3 Who Decides?: Consent, Capacity and Medical Treatment

*Mary Donnelly and Shaun O’Keeffe*

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### INTRODUCTION

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It is a fundamental ethical and legal requirement that consent should be obtained before providing medical treatment. Despite this, basic legal questions arise regarding consent for those who lack decision-making capacity to consent to treatment. Many of these questions will be addressed when the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) comes fully into force. This chapter identifies the impact of the 2015 Act on consent to treatment; the questions which will remain and the matters which still need to be addressed to provide clarity. First, however, we look at the current Irish law (the position prior to the 2015 Act coming into force).

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### CURRENT IRISH LAW

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Under current Irish law, everybody over the age of 18 who has decision-making capacity may consent to and refuse medical treatment. In *Fitzpatrick v K* [2008] IEHC 104, Judge Laffoy found that everyone over 18 years must be presumed to have capacity to consent to treatment but this presumption will be displaced if a person cannot comprehend and retain information about the treatment; cannot believe this information; and, cannot weigh the information in the balance in reaching a decision.

For young people over the age of 16 years, the position is a little more complex. The Non-Fatal Offences Against the Person Act 1997 says that: ‘[t]he consent of a minor who has attained the age of 16 years of age to any surgical, medical or dental treatment which, in the absence of consent, would constitute a trespass to his or her person, shall be as effective as it would be if he or she were of full age’ (s. 23(1)). Both the Medical Council’s Guide to Professional Conduct and Ethics (8th edn, 2016 as amended) and the HSE National Consent Policy (2013 as amended) recognise that young people may consent to medical treatment from the age of 16 years (presuming that they have decision-making capacity). However, both also recognise that the position regarding refusal of treatment is different. They are clear that where a young person refuses treatment, his or her views should be listened to and respected but that in some situations, where the consequences of the refusal are sufficiently grave, it may be necessary to make an application to court.

Where someone does not have the capacity to make a decision about medical treatment, the legal position differs depending on the person's age. For someone under the age of 18 years, their parents or legal guardians may give consent on their behalf. However, this authority to consent comes to an end when the person reaches 18 years (the age of majority). From this point on, as the HSE National Consent Policy notes:

'No other person such as a family member, friend or carer and no organization can give or refuse consent on behalf of an adult service user who him or herself lacks capacity to consent unless they have specific legal authority to do so.'

Although some health services have in the past sought consent from a person's 'next-of-kin', there is no legal basis for this practice and, in some situations (for example, where a 'next-of-kin' is not available or where family members disagree), this practice can lead to unnecessary delays in providing treatment.

Although they do not have legal authority to consent to (or refuse) treatment on behalf of someone who lacks capacity, those close to the person are still important in the decision-making process. The HSE National Consent Policy (2013 as amended) states that it is helpful to 'include those who have a close, ongoing personal relationship with the service user, in particular anyone chosen by the service user to be involved in treatment decisions, in the discussion and decision-making process' (para. 5.6.1). Importantly, the purpose of this involvement is not to make the decision but to provide greater insight into what the person would want to happen.

Where a person lacks capacity, the framework for decision-making as set out in the HSE Consent Policy (para. 5.6). In summary, this states that healthcare professionals should:

- Consider whether the person's lack of capacity is permanent or temporary
- Consider which options for treatment would provide overall clinical benefit for the person
- Consider which option, including the option not to treat, would be least restrictive of the person's future choices
- Support and encourage persons to be involved, as far as they want to and are able, in decisions about their treatment and care
- Consider the views of anyone the person asks you to consult and of people who have a close, ongoing personal relationship with the person
- Consider involving an advocate to support the person.

Where a healthcare professional reaches a professional decision based on clinical judgement and appropriate consultation, including eliciting the will and preferences of the person, it is generally accepted that treatment may proceed. Surprisingly, there is ongoing uncertainty regarding the legal basis for this. One possibility is an expanded understanding of the common law doctrine of necessity. This was applied by the Supreme Court in relation to a short-term deprivation of liberty in *AC v Cork University Hospital* [2019] IESC 73. The Court described the doctrine as applying ‘where there is a necessity to act, but it is not practicable to communicate with the assisted person, and the action taken is such that a reasonable person would in all the circumstances take, acting in the best interests of the assisted person’ (para 294).

Sometimes, for example, where a person refuses treatment or there is divergence or uncertainty regarding the best course of action, it may be necessary to refer the matter to the High Court. Depending on the circumstances, the Court may either use its inherent jurisdiction to make a decision for the person or it may admit the person to wardship. There are approximately 2,500 Wards of Court in Ireland at present. While a Ward’s Committee (the person appointed by the Court to act on behalf of the person) may give consent to minor medical procedures, consent to any serious medical procedure may only be given by the High Court, and the Wards of Court Office should be contacted in such cases.

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## RECENT DEVELOPMENTS

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Even before the commencement of the 2015 Act, there is increased recognition of the central importance of the will and preferences of a person who lacks capacity to consent to medical treatment. For example, the Irish courts increasingly emphasise the wishes and preferences of the person in making decisions (see eg *Re C* [2021] IEHC 318). Similarly, the law recently passed regarding COVID-19 vaccination for those who lack capacity to consent to vaccination requires that: ‘if he or she [is] unable to give such consent, the will and preferences of the person [is] established and the administration [is] for the benefit of the person’ (SI No. 698 of 2020).

The Irish courts have also recognised that refusal of treatment in an advance healthcare directive is legally enforceable in appropriate circumstances (*Governor of X Prison v PMcD* [2015] IEHC 259). A relevant advance healthcare directive is an important instruction to health professionals as to the will and preferences of the person.

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## CLARIFICATIONS IN THE 2015 ACT

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The 2015 Act will bring welcome clarity to many issues of capacity and consent to medical treatment, including requiring more support to be provided to people who have capacity difficulties and providing a clearer potential role for those close to the person. Some of the key clarifications are set out below.

### **Legal Requirement to Provide Support**

The 2015 Act requires ‘interveners’ to provide support to the ‘relevant person’ (a person whose capacity is in question or may shortly be in question). Interveners include health and social care professionals and so this obligation applies to all situations in which consent to medical treatment is sought. Under the 2015 Act, no-one may be considered unable to make a decision unless ‘all practicable steps’ have been taken to help them. Taken together with the presumption of capacity, which is also a part of the 2015 Act, this requirement should change the way in which consent is sought. It means that supporting the relevant person to make the decision for themselves must be an essential part of clinical practice.

### **Formal role for those chosen by the person**

One of the most important innovations in the 2015 Act is that it allows a relevant person to appoint someone to act as their supporter, either as a Decision-Making Assistant or a Co-Decision-Maker. This person has legal authority to access information and to provide support to the relevant person (in the case of a Decision-Making Assistant) or to access information and make decisions jointly with the relevant person (in the case of a Co-Decision-Maker). Where the relevant person has appointed a supporter, the supporter must be involved in the consent process.

The 2015 Act also makes provision for the involvement of someone close to the person where a person lacks capacity. The Circuit Court may appoint a Decision-Making Representative on behalf of the relevant person. Where possible, the Decision-Making Representative will be someone who has a close relationship with the relevant person. If authorised to do so by the Court, a Decision-Making Representative may consent to and refuse medical treatment on behalf of the relevant person. However, they cannot be authorised to refuse life-sustaining treatment.

### **Legislative Recognition of Advance Healthcare Directives**

The 2015 Act includes a legislative framework for Advance Healthcare Directives (AHDs), which sets out clear guidelines to allow a person to make a legally binding refusal of treatment and to make treatment requests. A directive-maker may also appoint someone to act as their Designated Healthcare Representative, and give this person authority to consent to and refuse treatment, including life-sustaining treatment, always with reference to the AHD.

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## THE GAPS THAT REMAIN

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The aspects of the 2015 Act outlined above provide valuable clarity around consent to medical treatment. They reinforce the importance of support and the centrality of the will and preferences of the relevant person and also provide a clear map of how different forms of supporters should be involved in the consent process. This will improve many aspects of the consent process.

However, there are still some gaps in the framework. First, there is uncertainty about the age at which the 2015 Act as a whole applies. Some elements of the 2015 Act (e.g. the legal authority to appoint a supporter; make an enduring power of attorney or an AHD) require the person to be aged 18 years or more. However, there is no general statement regarding applicability. This reflects a more general lack of clarity in Irish law in relation to children and young people, which urgently needs to be addressed.

Secondly, while the 2015 Act allows for the appointment of a range of different supporters/decision-makers, it does not give direction as to how consent to treatment should operate where a person lacks capacity and none of the arrangements in the 2015 Act are in place. In the early days following commencement, this is likely to be a common occurrence. Judicial clarification regarding the legal basis for medical treatment of people lacking capacity is desirable so that health professionals can make better decisions about when court involvement is required.

Finally, as identified above, a Decision-Making Representative does not have the authority to make a decision to refuse life-sustaining treatment. This leaves open the question of how such decisions should be made. Again, judicial clarification regarding when and whether an application to court is required would be helpful.

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## CONCLUSION

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The 2015 Act brings clarity to many aspects of the legal framework relating to capacity and consent to medical treatment. However, it does not resolve all questions and judicial clarification will be important. The HSE National Consent Policy will be updated to take account of the 2015 Act and while we await judicial clarification, this provides the best guidance available regarding how to address gaps in the legal framework.

## 2.4 Decision-Making Capacity: Standards Required by the Constitution

*Patricia T. Rickard-Clarke*

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### INTRODUCTION

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The *Assisted Decision-Making (Capacity) Act 2015* was enacted in December 2015 (2015 Act). It reforms the law on decision-making capacity and when fully commenced it will replace the 19th-century Wards of Court system. The focus of the 2015 Act is on a rights-based approach to decision-making capacity to meet the benchmarks required by the Constitution and Ireland's international human rights obligations under the *European Convention of Human Rights* (1950), *The Hague Convention on the International Protection of Adults* (2000) (the Hague Convention known as Hague 35) is incorporated in to the 2015 Act), and the *United Nations Convention on the Rights of Persons with Disabilities* (2006) (UNCRPD).

The purpose of this paper is to point out that even allowing for delays with the commencement of the 2015 Act, there is no legal impediment which prevents a contemporary perspective on capacity, which includes the need to respect the human rights of those whose capacity is at issue and particularly to ensure that their constitutional rights are vindicated.

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### JURISDICTION OF THE COURT

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The Wards of Court system has its origins in the notion of the monarch as *parens patriae* or guardian of the people to have charge of the care and custody of incapacitated subjects. In Ireland, the jurisdiction became exercisable by the Lord Chief Justice of Ireland and subsequently by virtue of the Courts (Supplemental Provisions) Act 1961 by the President of the High Court. The *Lunacy Regulations (Ireland) Act 1871* (1871 Act) and the Rules of the Superior Courts Order 67 sets out the criteria and procedures for bringing a person into wardship but does not confer jurisdiction. The jurisdiction was described by Hamilton C.J in 1996 as:

‘When a person is made a ward of court, the court is vested with jurisdiction over all matters relating to the person and estate of the ward and in the exercise of such jurisdiction is subject only to the provisions of the Constitution: there is no statute which in the slightest degree lessens the court’s duty or frees it from the responsibility of exercising that parental care’ (*In Re a Ward of Court*, 106).



The regulatory nature of the 1871 Act was recently reconfirmed by the Supreme Court when it stated: ‘it is a regulatory statute only. It is not the source of the wardship jurisdiction, which the Court has previously held to be broader than the statutory provisions. The jurisdiction now exercisable by the courts is broader than, and does not depend upon, the applicability of the 1871 Act.’ (*AC v CUH*, para 299/361).

The words ‘subject to the provisions of the Constitution’ are important and the courts have referred to the responsibility of the judge hearing the wardship matter to ensure constitutional rights are protected. The Supreme Court in *In Re a Ward of Court* stated: ‘By reason of the fact that the ward is a ward of court...the responsibility for the exercise of and the vindication of these rights rested on the judge’ (p. 166). In *FD Kelly J* confirmed that Order 67 Rule 6 of the Rules of the Superior Courts, provided that the making of a wardship order ‘was a judicial function that must be exercised in accordance with the Constitution and with constitutional propriety’ (2004).

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## RIGHTS ENSHRINED IN THE CONSTITUTION

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Article 40.1 provides that all citizens shall, as human persons, be held equal before the law.

Article 40.3.1 provides that the State guarantees in its laws to respect, and, as far as practicable by its laws to defend and vindicate the personal rights of the citizen.

These personal rights have been upheld by the courts in a number of wardship cases. In *In Re a Ward of Court*, the Supreme Court stressed the right to equality with Denham J stating that equality ‘is not a restricted concept, it does not mean solely that legislation should not be discriminatory. It is a positive proposition’. In addition, the Court referred to the constitutional right to autonomy, in the particular case, the right to make specific decisions in relation to the refusal and withdrawal of medical treatment (the application related to the issue of the withdrawal of life support). Denham J also referred to the unspecified right under the Constitution for the Ward to be treated with dignity, which is available to all human persons and is not lost by illness or accident (*In Re a Ward of Court*, 351).

The Court also held that the:

‘loss by an individual of his or her mental capacity does not result in any discrimination of his or her personal rights recognised by the Constitution, including the right to life, the right to bodily integrity, the right to privacy, including self-determination, and the right to refuse medical care and treatment. The ward is entitled to have all these rights respected, defended, vindicated and protected from unjust attack and they are in no way lessened or diminished by reason of her incapacity’ (*In Re a Ward of Court*, 163).

In spite of the clear constitutional provisions and the acknowledgment by the courts of the court's constitutional duties to respect the rights of those who lack decision-making capacity, in current practice we are still struggling with breaches of constitutional rights in wardship cases and trying to enforce outmoded concepts from the 19th century that are completely inappropriate. How capacity is assessed is a fundamental issue in respecting personal rights: 'An order making a person a ward of court has real consequences. It can deprive a person of the power to make many of the choices which are fundamental and integral to day-to-day life' (*AC v CUH*).

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UN SOUND MIND AND UNABLE TO MANAGE AFFAIRS V  
FUNCTIONAL CONSTRUCTION OF CAPACITY

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The 1871 Act provides that a person is taken into the wardship of the court and that a person must be declared to be 'of unsound mind and incapable of managing his person or property'. The 1871 Act does not contain any statutory definition of 'unsound mind.' It presents capacity as related to the person's status that is, in an all-or-nothing way, based on the presence of a disability. It is an across-the-board assessment of a person's capacity rather than in relation to a particular decision to be made at a particular time. MacMenamin J believed that an assessment of capacity on an all-or-nothing basis would not vindicate the constitutional rights as far as possible, since it would not take account of those with fluctuating capacity or those with episodic illness, or those who could make decisions in particular spheres (*MX v HSE*).

Prior to 2007, there was no guidance, either in legislation or at common law, as to how decision-making capacity should be assessed. In *Fitzpatrick v FK*, Ms Justice Mary Laffoy stated 'that having regard to the constitutional framework within which the capacity question must be determined... the relevant principles applicable to the determination of the capacity question are as follows': there is a presumption that an adult patient has the capacity, that is to say, the cognitive ability, to make a decision (in the particular case to refuse the medical treatment), but that presumption can be rebutted and the test is whether the patient's cognitive ability has been impaired to the extent that he or she does not sufficiently understand the nature, purpose and effect of the decision that has to be made and the consequences of accepting or rejecting it in the context of the choices available at the time the decision is made.

Following the *Fitzpatrick* decision, in 2009 the Medical Council issued its guidance that capacity should be assessed on this functional basis (Medical Council, 2009). The HSE's National Consent Policy of 2013 also provided for a functional assessment of decision-making capacity. In a case relating to capacity to make an enduring power of attorney in 2015, Baker J followed the approach as set out in the *Fitzpatrick* case and confirmed that the assessment of capacity is a legal test and must be tested having regard to the function being undertaken (*Re SCR*).

The functional construction of capacity is given statutory effect in the 2015 Act and provides that ‘a person’s capacity shall be assessed on the basis of his or her ability to understand, at the time that a decision is to be made, the nature and consequence of the decision to be made by him or her in the context of available choices at that time.’ The 2015 Act also provides that a person lacks capacity to make a decision if he or she is unable to:

The functional construction of capacity is given statutory effect in the 2015 Act and provides that ‘a person’s capacity shall be assessed on the basis of his or her ability to understand, at the time that a decision is to be made, the nature and consequence of the decision to be made by him or her in the context of available choices at that time.’ The 2015 Act also provides that a person lacks capacity to make a decision if he or she is unable to:

- a. understand the information relevant to the decision,
- b. retain that information long enough to make a voluntary choice,
- c. use or weigh that information as part of the process of making the decision, or:
- d. communicate his or her decision by whatever means.

In spite of the fact that this functional approach to the assessment of capacity has been part of the common law since 2007 and given statutory effect in the 2015 Act (albeit that Act has not yet been fully commenced), many of the wardship applications continued to be based on a medical diagnostic test as to the medical condition of the person the subject of the wardship application and not referable to the decision to be made at the time it is to be made.

The Supreme Court, noting the statement in the National Safeguarding Committee’s Report (2017) that there is a strong constitutional argument that assessment of capacity, for the purposes of a court, should focus on whether a Ward has the capacity to make a particular decision, at a particular time, in a particular context, added:

‘This argument may also be strengthened by the lack of clarity in relation to the legal test under the Lunacy Regulation (Ireland) Act 1871 for deciding if the individual is of unsound mind and incapable of managing his or her affairs. It would appear that there is no definitive judicial definition of what ‘unsound mind’ means. The lack of clarity around this definition, on which the wardship jurisdiction is founded, may also present a cause for concern given the scope of the jurisdiction – when a person is made a ward of court, the court is vested with jurisdiction over all matters relating to the person and estate of the ward’ (*AC v CUH*, para. 376).

It is understood that an assessment of capacity on a functional basis is now increasingly being used. However, there are still no Rules of Court or guidance on this issue.

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### PROCEEDINGS MUST BE FAIR

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The Supreme Court in rejecting the all-or-nothing approach to decision-making capacity also identified a lack of fair procedures and stated that ‘wardship proceedings must be fair and in accordance with constitutional justice’ (*AC v CUH*, para. 374). Some obvious examples are:

- The voice of Respondent in many wardship applications is absent and there is an absence of legal representation. As pointed out by the Supreme Court, the most striking feature of all of the litigation is that it proceeded without her voice being heard: ‘The decision of the court to deprive an adult of all capacity is of such significance that the absence of legal assistance may, in some circumstances render the process unfair’ *AC v CUH*, para 367.
- The Respondent does not usually receive copies of the medical reports upon which the application is being made and there is no standard procedure by which it is provided: ‘The decision to deprive a person of legal capacity cuts at the autonomy of the individual in a fundamental way, and it should not be made upon the basis of evidence that cannot be challenged by the person concerned’ (*AC v CUH*, para. 374). It must be open to the proposed ward to contest the evidence being put to the court, and to make the case that the medical criteria have not been met or that, in any event, wardship is not necessary or appropriate (*AC v CUH*, para. 368). There is now some evidence of medical reports being made available to the Respondent.
- In some cases it is not clear whether the criteria for wardship are met: ‘The Court does not know the extent to which the medical visitor took into account...capacity to make decisions in general, or whether the report focussed solely on the capacity to make a specific decision’ (*AC v CUH*, para. 375).
- A person may be subject to a wardship application where there are safeguarding risks. If the risk comes from a third party, then legal measures should be directed at the third party but the person should not be deprived of his or her constitutional rights.

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### CONCLUSION

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Given that a wardship order has far-reaching consequences, it is important that any such order is made in accordance with the fundamental rights guaranteed by the Constitution. Given the courts broad jurisdiction and its responsibility to ensure that constitutional rights of prospective wards are respected, Rules of Court or general guidance on wardship proceedings are necessary pending the full commencement of the 2015 Act. The 2015 Act sets out a clear legal framework as to the principles that must be followed to respect the dignity and rights of person whose capacity is at issue in particular those rights established by the Constitution. However, a huge cultural shift is required in order to move from a paternalistic approach embedded in our value system, to a society where each person is respected as a human person with individual rights.

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## 2.5 Moving on from the Only Show in Town

*Tim Hanly*

Social workers, along with other health and social care workers involved in adult safeguarding, face many challenges and obstacles in their professional lives. Putting the service user at the heart of all decision-making is a strong value and ethos of the social work professional. However, in the working environment with competing demands and finite resources, this value base is often tested. This is never more true than in the area of adult safeguarding and the law.

The current worldwide pandemic has shown that the State does need, at times, to intervene and limit the autonomy of its citizens. There is a lot of commentary recently about the common good in the debate about the strict public health measures. There is always a complex and difficult balancing act between respecting human rights and the need to intervene in the lives of people who lack decision-making capacity around their own self-protection. In my role as a General Manager of the HSE National Safeguarding Office, I often ask social workers and other health professionals about legal interventions into the lives of persons who are deemed vulnerable and at risk of abuse. In these discussions, I regularly encounter two recurring themes. The first is often manifested in sighs of exasperation and almost acceptance of the status quo, with many similar responses along the lines of: 'Well, there is a pressing need to intervene and we can't wait for the Assisted Decision (Capacity) Act 2015 (the 2015 Act) to commence.' However, the most common line is 'wardship is still the only show in town.' I hear the resignation and, at times, despair in the slow pace of human-rights based reforms and how this legislation from a bygone Victorian era remains the key legal measure. Whilst we have seen some advances in domestic violence legislation and general welfare provisions via the Health Acts, the initial enthusiasm when the progressive 2015 Act was passed has certainly waned with the passing years.

The second common theme is a concern with the wardship process itself. There is frustration often expressed with how the system has built up over years, with the application process being so legally driven that it relegates the input of the person at risk and the professional knowledge of well-trained, experienced professionals. Many social workers, who have come from the mental health and childcare areas of practice, express their dissatisfaction at their experiences in this context. As noted earlier, the State has a duty to intervene in the lives of citizens when required and this should be done in a way that respects the citizen's human rights. Social workers remain at the centre of this difficult interface in the world of adult safeguarding. Whilst they may be professionally frustrated, adults at risk of abuse are the ones who have waited too long.

My parting reflection from the excellent Cork Conference in UCC in November 2019 is this: we need to move on now from the only show in town and fully commence the 2015 legislation.

## 2.6 Liberty Rights and Impaired Capacity

*Mary Donnelly and Shaun O’Keeffe*

It is a fundamental constitutional principle that no citizen may be deprived of their personal liberty except in accordance with the law. However, it is common practice that some people are not free to leave health or social care facilities, often because staff feel they lack the capacity to make this decision and that it is not safe, or not otherwise in their best interests, to do so. Since the decision of the Supreme Court in *AC v Cork University Hospital [2019] IESC 73*, we have a much clearer indication of what is (and is not) legally permissible. This greater clarity reveals the inadequacy of the current legal framework and the urgent need for the Government to progress promised legislation to provide better protection for liberty rights of people admitted to hospitals, nursing homes and other residential care facilities. This chapter explores the treatment of the right to liberty in the decision in *AC v CUH*, examines the implications of this decision for health and social care practices and reiterates the need for urgent action by Government.

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### THE DECISION IN *AC v CUH*

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Mrs C, who was 93 years old at the time, was admitted to Cork University Hospital (CUH) in 2016 after breaking both hips. She was additionally diagnosed with dementia of moderate severity. Members of her family wanted to take her home, but this was refused by staff in the hospital, who believed that she lacked capacity to make the decision to leave and that her care needs would best be met in a nursing home setting. Mrs C signed a letter of self-discharge. However, when her son came to collect her, he was prevented from removing her from hospital. Subsequently, Mrs C was made a Ward of Court. *AC*, Mrs C’s son, argued that his mother had been unlawfully detained in the CUH.

The Supreme Court found that nobody, regardless of whether or not they have capacity to make a decision to leave hospital, can be deprived of their personal liberty except in accordance with the law (para. 394). This is the case even if the detention is believed to be in the best interests of the person (para. 394). A hospital does not have a general legal power to detain or to decide how the right to liberty should be balanced against other rights and the well-being of the person. However, the doctrine of necessity applies where there is a need to take action for someone who lacks capacity to make a decision to leave and the action is one that a reasonable person would take in the best interests of the person in the circumstances in question (para. 349). The Supreme Court found that the doctrine provides legal justification for the short-term detention of a

person in their own interest. However, since the doctrine of necessity is designed only to deal with urgent situations, it does not have sufficient safeguards and so can only be relied on for temporary justification of detention (para. 349).

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## IMPLICATIONS OF THE DECISION IN AC V CUH

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In light of this decision, it is possible to provide answers to several fundamental questions about the nature of detention (although much more difficult to solve the surrounding practical dilemmas).

### **When is someone being detained?**

In many cases, it is straightforward to determine that detention is occurring: the person indicates verbally or by their actions that they wish to leave a hospital or institution and isn't allowed to do so. However, it is not always necessary that the person is making active physical attempts to leave. If someone would not be free to leave if they tried or if a third party were to try to take them out, they are detained. Similarly, someone who is told not to leave and complies with this is not in fact free to leave and is therefore detained. Also, whether someone is detained and deprived of their liberty does not depend on whether or not they may lack capacity to make the decision to leave, nor on whether or not leaving seems to staff a wise or safe decision.

Being free to leave a hospital or other institution is also not the same as being able to leave. Some patients, because of physical or cognitive difficulties, may be physically unable to leave without physical or practical assistance, including, for example, arranging transport or providing a wheelchair. If staff refuse to provide such assistance – that is, any help that would normally be provided to someone who was being discharged – that person is not free to leave. It is not enough to say: 'You are free to walk out that door or to arrange your own transport' if one knows the person can't do so or to say: 'you are free to go if your family will take you' if one knows that this will not happen.

Some measures used in hospitals that may suggest detention include physical restraint, use of sedation, locks on ward doors, and continuous monitoring and supervision (for example, one-to-one care). However, these measures do not necessarily mean that a person is being deprived of their liberty. For example, locked doors on wards may be present for security reasons or aimed at other patients: the question to be asked is: 'Would staff unlock the door if he or she asked or implied that they wished to leave'? If not, he or she cannot be said to be free to leave.



### What about delayed discharge?

Sometimes, the person may be clear that their ultimate goal is discharge home but acknowledges that this will require planning and appropriate discharge arrangements, such as a care package or home modifications. Making such arrangements can take a frustratingly long time, but as long as the person agrees to remain in hospital while they are being made, there is no detention provided that:

1. If the person were, for example, to lose patience with the delays and insist on immediate discharge, they would be free to go, and
2. Genuine efforts are being made in good faith by staff to facilitate discharge in accordance with the person's wishes.

### What should be done when someone indicates a wish to leave?

When someone indicates a wish to leave a hospital or other institution, the first question to be asked is whether the person truly wishes to leave or whether they are being pressurised to do so by a third party (*AC v CUH*, para. 392). If satisfied that there is a genuine wish to leave and that the person has the capacity to make this decision, all the hospital may do is try to persuade the person to stay. However, if the hospital is concerned that the person may lack the capacity to make the decision to leave, it must arrange for an assessment of the person's capacity. This assessment should be conducted by suitably qualified professionals. The general principles of a functional approach to capacity should be respected, including starting with a presumption of capacity and seeking to support the person to make their own decision (including involving an advocate where appropriate). The information that the person needs to retain and use and weigh in making a decision to leave hospital will include the risks AND benefits of all options. For example, the risks of a decision to go home may include safety concerns (falls, accidents, wandering), difficulty with daily activities and burden on family and carers; the benefits may be that independence is valued over safety and that the person may be happier at home.

If the person is judged to lack capacity to make the decision to leave and they have clearly indicated a consistent and genuine wish to leave, a legal process must be followed. Until the 2015 Act comes into effect, the only available process is an application for admission to wardship. This is most unfortunate as, for reasons set out throughout this book, wardship is not an appropriate legal mechanism in a contemporary context. Any application for admission to wardship must happen 'within a reasonably short time' of the person's indication of a wish to leave (para. 351). Where this step is taken, it is essential that the person's own voice is heard and that they have independent representation or legal assistance during the process. The person and their representative must have access to all reports relevant to the case. This includes medical reports as well as, for example, correspondence from others outlining safety concerns about the person.

Arranging for capacity assessments and reports and making a court application can take some time, and a brief detention while this is arranged is lawful in urgent situations under the doctrine of necessity. However, depriving someone of their liberty is such a serious matter that there must be no unreasonable delay in seeking the assistance of the Court.

Some circumstances may create difficulty for staff in knowing when they need to apply to court. For someone with fluctuating capacity, there may be a reasonable expectation that the person's cognitive status may improve and that they may regain capacity. This is often the case in someone with delirium due to acute illness or those in intensive care units. In such circumstances, it may be reasonable to wait for an improvement before making the final decision to involve the court.

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#### DO THE PRINCIPLES IN AC APPLY OUTSIDE OF THE HOSPITAL SETTING?

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AC concerned detention in a hospital setting and the Supreme Court was clear that conclusions reached were intended to be applicable to that situation and were not to be seen 'as necessarily applying in full to private or family care arrangements' (para. 389). This then leaves the question of admission to residential care facilities, for example nursing homes. Although the Supreme Court did not address the matter directly in *AC*, the important judgments of the European Court of Human Rights in *HM v Switzerland* [2002] 38 EHRR 157 and *Stanev v Bulgaria* [2012] ECHR 46 are clear that protections against deprivation of liberty under the European Convention on Human Rights apply to detention in nursing homes and residential care facilities, as well as hospitals.

It has long been the case that sometimes people are admitted to nursing homes against their wishes, that they are not allowed to leave and that they are intended to remain there indefinitely, usually for the rest of their lives. It is difficult to see how this does not qualify as detention. Similarly, it is difficult to see how making an application for residential care placement (for example, by using the Nursing Home Subvention Scheme) contrary to the wishes of the person to be admitted is not a clear indication of an intention to detain.

In some cases, the person may have given a valid consent to admission but would not now be allowed to leave if they wanted to. It would seem that this too is, logically, detention. Other than a limited number of residents who are Wards of Court, there is no process for review of their detention or for them to assert their right to leave. This then appears to be a clear violation of the right to liberty of such residents, one which is occurring on a widespread scale in residential care facilities. It may be that the steps required to authorise detention may not be exactly the same in residential care cases as in hospital cases. Nevertheless, there is no logical reason why the essential principle of the AC case (i.e. that there must be a legal mechanism to protect a person's right to liberty regardless of their capacity) should not apply.

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## CONCLUSION

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The decision in *AC v CUH* lays bare the profound deficiencies in legal protections for the right to liberty of people with impaired capacity in Ireland. The case shows that the only legal mechanism currently available to protect this right is the antediluvian wardship process. While providing oversight of admission, the protection of the right to liberty which this provides comes at the cost of a blanket removal of the Ward's decision-making authority. This cost is clearly too high. It is widely acknowledged among law and policy makers, as well as by health and social care professionals, that an alternative legal mechanism is needed. A draft mechanism (which was to be inserted as Part 13 of the Assisted Decision-Making (Capacity) Act 2015) was published for consultation in December 2017 and the responses to this consultation was published in July 2019. There has been no evident progress since this time. The responses to the consultation show the scale of the challenge which legislators face in attempting to produce a framework which provides meaningful protection for the right to liberty of people in hospitals, nursing homes and other residential facilities without becoming overly legalistic and bureaucratic. This, however, does not obviate the need to address the very significant gap in the current legal framework to provide effective protection for the liberty rights of people with impaired capacity.

## 2.7 Lessons from Abroad

*Alex Ruck Keene*

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### INTRODUCTION

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In the past few years, significant legal reform efforts have been underway across the four nations of the United Kingdom and Republic of Ireland in the field of mental capacity. Those efforts have culminated in two new radical pieces of legislation on either side of the border in Ireland, one much more limited piece of legislation in the legal jurisdiction of England and Wales, and the promise of more to come in England and Wales as well as Scotland.

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### A COMPARATIVE PERSPECTIVE

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The Assisted Decision-Making (Capacity) Act 2015 ('the 2015 Act') was enacted in the Republic of Ireland to replace 19th century legislation relating to mental capacity, in particular the Lunacy Regulation (Ireland) Act 1871. It seeks to leapfrog over late 20th century mental capacity legislation such as the Mental Capacity Act 2005 ('MCA 2005') in England to secure compliance with the United Nations Convention on the Rights of Persons with Disabilities ('CRPD').

To that end, for instance, the 2015 Act uses the language of 'will and preferences' rather than 'best interests', and erects a complex structure of decision-making supports in the form of assisted- and co-decision-making agreements. The 2015 Act is not yet in force. Further legislation (either to be included within the 2015 Act or sit alongside it) is intended to provide a framework for the lawful deprivation of liberty of those with impaired decision-making capacity for purposes of providing care and treatment. The 2015 Act does not purport to address the regulation of treatment and detention for purposes of addressing mental disorder, which will remain covered by separate mental health legislation (the Mental Health Act 2001, itself to be amended in due course).

On the other side of the border, the Mental Capacity Act (Northern Ireland) 2016 ('MCA (NI)') will ultimately introduce a regime that is at the same time both less and more radical than that in the 2015 Act. It is less radical because it continues to use terms such as 'best interests' and appears on its face further from the interpretation of the CRPD advanced by the Committee on the Rights of Persons with Disabilities. It is more radical because, if and

when it fully comes into force, it will ‘fuse’ mental health and mental capacity legislation so that there no longer be separate mental health legislation (at least in relation to those aged 16 and over).

In England, the Mental Capacity (Amendment) Act 2019 (‘the MCAA’) represents the implementation by the Westminster Parliament of half of the proposals made by the Law Commission in its Mental Capacity and Deprivation of Liberty project (Law Com No 372, 2017). The missing half of the proposals was designed to give a ‘mid-life upgrade’ to the MCA 2005 by reforming the best interests test to secure (in essence) a rebuttable presumption that the person’s wishes and feelings should be followed, and also to provide greater procedural protections around the use of the ‘general authority’ in s.5 MCA 2005 in the case of serious interferences with personal autonomy. Those were not taken forward by the Government, which focused instead on the proposals to reform the (in)famous Deprivation of Liberty Safeguards (‘DoLS’), an unwieldy administrative mechanism to authorise deprivation of liberty in health and care settings. The MCAA represents a modified version of those proposals, and is due to come into force in April 2022.

In addition to these completed (if not yet implemented) legislative reforms, others are on the horizon. In Scotland, the Scottish Government is moving towards the reform of the Adults with Incapacity Act 2000 (‘AWI’) and the Mental Health (Care and Treatment) Scotland Act 2003; precisely how radical the changes will be remains to be seen, although initial signs are that the proposals will be bold. In England and Wales, an independent review of the Mental Health Act 1983 under Sir Simon Wessely reported in December 2018, and the UK Government has committed to legislation to respond to the review’s recommendations. These recommendations stopped short of ‘fusion,’ but set down a series of confidence tests to be satisfied before a move towards fusion could be considered.

Against this backdrop, what broader themes can we draw out? In this section, I draw not just on my observations of the developments across the four nations, but also direct personal involvement, above all in those in England and Wales (as consultant to the Law Commission project and then legal adviser to the MHA review).

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## HANDLING UNCERTAINTY

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One continuing theme for me has been as to how well the relevant parts of any given system can handle uncertainty. The better that they can handle it, the easier it is to come up with more creative solutions to problems which maximise the chances of getting the ‘right’ answer in any given situation. The more difficult they find it to handle it, the more rigid the approach that they have to take, and the greater the consequence for harsh outcomes in any given case.

The creative solutions that are being proposed to enable more people to exercise legal capacity in more domains can run rapidly into the practical difficulties imposed by those operating systems that require clear-cut answers. I can, confidently if depressingly, predict that the implementation of assisted- and co-decision-making arrangements under the ADMCA will be complex, especially where decision-makers (for instance clinicians) need to be clear as to whom they are obtaining consent from in contexts where the consequences may be serious.

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### IS IT BETTER TO BE SILENT OR EXPRESS?

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One question that has increasingly exercised me has been as to whether it is better to seek to cover all contingencies expressly, or to be silent. In this regard, it has become increasingly clear to me quite how unusual the MCA 2005 and the MCA(NI) are in codifying a doctrine of necessity and seeking to limit it by reference to principles and a set of pre-conditions (more stringent in the case of the latter). The 2015 Act contains no codification, and therefore allows (implicitly) the common law doctrine of necessity to survive – potentially to cover the vast majority of actions that are actually taken in relation to those with impaired capacity.

On one view, being silent – or at least not prescriptive – about all contingencies could be viewed as a thoroughly bad idea, because it allows for arbitrariness, as well as providing no basis upon which the decision-maker can be held to account. On the other hand, there is a very respectable argument that seeking to provide legal frameworks that apply in all circumstances leads inexorably to the juridification of health and social care: in other words, the insertion of legal norms (and claims to authority by lawyers and judges) into fields into which the law has no proper place. There is, further, a lobster pot effect – once the lawyers have colonised an area, it is extremely difficult to get them out.

Further, setting out a comprehensive legal framework designed to limit the scope of actions by those in positions of power (as s.5 MCA 2005/s.9 MCA(NI) could be seen to be doing), could just as easily be read as a message that those in such positions are entitled to use that framework. It is, in this, telling that s.5 MCA 2005, which was deliberately cast as a defence by the UK Parliament, is now routinely referred to by English courts, including by Lady Hale (see *N v ACCG* [2017] UKSC 22 at paragraph 38) as a general authority to act. It was in substantial part because of concerns that this authority was being routinely misused by those paying lip service to the formalities but ignoring the principle underpinning the MCA that the Law Commission in its 2017 report proposed limiting its availability in relation to certain key decisions. As noted above, the Westminster Government chose to take a different course.

Another area in which it may well be the case that legislative silence leads to unanticipated consequences is the fact that the 2015 Act does not include a ‘diagnostic’ test for purposes of identifying whether a person has decision-making capacity. In other words, and unlike the legislation in all parts of the United Kingdom, there is no requirement that the person has some form of disability or disorder of the mind or brain for them to lack capacity for purposes of the Act. This was a deliberate decision on the part of the Irish legislature so as to meet the challenge of the CRPD Committee that mental capacity legislation discriminates against those with disabilities. I think that there are, however, questions to be asked as to how the laudable intention of the legislature will pan out in practice.

It is perhaps of some interest that capacity legislation in New Zealand (the Protection of Personal and Property Act Rights Act 1988) which, similarly, does not include a ‘diagnostic’ element, is routinely interpreted as requiring one, if only to be able to explain why it is considered that the person in question lack the capacity to make the relevant decisions. It will be very interesting to see whether the same requirement is imposed in practice by the courts in Ireland. One area where I suspect that this may well be tested is where orders are sought in relation to those who are perceived as ‘situationally vulnerable.’ The very broad interpretation of capacity contained in the 2015 Act could have some surprising consequences – for instance, to reach the conclusion that a victim of domestic abuse lacks capacity to decide whether or not to return home to live with their abuser, even though they do not have any recognisable mental disorder or cognitive impairment.

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## CONCLUSION

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We are, as I write, in a slightly curious limbo stage awaiting the implementation of legislation in three of the four jurisdictions under consideration, and I have no doubt that implementation will in due course throw up not only issues that have been identified to date, but also those that could not yet have been anticipated. However, both as implementation takes place and as the process of thinking about where reforms may go next, I hope that each of the four jurisdictions will continue both to learn from each other and to spur each other on.





## 3 The ‘Relevant Person’ — A Recalibration for the Centrality of Rights or Just More Semantics?

### 3.1 The Assisted Decision-Making (Capacity) Act 2015: The Ethical Relevance of the Relevant Person in Healthcare Decision-Making

*Joan McCarthy*

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#### ETHICAL AIM

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The ethical aim of the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) is to ensure that everyone who is in need of health services in Ireland is at the centre of decision-making concerning their own health and well-being. The 2015 Act prescribes that those accessing the health services should be empowered, enabled and facilitated to make decisions about their medical treatment and care in so far as this is possible. Where an individual – described as a ‘relevant person’ – may have difficulty making some decisions without support, or where a person may lack capacity to make some decisions at a particular time, the 2015 Act outlines a range of procedures to assist them. These aim to ensure that the person is genuinely included in the decision-making process regarding their treatment and care and that their rights and interests are core to all decisions and interactions with them.

The key ethical principle that underpins the 2015 Act is that of autonomy, which refers to an individual’s capacity to make decisions for themselves and to be free to live their lives according to their own values and beliefs. Autonomy is associated with terms such as self-determination and self-rule. Historically, it has been viewed as the foundation of rights such as the right of privacy – the right of a person to be free in their private life from interference from the State – and the right of bodily integrity – the right of a person to be free from assault and to have control over their body. These rights are referred to in the Guiding Principles of the 2015 Act as rights to ‘dignity, bodily integrity, privacy, autonomy and control over his or her financial affairs and property’ (Section 8). Contemporary notions of autonomy owe much to Isaiah Berlin’s account which draws attention to the unique capacity of human beings to adopt their own life plans and to carry them out:

‘I wish to be an instrument of my own, not other[s]’ acts of will. I wish to be a subject, not an object... deciding, not being decided for, self-directed and not acted upon by external nature or by other[s] as if I were a thing, or an animal, or a slave incapable of playing a human role, that is, of conceiving goals and policies of my own and realising them’ (Berlin, 1969).

Respect for autonomy, on this view, means that restricting, without justification, a person’s sphere of autonomous choice and action is to treat that person, not as an individual capable of selecting and acting on their own values and goals, but merely as a means or an instrument, to achieving the goals of others.

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### ETHICAL OBLIGATIONS OF HEALTH PROFESSIONALS

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Applied to healthcare, the principle of autonomy confers certain obligations on health professionals. Firstly, health professionals are obligated not to interfere with or constrain a person’s autonomous decisions in relation to their medical treatment (e.g. their refusal of interventions such as blood transfusions or life-prolonging treatments.) Secondly, health professionals are obligated to recognise, support and enable the unique values, priorities and individuality of patients (e.g. provide them with adequate information about their medication and treatment that is meaningful to them.)

By prioritizing the person’s own view of what is best for them, respect for autonomy acts as an antidote to the paternalism of the past, which gave the health professional, not the patient, moral authority in decision-making. A letter of complaint to a hospital administration offers insight into the kind of paternalistic practices that people accessing health services in Ireland might be familiar with, at least up to recent times:

‘What about people who have no one to stand up for them, who are impressed by white coats and other symbols of power, who take everything told them at face value, who are helplessly at the mercy of every arbitrary action and highhanded decision made on their behalf? It is just not right that a human being who is sick and suffering cannot count on the best possible care and support. It is not right that people’s innocence, naiveté and inexperience are exploited to make them a plaything of monetary interests. It is not right that one has to fight for the simplest decencies...

Last but not least, the opportunity to speak with the responsible and attendant physicians is not a privilege and not a generous offer, but should be a matter of course...and not be the occasion for extraordinary gratitude.’ (Emrich et al, 2014 [case 465])

This letter was penned by a German patient advocate, Mrs Heinrich, who was complaining about the odyssey of a patient through various clinical units and inconsistent recommendations for therapy and procedures. Her insightful commentary points to the way in which illness, and habituated routines, can transform people into patients who become vulnerable to the decision-making power, authority and privilege, of health professionals. If paternalism is the problem in these situations, then respect for individual autonomy is at least one of the remedies. On receiving this letter of complaint, the medical director of the hospital subsequently invited Mrs Heinrich to join a process of conflict resolution that, presumably, put the man concerned at the centre of decision-making.

As central as the principle of autonomy is in the 2015 Act, however, it is also important to point out that honouring it does not involve opening up the health services to rampant individualism. Respect for autonomy acts as an antidote to coercion; it does not give people who use the health services permission to have or do whatever they want. Just as the exercise of autonomy is limited in life in general (e.g. a person doesn't have the right to inflict substantial harm on others), so too, the exercise of autonomy is limited in healthcare settings on the basis of duties owed to other people. For example, it may be morally acceptable to limit a person's freedom of movement if they have a contagious disease on the basis of the harm that might be caused to others if they refuse to be quarantined. Secondly, given that medical procedures and healthcare services are scarce resources in great demand; individuals cannot insist on whatever kind of medication or treatment they want – in many democratic systems around the world, individuals cannot randomly demand more than is deemed fair and cost-effective. Moreover, health professionals are generally not obliged to provide medication or interventions that they believe are not needed, won't work or add benefit. In short, autonomy is about individuals but it is also about communities.

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### RELATIONAL AUTONOMY

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Contemporary accounts of autonomy view it as best achieved by recognizing our interdependence – the way in which we depend on each other – as well as our independence. On this relational view, our relationships, family, and community connections – our social embeddedness – enable and inhibit the scope of autonomy (Mackenzie and Stoljar, 2000). Applied to healthcare, this means that realizing the promise of the 2015 Act will require ethical commitment as well as ethical and practical work on the part of health and allied professionals, the wider community as well as the relevant person themselves. So, for example, health professionals have a role in recognizing how obstacles such as poverty and discrimination might constrain a person's autonomy as well as the ways in which enablers such as education and inclusion might facilitate it. They also have a role in supporting a person to think through their values and beliefs and deepen their self-trust and self-understanding in light of their diagnosis and illness; just as they have a role in trying to ensure that there are timely treatment and care options actually available to them.

In a similar way, the relational view of autonomy does not assume that people who use the health services are solely self-interested consumers of health commodities. Instead, it recognizes that their concerns may often be more social than medical – based on deep attachments to other people toward whom they feel responsible. For example, a parent may be primarily concerned about the care of their children in their absence and not the illness that they are battling. In sum, the choices and priorities of relevant persons may not always (if ever) be motivated solely by self-interest; they are also likely to be motivated by a sense of obligation towards, and solidarity with, others.

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## CONCLUSION

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The 2015 Act adds legal weight to the incremental changes that have been taking place in the Irish health services for at least the last two decades. These changes, articulated in professional codes and HSE strategic plans and policies, emphasise the moral standing and moral authority of the person who uses the health services and shift the balance of power between patients and health and allied professionals. With its clear emphasis on the decision-making authority of the relevant person, the 2015 Act continues this work. However, it is important to point out that there are also likely to be power asymmetries among the range of relationships that the Act recognizes (e.g. relevant persons, family members, advocates, assistant-decision makers, co-decision makers, decision-making representatives and designated healthcare representatives). As such, all of the stakeholders involved, including the Office of Decision Support Services, the HSE and the Department of Health, need to recognise that it will take a lot of practice to change practices. Many or most people using health services in Ireland will need to practice identifying, understanding and communicating their healthcare preferences and needs in respectful ways. Those who support relevant persons, if and when support is needed, will need to learn and practice the ways in which they can authentically and transparently articulate their voices and interests. Alongside these actors, health and allied professionals will depend on the support of a positive organisational culture so that they have the time and resources needed to negotiate the ethical demands, policies and practical procedures that maximising the participation of the relevant person in decisions regarding their treatment and care will require.

In sum, the 2015 Act will have to be genuinely embraced by everyone and every organisation it impacts in order to fulfil its potential to further democratise and humanise the provision of healthcare services in Ireland.

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## 3.2 Removing Wardship

*Leigh Gath*

In the middle of the 19th century, while Ireland was still under British rule, and Queen Victoria was on the throne, the Lunacy Regulation (Ireland) Act 1871 was born. At the time, people who lived with mental health issues, dementia, or who had an intellectual disability were seen as being not capable of making decisions for themselves, so the courts would take over all of their decision-making. This included where they lived, what happened to any lands or property they may have, and what happened to their finances.

Over the last 150 years, Ireland has moved on in many ways, but as time passed for most other people, people with intellectual disabilities still find themselves with no right to make their own decisions in some cases. People with intellectual disabilities can be treated in a childlike way and not trusted to know what is best for them. Services and family members sometimes make decisions for them, without asking the person what they want, what their will and preference would be. These decisions can be about where the person is going to live, what to do with the person's money, or whether to undergo a medical procedure.

Following a major campaign from disability advocates, the Government signed the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) into law in December 2015. Once commenced, the 2015 Act will repeal the Lunacy Regulation (Ireland) Act (the name is offensive in itself) meaning people will no longer be made a Ward of Court. Under wardship, the Committee of a Ward of Court manages the affairs of the Ward who, because of dementia, intellectual disability or other issues, is deemed unable to make decisions for themselves regarding their money or property matters, and, in some instances, about their healthcare treatment or where they will live. When the person is a Ward of Court, if they want new clothes, or a TV, etc., they have to go to the Office of the Wards of Court and be given their own money.

The 2015 Act will mean that, for the majority of decisions, people with intellectual disabilities and older people will be able to have someone that they choose to help them make decisions for themselves regarding their own lives. They, finally, will be the major part of a decision-making process involving their own lives instead of being told what is happening to them. What the person wants, known in the 2015 Act as the person's will and preference, is central when supporting the person to make a decision. We will move away from acting in the person's 'best interests', which may not be what the person wants, to putting their wishes and preferences at the centre of the decision-making.

The role of the decision-making supporters is key to ensuring the 2015 Act works in practice. This will represent a huge shift from wardship, where a person is determined to lack capacity to make all decisions in relation to their life, to a system which is much more

nuanced – people can have different levels of support for different decisions. And, in the majority of cases, the person will decide who they want to play that role of supporter. Even if the Court is appointing the supporter (in the case of a decision-making representative), they need to take the will and preference of the person into consideration when appointing the supporter.

The range of decisions that the supporters might assist with is very broad, from the day to day decisions of what to eat and what to wear, through to bigger decisions like where to live, or how to spend their money. And sometimes, the person may make a decision that the supporter feels is unwise. The 2015 Act is clear that a person cannot be seen to lack capacity because they are making an unwise decision, or because they have made an unwise decision in the past. Everyone has made decisions that are seen to be unwise at some time in their lives. However, for people who may live in residential services, they are deterred from making these kinds of decisions because of the risks that may be involved. The role of the supporter is to ensure that they understand all of the information in relation to the decision that they are making, and any consequences that there may be.

Even if the decision isn't seen as being unwise, it is important that any decision-making supporters do not overrule the decision of the person. The supporter is working in partnership with the person and needs to listen to the person that they are supporting – actually listen to what they are telling them – as they may be very aware of the potential consequences of what they are deciding to do.

However, when it comes to the new decision-making supports, the 2015 Act is not perfect. One of the categories of people NOT allowed to be a decision-making supporter under the 2015 Act is a service provider or anyone working for them. For many older people with intellectual disabilities or significant mental health issues who have been in the care of the State since childhood, their carers in the service are the only people close enough to understand the individual, the only people who know their will and preference. The person might see these staff members as their friends because they have no-one else in their lives. While I can fully understand this is to protect the individual, there is no provision to allow for exceptions, even if the person who requires support to make decisions asks for that specific person to help them.

But while there are some areas of the 2015 Act I think could be improved, it will make a huge difference in people's lives. The decision-making supporters will play a key role in supporting people to be in charge of their own life. It emphasises that all adults, including those with intellectual disabilities and dementia, have their own will and preference, and therefore have the right to make their own decisions. They might need support to make or execute their decisions, but they can make their own decisions, and they have a right to have those decisions honoured.

While writing this piece, I have been reflecting on how the 2015 Act will impact on my day-to-day work as the HSE's Confidential Recipient. I act as a voice for vulnerable older people and people with a disability, therefore a number of people I work with could be seen as being the 'relevant person' under the 2015 Act. A person's decision-making supporter might play a key role when I am providing advice to a person about a concern they have, or if that concern needs to be escalated. Or I might receive correspondence from a decision-making supporter concerned about someone that they are supporting. We should both be acting as the voice for the vulnerable older person or the person with a disability, and I would like to think that we will be able to work in partnership for the best outcome for the person.



### 3.3 The Assisted Decision-Making (Capacity) Act 2015 and People with an Acquired Brain Injury

*Lorraine Crawley and Grainne McGettrick*

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#### INTRODUCTION

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This chapter examines how the Assisted Decision-Making (Capacity) Act (the 2015 Act) will impact the lives of people with an acquired brain injury (ABI) and their families. It discusses some of the common elements that people with ABI share with others covered by the 2015 Act. The chapter gives the view of the clinician practitioner and presents some of the key issues using a case study approach.

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#### THE CONTEXT OF ASSISTED DECISION-MAKING AND BRAIN INJURY

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The move towards assisted decision-making for those who have experienced an acquired brain injury (ABI) is a significant development. By its definition, a brain injury is something that occurs after birth and it includes both traumatic injuries such as falls, car accidents and sports injuries, and non-traumatic injuries which includes strokes and tumours. Many people who experience an ABI have experienced a typical developmental trajectory into adulthood, such as achieving educational qualifications, learning to drive, working, being in a relationship, renting/buying a house and travelling abroad. They may also have had to make health decisions, which in some cases could be about medical treatments. In essence, these are all examples of choice, responsibility and freedom of movement. While as adults we may consult with significant others, peers and/or professionals about the bigger decisions in our lives, we ultimately have control about the decisions we make, whether those decisions may be perceived to be 'wise' or 'unwise'. And, over time, we are accruing the experience of having the autonomy to make decisions.

However, the consequences of a brain injury can be devastating – both for those who experience it and for their family members. There can be long-term impacts on cognitive/thinking skills which includes attention, memory, problem-solving, numeracy and literacy. The very skills we rely on to make both small and large decisions, therefore, can be compromised and/or questioned by those around us. In many instances, this can be as a result of

family feeling the need to protect the individual with the ABI, particularly after the often traumatic experience of the brain injury itself.

However, legally, to date this question about decision-making has been on an all-or-nothing basis. And therefore, people post-brain injury, who had experience of making all the usual decisions we have control over in our lives, have been faced with having these powers legally removed. In addition to this, the brain injury may not fall under the category of progressive or of unchanging; indeed, studies suggest that with early access to specialised intensive neuro-rehabilitation, there can be positive outcomes for regaining levels of independence (Burke, McGettrick, Foley, Manikandan and Barry, 2020). The 2015 Act will, therefore, provide a mechanism that gives scope for adults with ABI to experience more empowerment in how they lead their lives.

While the changes to legal capacity have been welcomed by brain injury services, given core values relating to dignity, respect and choice, there are aspects of 2015 Act that will bring challenges (Waldron, Casey and McGettrick, 2017). One of the primary issues relates to difficulty with insight, which can occur following a brain injury. How to navigate the appointment of a decision-making assistant in these circumstances will require practical solutions. Another aspect pertaining to difficulty with insight in brain injury is that making a choice to do something does not necessarily translate into being able to do that thing, such as live independently in the community and declining supports. Meeting the requirements of the new legislation in these circumstances highlights the need for clarifications on assessment and support for the person with brain injury.

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## ROLE OF THE FAMILY

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The positive implication of the 2015 Act for families is that it will give them legal recognition when supporting decision-making with their family member who has a brain injury. A family member or family members will continue to have a role in providing valuable information about the individual's will and preferences and may be asked to be part of co-decision-making agreements. As highlighted previously, most people we meet who have experienced brain injury had a typical life trajectory beforehand and their preferences would have been generally known to those close to them. We have found that some of the most stressful decisions that a family may have to make on behalf of their family member are related to health; the new advance healthcare directive will have a person's decision made clear. This has real potential to reduce pressure on the family to make these decisions and lessen conflicts that can arise when family members disagree.

Where the new Act may represent a challenge for family members is that as decisions will be considered on a case by case basis, they may not be in agreement with their family member being deemed to have the capacity to make certain decisions with limited or indeed no input from them. They may feel concerned that the person may be targeted as vulnerable,

particularly in matters related to finances. Family members could argue that ‘unwise decisions’ are the direct consequence of the brain injury or that the person is less likely to understand the consequences of ‘unwise decisions’, whereas in the new Act this does not indicate a lack of capacity. Moreover, the individual who has experienced the brain injury will continue to have many of the responsibilities that were present in their life beforehand, which could include parenting decisions and finances (e.g. mortgage). In these contexts, they are likely to have preferences about how they continue to have a sense of power/agency in these matters, which may conflict with family members’ opinions. For families with experience of the previous system, they may need an adjustment period as their role changes. In these instances, specialist brain injury services have the potential to provide a supportive role for family members as they gain an understanding of the changes brought about by the 2015 Act, to acknowledge and hear their concerns, and to explore ways of working with the family, in conjunction with the person with ABI, in order to promote the purpose of the Act.

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### ROLE OF CLINICIANS

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While the changes brought by the Act are in line with human rights, it has been acknowledged that, similar to families, there will be a period of change and adjustment for clinicians in following the new approach, which will necessitate training and guidance (Murphy et al, 2020). In the context of acquired brain injury, this is particularly relevant for clients who access neuro-residential services or are residing in nursing homes. In these instances, clients may be more likely to have a profile classified as higher need than those living in the community/at home, due to the physical and cognitive issues arising from the brain injury. It has been suggested that, rather than focusing on Advance Healthcare Directives solely, it may be an opportunity to engage in conversations about general healthcare planning with the individual with a brain injury in order that more present-focused issues can be addressed in line with this new legislation (Davies et al, 2019). It has also been highlighted that building therapeutic relationships with people with ABI over time can assist in understanding the communication system that works best for them and provides scope that they will trust those working with them to support their decision-making (Davies et al, 2019).

Under the 2015 Act, the role of the multi-disciplinary team (MDT) may come more to the fore in terms of a team assessment through a combination of clinicians, rather than reliance on the previous approach of the medical professional/psychiatrist. In ABI settings, this may include clinicians from psychology, occupational therapy and speech and language therapy in order to gain a multi-disciplinary perspective on the specific decision and how to support the individual in the decision-making process. However, one form of assessment cannot dominate; for example, the need for comprehensive neuropsychological assessments needs to be considered with a degree of caution, as McDermott and O’Kelly (2019) highlight. There is a limitation in what the tests can ascertain, as there is a possibility for there to

be a discrepancy between global cognitive ability and capacity. As questions continue to be raised by clinicians on what exactly their role will be in practice, it is advised that they consider the principles of the Act and other relevant documents such as the National Consent Policy and Supporting people's autonomy: a guidance document from HIQA (McDermott and O'Kelly, 2019).

The 2015 Act will bring challenges to clinicians in the brain injury setting, and some of these challenges may only become evident with time. The dual role a brain injury service may have in supporting both the person with ABI and the family in the context of this new framework may lead to ethical considerations as to who the client is and where the boundaries are in terms of the family's perception of their role. There may also be conflict within the team if there is not a consensus by clinicians. And, in practical terms, many brain injury teams do not have access to a full MDT. In all cases, reference to ethical codes and the above-named documents will be vital in navigating these issues.

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#### CASE EXAMPLE: MOVING FROM THE WARD OF COURT SYSTEM TO THE NEW LEGISLATION

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To illustrate how the 2015 Act will bring positive changes to the lives of people with ABI, we present a fictional case example that highlights one of the main capacity issues we come across in brain injury services: that of financial capacity. Ann is a 58-year-old woman. She is widowed and has two adult children. Ann is a trained nurse and was at managerial level at the time of the brain injury. She also owns a number of rental properties in a consortium with her late husband's extended family. Ann experienced a traumatic brain injury from a car accident, which resulted in multiple physical and cognitive difficulties. Due to significant changes in her short-term memory, problem solving and numerical skills, her adult children sought legal advice on how to protect Ann in terms of her finances. One of her children had significant concerns about Ann's ability to make decisions. In the Ward of Court system, the 'protection' of Ann in these circumstances would extend far beyond her property assets and would also involve restriction upon her previous adult liberties, such as the choice of where to live or to travel abroad without requiring permission. If Ann challenged the ruling, then she would likely be caught in lengthy and costly legal proceedings. And, in the context of an acquired brain injury, rather than it being associated with progressive decline, with intensive rehabilitation there is potential that Ann may experience some improvements in her cognitive skills over time.

Under the 2015 Act, the focus will be on the exact question about which Ann's family are concerned (financial management of her property assets) rather than it being an overarching assessment of her ability to make decisions in all aspects of her life. It will also be more open to reassessment in line with the possibility that Ann's cognitive skills for that particular aspect of her life may alter with rehabilitation and time. Any specific assessment would focus on how to support Ann in maintaining or, if possible, relearning

skills she had previously. There would also be a more positive focus on Ann being an active decision-maker (with support where required) regarding her finances whereby she is given more autonomy to select who can support her with this. Ann's children may require support in understanding the terms of the new Act; if it results in one of them being appointed as a decision-making assistant, Ann will have responsibility for the final decision. Overall, for issues similar to these, the 2015 Act will better connect with service and clinical ethics and values about a person-centred approach, and will empower clients living with a brain injury while also taking into account the supports that they may require for specific situations.

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## 3.4 Services and Supports: Views from Focus Ireland

*Karen Doyle*

Since our founding, Focus Ireland has always worked with some of the most marginalised and vulnerable people in our society. For over 35 years, Sr. Stan's vision that everyone has a right to a home has encouraged and empowered the staff of Focus Ireland and has given hope to those who have often been left behind by society.

Our values have always guided us in our work and in all our interactions with customers, providing quality services that are professional, appropriate, responsible and accessible, in a transparent manner. We aim for clarity, simplicity and minimal bureaucracy in our systems of engagement and access to services, and we work in a flexible manner on accommodating the changing needs of our customers. Focus Ireland welcomes the full implementation of the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) and is preparing to support and empower our customers and staff in their understanding of how the 2015 Act will impact on them – both professionally and personally.

Focus Ireland is very aware that all of us, at some stage in our lives, may be impacted by issues relating to decision-making and capacity. Our work with customers covers a range of support roles, from basic social needs for the economically homeless to more long-term support for those who have a history of substance misuse, mental health issues or who come from a care background. Regardless of the circumstances of someone accessing our services, our method of engagement comes from a rights-based perspective. As an organisation, we are committed to protecting the human rights of people using our services and embedding a rights-based approach in all of our work. All supports provided to customers are based on the individual needs of those presenting to us for support.

A question that is regularly asked within our services is 'What happens when a person is presenting as substance-affected, or is going through a particularly difficult period of mental health? How do we know what they want when they can't tell us themselves?' I believe this is one area in which the 2015 Act can support staff and customers alike. Its implementation will give staff greater clarity and direction on the approach they should take in difficult circumstances. The Act provides a framework that will make it clear that the known will and preferences of our customers take precedence over individual staff members opinions. It will allow us to have legally appropriate conversations with our customers about what action they would like to take when they are not in the space to make or communicate these decisions themselves. It will allow customers to feel an element of control over their lives that is often lacking. It will also remove the burden on staff that they need to make the 'right' decision for someone in difficult situations where it's not clear what 'right' means.

As mentioned previously, Focus Ireland supports some of the most marginalised in society, some of whom have lived under a regime of repressive and controlling institutions where rights, choices and opinions were non-existent. We support individuals who have sought solace in drug use as a means to deal with issues in their lives, how do we support these individuals to make decisions and have their opinions heard in all elements of their lives when much of society has written them off?

As an organisation and as individual staff members, we have had to find ways to empower and support these individuals in making decisions about elements of their lives that they have never had control over in the past. In many cases, the individuals concerned did not believe there were choices available to them. This has presented a challenge to both the staff members and to the individuals concerned, but through a long-term commitment to the individual and building up a trusting relationship within professional lines, we have supported many customers in finding their voices and to open their lives to choices they previously believed were impossible. These decisions range from how to spend their own income, who to allow into their property, who to engage in a relationship with – decisions many of us take for granted. Focus Ireland has long sought a legislative framework to help us respond to these questions and we welcome the commencement of the 2015 Act, which will provide the most vulnerable in our society with the voice to have their opinions heard and acted upon.

During this current crisis (COVID-19 pandemic), our customers are suffering due to a lack of services and supports that they would normally have access to. This exacerbates the feelings of loss of control, isolation and confusion which can be a daily element in their lives. As in every crisis, the people who are most vulnerable are those who suffer most. We are responding to this by talking to our customers and asking what they need, what will make their lives that bit easier and what will help return some sense of control to them in a situation that is so extraordinary. While this type of support is a normal element of key work, it also underlines the importance of having someone who knows you, knows how you like to be communicated with and knows what your preferences are in times of crisis. While our key workers carry out this work as a daily part of their roles, the introduction of more formal decision-making supports that the 2015 Act provides is to be welcomed. It provides an element of certainty that can often be lacking.

It will allow people to have choice and control over who they want to support them with day-to-day decisions, but also with the really big ones which we all struggle with from time to time. The implementation of the 2015 Act will give our customers a formal right to make these decisions themselves in whatever way they choose. These are rights that some of us take for granted, but that customers who have faced a lifetime of adversity have never considered as being within their reach.

The introduction into legislation of advance healthcare directives will be especially important in many of our residential services. These services house quite a number of people who are long-term tenants of Focus Ireland, having originally had varying experiences of homelessness, institutionalisation, a history of care or enduring mental health issues. Many of these customers are elderly and have no family support. The ability to make healthcare decisions in advance, prior to any emergency or crisis, will be a huge source of relief to both the customers themselves and the services who support them. Quite often, people become unwell in our services and have no external support mechanisms. As a result, Focus Ireland staff take on both the caring role but also the advisory role in terms of healthcare and planning for future needs. While this is not ideal, it is a case of making the best supports available within the resources we have available to us. To have a legislative framework and supporting documentation in the form of an advance Healthcare directive will further empower our customers to ensure their will and preferences are foremost when vital healthcare decisions are made.

We are very aware of the differing needs of our customers, many of which change every day. With this in mind, our key working and support services work from a model of support and regular communication. We fully believe in and support the principles behind the decision-making processes outlined in the 2015 Act and currently work from the principles outlined below:

- Recognition that decision-making looks different for different people
- Many people need things explained in a clearer, more simple manner and may need information reiterated regularly
- People might need assistance in gathering the information needed to make an informed decision
- People might need someone to make decisions with them
- Even if a decision needs to be made by a decision-making representative, a person's own input is still valuable and we advocate, where possible, for the known wishes of the person to be taken into account in any decisions made.



Despite working from these principles, currently we believe that it is necessary to fully implement the 2015 Act as a matter of priority to ensure that all customers and staff have a legal framework supporting the decision-making process.

The full implementation of the Decision Support Service will be welcomed as a positive step towards governance, oversight and support in this area.

## 3.5 Assisted Decision-Making and the National Clinical Programme for People with Disability

*Michael Walsh, Deirdre O'Donnell and Malcolm MacLachlan*

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### INTRODUCTION

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Knowing what you think is sometimes quite difficult. So is making choices and acting on your best intentions. Ells (2003) argues that, for most people, the requirements for making informed choice – entailing intention, understanding and absence of controlling influences— are often simply not met. This may be especially so in health contexts where power relations, expert knowledge, contextual restraints and necessarily limited and partial subjective experience, can all undermine the extent to which one is truly ‘informed’. Sharing decisions with others can also be difficult. For example, clinicians sharing decision-making with service users in mental health settings – even where people are recognised as having full capacity – is seen as complex and often challenging for clinicians; indeed, it is something required to be addressed in clinician supervision sessions (Beyene et al, 2018).

There are some people whose ability to make decisions about their lives and choices is significantly impacted by a specific impairment or condition. In an equitable society, with appropriate supports, people can continue, regardless of their impairment or condition, to exercise their right to making decisions about everyday aspects of their life.

Being informed to make choices, sometimes with the assistance of another person, is enshrined in Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). This Article obliges State Parties to ensure that people with disabilities have legal recognition as a person, the same legal capacity as other citizens, access to the means to exercise this capacity, and provision of safeguards to respect the rights, will and preferences of the person. Carney et al (2019) ‘cautions against expectations that mere enactment into law or adoption within programs of support will prove to be a panacea’ (p. 1). In this chapter we briefly think through how – from the perspective of the recently established National Clinical Programme for People with Disability (NCPPD) – health and social care systems can respond to the opportunities and challenges that commencement of the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) will entail.

We consider assisted decision-making (ADM) in the context of some of the challenges we encountered during the response to COVID-19, which coincided with the initiation of the NCPPD. We then highlight the systemic facilitators and barriers that must be considered to ensure that real and informed choices are enacted which respect the will, preference and rights, of people with disability.

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## COVID-19 LEARNING AND ASSISTED DECISION-MAKING

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The rapidity of COVID-19 exposed the weakness of a system that is not yet supported by commencing of the 2015 Act. The NCPPD contributed to discussions and guidance on advanced care planning, Do Not Attempt Resuscitation (DNAR) decisions, end-of-life care decisions and ethics in critical care decision-making during COVID-19. Concern was expressed to the NCPPD by organisations of persons with disability (OPDs) that guidelines developed in other jurisdictions, which conflated frailty and comorbidity with disability, were not only discriminatory but unfounded. Furthermore, these were sometimes prejudicial to people with disability regarding what might constitute a good long-term functional outcome; one of the criteria suggested for decisions regarding ventilation and resuscitation. Even for those with full capacity, it would have been very difficult for a person to query a decision to, for instance, withhold ventilation procedures. For someone lacking capacity and without supportive services for ADM, it would have been extremely difficult to contest decisions, either to ventilate or not ventilate. Without ADM services, there remained a danger that the will and preference of people with disabilities – particularly people with intellectual disabilities – may have had to be guessed by a stranger, in stressful demanding conditions, which may not have upheld their rights according to the CRPD.

There is a dearth of trained staff and paucity of support systems to facilitate difficult discussions such as those required for advance care planning and end-of-life decisions. Some examples of good practice that could be scaled up include the use of hospital passports and the training of residential care staff, families, carers, supporters and the general public on having difficult conversations and enacting advance care planning, where appropriate. It is important not to discriminate by targeting particular populations such as older people or people with a disability in terms of advance care planning, which was reported in some jurisdictions during the early stages of the pandemic. Advance care planning is a consideration for many in society. However, the COVID-19 context demonstrated a need for greater access to advocacy services – facilitated in-person or online – and access to full information in a timely manner and in accessible formats. The commencement of the 2015 Act could stimulate a formalised structure of legally acknowledged and trained supports, the legal standing of advance care directives, independent oversight and register of support arrangements and agreements, and a code of practice to guide supporters and health and social care workers.

Through engagement with OPDs, service provider organisations and HSE personnel, the NCPPD was able to support the Department of Health in producing ‘Ethical considerations relating to critical care in the context of COVID-19 - Supplemental Information’. While this reassured OPDs and provided helpful guidance for clinicians in terms of critical care decisions, these were reactive measures. The commencement of the 2015 Act could have anticipated this consultation process, and established guidance regarding the lack of a strong

relationship between disability and quality of life, helping to mitigate any unintentional biases from clinicians and allowing them to make better informed decisions.

The response to COVID-19 has also highlighted accessibility concerns for our service users. While there was much information provided on COVID-19, this was not always in accessible formats or delivered in a timely manner to facilitate fully informed decision-making. Supporters and advocates being able to accompany persons to hospital, community hubs or GP practices is an important element of access for some people with disabilities and of a range of different types of disabilities. The right of advocates and supporters to accompany persons with disabilities to appointments was clearly stated and was a subject of debate and lobbying in the initial stages of the pandemic. Many services switched to online, for instance using teleconferencing, but sometimes using platforms that presented accessibility challenges or difficulties to some people in terms of accessing these technologies. Commencing the 2015 Act would create the requirement of both specific organisations and systemic structures to facilitate access across the full range of functional impairments. We now consider what is required systemically to support the effective introduction of ASD within the health and social care context.

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#### SYSTEMS STRENGTHENING FOR ASSISTED DECISION-MAKING

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The central tenet of Article 12 of the UNCRPD and of the ensuing 2015 Act is to ensure that all adults, including those with a cognitive disability, are provided with the opportunity and the support to participate as equal citizens in all decisions that affect their lives, including their health and social care. While the 2015 Act offers a legal framework for ADM within health and social care service delivery, there is no clear understanding of how this complex legislation can be implemented into everyday practice (Bigby et al., 2019; Cahill, 2018; Davies et al., 2019; Gooding, 2015). Significant consideration needs to be given to the responsiveness of the health system and what implementation of ADM might mean for the systems in which health and social care is experienced, managed, organised and delivered (Ní Shé et al., 2020). Ascertaining will and preferences, supporting insight and enabling genuine choice for service users is complex and time-consuming. It requires a restructuring of physical infrastructure and resources, consideration of the social relational aspects of lived experiences, as well as ongoing professional development and training in conjunction with public education and preparation (Davies et al., 2019).

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#### INDIVIDUAL SERVICE USER FACTORS

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Capacity building for individual service users, as well as potential decision supporters, is essential for the effective implementation of ADM (Bigby et al., 2019). This entails public awareness campaigns and guidance to foster public engagement with ADM and generate

an understanding of the legislative mechanisms to support decision-making. Education and public information regarding the legislation, as well as the supports available for those who require assistance with decision-making, falls under the duties of the Director of the Decision Support Services. The NCPPD supports the idea that all programmes should be co-designed with service users, tailored to their lived experiences and emphasise personal autonomy and the human right of service users to direct their lives and safeguard their decision-making (O'Donnell, 2020). Educational curricula should include a focus on advance care planning, legal expressions of will and preference, the role of tiered decision-supporters, as well as practical strategies for decision supporters providing assistance for decision-making in multiple contexts.

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#### FACTORS ASSOCIATED WITH HEALTH AND SOCIAL CARE PROFESSIONALS

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Health and Social Care Professionals (HSCPs) are required to understand the clinical and social circumstances which impact upon functional capacity. This includes knowledge and skills for assessing capacity, which is time- and issue-specific. Furthermore, they require the skills to respond, interact and support service users throughout the duration of their care journey (Goodridge et al., 2019). This is particularly relevant for service users who have impaired communication competence and/or fluctuating cognition.

Formal education as well as ongoing training and development should also focus upon enhancing the competence of HSCPs to build service user capacity for decision-making (O'Donnell et al., 2018). This encompasses interpersonal communication skills as well as understanding of a 'total communication approach' (Bradshaw, 2000). This includes the use of assistive technologies such as communication aids, augmentative and alternative communication, as well as communication passports and assistive technology passports (Maalin et al., 2019).

Strong interprofessional collaboration which is inclusive of the service user is essential for supporting decision-making in complex care planning across services (Bunn et al., 2018). This entails an understanding and valuing of disciplinary roles and ADM competencies and skills, as well as the cultivation of trust, shared decision-making and distributed leadership (Anjara et al., 2020; De Brun et al., 2019). Furthermore, opportunities for interprofessional mentorship and reflection are essential to support the development of ADM competencies and confidence among HSCPs (Davies et al., 2019). This is particularly relevant for supporting HSCPs to navigate the social and relational aspects of complex care planning with services users and their decision-making supporters.

The requirements outlined above will involve a restructuring of the educational programmes at both undergraduate and postgraduate level as well as ongoing professional development (Davies et al., 2019).

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## CONTEXTUAL FACTORS

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Service users as well as HSCPs are often disempowered by a system of care which is under-resourced to facilitate decision-making (Ní Shé et al., 2020). There is real disparity in Ireland between the will and preferences of service users and the resources required to realise their supported decisions particularly in the context of state dependency on family care provision (O’Sullivan, 2019). A pre-requisite for effective implementation of ADM is adequate resourcing of community care (Bigby et al., 2019; Bunn et al., 2018). This resourcing should include personal assistant and home care hours as well as infrastructural re-organisation to improve transport, housing, tele-health and mobile integrated health and social care teams.

The lack of integration of care for service users transferring across services may be experienced as repeated assessments or repetition of information, as well as gaps in service delivery (Baxter et al., 2018; Ní Shé et al., 2020). A fully resourced and realised Sláintecare national policy for health service reform towards integration of services should result in improved continuity of service delivery as well as an interprofessional collaborative team approach across service domains (Anjara et al., 2020). This would support the implementation of ADM through the development of pathways for information sharing and care coordination and would be entirely consistent with the ethos of the National Disability Inclusion Strategy (NDIS), noted above.

A further contextual factor supporting the implementation of ADM is the requirement for a reduction in standardised approaches to service delivery and metrics which solely focus on direct clinical care and service user turnover. A revision of the systems of documentation and metrics should capture and measure practices for building capacity; recognising the individual or team efforts for personalising care (Bridges et al., 2019). Without adequate explicit measurement and documentation, this complex relational work can be hidden among competing powerful institutional drivers that may instead depersonalise care (Bridges et al., 2019).

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## CULTURAL FACTORS

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Implementation of ADM requires HSCPs, service users and decision-making supporters to navigate the tensions that may exist between the best interests of service providers and individual decision-making autonomy. A cultural context of risk aversion may create a tension between a protectionist duty of care (particularly in relation to safeguarding against abuse) and individual rights to autonomous decision-making (Donnelly, 2019; Gooding, 2015; Phelan and Rickard-Clarke, 2020). A genuine understanding of autonomy is therefore required by all individuals operating in the health and social care system, including service users as well as organisational leaders and management. This understanding should encompass recognition of indicators of coercion or undue influence.

A culture of risk aversion underpinned by fear of litigation and individual accountability may also mitigate against HSCPs supporting the right of services users to make risky or unwise decisions (Donnelly, 2019). It has been argued that many parts of the health and social care system in Ireland are characterised by hierarchical command and control leadership styles (De Brun et al., 2019; McAuliffe et al., 2017). Collectivist leadership within healthcare is necessary to empower HSCPs to advocate for service users within a context of risk management. HSCPs should feel supported and valued within an inter-professional team context to advocate for the decision-making capacity of service users. Furthermore, services users themselves should feel included and valued as partners in their own care planning.

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## 3.6 Assisted Decision-Making: The Importance of Inclusion

*Bernard O'Regan*

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) seeks to move to a social model of disability, in which the emphasis is on removing the social and physical barriers that impede people with disabilities living full lives as citizens. Instead of trying to 'fix' the person with a disability, society needs to 'fix itself' so that it fully includes people with disabilities to exercise their rights on an equal basis as every other citizen.

One important component of how Ireland can meet its obligations is through the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act).

While there are challenges, the full implementation of this legislation, and the supports to ensure its proper implementation, are essential. In the absence of its implementation, a central lever to ensuring the autonomy, rights and equal treatment of people with disabilities is restricted and an important obligation in meeting the State's obligations under the UNCRPD remains limited.

The 2015 Act is potentially one of the most important and game-changing pieces of legislation for people with disabilities in Ireland. It recognises that all people have legal rights, including the right of each person to make decisions and choices for themselves, and enshrines the right to be treated with dignity and respect. The legislation ensures that we can plan ahead and that the decisions we make now about our future wishes can be recorded in the event that we may lose capacity in the future. The legislation supports the autonomy and equal rights of each person.

This is important legislation for all citizens, but it has particular resonance and significance for people with disabilities, people with cognitive impairments and those with diminished capacity. It also has particular importance for those who support them, families and service providers.

Inclusion Ireland rightly states that "This ground-breaking legislation will result in significant improvements in the lives of persons with intellectual disabilities as their ability to make decisions for themselves will be enshrined in law."

The impact of this legislation, apart from citizens themselves, will also be important for those providing health and social care services, policymakers, the courts system and those providing legal and financial services.

Of course, the scale of its impact will be determined both by the timeframe within which it is commenced in full and by the resources that are made available to ensure that all aspects of its potential are realised – especially the resourcing of the Decision Support Service, which could easily become overwhelmed if adequate resources are not provided. The Department of Justice and Equality has indicated previously that as many as 220,000 people could be affected by diminished capacity and need the involvement of the Decision Support Services. In light of the individual circumstances and often the complexity of those circumstances, the demands on the service could be significant.

The 2015 Act has particular significance for people with disabilities. Every day, people with disabilities, especially those with intellectual disabilities, have decisions made for them or have limited input into these decisions: how they spend their day, where and with whom they live, as well as routine decisions about the clothes to wear, who they spend time with, and the staff who support them. We can't have a situation where we are so focused on the big-ticket decisions that we lose sight of the importance of the 'bread and butter' decisions of everyday life that will, in effect, have more impact and significance on how people with disabilities live their lives. This is where the real impact of the legislation in leading to the attitudinal change needed will be evident.

There will be significant hurdles to overcome if we are to ensure the legislation has the impact needed. The assumption of capacity on the part of each person must be realised in a cultural, societal and family context where we defer to the voice of parents about their adult children with disabilities. For many families, this legislation will be welcome; but for many, once the implications of its import are understood, it will seem to challenge the perceived primacy of parental decision-making, authority and control. This legislation needs to be supported by attitude change; change in how people with disabilities are seen in society; change in attitudes that the UNCRPD seeks.

It will also, and importantly, challenge the patriarchal role of service providers, especially in the context of people with significant cognitive disabilities who need substantial support to exercise will and preference, ensuring they support people as equal citizens, respecting their right to make choices and decisions, including decisions that service providers may not always support or agree with. Many providers try to support people with significant disabilities in important ways, but this can sometimes wander into excessive control and disproportionate influence on the decision-making of the people they support.

Service providers will need to be considered in their approach. The temptation to have a 'one size fits all' approach or an 'organisation-wide strategy' will fall short of what is

required. They will need to recognise the different levels of capacity and select the right level to determine the correct access point for assessing decision-making while respecting the independence of each person. They will need to ensure that the staff they employ understand the requirements of the legislation and are able to apply it in their everyday work; they will need to have their own assumptions challenged and, perhaps, be able to challenge the organisation they work for.

Central to the 2015 Act is the requirement to take a functional approach to assessing capacity. The Act provides that a person's capacity must always be assessed in a 'time-specific and issue-specific way'. Any cognitive impairment is relevant only if it actually affects capacity. This contrasts with the 'blunt instrument' approach under the Wards of Court system which declares a person to be of unsound mind and incapable of managing his or her affairs.

Importantly, the legislation recognises that there is a hierarchy of complexity in decision-making and that a cognitive deficit only has relevance if it actually impacts on the decision to be made. Equally, making a 'bad' decision is not seen as a gap in capacity. The need for support in making one decision due to capacity deficits does not result in the loss of independent and autonomy to make other decisions.

The importance of safeguarding this for individuals with disabilities, especially those who are in receipt of significant services and supports, is critical. The risks for people with disabilities that the service system can easily come to conclusions about a person's capacity for decision-making based on an example of one situation or decision, are high. The oversight and enforcement, including support for implementation, will be important to safeguard people with disabilities from this risk.

One concern about 2015 Act is that it will inadvertently catch a lot of people in the ID sector in the decision-making representative net. This is a court-appointed person who makes decisions for the relevant person. This is because individuals must have capacity to consent to the lower levels of support (assisted decision-making and co-decision-making) and a significant majority will struggle to do so. Specifically, the decision to live in a supported living arrangement, sign an individual service agreement, live in a designated centre or agree to attend a day support programme could become challenging. Each of these decision points may require a court process to identify a person who is able to represent the person in this decision. Individuals in service arrangements will need to consent for them, if they can't do so given their capacity limitations, then a court-appointed process will be required. An informal process will not work as the person must consent to be able to set out of these up.

There is some concern that the scale of demand for the Decision Support Service is underestimated. To illustrate the point, there are approximately 8,400 people with

disabilities, primarily people with intellectual disabilities, in residential services. Each of those people will require access to the Decision Support Service in relation to a wide range of decisions – decisions about the use of their personal resources, decisions about the supports and services they access (including in the context of availing of personalised budgets and determining which provider to engage with), decisions about healthcare and end-of-life care, decisions that may be in conflict with the views of families and/or service providers.

COVID-19 brought into sharp relief the potential healthcare risks for some people with disabilities who also have health conditions. The fact that they have a disability did not, in the vast majority of cases, make them any more at risk of the disease than any other citizen. However, they were routinely included in the so-called ‘vulnerable’ category. This served to further reinforce the perception of people with disabilities as being characterised by vulnerability and needing to be cared for. At a time when citizenship, autonomy, independence and will and preference must be the drivers, we defaulted to lower thresholds. The implementation of the legislation and the proper resourcing of the structures for its delivery in the lives of people with disabilities will, on the one hand, need to challenge this negative perception, while also leading to wider societal change in attitude to, and thinking about, how people with disabilities are included as equal citizens.

## 3.7 Who Decides and How?

*Sarah Lennon*

When I began working for Inclusion Ireland in 2006 on a project with this abstract title, little did I know that this would become one of the most pertinent questions of my life, dominating my professional and, at times, my personal life. I was employed to deliver an information provision and training programme to people with intellectual disabilities and their family members on wardship, decision-making and capacity law. As a law student, I had certainly studied the Ward of Court system, but my legal education had given scant regard to how the Lunacy Regulation (Ireland) Act of 1871 impacted on individuals and their families once a person was made a Ward of Court and had to live with the consequences of the removal of their legal capacity. I was to learn quickly that this was a very real problem, as was the absence of a legal recognition of supported decision-making.

Part of my new role was to field information queries and produce accessible information materials and very quickly, it became obvious that regardless of the reason a person called the Inclusion Ireland office, the vast majority of enquiries contained, at their heart, a question of decision-making. Most callers were parents of people with intellectual disabilities or people who worked in disability services, with very few calls from people with a disability. This was not indicative of a lack of interest or that people didn't need support, rather a mark of a need to improve accessibility and to build more networks. In 2019, when I finished working in Inclusion Ireland, this situation had improved significantly and people with intellectual disabilities were at the heart of calls to repeal the Lunacy Act and commence the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act).

Back in the 2000s, the lack of legal clarity had resulted in a swathe of informal arrangements arising, such as medical professionals requiring families to sign consent forms, financial institutions insisting on joint bank accounts or service providers requiring family members to sign contracts for care. Very few, if any, of these practices were concerned with supporting the individual to make his or her own decisions, rather to create comfort that a sort of legal framework was being put in place to ensure that decisions were 'signed-off'. The irony of that being that these practices had no real basis in law anyway.

The joint bank account issue was one of the most frequent and significant problems, with many people with an intellectual disability having been refused

access to a bank account unless it was jointly with a family member. Not only did this leave the person with an intellectual disability open to financial abuse, it also meant that the person could be left in a vulnerable situation should their family member pre-decease them.

Some of the other enquiries that I fielded during that time involved people with intellectual disability being refused an operation because of a perceived lack of capacity to consent, decisions being made about where a person with an intellectual disability would live without their involvement in making that decision, financial decisions being made, or in many cases not made, meaning that a person with a disability accumulated savings but had little quality of life.

Concerns about people with intellectual disability and their right to sexual relationships were also commonplace with people who worked in services concerned that providing sex education would be a breach of the criminal law.

One of the most common queries that I fielded surrounded the area of wills and inheritance. Parents called to ask about who they could leave guardianship of their adult son or daughter to in their will, having mistakenly believed that they were their son or daughter's guardian. The information that there was no adult guardianship in Ireland, coupled with the prospect of a person with an intellectual disability becoming a Ward of Court as a result of inheritance, was regularly met with disbelief, incredulity and often anger. Family members wanted to know 'what will happen after I am gone'.

I worked, too, with individuals affected by having been made a Ward of Court. The reasons for being made a Ward of Court were typically financial ones, such as inheritance, ownership of land or damages following a court case.

Individuals who were subsequently made a Ward of Court spoke of having been seen by a medical visitor but not being fully aware what was happening. Families of people being made a Ward of Court spoke of being told that it would protect their family member. Seldom was the overarching impact of being Ward of Court made clear and that decision-making would be removed from the individual in relation to all aspects of their life and for many, life would become administrative, burdensome and that simply, decisions would be made about their lives without any say from the person themselves.

In the early 2000s, Inclusion Ireland was one of a small amount of voices trying to promote the idea of legal capacity – in other words that a person has the right to make decisions and have those decisions recognised regardless of any diagnosis, impairment or disability. At that time, the conversation was largely focused on mental capacity in spite of Ireland signing, with great fanfare, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007. Article 12 of the Convention makes clear that 'persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life'. A



subsequent opinion of the CRPD Committee would make this position even clearer and state that all forms of substitute decision-making were contrary to the Convention.

On one occasion, I represented Inclusion Ireland at an Inclusion International event where different representatives spoke about their countries' implementation of the UNCRPD and when it came to my turn to speak, I spoke about the primary barrier being legislation from the 19th Century, when Ireland was ruled by Queen Victoria, being contrary to Article 12 and that far from it being a relic of times gone by, it was being utilised on a regular basis to remove decision-making rights from older people, people with disability, mental illness and acquired brain injury. The other participants were both fascinated and incredulous and in that moment, I felt ashamed of Ireland.

Throughout the 2000s and into the next decade, the legislative and public policy landscape was dominated by the idea of a Public Guardian, substitute decision-making and adult guardianship. For Ireland, it seemed that a leap from the Victorian-era Lunacy Act into the modern world of recognising legal capacity was a leap too far.

Several Bills made their way through the houses of the Oireachtas, but none would ultimately bear fruit. Many advocacy organisations, academics and individual advocates would persistently engage on proposed legislation during this time, but ultimately there was no meaningful progress.

When the Assisted Decision-Making (Capacity) Bill was finally published in 2013, it was clear that the many years of advocacy had paid off to an extent and what was published closer reflected a rights-based approach to supporting decision-making and a move away from the paternalistic, guardianship approach. It was also clear that the Bill was imperfect and a further two years of engagement followed. The willingness of both the Department and Minister Kathleen Lynch to engage with civil society during that time saw over 1,000 amendments made during the two years before enactment in the dying embers of the 31st Dáil. In fact, there were tense scenes in Leinster House as a last-minute vote threatened to scupper the entire Bill, only for the government to prevail and see the Bill pass.

While the 2015 Act remained imperfect, and not compliant with the UNCRPD in allowing for substitute decision-making in certain circumstances, the legislation promised to drastically overhaul the Lunacy Regulation Ireland Act.

For Inclusion Ireland, I engaged with our members and the people the organisation represented. This involved informing people through accessible information publications, online training tools and during one summer period a capacity road-show. It also involved consulting with people on what the main barriers were and what could address those barriers.

On one infamous occasion, as I gave a presentation on the benefits of Assisted Decision-Making to a packed parish hall in the south of the country. I spoke about how it meant that people, whose capacity was in doubt, could select the person they wanted to support them to make a choice. I spoke about how there would be no automatic right for anyone to be the supporter and how there was a responsibility on the supporter to build the capacity of the person themselves to make their own decisions. This did not go down well with some of the attendees, with one in particular branding me a 'f\*\*\*in' lunatic' before storming out of the meeting hall. Her choice of words was not lost on me at the time.

What the experience showed was that there was great fear, particularly among family members, of the changes that Assisted Decision-Making was going to bring. Many families felt they were doing ok the way things were, so I relied more on the case studies of how when things went wrong, how the only option was the Ward of Court system and how that impacted on lives.

There was less fear among people with intellectual disabilities when we discussed having the right to make decisions about their own finances, health or personal welfare. Instead, many people spoke of wanting greater opportunity to make choices and wanting the chance to make decisions having had little opportunity to do so.

With Inclusion Ireland, I ran workshops on healthcare decisions, making a will, marriage and relationships and making decisions about money for people with intellectual disabilities. These were ostensibly training workshops, but were fundamentally about reaffirming people's rights to make their own decisions. The workshops also made clear that people already had these rights and that any change in the law was about them getting the support of their choice to exercise these rights. It was clear from these workshops that many people with intellectual disabilities, particularly those who lived in institutions, did not have day-to-day control of their money. It was also clear that they wanted this control.

The message from people with an intellectual disability was about support. For them, the question of 'who decides and how' was less about the 'who' and more about the 'how'.

People spoke about support and how, very often, the support was not the support of their choosing. Individuals who attended disability services spoke about how the staff roster was the primary support system and if they needed to go to the doctor or the bank, it was down to chance who supported them. People who got support from family spoke about wanting support from different family members for different matters, such as a sister or a brother rather than their parents in some situations. People who did make their decisions independently spoke about being refused financial services or medical care until a family member was involved.

The fact that the 2016 Programme for Government failed to even mention the 2015 Act was a bad signal and it has been no surprise that the commencement of the act was stalled for a time. What had not stalled, however, is the desire among people with intellectual disabilities to make their own decisions, control their own lives and have the support that they choose to make those decisions.

Large numbers of people with intellectual disability have been made a ward of court in the five years since enactment and the reasons for that happening have also expanded from the traditional financial ones. Besides that, there has been a half a decade of opportunity lost for people with intellectual disabilities, or anyone whose capacity is in question, to exercise their legal rights to make decisions, with the support they may require.

While the enactment of the 2015 Act and the subsequent ratification of the UNCRPD were important moments in the recognition of the legal capacity of all people, the question has since moved from 'who decided and how' to 'who decides and when?'. People with intellectual disabilities will hope that their 149-year wait is almost over.

### 3.8 Mind the Gap: Practical Considerations with Regard to the Assisted Decision-Making (Capacity) Act 2015 from the Perspective of Family Carers

*Clare Duffy*

‘There are four types of people in this world: those who are carers, those who were once carers, those who will be carers and those who will need carers.’

More than five years have passed since the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) received presidential assent. Described as a ground breaking piece of legislation, the signing into law of the 2015 Act was a significant milestone in Irish legal history. It represents a triumph of autonomy by recognising that, as far as possible, all people have the right to live a life of their choosing and to play an active role in decisions about their personal welfare, property and affairs.

While the 2015 Act is rightly focused on people with diminished capacity or those whose capacity may be called into question in the future – a.k.a. the ‘relevant person’ – there are many other groups of people who are relevant to the Act and to ensuring its principles are respected. This paper explores the practical issues affecting one of these groups, family carers: the family members and friends who care for a person due to their illness, frailty, disability, a mental health difficulty or addiction and who are the most likely person to bring the legislation to life by assuming the role of a decision supporter or ‘intervener’. The successful implementation of the 2015 Act seems predicated on their willingness and ability to assume the various decision support roles legislated for and, as such, every effort should be made to consider their needs as we move towards full commencement of the Act.

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#### PRACTICAL CONSIDERATIONS

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##### **The tensions and interdependencies of disability and care**

The tensions and interdependencies between the theoretical positions of giving and receiving care and, more broadly, disability and carer policy are well documented, however they have been brought into sharper relief with the ratification of the UNCRPD and the passing of the 2015 Act. While its introduction has been lauded, certain aspects of the 2015 Act are much debated in this regard, particularly Part 5, which legislates for court appointed decision-making representatives (DMR), with some arguing that this form of ‘substitute decision-making’ goes against the spirit of the 2015 Act and undermines individual autonomy. There is also a growing narrative with regard to the role of family carers, with the

suggestion that they can in some way disempower people with disabilities or obstruct their decision-making autonomy and an emerging aversion to the term ‘carer’, which is perceived to be based on unequal relationships characterised by emotion and dependency. While it is not our intention to pit carers and carer advocates against the disability movement, whose ambitions we fully endorse, we believe it is important to acknowledge this tension rather than ignore it. The reality is that once commenced, a significant number of family carers for adults with profound disabilities will have little choice but to take on the role of DMR unless they wish to see the role filled by a professional paid for by the State. Few would live the life of a family carer without an absolute commitment to the welfare of the person they are caring for and we believe that such carers should be supported and enabled to assume the role of DMR and that this should incorporate appropriate safeguards, for both the relevant person and the DMR.

#### **Mind the Gap – transitional arrangement for family carers**

The delay in commencing the 2015 Act, in particular Parts 3, 4 and 5, has created a legal quagmire whereby the protections it has legislated for (i.e. assisted decision-making agreements) are not yet available, meaning carers have no legal status in terms of decision-making in the interim. At the same time, passage of the Act involved highlighting, correctly, that next of kin and consent policies widely accepted heretofore have no legal basis. As a result, there has been a marked increase in Ward of Court applications as people seek legal certainty. This has created a situation entirely at odds with the principles of the Act and undermines the relevant person and their family, who now have no mechanism through which to formalise the decision-making support required.

While Family Carers Ireland are eager to see the commencement of these parts of the Act, we are calling for interim measures to support their introduction. In our interpretation, the goodwill, custom and practice on which carers have traditionally relied when engaging with health professionals, for example, will become illegal on the day that Part 5 is commenced. We estimate that at least 25,000 family carers will have to apply to the courts for a determination under the Act immediately on its commencement, with no prospect of the system being able to cope with this surge. To avoid overburdening the courts system, we believe appropriate transitional arrangement for carers of people who require a DMR are needed, similar to the three-year review period proposed in respect of the transfer of existing Wards of Court (c. 4,000 cases). Without such an initiative, it is likely that an application will be made to injunct the commencement of the act on the basis that the delays in the court system are themselves a denial of the rights of both the person with disabilities and their family carers under the 2015 Act.

### **Providing practical support for decision supporters**

While the relevant person is at the heart of the 2015 Act, decision supporters are its cornerstone. These decision supporters will most often be family members, neighbours or friends who carry the normal responsibilities that life brings – work, family, education, home – but, by virtue of ‘volunteering’ to act as an intervener, are accepting very considerable additional responsibilities. This is exacerbated for family carers who are also responsible for the care of their loved one, often on a full-time basis. If family members and friends are to fulfil the demands required of decision supporters, then it is critical that a range of measures are in place to support them, including dedicated training and information workshops, online resources, a helpline, information packs and, for more complex cases, the support of a dedicated key worker.

### **Resourcing the new system**

The 2015 Act outlines determination of capacity as a function of the Circuit Court. Family carers are unclear as to how the Circuit Court will make this determination or the costs involved. While the intention of the 2015 Act is to assist people to make their own decisions in so far as possible, there will inevitably be situations in which capacity will need to be assessed by an independent assessor or panel of experts. Section 50 provides that in making such a declaration, the Circuit Court ‘shall have all such powers as are necessary to assist it’ including directing the preparation of expert reports. It is unclear how this will work in practice given the very significant waiting times members of the public encounter when trying to access specialist health professionals. We have also experienced a reluctance from some medical professionals to complete the reports required for certain disability-related social welfare schemes due the pressures they are under. The significant financial costs of obtaining appropriate medical reports must also be considered and assurances given that this burden will not fall to family carers to meet. In terms of the assessment of capacity itself, families have questioned the ability of an independent assessor or an expert panel to assess an individual’s capacity based on a desk review of medical reports and are calling for all assessments of capacity to incorporate a face-to-face assessment.

### **Achieving cultural change**

The saying that carers use not only their hands but their hearts and heads as well captures the close emotional bond that often exists between a carer and the person for whom they care. As a consequence, they find it particularly challenging to allow their loved one the freedom to make his or her own decisions, particularly when they deem those choices to be unwise. The realisation that they are not the default decision-maker for their loved one comes as a shock to many carers, who routinely make decisions on their behalf without understanding that they have no legal mandate to do so. The emotional impact of this, particularly on parents of adult children with a disability, is enormous, with some articulating feelings of being ‘locked out’ of their loved ones life, being undervalued and disregarded after many years of being actively involved in their decisions. Such is the intensity of these feelings

that it is not unusual for a carer to become upset during discussions on this matter. Of particular concern to us is that the majority of family carers we engage with have little or no understanding of the 2015 Act or the implications it has on them or their loved one.

The magnitude of change required by the 2015 Act must not be viewed as only the concern of people with disabilities, their families, carers and health services, but rather will require a transformation in thinking across every aspect of society – within government, in homes, workplaces, hospitals, schools, colleges, banks, shops, restaurants, public transport, etc. If we are to come close to achieving the ambitions set out in the 2015 Act, then no individual, disabled or not, should be unaffected. The House of Lords Post-Legislative Scrutiny Report on the England and Wales Mental Capacity Act 2005 found the 2005 Act has suffered from a lack of awareness and a lack of understanding and failed to achieve the cultural shift required, stating ‘for many who are expected to comply with the Act it appears to be an optional add-on...’ and that ‘the prevailing cultures of paternalism (in health) and risk-aversion (in social care) have prevented the Act from becoming widely known or embedded.’ The report also emphasises the lack of evidence of the use the Act in sectors including banking and policing. We must use the learning of our UK colleagues to better inform our practices and ensure we don’t replicate the mistakes that were made.

### **Relational Autonomy – When a bad decision affects me!**

A fundamental principle underpinning the 2015 Act is a person’s right to make a decision, even though others may think it unwise, so long as they are deemed to have the capacity to make it. This raises important, but not uncontentious, concerns by family carers who question what rights they have if/when such decisions affect them. For example, in the case of a relevant person who chooses to spend much of their weekly disability payment on fast food, alcohol or cigarettes but has nothing left to contribute towards their living costs. Or a person who buys a pony that will live on the carer’s front lawn. While these scenarios may seem pedantic, they are not uncommon scenarios in caring families. With a growing recognition of the relational aspects of autonomy – that people’s identities, needs, interests and autonomy are shaped by their interpersonal relationships and mutual dependencies – what, if any, protections are to be afforded to families who are likely to be personally affected by unwise decisions?

### **Advance Healthcare Directives**

Part 8 of the Capacity Act places advance healthcare directives (AHDs) on a statutory footing. When commenced, it will enable people to be treated according to their will and preferences by providing healthcare professionals with information in relation to their treatment choices. The Act allows for the nomination of a ‘Designated Healthcare Representative’ (DHR) who will have the power to advise and interpret the directive-maker’s will and preferences with reference to their AHD and/or the authority to consent to or refuse treatment, up to and including life-sustaining treatment as determined by

the AHD. Various international studies have shown that family members are the most frequently nominated as a DHR. While the 2015 Act legislates for many different decision support roles, few carry the responsibility of the DHR, who must oversee possible life-ending decisions.

While the raft of practical challenges associated with advance care planning are well documented – validity, storage, retrieval, interpretation – we wish to highlight two specific considerations likely to affect family members assuming the role of DHR. The general reluctance to talk about death and dying, a lack of knowledge and understanding of the clinical management of dying patients, religious beliefs and a traditional trust in the medical profession all contribute to an under appreciation of the value of AHDs and their low take-up. When discussions on advance care planning do take place, they can be rushed and relatively generalised, leading to the risk of a discrepancy between the directive-makers will and preferences and the DHRs interpretation. If advance care planning is to become part of mainstream patient-centred care, more will have to be done to facilitate these discussions by educating clinicians and the public about the benefits and mechanics of AHDs; providing accessible formats that enable people to accurately document their will and preferences; devising methods for the periodic review of AHDs; and ensuring congruence between expressed patient wishes and actual treatment received. Finally, it is important to consider the practical and psychological needs of DHRs given the grave responsibility they carry.

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## CONCLUSION

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It is said that the loftier the building, the deeper the foundations must be laid. Family Carers Ireland acknowledge the foundations that are being built and the very considerable efforts being made by many to ensure we achieve the lofty ambitions of the 2015 Act. None of us know what the future holds for us or our loved ones, but we do know that it will be better place in which to grow old and live well because of our efforts now.



## 3.9 Assisted Decision-Making: A Perspective from Age Action

*Corona Joyce and John Lombard*

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### INTRODUCTION

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Age Action's mission is to achieve fundamental change in the lives of all older people by empowering them to live full lives as actively engaged citizens and to secure their rights to comprehensive high-quality services according to their changing needs. Age Action recognises that human rights have a fundamental role in shaping the care and treatment provided to people, including how we access and receive care, and how we are supported to make decisions central to our lives.

The Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) will play a crucial role – when fully commenced – to support all of us in how decisions are made, facilitated and supported. This legislation will be especially important in supporting the rights of us all in older age and in ensuring that our will and preferences directly shape the care and treatment provided.

Like many other countries, Ireland is experiencing a demographic shift where those aged over 65 represent an increasing share of the total population. At present, just over 13% of the total population is over 65 years of age (Lombard, 2020). Each year in Ireland, the over 65 age group increases by 20,000 people. Looking forward, the number of people aged over 65 is projected to increase very significantly to close to 1.6 million by 2051, from one-fifth to almost one half of the working population over the next three decades (CSO, 2018). The Department of Health's Capacity Review sets out that the 65-74 age cohort will increase by 42.9%, the 75-84 age cohort will see an increase of 75.9% and the 85+ cohort will see an increase of 95.5% by 2031 from 2016 figures (CSO, 2018). The pressures of COVID-19 in recent months have already shown the potential risks of an overburdened healthcare system that does not integrate a rights-based approach to the design, delivery and review of its policies and practices.

The forecasted demographic shift makes the full commencement of the 2015 Act ever more important as it will shape the life of older people in Ireland in a multitude of ways. This chapter will concentrate on the manner in which the 2015 Act will shape healthcare decision-making for older people.

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## HUMAN RIGHTS, DIGNITY AND AN AGEING POPULATION

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Central to healthcare decision-making is the concept of autonomy. Autonomy relates to a person's right to control and shape their own life: it is therefore closely tied to the concepts of both informed consent and treatment refusal. The promotion of a person's autonomy and supporting their involvement in healthcare decision-making are essential features of the 2015 Act, with elements including recognition of the functional approach to capacity, the use of guiding principles in place of best interests, the establishment of the Decision Support Service, the formalisation of decision-making supports, the abolition of the Ward of Court system, changes to enduring power of attorney and the provision of a statutory framework for advance healthcare directives.

During 2019, Age Action partnered with Dr John Lombard of the University of Limerick on an Irish Research Council-funded project to examine the experiences of older people regarding autonomy and consent in healthcare, familiarity with decision-making practices and awareness of forthcoming decision-making supports such as the 2015 Act. In total, 283 respondents completed the research questionnaire, which captured the thoughts and experience of the older person, and its findings are reflected throughout this text here. It highlighted concerns about the purpose and role of advance healthcare directives and uncertainty about the purpose of an enduring power of attorney. Respondents also gave voice to their experience in receiving information and their involvement in healthcare decisions. These findings were echoed in research subsequently conducted by Age Action with Dr Hope Davidson under the auspices of an IHREC grant, which found low awareness amongst older people of how decisions are made if someone is unable to do so themselves, a misunderstanding of the next-of-kin authority to make decisions and also general confusion over how the 2015 Act would affect them (Davidson, 2020).

Commencement of the 2015 Act will provide legislative clarity on several of these points and will provide an important signal that the autonomy of all persons should be supported and recognised at all stages of life in Ireland.

In the 2019 collaborative study, 75% of respondents felt they were involved in making decisions about their medical treatment (Lombard, 2020). Some 23% felt they were somewhat involved and 2% did not feel involved at all in the decision-making about their treatment. The most common barriers to involvement included not being provided with the opportunity, and communication difficulties. The issue of inclusion and being involved in making decisions about medical treatment were seen as being especially important by the respondents, as illustrated by the open-ended responses:

'The subject should always be listened to and their wishes taken seriously, not discounted, ignored or overridden.'

‘Patients should be fully involved in their healthcare decision-making for best outcomes.’

‘Patients should have choices of care if they wish.’

Older people enjoy the same rights as anyone else in society and they are fully entitled to be involved in decisions about their healthcare. The 2015 Act serves as an important legislative statement that vulnerable persons should be supported and not excluded from what are often deeply personal decisions.

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### THE ASSISTED DECISION-MAKING (CAPACITY) ACT 2015

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The research conducted in 2019 showed low awareness of the 2015 Act and its provisions: knowledge dissemination events are needed in the lead up to commencement with a focus on healthcare and legal professionals, and individuals who will ultimately be affected by the legislation. This rounded approach to knowledge dissemination is essential to ensure that older people are not limited in realising their human rights at any stage.

In responding to questions on the topic last year, just under three-quarters of respondents were not aware of the 2015 Act, with 8% selecting ‘Not Sure’ (Lombard, 2020). Just under 19% of respondents were aware of the 2015 Act. It must be noted that awareness of the Act varied based on the highest level of schooling completed. As the respondent group was well-educated, this may have raised the levels of awareness beyond what might be expected in a broader sample. A desire for greater information about the 2015 Act was seen in the open-ended responses:

‘I’d like more information in the public domain...I would like to attend a public talk on the subject.’

‘Information and explanation need to be highlighted and made more easily accessible to older people. More awareness in general of Assisted Decision-Making (Capacity) Act 2015.’

If someone is not aware of the 2015 Act, then it is less likely that they will be aware of the supports contained therein and be able to realise their rights to access them.

A further point highlighted in the research responses was that the information should be provided in a way which is clear and understandable: in effect, the information should not be communicated using clinical terms but should be in terms which can be readily understood:

‘Should be all in plain English, not a series of medical jargon.’

‘Make sure information provided is clear, understandable to even the least educated. Make sure the client is totally au fait with what's available and where it can be sourced.’

‘Information needs to be in plain English i.e. K.I.S.S (Keep it Short and Simple). As sometimes hospitals and GPs speak in medical terms known only to medics.’

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### ADVANCE HEALTHCARE DIRECTIVES

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Advance healthcare directives are provided for by Part 8 of the 2015 Act. This provides a way for giving voice to the will and preferences of an individual at a point where they no longer have sufficient capacity to indicate their preferences for healthcare. It is an important element of the healthcare decision-making toolkit.

In the 2019 study, 61% of respondents did not know what an advance healthcare directive is, and 17% were not sure. Just over half (55%) did not know whether they intended to complete an advance healthcare directive.

The lack of information is severely limiting access to this form of advance care planning for those who completed the research survey. Only 8% of respondents had completed an advance healthcare directive, however further responses showed that it would appear that some respondents confused an advance healthcare directive with a power of attorney. This raises significant questions about the way in which information is being communicated to the older person.

The responses illustrate the uncertainty and challenges that older people can often experience in trying to exercise precedent autonomy. There is also concern over whether an advance healthcare directive would be adhered to in the current system:

‘Later down it is very difficult to know if your opinions will be carried through if you are not able to stand up for yourself. Advance care directive depends on who is looking after your affairs and has an interest in seeing that you are cared for properly.’

This concern may, in part, be addressed by the appointment of a designated healthcare representative which is provided for under Section 87 of the 2015 Act. Closely linked to this comment is a concern about how to alert healthcare professionals to the presence of an advance healthcare directive:

‘I worry where is the best place to keep my advance healthcare directive. In cases of sudden illness/ambulance/hospitalisation/GP it is not consulted. Should older people be encouraged to keep a list of current medications or a copy of their AHD by their front door? ... AHDs are not only for older people – serious illness can strike at any age!’

As discussed above, greater – and clearer - information may encourage more discussion of advance care planning and, significantly, it could reduce some of the confusion surrounding the enduring power of attorney. This confusion was a recurring theme as demonstrated by two of the comments set out below:

‘I would certainly consider completing such a directive but would need a lot more information in order to reach an informed decision.’

‘It would be helpful if a practitioner discussed the above. Also, I am confused about enduring power of attorney.’

The 2015 Act may ultimately bring greater clarity to this area, but it currently occupies a grey zone.

The manner in which support, information and services are provided is an important consideration. Many respondents referred to the availability of information in hard copy while no respondent asked for additional material to be made available online:

‘As we’re nearly all living longer help should be offered in relation to health and aging. Everything now seems to be ‘online’ forgetting those who can’t cope online – even after ‘getting started’ courses.’

Digital exclusion is a reality for at least 50% of people over the age of 65. A third of people aged 65-74 have never been on the internet, and almost half lack basic digital skills (Eurostat). It is vital that people offline are not disadvantaged when it comes to receiving services and supports under the 2015 Act.

Concerns also exist regarding the level – and varied – costs of services under the 2015 Act. Age Action is frequently contacted by people unsure as to the cost of an enduring power of attorney in particular, and at times they have been quoted fees that prevent them from completing the process. Affordability is key to ensuring equality of outcomes for all who wish to pursue this planning, with high costs effectively acting as a barrier for the three-quarters of over-65s who rely on a State supports for their main income (OECD, 2019).

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## THE TRANSITION FROM THE WARD OF COURT SYSTEM

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The 2020 Programme for Government made a commitment to commence the 2015 Act to abolish wardships. Until commencement, people will continue to be exposed to the Ward of Court system.

Greater clarity on the process by which wardship will be reviewed is needed as well as on the supports to be implemented and the protections which will be available for existing Wards of Court as the transition to the new system takes place. We are also concerned about the lack of detail in relation to the implementation and resourcing of capacity assessments. Until steps towards full commencement begin, this uncertainty will remain.

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## CONCLUSION

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When fully enacted, the 2015 Act will play a crucial role to support all of us in how our healthcare decisions are made, facilitated and supported. Without full commencement of the 2015 Act, various levels of decision-making supports as committed to under the 2015 Act are not operational and they are leaving people in limbo without the ability to fully realise and protect their rights.

All of us should be supported to know and claim our rights in relation to how we decide what health and social care services we want to access, and to make decisions over our own lives.

It is crucial that the legislative and policy changes under the 2015 Act are urgently expedited and resourced. This is needed to ensure that the rights, freedoms and dignity of all of us are promoted and protected to the greatest extent possible across the life course.

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### 3.10 Will and Preferences in the Assisted Decision-Making (Capacity) Act – Key Achievements and Missed Opportunities.

*Eilíonóir Flynn*

As a researcher at the Centre for Disability Law and Policy, I had the privilege of working with a civil society coalition (including organisations representing older people, people with disabilities and people with experience of the mental health services), which sought to influence the development of the Assisted Decision-Making Capacity Act 2015 (the 2015 Act). In this piece, I will reflect on the main achievement of the coalition in the first four years of our work (2011-2015) – the shift from ‘best interests’ to ‘will and preferences’ as a guiding principle of the legislation. I will also share what I believe to be the main missed opportunity in the 2015 Act, regarding the amendments developed by the coalition which would have led to the 2015 Act being fully compliant with the UN Convention on the Rights of Persons with Disabilities (CRPD).

The Programme for Government 2011 included a commitment to introduce a ‘Capacity Bill that is in line with the UN Convention on the Rights of Persons with Disabilities’ (Department of An Taoiseach, 2011). Subsequently, the Oireachtas Joint Committee on Justice, Defence and Equality called for submissions in August 2011 from interested parties on the content of what was being referred to at the time as the Mental Capacity Bill (Oireachtas Joint Committee, 2011). From this call for submissions, a coalition was formed of interested organizations and individuals in the fields of intellectual disability, mental health and older people, co-chaired by the Centre for Disability Law and Policy and Amnesty Ireland. Our purpose was to discuss whether a joint approach to legal capacity reform could be developed across these interest groups.

The coalition decided to develop a ‘Principles’ document that we hoped would influence the eventual capacity legislation. During the development of the principles, some of the groups involved in the coalition were invited to present views to the Oireachtas joint committee on Justice, Defence and Equality as part of the pre-legislative scrutiny process, to determine what the capacity legislation should look like. We had hoped to have agreed the principles by then, but discussions were still ongoing on key matters within the group, so it was not possible to get sign-off from all the key players in time for the Committee hearings. Instead, efforts to align our positions were made as much as possible among those of us presenting to the Committee but some key tensions emerged regarding whether guardianship or a similar form of substitute decision-making should be included in the legislation (Statements to Oireachtas Joint Committee, 2012).



We continued to work on agreeing a consensus position thereafter, and two months later, the final agreed version of the Essential Principles for Legal Capacity Reform were published this coalition of civil society groups, setting out 10 key principles to be adhered to in legislation designed to comply with Article 12 CRPD (Amnesty Ireland and Centre for Disability Law and Policy, 2012). The Principles document emphasised the need for a shift away from ‘best interests’ to respect for ‘will and preferences’ as a key priority of the legislation:

‘[I]nstead of guardianship and other people making decisions in the ‘best interest’ of the person, the top priority of the new law must be to make sure people are supported to make their own decisions wherever possible. The new law should not take away people’s right to make their own decisions’ (Principle 3(a)).

The Principles document also acknowledged that, where will and preferences remained unknown and a nominated person needed to be appointed to take a decision on another person’s behalf, that this decision would still need to be based on the individual’s will and preferences:

‘[W]here the ‘will and preferences’ of the person are not known, the facilitated decision-maker has to determine what the person would want, based on all the information they have about the person (spending time with the person and trying all forms of communication, speaking to those who know the person well, thinking about the person’s life, their likes and dislikes, etc.)’(Principle 8).

One month later, in May 2012, the Oireachtas Justice Committee published a report of its oral hearings, endorsing the support model of legal capacity, and requiring a shift away from the ‘best interests’ model of substitute decision-making towards an approach which respects the will and preferences of the individual (Oireachtas Joint Committee, 2012). The Committee noted that:

‘Concerns were raised by the use of the best interest model. It was stated to the Committee that this was a model of the past. It demonstrates the paternalistic view of trying to determine what the best interests of a person are, even of a person who can decide for himself or herself what his or her best interests are. It was put to the Committee that best interests are usually what the professionals see as the person’s best interests. Its inclusion in the legislation was questioned and it was suggested that it was contrary to the UN Convention on the Rights of Persons with Disabilities, which never mentions best interests in relation to adults’ (Oireachtas Joint Committee, 2012: p. 8).

Furthermore, on the issue of will and preferences, the report notes ‘The Committee was told that it was critical that the will and preferences of the person remain central in all forms of decision-making, even when a person can no longer express himself or herself’ (Oireachtas Joint Committee, 2012: p. 10).

The Bill as published represented a significant departure from its predecessor, the General Scheme of the Mental Capacity Bill 2008. One of the most significant changes, and one which had been strongly advocated for by the coalition was the removal of ‘best interests’ – the key guiding principle of the 2008 Scheme, and its replacement with ‘will and preferences’ in the guiding principles of the 2013 Bill (Assisted Decision-Making (Capacity) Bill 2013 (Ireland), Section 8(7)(b)). Section 8 of the Bill, and indeed the final Act, requires intervenors under the legislation to ‘give effect, in so far as is practicable, to the past and present will and preferences of the relevant person, in so far as that will and those preferences are reasonably ascertainable.’ In both the Bill published in 2013 and the final 2015 Act, there is no reference in the legislation to the ‘best interests’ of the individual as a guiding principle for decision-making, although in the final Act a new principle requiring intervenors to act ‘act at all times in good faith and for the benefit of the relevant person’ was introduced (Assisted Decision-Making (Capacity) Bill 2013 (Ireland), Section 8(7)(e)). This statement did not appear in the 2013 Bill but was added during the parliamentary debates on the Bill.

Following the publication of the 2013 Bill, the coalition focused on the need for amendments to the legislation to bring it into compliance with the CRPD and better respect the rights of those who were likely to come within the scope of the law. The Bill introduced three new roles – the decision-making assistant, co decision-maker, and decision-making representative. However, eligibility for these options was all dependent on whether an individual passed the functional test of mental capacity – if they did, they could have a decision-making assistant, or co decision-maker; if they did not, they could be appointed a decision-making representative. A few months after the Bill came out in July 2013, the UN Committee on the Rights of Persons with Disabilities published Draft General Comment 1, in October 2013, and the General Comment was finalised in April 2014. In the final General Comment, the Committee clarified that where functional tests to assess mental capacity are applied in a discriminatory manner to persons with disabilities and result in denials or restrictions of legal capacity they violate the CRPD (Committee on the Rights of Persons with Disabilities, 2014). The Committee clarified that even where legislation did not explicitly include persons with disabilities in its description of whose mental capacity could be assessed, the functional test of mental capacity often indirectly discriminates against persons with disabilities because they are often more likely to be asked to undergo an assessment in the first place, and more likely to be found to fail the assessment than non-disabled people or people without a label or diagnosis of disability or impairment.

The 2013 Bill used the functional test of mental capacity as a ground for depriving an individual of legal capacity through the appointment of a decision-making representative,

and despite the best efforts of the coalition to change this, the 2015 Act retains this same approach. This represents, in my view, one of the most significant missed opportunities of the 2015 Act. We had come so far – we had convinced legislators of the need for supported decision-making to be the main focus of the Act. The drafters of the legislation had accepted that ‘best interests’ was no longer a valid principle to guide decision-making in respect of adults – a huge victory. However, with the retention of the functional test of mental capacity, we risked undoing all this progress, and in fact, leading to a situation where more people were formally deprived of their legal capacity under the new law than were currently subject to the archaic Ward of Court system.

Together with Piers Gooding at the Centre for Disability Law and Policy, I wrote a memo for the Department of Justice in June 2014, outlining a way to bring the Bill into compliance with the then adopted General Comment 1. We argued that the Bill could change the eligibility for different decision-making arrangements to ensure it did not rely on a functional test of mental capacity. Instead, we suggested adults could choose their preferred support arrangement (assisted or co decision-making) as long the individual’s will and preferences were known. The last resort appointment of a decision-making representative could be reserved for situations in which the person’s will and preferences remained unknown, after significant efforts to support the person and to discover her will and preferences have been made. In such situations, we argued that decisions made by these representatives would be guided by the principle of ‘best interpretation of will and preferences’ as set out in General Comment 1. The memo included our suggested wording of amendments to the Bill which would achieve our recommended changes, and was supported with reference to existing proposals for legal capacity reform, especially those developed by the Canadian Association for Community Living (2014). However, these proposals did not ultimately bear fruit in the amendments drafted by officials and put forward by the Minister during the parliamentary debates. While the coalition continued to work with both government and opposition parliamentarians to introduce these amendments (Seanad Eireann, 2015) they were not accepted by the Minister during the parliamentary debates and the 2015 Act continues to retain the functional assessment of mental capacity as the determining factor in whether a person can receive support, or whether she will have her legal capacity restricted or denied through the appointment of a decision-making representative. The only saving grace is that at least the representative is required to make decisions based not on ‘best interests’ but giving ‘effect, so far as is practicable to the individual’s will and preferences’ (2015 Act, 8(7)(b)).

Ireland is soon due to submit its first State Report to the UN Committee on the Rights of Persons with Disabilities, and the 2015 Act also requires a review before the fifth anniversary of its enactment (2015 Act, s. 146.) These present important opportunities to reflect on the Act, and on all we have learned about the right to legal capacity at the international level in the past five years. Now that more countries have enacted laws that are compliant with General Comment 1 (Decreto Legislativo No. 1384 [Peru, 2018]; Ley 1996 de 2019

[Colombia]), Ireland can no longer argue that the shift away from functional tests of mental capacity towards respect for and, where necessary, a ‘best interpretation’ of will and preferences is impossible or without legal precedent. Together with others directly impacted by this law, I will continue to advocate for its reform, to bring Ireland fully into compliance with its obligations to respect the human rights of persons with disabilities.

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## 3.11 The Assisted Decision-Making (Capacity) Act 2015: A Mental Health Perspective

*Fiona Coyle*

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### INTRODUCTION

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The Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) can be instrumental in giving voice to people with mental health difficulties in decisions that directly affect them, including in their own mental health care and treatment. The importance of individuals being listened to and being active partners in their own mental health care is well recognised and is a core component of the recovery ethos. The ethos is based on principles of partnership, choice and listening to the person and embraces a deep-seated respect for the individuals' expertise and knowledge based on their own personal experience. The recovery approach has underpinned Ireland's national mental health policy since 2006 (A Vision for Change, 2006) and has achieved a renewed focus in Sharing the Vision (DoH, 2020).

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### CENTRALITY OF THE VOICE OF THE PERSON

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Despite a continued commitment to implementation of a recovery-orientated mental health system, such practices are not yet routinely embedded, with many individuals experiencing mental health service delivery that is not consistent with principles of partnership and choice. Recent research on the experiences of people who have used the mental health services in Ireland highlighted that many participants reported that they are not satisfied with the services they access. Many indicated that they do not feel listened to (just one-third (32.5%) of participants felt that they were 'always' well supported and listened to by their current psychiatrist), nor do they feel treated with dignity and respect (Mental Health Reform, 2019). Individuals also reported a high focus on medication in their treatment (60% of participants reported a high focus on medication as part of their treatment and care), with many indicating that they were not involved as much as they would like in decisions about the medication they take (Mental Health Reform, 2019).

Recent reports, published by Ireland's mental health regulatory body, the Mental Health Commission, have drawn attention to issues of considerable concern in the operation of acute and community mental health settings. In its 2020 report on individual care planning (MHC, 2020), the Commission

criticised the quality of individual care and recovery plans, in particular, the continued lack of involvement by people who use the services in their own plans. As reported by the Commission in 2019, restrictive practices, including physical restraint and/or seclusion, were used in the majority of in-patient mental health services in 2017 and 2018 (MHC, 2019). Of particular concern is the significant increase in the use of such practices over the last decade, despite guidance on the reduction of coercive practices in mental health settings. In total, there were 7,420 episodes of restrictive practices reported to the Mental Health Commission in 2017 and 7,464 in 2018. When the Commission started reporting on restrictive practices in 2008, there were 4,765 combined episodes of physical restraint and seclusion. In December 2014, the Commission published a Seclusion and Restraint Reduction Strategy, which set out a framework for the reduction of restrictive practices in approved centres (MHC, 2019).

In other research, it has come to light that some people in community residences (or supported accommodation) could live independently, given the right supports. In a review of the Galway/Roscommon community mental health services published by the HSE in 2014, the review group found that some people in community residences were being over-provided with care and that some could have lived independently. Similar findings were identified in earlier reports including the HSE's Value for Money Review of the efficiency and effectiveness of long-stay residential care for adults within the mental health services in Ireland and the Mental Health Commission's Happy Living Here Study.

There is no doubt that the continued lack of appropriate services and supports provided to individuals to live independently is in contravention of their rights to dignity, autonomy and equality. It is imperative that people with mental health difficulties are empowered to make decisions about issues that directly affect them, including on housing, and that extend to matters such as where they want to live and who they want to live with.

The guiding principles of the 2015 Act, such as the presumption of capacity, the provision of decision-making supports and respecting the will and preferences of the person can enable and empower people to be decision-makers in their own lives. This includes their own mental health care and treatment. At a one-to-one level, working with individuals as equal partners in their own care and supporting them to make decisions is essential to redressing the traditional power imbalance between people who use the services and mental health professionals. As described by Patricia Deegan, a leading mental health advocate, the traditional approach whereby individuals were passive recipients of professional expertise must give way to a process of reciprocal exchange between professionals and those who use the services (Deegan, 1988).

These principles of partnership and participation are not only reflected at national level but are firmly enshrined in international human rights treaties. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) promotes principles

of autonomy and self-determination and affirms the positive value of individuals with a mental health difficulty as full citizens. The human rights-based approach reflected in the UNCRPD views people with disabilities as the subjects of rights or rights holders rather than as the passive recipients of benefits, while at the same time placing an obligation on the State to respect, protect and fulfil the human rights of people with disabilities.

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### ADVANCE HEALTHCARE DIRECTIVES AND THE PART 4 EXEMPTION

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There are some significant shortcomings of the 2015 Act that will need to be addressed if the legislation is to adequately protect people with mental health difficulties. Advance healthcare directives (AHDs) have been included in the 2015 Act and will provide a way for people to articulate their will and preferences for a later date when their views may become unclear or unknown. However, under the 2015 Act, people who are detained in hospital for mental health treatment are specifically excluded from legally binding directives. They have no legal right to have their advance wishes respected, even though they had capacity to make decisions about their mental health care and treatment at the time of making their directive. There is no other group of individuals that are specifically excluded from this legal right, a shortfall which is clearly contrary to international human rights standards, including the UNCRPD.

This provision is particularly worrying as it is precisely when people are being treated under the Mental Health Act 2001 (the 2001 Act) that many will wish an advance directive to take effect. Too often, mental health difficulties are seen as ‘separate and different’, and the same rights and protections are not extended to people who use mental health services as to others. The use of differential standards for treatment decisions during involuntary detention perpetuates stigma, limits the use of advance directives in mental health settings and ultimately jeopardises the recovery process.

Advance healthcare directives have the potential to increase trust in the mental health services, empower those who use the services, increase treatment engagement rather than refusals, reduce crises and, even in crisis, reduce the need for coercion and ultimately promote recovery. To make a blanket denial of a person’s preferences and concerns when they are made involuntary – which is precisely the moment such directives become most important – is simply unjust. Furthermore, even if advance healthcare directives are legally binding during voluntary admission, the threat of coercion and the possibility of being made involuntary at any time limits the impact of their existing status.

There are other anomalies within the 2015 Act as it relates to mental health. This is clearly reflected in the ‘Part 4 exemption’ which states that nothing in the 2015 Act ‘authorises a person to give a patient treatment for a mental disorder’ or ‘consent to a patient being given treatment for a mental disorder if, at the time when it is proposed to treat the patient,

his or her treatment is regulated by Part 4 of the 2001 Act'. While this provision does not mean that the 2015 Act does not apply to people who are detained in hospital for mental health treatment, it does raise questions about the role of decision-making supporters in this context, which are not adequately addressed in the legislation. It is essential for the purposes of equality that people with mental health difficulties and, more specifically, those who are detained under the 2001 Act are treated the same as everyone else.

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### COHERENCY BETWEEN THE 2001 AND 2015 ACTS

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Achieving the aspirations of the 2015 Act, certainly in the context of mental health, is largely dependent on other policy and legislative frameworks. The full commencement of the Act has enormous potential to promote the rights of people with mental health difficulties. However, it is imperative that it is complimented through full reform and implementation of the 2001 Act.

There continues to be serious gaps in the 2001 Act, including that the legislation is underpinned by the paternalistic approach of 'best interests', completely contrary to the principles set out in the 2015 Act, which are based on the person's will and preferences and supporting people to make their own decisions. Other shortfalls of the 2001 Act include the absence of a legal right to advocacy supports, the lack of legal rights to information for people in hospital on a voluntary basis and the ongoing practice of 'de-facto' detention. This practice occurs due to a fundamental flaw in the 2001 Act, whereby there is no definition of 'voluntary patient'. Presently, people who do not have capacity to consent to admission and who do not object to admission are being classed as voluntary patients, even though they are not able to consent to admission. Moreover, they do not receive external review of their detention, nor the oversight protections provided to 'involuntary patients'. There is considerable interaction between the 2001 and 2015 Acts, and it is imperative that existing conflicts and inconsistencies are resolved to ensure coherency between these two fundamental pieces of legislation.

Furthermore, there is a requirement for a coherent legal and policy framework to ensure the effective implementation of the principles of autonomy, empowerment and self-determination. Ireland's new mental health policy, *Sharing the Vision: A Mental Health Policy for Everyone*, published in June 2020, lays the building blocks for a mental health system that empowers people and facilitates them to direct their own mental health care. There is a renewed focus in *Sharing the Vision* on principles of partnership to ensure people who use the mental health services, as well as families and supporters are central in the design, development and delivery of services, and to be key decision makers in their own recovery planning. It highlights the importance of mental health services adapting to meet the individuals' wishes and preferences and recognises that self-determination is a vital part of successful treatment and recovery (Department of Health, 2020).



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## IMPLEMENTATION

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No doubt, the commencement of the 2015 Act could be enhanced through the development and promotion of advocacy supports to ensure that the principles of the Act are brought to life and effectively implemented in practice. The limited capacity of existing advocacy services and the significant gap in such supports for people with mental health difficulties – in particular, those living in the community – is an ongoing obstacle to empowering people to be their own decision-makers. A recent small-scale study carried out by Mental Health Reform identified that there is a very low level of awareness of existing advocacy services for people with mental health difficulties and very few individuals have accessed such services. Moreover, this group of participants were more likely to disagree than to agree that they are able to self-advocate. When asked ‘how confident you would be in making a complaint’ about a range of different services, including housing, employment, education, mental health, a very small minority of participants stated that they would be fully confident in bringing such a complaint.

What is required, in the context of mental health, is the establishment of a national, independent advocacy service, that is placed on a statutory footing and is accessible to all individuals with mental health difficulties, including those in hospitals, day centres, training centres, clinics and throughout the community. There is a need to expand the availability of existing advocacy services to ensure that any person subject to the 2015 Act can get access to an independent advocate.

There are of course other measures that must be taken, including the provision of training and guidance for staff and management on the 2015 Act, to ensure they are adequately supported to comply with the Act and the supporting codes of practice as it relates to mental health service delivery. This includes guidance on the practice of positive risk-taking, based on the principles of the Act. It is also imperative to ensure that people with mental health difficulties are sufficiently informed of their rights under the 2015 Act and ultimately, the type of service they should expect, based on the principles of the Act. Information should be provided in a clear and accessible manner and in a variety of formats and range of languages to ensure it reaches all groups of individuals. For example, many people using mental health services will not have access to the internet, email or smart phones. Additional guides or tools may include videos and audio recordings to ensure accessibility for people with visual or hearing impairments. A short pamphlet/ leaflet highlighting key points relating to the 2015 Act should be designed and provided to services across the country. This should be complimented with the provision of posters and other promotional materials. Materials should also be developed in different languages. The ongoing issue of stigma and the misconceptions surrounding people with mental health difficulties, including those in acute settings, must be tackled. The involvement of family members, carers and supporters should be encouraged and facilitated by services, except where the individual does not consent.

While the enactment of appropriate legislation, such as the 2015 Act, is essential, a cultural shift is also required. Services and staff must work from the mindset of empowering individuals in order to instil principles of autonomy, self-determination and respect for the will and preference of people using their services. While such principles are already practiced among many services and professionals, they have yet to be deeply embedded at a systemic level, both within and across systems.

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#### ACKNOWLEDGEMENT

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It is important to acknowledge that this chapter would not have been possible without the expert input and knowledge of Mental Health Reform staff members. Thank you to all who played a role in this.

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## 3.12 Living with Autism: the Contribution of the Assisted Decision-Making (Capacity) Act 2015

*Adam Harris*

In the course of my work with AsIAM, Ireland's National Autism Charity, I speak to people every day about their experiences of being autistic in Ireland. One of the strong messages that we hear all the time is that while there has been an increased awareness of autism over the last couple of decades in Ireland, there isn't a true understanding of it, and the voice that is often missing from the discussion of autism is the voice of autistic people. In fact, I felt while growing up, that some of the biggest barriers that I faced came from how the world operated. I think that a huge stigma existed where autistic people were afraid to share their experiences. A lot of the barriers autistic people face every day are due to not educating other people. And while autistic people adapt to a world every day that isn't built for autistic people, I believe that society needs to meet people halfway to make true inclusion possible.

Ireland has a history of writing brilliant pieces of legislation and policy, but they aren't implemented or funded adequately. And I think many of us were worried that the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) was running the danger of joining that club, especially since it has been a number of years since its passage through the Oireachtas without being fully commenced, so it is great to hear that the Government is committed to commencing it in 2022. But as with any legislation, it is vital that it is commenced in full and that it is adequately resourced.

In the context of Ireland's obligations under the United Nations Convention on the Rights of Persons with Disabilities, it is important that we move away from the idea that because someone communicates or interacts differently to the majority of people, this is not good communication. And just because the person may make a decision differently to other people, or may approach the decision differently, that their decision is invalid, or that they shouldn't be allowed to make decisions, or that they should be protected from the world. Autistic people should be allowed, and supported, to have the same experiences as everyone else and to make the same mistakes as everyone else. I think that the 2015 Act is a really important piece of legislation that can make a big difference, and can change how we talk about disability and how we see people who think differently within our society.

I welcome the fact that the 2015 Act is not diagnosis-led – a big difference from similar legislation in the UK. There can be a very black and white approach at times, and the 2015 Act moves away from that. I think we fail to recognize that autistic people very often might be able to make most decisions for themselves, but might need some support in making those decisions. And sometimes that support might only be required in a very specific area. There has been a terrible hierarchical approach to autism whereby if you had a diagnosis of, for example, what at the time would have been called Asperger's Syndrome, you perhaps weren't supported enough; people might underestimate your support needs and presumed that you had some savant ability almost by default. And for other people who might have communicated without speaking, or maybe they had a co-occurring intellectual disability or mental health condition, the fact that they were autistic was nearly spoken about as a sad thing, and straightaway, there was a glass ceiling placed above their heads in terms of life choices. Just because someone communicates non-verbally does not mean that they are not communicating, or demonstrating what their will and preference is. I hope that the flexibility of the 2015 Act will mean that people get the right support at the right time with their decision-making, that the emphasis is placed on people being able to live as independently as possible, and that everyone should have a voice. When we talk about autism, we're talking about scattered skill sets. A person might be really, really strong and independent in one area and not in another – not just in their day-to-day life but also in their decision-making. For example, a person might be able to make all decisions around their employment because they might be in a really comfortable space within the area that they work in. But, in managing their financial affairs, for example, that might be really difficult because of challenges with executive functioning. So, the specificity of the decision-making is really important and will make a difference. This will be a huge change from the current legislation in this area, the 1871 Lunacy Act, which is a dreadfully blunt instrument and it is nothing short of a national disgrace that it has been left in situ for so long.

What really disturbs me is that people who don't know a great deal about autism, or the person they're dealing with, are sometimes making very significant decisions for that person. When the 2015 Act is commenced, we will need to make sure that the people who are appointed to support the person with decision-making, or indeed in some circumstances to make decisions on their behalf, know the person well and prioritise their interest, will and preferences. If this is not possible, they should have had very significant training in the area making sure that their understanding comes not from a medical model, but from a rights-based model of disability.

I hope that families also welcome the 2015 Act and see it as a resource and a support to their whole family life. I know some families may be legitimately concerned because they feel that they might lose their voice or their right to be an advocate for their loved one, but I hope that the 2015 Act actually gives clarity to their role. Nobody currently can make a decision for another adult unless they are a Committee for a Ward of Court, but we know that family members are making decisions on behalf of their loved ones every day of the

week. When the 2015 Act is commenced, family members can have a legally recognised role, supporting their loved ones to make decisions.

Families of autistic people can face a lot of adversity interacting with state agencies and service providers, fighting for service provision that may not be available due to resource shortages. Because of this, families can often feel very protective of the people that they are supporting. As a result, the families don't feel confident to cut the apron strings a bit, to let the young person begin to take risks. So there is a big education component to the 2015 Act, for both families and autistic people. Autistic people need to be encouraged to make their own decisions, including young people so that they have the skills to advocate for themselves when they turn 18. And families need to trust services to allow autistic people to take risks.

Can you imagine what life would be like without risks? Without unwise decisions? Without doing crazy, impulsive things? These decisions can be what makes life interesting. But when we talk about autistic people and other disabled people, we forget that people actually want to live their lives and do things, and not just attend services, designed by someone else, until they are elderly. And this is how it has played out for so many people, and that cannot be allowed to continue. Hopefully the 2015 Act can change this and allow people to take risks, and to live the life they want to live.

There needs to be a partnership approach for the 2015 Act to work. Sometimes autistic people are expected to self-advocate but are not given the support to do that or to make the informed decisions which they want to make. Some organisations can still be reluctant to deal with advocates, including when an adult nominates their parents or other ally to support them. The 2015 Act means that organisations should be open to supporting assisted decision-making, strengthening relationships and improving outcomes in the process.

I welcome the fact that the legislation is in place. It is important that we make sure that everyone understands what the 2015 Act is trying to achieve and that disabled people are supported in understanding and accessing the provisions of the 2015 Act so that true autonomy and effective self-advocacy can be realised.



## 4 At the Core of the Act—Will and Preference, Support, Unwise Decisions, Risk and Liability—Reflections on Practice

### 4.1 Supporting Adults with an Intellectual Disability to Make Decisions: Reflections from an Organisational Perspective

*Elaine Teague*

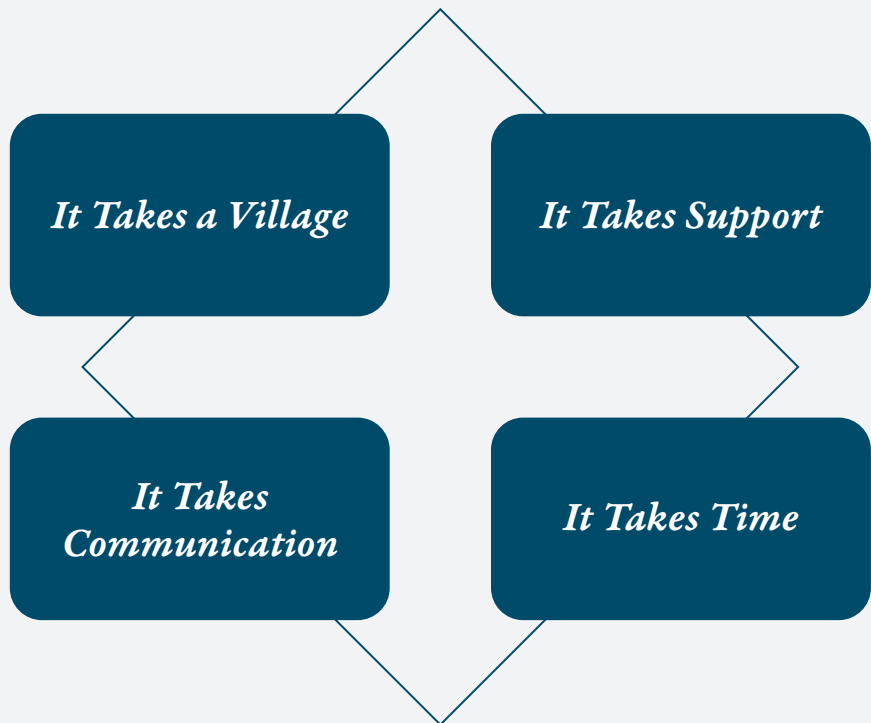
The Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) represents a very significant change in the way we support adults, including those with an intellectual disability, to make decisions. The 2015 Act will have significant impact on the delivery of health and social care services to this cohort of people as we move away from decision-making based on ‘best interests’ towards decision-making based on ‘will and preferences’. When the 2015 Act is commenced, it will reform the legal framework for supporting vulnerable adults and will replace the Lunacy Regulation (Ireland) Act 1871. However, it will go much further than that. It will provide statutory oversight of decision-making and will require careful consideration about what decisions a person can make, what decisions they will have help to make and what decisions someone else will make on their behalf.

The most recent census identified that there are approximately 18,000 adults with an intellectual disability in Ireland. The focus of this section of the paper is on how a large organisation supporting 1,000 adults is preparing for the implementation of the 2015 Act and it will finish with some reflections on the process so far. This paper is not intended as a road map but as a practice example of what has been done – there is significantly more to do!

Over the past 12-18 months’ questions and queries relating to supporting individual’s will and preference arose (two of the case examples are included in the next chapters). It became clear that a change in the organisational approach to supporting decision-making was required. When we embarked on this work, the enormity of the change that is required and the uniqueness of each person’s circumstances was almost paralysing; the question quickly

became ‘where do we even start?’ We started with ‘what does the literature tell us?’ The answer: it tells us that if you are implementing a large-scale change, then there are frameworks to help. Implementation focuses on ensuring a change such as the 2015 Act becomes embedded into everybody’s practice, it becomes ‘the way we do things around here’. For it to become embedded, there are many things that must change (systems/structures/practices) and an implementation framework provides guidance on what to change, when to change it and how to embed the change into everybody’s practice.

The framework selected by St. Michael’s House for implementing the 2015 Act is the Active Implementation Framework (AIF) developed by (Fixsen, et al., 2005). This framework provides a structure and four key ‘ingredients’ for effective implementation. It uses simple language and has many practice examples that we could call on. Each of the ingredients provides another layer of support for implementation.





### **It takes a village**

Like the old phrase ‘it takes a village to raise a child’, it takes a village to implement the 2015 Act. An integrated team approach to implementing the 2015 Act was required rather than each department/service area developing their own approach. The village (called the ADM steering group) started with those that were interested and willing to progress assisted decision-making (ADM) in the organisation. The steering group included Health and Social Care Professionals, Medics, staff training specialists and members of the executive management team. It expanded to include colleagues from the HSE and other staff members who could support the implementation of ADM. Our organisation also contributes to other ‘ADM Villages’ – for example, we are members of the National Federation of Voluntary Bodies ADM steering group. These groups provide a good platform for information sharing among agencies providing supports to adults with an intellectual disability.

A key decision for us was to ensure our village was inclusive of adults using the service. Our organisation’s Communication Policy clearly states that adults are consulted with and provide management with information about topics of importance to them. Making decisions is important for adults in our service. So, we began by asking the people who use our service what did they think were the key messages about ADM. A group of adults meet once a week to advise the ADM steering group of priority areas for them. It is part of our work plan is to grow the village further over the next 12-18 months.

### **It takes support**

This relates to support for service users, their families and staff members to understand what ADM is, what it means for each of them and what needs to change when ADM is implemented. Support also relates to organisational policies/procedures and structures that support decision-making in line with ADM. We decided that as policies were due for review, we would update them in line with the principals of ADM. An important example is the Risk Management Policy, which now focuses on positive risk-taking and includes the right to make a decision that the staff/organisation does not agree with (this does not mean the person does not have capacity to make the decision!). The balance between rights and safety is always at the forefront of discussions relating to taking risks. Previously, the key principle was ‘what is in the person’s best interest?’ Now, the approach is ‘what does the person want and what can we do to support it, even if there is a risk?’ Building practice examples relating to supporting decision-making in ‘risky’ situations, and providing leadership to ensure the person’s will and preference is taken account of when decisions are being made, helps to provide support for other staff members to ensure the person’s voice is central to the decision being made. The case examples from St. Michael’s House are examples of ‘risky’ situations and the approach to supporting the person’s view to be central to the decisions being made.

Our work plan identifies the development of a series of supports that are required to implement ADM – these supports primarily focus on using current structures to implement ADM. For example, the organisation has a robust person-centred planning system that captures and records the will and preference of the person (not currently called that) and our work plan identifies how staff can link ADM and person-centred plans. Thus, it is not creating a new structure but, by amending an existing structure, can confidentially demonstrate the person’s will and preference.

### **It takes communication**

‘It takes Communication’ focuses on ensuring high quality, high-frequency communication about ADM for all stakeholders. It is also concerned with learning what the barriers are to implementing ADM from service users and from staff and identifying strategies to overcome the barriers. Communication about ADM has started in the organisation and there are more communication strands planned. We are focusing on the key principles of the Act because other parts may be amended or updated.

The adults who use our service have designed an easy-to-read poster that introduces ADM and have plans for a series of posters relating to how the Act will impact on them. Communication with all stakeholders forms part of the ADM work plan.

### **It takes time**

The literature identifies that it takes between 2-4 years to fully implement a new way of working. This timeline will begin in earnest when the Act is fully commenced. However, we took the view that there are many reasons to start planning now for implementation. Building knowledge among service users and staff about the Act will take time. Identifying will and preferences will take time to do well. Supporting service user to build their capacity also takes time. A work plan for the next 2-4 years is developed and includes significant elements of growing our village, developing our support structures and systems and developing the communication strategy.

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## REFLECTIONS FROM PRACTICE

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So, now that we are one year on from the establishment of the ADM Steering group and using implementation science to guide us, what have we learned?

### **Start and Get Better**

The feeling of not knowing where to start can be paralysing – sometimes it’s easier to do nothing than start. Waiting for the 2015 Act to fully commence, waiting for case law to emerge, waiting for Supreme Court judgments, not having enough resources, being busy with other matters are all reasons not to get started. However, by starting, you learn what

is needed. There is no such thing as the perfect time to get started – start slowly and get better over time!

### **Include the adults who use the service**

By including adults who use the service to help guide the key messages and priority areas, it lessens the risk that it becomes a bureaucratic exercise. Service users keep us focused. They know what is important to them and it is our role to respond to that.

### **Don't overcomplicate it**

Look at what you have in place – what can be useful to you? By using existing structures, you can reassure people that not everything will change. Pick a few key things to focus on and communicate those. We identified two key messages:

- Will and preference instead of best interest
- Build capacity rather than assess capacity

### **Culture eats strategy for breakfast**

Culture is ‘how we do business around here’ – we learned that if you start with the willing (those who are already committed to a rights-based approach) you can win the hearts and minds of others. There will always be people who do not think ADM is necessary. Do not focus on convincing them – save your resources for those who are open to being convinced. Building case examples, one person at a time, one decision at a time can help to shift culture and show people the alternative way. It also allows the organisation to learn what is needed (e.g. policy updates/coaching for staff, etc.)

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## RESPONDING NOW IN THE ABSENCE OF THE COMMENCEMENT OF THE 2015 ACT

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It can be difficult if you find yourself thinking ‘if only ADM was commenced, then we would approach a decision in this way.’ Can you apply the ADM thinking now? If not, why?

Some of the questions we find ourselves asking are:

‘Can you work with people to build their capacity to make a decision in the absence of commencement?’

‘Do we know the person’s will and preference? Can that guide the decisions?’

‘Can you make a referral to an independent advocacy service? Can they help

represent the person's will and preference? Wardship has become the very last resort as it prevents the person from being allowed to make any decision.'

St. Michael's House is more than one year into learning and understanding the impact that the 2015 Act will have on the people we support and the services we provide. We have learned a lot from our year and one thing is very clear – we have a LONG way to go before we are ready for the 2015 Act but we have a path to help us get there. The case examples that follow will demonstrate the importance of addressing each issue as it arises, using the key principles from the Act to guide us, learning from the example, modifying structures, systems and approaches to reflect what we have learned.

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## 4.2 Supporting People with Complex Communication Needs

*Caroline Howorth*

With thanks to Liam's primary SLT Mary Sloan for her role in supporting this situation.

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### BACKGROUND

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Communication plays a central role in all of our lives. It enables us to have control, make friends, become independent, make choices and express ourselves (Goldbart and Caton, 2010). Without good communication, individuals struggle to achieve the fundamentals required for citizenship, humanity and improved quality of life.

All people communicate in some way. All forms of communication are equally valid. Some people communicate in a pre-intentional way (i.e. others often interpret their behaviour). Some use non-verbal communication. Some use alternative and augmentative communication. Some people use verbal communication in a variety of ways (single words, phrases, sentences). Generally, people don't use one single means of communication; they combine a variety of modes to understand and get their message across.

Many Irish disability policies and legislation, including the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act), identify that everyone should receive the support they need to be involved and make decisions important to their lives. However, it is often difficult to be involved if you have severe communication difficulties. Implementing good communication is proactive and ethical as it prevents reactive, restrictive interventions (RCSLT, 2013). This essay discusses why communication is central to decision-making and how people with complex communication needs can make their own decisions wherever possible.

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### COMMUNICATION AND PEOPLE WITH AN INTELLECTUAL DISABILITY

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Most people with an intellectual disability have some speech, language and communication difficulties. These can be hidden, overlooked or over-emphasised. According to the Health Research Board 2016 (NIDD, 2017), there are 17,872 adults registered in Ireland as having an intellectual disability.

Emerson et al (2001) estimate that up to 90% of people with learning disabilities have communication difficulties. Around 50% of these have significant difficulties with both expressing themselves and understanding what others say (RCSLT, 2010). Many will face challenges in accessing standard written information that has not been adapted to suit their needs.

This discussion focuses on complex communication needs as experienced by people with Profound and Multiple Learning Disabilities (PMLD). People with PMLD are unique and individual. Generally, people with PMLD have more than one disability, have a profound intellectual disability and experience complex health needs. Many people with PMLD may not communicate using formal communication like speech or symbols. But this does not mean that they cannot communicate. Their preferred ways of communicating may include vocalisations, body movement, facial expression, eye contact or behaviours. Communication partners must interpret their reactions and support them to maximise their communication skills (SMH, 2014). People with PMLD benefit from a Total Communication Approach that means all modes of communication are available to them (e.g. speech, manual signs, photographs, symbols) alongside other elements of non-verbal communication. It allows the person to use multiple ways of expressing their thoughts and feelings (e.g. vocalisations, movements, taking someone by the hand). It increases success in understanding and expression.

According to the Involve Me Project, people with PMLD and complex communication needs are some of the most excluded in society. People with PMLD should be involved in all decisions that affect their lives – we should hear their preferences and enable them to share their experiences. However, the Joint Committee on Human Rights ([www.parliament.co.uk](http://www.parliament.co.uk)) reported that people who have complex needs often do not have a say in decision-making because people do not know how to communicate with them. Their ability to participate is underestimated.

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#### WHY DO PEOPLE WITH COMPLEX COMMUNICATION NEEDS EXPERIENCE DIFFICULTIES IN MAKING DECISIONS?

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People with PMLD and complex communication needs can experience many difficulties when it comes to making decisions. But many of these challenges are not located within the person themselves. A person's ability to make decisions will be directly influenced by the nature of their communication environment and the skills of their communication partners. Our role is to ensure the correct supports are in place to identify the person's preferences and act upon these.

### Communication Environments

It is more challenging for people with PMLD to communicate if the space, light and layout of the setting have not been considered. Can they see people's faces when communicating? Can the room accommodate 1:1 communication? Noise levels will affect a person's ability to make their preferences known. What is the general noise level? Can everyone hear or be heard? Does the general communication environment promote the use of visual supports? Are objects, symbols or photos consistently and widely used? Do staff know how to use these? Are people familiar with visual supports so they are not seeing them for the first time when making an important decision? Is there time within the communication environment to allow conversations to happen? People with PMLD require extra processing and response times. Does the setting facilitate this?

### Communication Partners

Staff should be supported to apply communication skills that are critical to enabling people with PMLD to engage in decision-making. If the staff member is not aware of the person's preferred communication systems, then real decision-making will be challenging and potentially tokenistic. Staff also need to be aware of their own communication style and how this affects interactions. For example, a direct communication style (using commands and questions) is unlikely to uncover the subtleties of a person's non-verbal communication attempts. A responsive communication partner provides enough time and understands the value of silence and observation in correctly interpreting what a person is telling us through their sounds, movements and actions. Responsive communication partners understand that opportunities must be created to support the person to express their preferences on a topic of importance to them.

It is our responsibility to be aware of barriers to decision-making and understand how to provide a supportive communication environment with skilled communication partners. Failure to make reasonable adjustments to meet communication needs will mean people with ID continue to be vulnerable (Emerson and Baines, 2010) and risk being omitted from participating in the decisions that are important to their lives.

### Case Study: Liam – communicating preferences around modified fluids (dysphagia)

Liam is a 49-year-old gentleman in full-time residential care. He is a friendly, engaging man enjoying a close relationship with his father. Liam has PMLD – a diagnosis of ASD, intellectual disability and complex communication needs. He predominantly communicates through body movements, facial expressions and interpretation of his echolalia. Liam has regular fluctuations in respiratory status and a history of aspiration pneumonia. Liam loves going out for coffee and values his independence.

Because of his aspiration pneumonia, Liam had a video fluoroscopy. It showed fluid going into his chest when he drank Regular, Grade 1 and Grade 2 fluids. This could potentially

be a contributing factor towards continued occurrence of his aspiration pneumonia. The Speech and Language Therapist recommended Liam switch to Grade 3 (pre-IDDSI) thickened fluids. This decision was endorsed by the MDT to manage Liam's medical stability.

Immediately, people close to Liam observed significant changes in his well-being. He began engaging in high-risk behaviours – attempting to drink poisonous substances and attempting to drink from a boiling kettle. Increased staff supervision was then required, which reduced his valued independence. His activities became more restricted and his quality of life reduced. To those who knew Liam well, none of these were usual behaviours. He was communicating distress since his drinks were modified.

This happened in 2018 as our organisation was attempting to move towards ADM principles. Previously, medical health would have been the primary risk and Liam's behaviour viewed as 'non-compliance'. The recommended guidelines would have stayed in place or adapted by the doctor with the SLT stepping out of care.

Instead, Liam's father and staff saw the necessity for a different approach. They listened to Liam's perspective. He was clearly communicating dissatisfaction with the change to his regular fluids. They gathered views from people important to Liam – his father, his key workers. They remembered how important coffee is to Liam and how increased supervision was reducing his preferred independence. They thought in terms of Liam's will and preference and reflected on what really was an 'unwise' decision?

The focus was on identifying a solution that suited Liam. They reintroduced regular fluids alongside a prophylactic antibiotic. Regular reviews were provided by the doctor and MDT and staff received regular training from the SLT to increase mealtime safety.

Almost immediately, Liam returned to his usual personality and became more content. From this, the team believed they had acted in line with his will and preference.

If the situation arose today, what would we do differently? From observing Liam's preferences and gathering information from those closest to him, the team may deem thickened fluids too restrictive and impactful on Liam's quality of life. Therefore, adopting the principle of only intervening when necessary, modified fluids might not be trialled at all. It is a complex decision to make. Would Liam's choice seem an 'unwise' one? Whose role is it to decide the greatest risk – drinking unmodified fluids, which may or may not contribute to aspiration pneumonia versus prescribing thickened fluids, causing the person to engage in high-risk behaviours and experience markedly reduced quality of life?



For the purposes of this essay, the message is clear. Liam communicated his preferences and these were confidently understood by those who ‘listened’ to his voice. All forms of communication are valid. People with complex communication difficulties can make their will and preferences known with the right supports.

### **Reflections from practice: strategies to support people with PMLD and complex communication needs to make decisions**

If people with PMLD are to expect assistance to make decisions about their lives, staff need to know what good communication support ‘looks like’ and what reasonable adjustments must be made. Below are techniques and approaches that staff and family members should be supported to use to interpret the preferences of people with PMLD (from *Involve Me*, 2008).

- i. Take time - get to know the person well. Be responsive. Speak with people who already know the person very well. ‘Listen’ to the person. Use what you learn to ensure wider decisions are made in line with the person’s preferences.
- ii. Does the person have a communication passport? This can hold valuable information about the person’s strengths and needs, their preferred ways of communicating and supports that are likely to facilitate successful interactions.
- iii. Establish the person’s preferred ways of receiving and giving information. Some people might only make their preferences known through their behaviour or reactions. Others might point, look or choose from a small number of options. Find out more about developing accessible information and what this would look like for the individual you are supporting.
- iv. Identify the person’s preferred communication environment.
- v. Breakdown the specific decision/choice about which you want to find the person’s views.
- vi. Consider the person’s previous experience of giving or receiving information and making decisions. Do they routinely make decisions? What kind of decisions have they made? Some people may have very limited experience in this regard and even the concept of ‘making a decision’ might be new.
- vii. Because people with PMLD are so dependent on others to interpret what they want, there can be conflicts of opinion about what their communication means. Be open and honest and share evidence of why you think the person might be expressing a particular preference. Don’t make assumptions about what you think the person means.

- viii. Be a responsive communication partner – make listening easier by saying less; make the message visual by showing the person objects/ pictures/ signs; make it multimodal by taking a Total Communication Approach; give lots of extra time by going slow.
- ix. Above all – don't give up!

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## 4.3 Responding to a Couple's Request for Support with their Relationship

*Niamh Holland*

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### BACKGROUND

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The individuals who use St. Michael's House services are supported to make decisions all the time. Some of these decisions require more consideration and service users' often need additional supports when making these decisions. Decisions that involve an element of risk are often difficult for both the individuals themselves and the staff or family members supporting them.

The area of sexuality and relationships has always been a sensitive one in services for people with disabilities and in particular intellectual disabilities. Over the past few decades we have moved from denying people with disabilities the right to express their sexuality but there is still a lot of work to be done in this area to truly acknowledge people's right to a full and fulfilled sexual life. There are always more reasons why NOT to support an adult to engage in certain behaviours than reasons TO support: 'Couple relationships are central to adult lives in the general population, but less accessible to adults with intellectual disabilities' (Neuman 2020).

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### PERSONAL AND SEXUAL DEVELOPMENT POLICY AND ORGANISATION'S POSITION

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St. Michael's House have a long history of supporting adults to develop and maintain relationships. In 2007, the organisation supported three couples to move into accommodation together supported by staff in the service. To support this new service initiative, the organisation developed a clear policy. This policy, 'Supporting the Personal and Sexual Development of People who use St. Michael's House Services', was developed to support both the individuals who use the service and also the staff that support them. The policy was developed following guidance from the EU Convention on Human Rights.

While recognising the complexities and challenges involved, St. Michael's House wishes to support those who use our services to live as full and fulfilling a life as possible and that includes recognising their right and need for sexual expression in the same way as those who do not have an intellectual

disability. To ensure that the policy was promoted across the organisation it was decided that it was necessary to establish a specialist group to oversee the implementation of the policy. This group PAIRS (Personal and Intimate Relationship Support) comprises of clinicians, managers and social care workers across all areas of the service. This group meets monthly and plays a role in supporting staff requests for advice and guidance with issues relation to the sexuality of all individuals using the service. One such request for support is the case outlined here.

The case discussed here relates to a couple seeking to progress their relationship but requesting support from staff to achieve their desired outcome.

This couple – Frank, a man in his 40's and his girlfriend Alison, in her 30s – were planning on attending a conference with a number of other adults from the same day service that was being supported by staff from the unit. Frank and Alison approached the staff supporting the break and expressed their wish to share a bedroom in the hotel and asked for support to arrange this. This couple had been in a relationship for a number of months. However, Alison discussed with staff that her mother was not supportive of the relationship and she felt sure her mother would not want her to share a room with her boyfriend.

While the request was in line with the organisation's policy and staff were keen and willing to support the request, it was not something they had any experience with and they wanted to ensure they were supporting the couple in line with the organisations policy.

Historically, services have struggled with supporting the choices of adults that were considered 'unwise' or 'risky': 'Where choices have been available between facilitating the sexuality of people with ID and protecting them from unwanted sexual encounters, services have typically sought to prioritise protection over empowerment.' (Keywood and Flynn, 2003). This has often resulted in individuals with ID leading safe but lonely and isolated lives.

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### STEPS TAKEN TO SUPPORT THE REQUEST

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When the request was received from the couple, the staff member discussed with them that whilst she was happy to support them that she would need their consent to discuss it further with her manager to ensure she was following procedure correctly. The manager contacted the Chair of the PAIRS committee and, without disclosing personal information, outlined the nature of the request and looked for direction with regard to how best to proceed.

It was agreed that two members of the committee would be nominated by the Chair and they would explore the nature of the request in more detail. It was considered important to get an understanding of:

- a. The status of the relationship
- b. To conduct a capacity check – this was in line with the policy at the time, dated 2008, which recommended conducting capacity assessments where issues in relationships were raised.
- c. To explore the knowledge and previous training the couple had received to ascertain their level of awareness and understanding of sexuality and intimate sexual relationships, including their understanding of contraception
- d. Family/residential service awareness and involvement in the relationship and the holiday request
- e. To garner information on the impact/ understanding of the other adults participating in the holiday
- f. Supports available for the staff going on the holiday.

In order to gain the above information, staff in the unit who knew both individuals well met with them and explained the process and the steps that were proposed to help their request be most successful.

The following steps were taken, which were in line with the policy at the time. The couple agreed to meet with the two members of the PAIRS committee and this meeting was very positive and productive. It was clear that the couple were very committed to each other and had been in a relationship for a number of months although they knew each other for a number of years. It was the opinion of the two clinicians that they both wished to pursue the request to share the room and that there was no question of any coercion on either party. Frank lived in a residential service within the organisation and felt very supported by them and had no difficulty discussing the holiday with his family. However, Alison lived at home and was less confident about discussing the request with her family and was very concerned she would get a negative response.

St. Michael's House works closely with families to support the individuals in our service. We strive to work in partnership with families and respect and value the role they play in the lives of the people who use our service. However, in this instance we chose to follow the policy 'Supporting the Personal and Sexual Development of People who use St. Michael's House Services', where it was clear that our role is to support the individual and their desire to live a fulfilled life. This involved some delicate discussions with the adults and support from those that knew them well and worked closely with them.

‘While recognising the complexities and challenges involved, St. Michael’s House wishes to support those who use our services to live as full and fulfilling a life as possible and that includes recognising their right and need for sexual expression in the same way as those who do not have an intellectual disability’. (‘Supporting the Personal and Sexual Development of People who use St. Michael’s House Services’ policy)

The couple were open about discussing their previous education in the area of relationships and sexuality. Given the nature of the request, it was considered important to discuss issues relating to consent and also ensuring they had sufficient information regarding contraception without making any assumptions. Whilst the couple had requested to share a bedroom they were not more explicit than that and did not wish to discuss the more intimate aspects of their relationship.

The nominated members of the PAIRS committee also met with the manager and staff member supporting the holiday to discuss with them their roles and responsibilities and ascertain how they felt about supporting the request. It was evident that the staff were fully supportive of the request and had no immediate concerns. The staff member did seek direction regarding how best to inform the families, in particular Alison’s family, who had expressed concerns about the intimate nature of the relationship.

### **Actions taken**

Support was offered to Alison over the course of three sessions with a psychologist and she was encouraged to discuss the relationship with her mother. She was supported to inform her mother about the holiday and the decision that she and Frank had made. Alison really appreciated the support she received. She felt confident talking to her mother as she had availed of opportunities to role play the discussions. Alison’s family were also reassured that staff from the day service would be there to support them. When staff discussed the situation with the family, it appeared that their concerns were borne out of a wish to protect rather than restrict, which opened up a discussion about that difficult balance between empowerment and protection.

One of the challenges for services working with people with intellectual disabilities is how to meet the twin objectives of sexual empowerment and protection. In this case, all involved felt that they had achieved the balance of supporting the request and empowering the adults at the centre of the request while also being very aware of their safety.

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### THE OUTCOME

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The holiday went ahead and was a great success. The couple enjoyed the break and felt supported and valued as staff had listened to them and supported their decision. While

the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) was not in place at the time that this couple requested support, on review it was felt the steps that were taken were largely in line with the main guiding principles of the Act. The adults' will and preferences were respected and the least restrictive alternative was supported. Alison was provided with the support she required to discuss a sensitive issue with her mother as opposed to staff having that discussion with her mother and disempowering her.

### What we would do differently now?

On reflection, in light of 2015 Act and our knowledge of how this legislation should be implemented, we would assume capacity, which would influence the supports that would be offered. This request would ideally be supported at a local level by staff without involving a number of people they didn't know well. While the PAIRS committee is a valuable resource for staff, on this occasion they managed the situation rather than offering guidance and support to the day service staff to support the request.

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## CONCLUSION

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Acknowledging that adults have the same rights regarding their sexuality and sexual expression as their peers without disabilities and ensuring that their rights are respected and supported is the responsibility of all those involved in providing services:

The Guidance for Designated Centre: Intimacy and Sexual Relationships (GDE6) HIQA states:

‘Providing people with disabilities with education and information not only supports them in developing the depth and breadth of their relationships but also in expressing preferences, reporting abuse and thereby helping to protect them from harm.’

This paper sets out one organisation's approach to the 2015 Act for adults with an intellectual disability, focusing on a person who was able to describe in words her will and preference and who needed support to ensure her voice was heard by her family. A number of key principles of the 2015 Act can be applied:

- i. Assume Capacity
- ii. Support people to build their capacity by providing information to them in a format they can understand.
- iii. Making ‘unwise’ or ‘risky’ decisions is not evidence of lack of capacity
- iv. Do not intervene unnecessarily
- v. Take account of will and preference of the person.

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## 4.4 Promoting the Autonomy and Enhancing the Capacity of People with Severe and Profound Levels of Intellectual Disability

*Caroline Dalton*

The introduction of the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) and the formal ratification of the United Nations Convention on the Rights of People with Disabilities by Ireland in March 2018, speaks to a societal, governmental and legislative commitment to promoting the capacity and autonomy of people with disabilities, including those with intellectual disabilities. Promoting the capacity and autonomy of individuals is a complex principle which can prove difficult to uphold in a real-world context. Not all individuals will have the capacity to make all the decisions they are faced with in life, and not all individuals may want to make these decisions. However, irrespective of individual circumstances, respecting the autonomy of individuals and enhancing their decision-making capacity when required are fundamental principles which should be upheld.

The introduction of the 2015 Act holds the key to ensuring the autonomy of individuals is respected and their decision-making capacity is enhanced. The enactment of this legislation will help to ensure that the autonomy of individuals is upheld, specifically where issues in relation to capacity arise, such as is the case for people with an intellectual disability. Many people with an intellectual disability will have both the capacity and autonomy to make decisions for themselves. However, some individuals, such as those with a severe to profound level of intellectual disability may lack the capacity to make these decisions. Where individuals are deemed to lack capacity, it does not follow that their right to autonomy should be dismissed. In fact, it is precisely in this situation that any desires, hopes, beliefs and values held by the person with a severe to profound level of intellectual disability should be affirmed.

Of significance, in terms of differences between the current wardship approach and the processes set out in the 2015 Act is that under wardship, there is no obligation to articulate the 'will and preference' of the Ward. This has left individuals, and specifically those with a severe to profound level of intellectual disability, without a voice. With the commencement of the 2015 Act, individuals will be assigned an intervener whose role it is to maximise the autonomy of each individual under the Act. The intervener will also ensure,

insofar as practicable, that the individual involved can participate in decision-making, taking into account the will and preferences, beliefs, values and other factors of relevance to the individual. The intervener can also consider the views of those named by the individual involved, or an individual appointed to support the person when making decisions.

This represents a fundamental change in how people with a severe to profound level of intellectual disability will be dealt with under the law, reflecting both a functional approach to capacity and a relational approach to autonomy.

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### FUNCTIONAL APPROACH TO CAPACITY

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Every effort needs to be made to promote the decision-making capacity of all individuals, including those with a severe to profound level of intellectual disability. The 2015 Act will, when fully in force, promote a functional approach to capacity which recognises that the capacity of individuals to make decisions can vary, dependent on the decision to be made and the context in which it is being made. Capacity can be viewed as a constructed state as, according to McCarthy et al. (2011), it is not simply a characteristic to be assessed but one that can be developed. This speaks to a relational perception of capacity and a relational approach to promoting individual autonomy, which requires that efforts are made to enhance a person's capacity and address factors, where possible, which might impede a person's capacity, such as having a severe to profound level of intellectual disability.

This concept of capacity, which underpins a functional approach to its assessment implies, that where issues relating to capacity arise, efforts should be made to facilitate individuals to make decisions for themselves (McCarthy et al. 2011). This is of particular importance to people with severe to profound levels of intellectual disability, where additional supports may need to be put in place to ensure that issues arising relating to communication and cognitive difficulties are adequately addressed. Such supports may include the use of advocates, easy-to-read materials and augmented or alternative forms of communication, such as sign language, picture exchange communication systems (PECS), intensive interaction and assistive technologies (Dalton and Sweeney, 2011). Additionally, where issues arise with respect to an individual's capacity, it is incumbent on professionals to consult with appropriate experts in the area of capacity, such as psychiatrists or psychologists. Legal advice should also be accessed as required.

It is evident from the above that a variety of individuals may be required to support individuals with severe to profound levels of intellectual disability. Individuals involved in these 'circles of support' may include family members, friends, carers, including health and social care professionals and members of the legal profession. The involvement of such a diverse group of individuals in supporting the individual to make decisions speaks to a relational approach to promoting autonomy.

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## RELATIONAL AUTONOMY

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The concept of relational autonomy recognises that an individual's identity is to some degree a product of his or her social relationships. In essence, relational autonomy embraces the idea that people are social beings, whose choices and decisions are facilitated in the context of their social circumstances.

This is particularly important for those with a severe to profound level of intellectual disability, who are often heavily dependent on the support of others in order to live their lives. Whilst acknowledging the interdependency of human beings and the importance of social relationships, Beauchamp and Childress (2013) alert us to the dangers of oppressive social relationships and social norms which can compromise autonomy. This form of relationship, according to McCarthy et al. (2011) prevent the development of the core competences required to facilitate decision-making, namely self-trust, self-understanding and self-worth.

However, while it is important to be mindful of the negative influence of coercive or over-controlling relationships, it is also of importance to recognise that positive, respectful relationships can foster and promote the autonomy and capacity of individuals. These positive relationships are particularly important for those who will need the support of those who know them well to effectively engage in decision-making, such as family members, friends and carers who can ensure that decisions are made 'with' as opposed to 'for' the individuals involved. This perspective of autonomy, referred to as relational autonomy, gives recognition to the view that people are not always motivated by self-interest but are motivated by their attachment to, and in solidarity with, others (McCarthy et al. 2010; 2011).

The 2015 Act enshrines in law a functional approach to capacity and a relational approach to autonomy. How, then, can we ensure that the changes envisioned under the law come to fruition? How do we ensure that people with a severe to profound level of intellectual disability make their voices heard?

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## PROMOTING AUTONOMY IN A REAL-WORLD CONTEXT

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A relational approach to enhancing capacity and promoting autonomy underpins the 2015 Act. It reflects a changing societal perspective of disability, reflecting a discourse which emphasises capacity as opposed to incapacity. Furthermore, it provides a mechanism for people to have a voice, as the 2015 Act is focused on enabling people to participate in decision-making, with support, when required. This directly contrasts with the wardship process, which left those with a severe to profound level of intellectual disability without a voice. Those who heretofore have been silenced, can now have their voices heard.

However, as emphasised in the 2015 Act, the provision of constructive supports for those with severe to profound levels of intellectual disability is imperative to ensuring their right to autonomy is upheld. As previously stated, some people with an intellectual disability may require, or wish to have, the support of those in their social circle when making decisions.

Individuals within the person's 'circle of support', such as family members, friends, health and social care professionals or any individual who knows the person well, may be instrumental in promoting the autonomy of these individuals by putting in place the requisite supports to enhance an individual's capacity. Those involved in 'circles of support' for people with severe to profound levels of intellectual disability, can collectively use their shared knowledge of the individual to promote autonomy and decision-making capacity and to advocate, where necessary on their behalf.

However, applying a relational approach to enhancing decision-making capacity and promoting autonomy will take time. Decision-making discussions cannot be a once-off event if those involved truly want to identify the will and preference of the individual they are supporting. Therefore, these decision-making discussions will need to be held in a timely manner. This is particularly true for those with more severe forms of intellectual disability, who will need time to develop trusting relationships with those supporting them. Those supporting people with a severe to profound level of intellectual disability will also need to be particularly cognisant of their role in promoting the autonomy of these individuals and applying a relational approach to enhancing capacity. Those who know these individuals well can draw on their past experiences of the individuals involved, their likes and dislikes, or things that caused them distress or enjoyment, to inform decision-making processes.

To ensure that discussions are held in a timely manner and capture the will and preferences of the individual involved, it is suggested that a relational approach to autonomy and decision-making be integrated into person-centred planning, currently widely used with people with an intellectual disability (Kingsbury, 2010). Person-centred planning is a process used to support individuals to identify what they want from their life and what needs to be done to help the person achieve these life goals. This form of planning is reflective of a holistic approach, where the primary focus is on the individual involved (NDA, 2005), as envisioned under the 2015 Act. It requires that appropriate mechanisms for effective communication are available to all parties involved in planning conversations. Reflective of a relational approach to promoting autonomy and decision-making capacity, the importance of relationship building and the inclusion of parents, siblings, other family members and close friends is emphasised. Both relational autonomy and person-centred planning hold true to the concept of trust – trust that those involved will hold true to the expressed will and preferences of the individuals involved and, most importantly, will act on these when required. However, trust takes time to build between individuals. Therefore, a relational approach to autonomy as envisioned under the 2015 Act will take time, commitment and resources.

Where decisions need to be made, starting discussions as early as possible would be advisable, and ensuring that the person themselves and those who support them are included is paramount. However, inclusion of the person themselves and those who support them must go beyond making them aware of and ensuring their presence at any discussions. Effective methods must be found to ensure these individuals actively engage in these discussions and their will and preferences are understood and, most importantly, acted on in good faith. A process needs to be put in place which identifies supporters in an individual's life who can attest to the individual's capability. Such a process would also need to facilitate the documentation of how the individual communicates, informs decisions, makes decisions and what decisions the person has previously made.

The emotion attached to facilitating this form of decision-making process, which truly seeks to establish the will and preference of the individuals involved, should not be underestimated. Additional supports may need to be put in place for individuals involved and those supporting them. Furthermore, when decisions are made, they will need to be revisited to account for changing circumstances and perspectives of all those involved. Facilitating these ongoing conversations as part of the decision-making process will also capture changes in the will and preferences of those involved which can occur over time, ensuring that those supporting the individual can react and adapt to their changing will and preferences.

To conclude, the 2015 Act will require significant changes in how decisions are made with people with severe and profound levels of intellectual disability. Not only will people with an intellectual disability need support, so too will those who support them. The changes envisioned by all individuals under the act will only come to fruition if the requisite time, energy and resources are provided to promote the autonomy and capacity of those with a severe to profound level of intellectual disability, when engaging in decision-making. However, if these supports are provided, the capacity and autonomy of both people with intellectual disability themselves and those who support them will be enhanced. We will grow and learn together, and respectful, trusting relationships will be forged, to the benefit of all.

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## 4.5 Supporting Capacity to Manage Money

*Judy Ryan*

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### INTRODUCTION

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The Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) provides for reform of the law in Ireland relating to persons who require or, who may require assistance in exercising their decision-making capacity, now or into the future. Underpinned by a number of core principles, this legislation is intended to safeguard and respect the rights of the person, their dignity, bodily integrity, privacy and autonomy while giving effect to past and present wishes. Adopting a human rights-based approach, the 2015 Act espouses a position of equality in decision-making, where the assumption of capacity is implicit and only questioned when proven otherwise.

Capacity is defined in the 2015 Act as the ‘ability to understand...the nature and consequences of a decision to be made by him or her in the context of available choices at the time’ (s. 3(1)). The decision-maker is defined as the ‘relevant person’ and is described as a person whose decision-making capacity is in question or may shortly be in question in respect of one or more than one matter (i.e. a person who may have difficulty reaching a decision without the support of someone).

For the purpose of this piece, the relevant person referred to in the 2015 Act is a person with an intellectual disability. The past decades have seen a gradual shift internationally and in Ireland from traditional institutionalised, biomedical approaches to care and support for those with an intellectual disability, to one based on social inclusion, societal balance and holistic care and support in line with international policy on disability and the United Nations Convention on the Rights of Persons with Disabilities (UN 2006), ratified by Ireland in 2018. The welcome recognition of people with a disability as equal citizens in every aspect of life necessitates an informed approach by nations. Nevertheless, there is progress to be made in support of people with an intellectual disability to move in a sustained way from a protectionist position where the person’s next-of-kin was considered key in the decision-making process to one where the focus belongs to the individual affected by the decision and one based on their will and preferences. Historically in Ireland, it would have been common practice for those accessing residential care to be absent from decisions affecting their lives. In large congregated settings for example, decision-making authority for those residing in services

would have been signed over to the service provider on an annual basis by family members. Consultation with the relevant person wasn't considered at any stage of this process; indeed, the relevant person in all likelihood had no awareness of this practice.

The 2015 Act places a legal obligation on all health and social care personnel to support a person whose capacity is or may be in question or who may lack capacity to make a decision. With the presumption of capacity as the starting point, the 2015 Act requires that persons are treated as unable to make a decision only where all practicable steps which have been taken to support their decision-making have proved unsuccessful. Decision-making involves gathering information, examining options or alternatives from a range of choices in order to reach an outcome. However, for people with an intellectual disability who were traditionally excluded from involvement in personal decision-making, to progress from novice to expert decision maker requires reflection and support. Different life events require different levels of decision-making and in order to enable person-centred support, a culture that recognises individual autonomy as core to practice must be present in addition to a developed understanding of the core principles of the 2015 Act.

In 2015, work began with a group of nursing colleagues in the HSE Dublin Midlands region in conjunction with a group of consenting adults with an intellectual disability residing in services on a pilot project to understand how the 2015 Act could be supported in practice. The capacity to manage personal finances was the issue for consideration. Applying the principles of the 2015 Act to financial management formed the broad heading applied to the pilot project.

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### THE LEARNING FROM THE PILOT PROJECT

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The initial direction of this project was to work with the person to access their capacity using the broad heading 'capacity to manage their money'. As a starting point, a facilitated introductory conversation/chat about money took place to ascertain the level of access or understanding about their money which each participant had. This proved invaluable. Looking at all the income sources an individual had and starting with allowances, it quickly emerged that those involved in the pilot project had little or no knowledge of allowances they received from the State. The disability allowance for example was, for most, an abstract concept with no tangible regular financial transactions taking place. The charges paid to the supporting organisation were similar, as these were transacted through the direct payment to the services. Excluding the person from decision-making because of a perceived lack of capacity surrounding a process they have little or no knowledge of is not in line with the principles of the 2015 Act, and necessitated capacity-building in order to enable an informed decision. The time spent explaining these payments and charges was valued by the participants and contributed to their understanding of their money.



The 2015 Act recognises that decision-making is issue- and time-specific and that the inability to make one decision does not translate to an inability to make all decisions. Consequently, the lack of understanding of intangible financial transactions about one aspect of financial management does not translate automatically to a lack of capacity to manage all financial transactions. Following on from consideration of the allowances, understanding a person's capacity to pay their bills was considered. Again, the starting point was a conversation with the participants to ascertain their appreciation of the bills they had to pay and how these transactions occur. Questions posed throughout conversations with the participants included questions relating to payment processes, whether direct or online payment methods were used. Having a bank/credit union account, having access to your money and understanding and using a bank card all emerged as separate but connected aspects of money management discussed with the participants. The final stage of money management addressed within the project related to the money a person had in their purse. Understanding transactions in the shop and knowledge of the actual value of an item or what a reasonable cost for that item may be was highlighted. Recognising the value of a note against a purchase materialised as areas for capacity-building. Conversations occurred over a number of sessions, using different approaches and support material to facilitate the participants understanding. Time was required to facilitate the overall process to enable assessment of capacity take place.

During this project, there were ample opportunities to build personal decision-making capacity through learning. Conversations with the participants raised many questions and highlighted challenges they face, which proved invaluable in the facilitation of informed decision-making. The risk of making assumptions about decision-making capacity in the absence of a knowledge base or time to enable capacity was a cautionary tale. A collective approach to capacity assessment where required is beneficial. Assessment of capacity by a person with limited knowledge of the individual poses a challenge. Assessment of capacity to manage personal finances was not the correct starting point. Money, in this incidence, meant lots of different things to different people and ranged from getting a disability allowance, to buying food, paying bills, to the change in your purse. At the outset the need to spend time engaging with the person informally, getting to know more about them proved not only beneficial but necessary. Providing information using formats personalised to the individual's communication style was required to enable what emerged as a stepped process. Communication is a primary consideration.

We make decisions every day; everything we say and do is the result of a decision, whether we make it consciously or not. For every choice, big or small, there's no easy formula for making the right decision. The best we can do is to approach it from as many perspectives as possible and then choose a course of action that seems reasonable and balanced at that time. Decision-making capacity can fluctuate but developing decision-making capacity is progressive and is dependent on supportive information.

Unpicking the principles of capacity assessment coupled with recognition of the need for change within this project was enlightening and highlighted the need for collective preparation for full operationalisation of the 2015 Act.

“Take away a man's freedom of choice, even his freedom to make the wrong choice, is to manipulate him as though he were a puppet and not a person.”

—Madeline L'Engle

## 4.6 Advocacy and the Assisted Decision-Making (Capacity) Act 2015

*Joanne Condon*

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### INTRODUCTION

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The vision statement of the National Advocacy Service for people with disabilities (NAS) states that we recognize the capacity of people with disabilities to make their own decisions equally with others, in accordance with the UNCRPD (2006). The reality is that, for some people, exercising that capacity has been a huge struggle for a very long time. For people with disabilities in particular, their decisions are often not respected on an equal basis with others. Upholding the centrality of will and preference and personal autonomy in decision-making for people with disabilities has for many years necessitated the support of independent advocates. The Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) will place an obligation on those interacting with a ‘relevant person’, as the Act refers to individuals, to support them to make their own decisions in so far as possible. The legislation, in this way, holds huge potential as a legal tool to progress human rights for people with disabilities and to embed the principles of the UNCRPD into Irish law.

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### LOOKING BACK TO MOVE FORWARD

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In order to fully appreciate why so many people have had their basic rights infringed for so long, it is necessary to look back at the Irish context in which this struggle has arisen. People with disabilities in Ireland have long experienced ‘othering’. Canales (2010) identified othering as power within relationships for domination and subordination, with the potential consequences of alienation, marginalization, having decreased opportunities, internalizing oppression and experiencing exclusion. Put simply, othering is a discriminatory behaviour arising from the belief that people with a disability are somehow inferior to non-disabled people.

Ireland’s ‘othering’ legacy is evident in the segregation model that led to so many people with disabilities being placed together in large institutions, separated from the rest of society, promoting the concept further of ‘us’ and ‘them.’ Denying association with this group of people in this way also acted in denying that group’s basic humanity. It was generally presumed that such individuals were unable to give consent or make decisions due to

their disability, particularly if they could not communicate verbally. This exacerbated the person's dependence on others to make decisions for them 'in their best interests' and people became accustomed to being the subjects of decisions rather than active participants in their own lives. Alice Walker encapsulated this concept quite precisely in her quote: 'The most common way people give up their power is by thinking they don't have any.'

It is essential to point out that the 2015 Act makes no reference to the 'best interests' standard that has provided the basis for decision-making historically in Ireland and indeed in many other jurisdictions. It is not about what others feel or think is best for an individual, or what they feel is the safest option. Rather, central to the 2015 Act will be keeping the person's own will and preference at the heart of all decision-making and respecting their personhood at every opportunity.

The role language plays in 'othering' has also been significant. The often deficit-based language we have used in Ireland over the years has served to perpetuate marginalization and subordination further for people with disabilities. Significantly, the 2015 Act, at long last, will remove the words 'lunatic' and 'imbecile' from our legislation and will repeal the Lunacy Regulation (Ireland) Act 1871 governing the Ward of Court system, which allows for Wards of Court to have their civil liberties restricted if found not capable of managing their own affairs.

The way disability has been conceptualized in Ireland has changed significantly over time. The biomedical model positioned disability purely in terms of impairment, the medical model focused on medical care of the 'patient' who needed treatment, the charitable model depicted people with disabilities as victims of circumstances who were deserving of pity, which endorsed a paternalistic view of individuals and furthered the need for them to be 'protected', 'minded' and 'taken care of' and to have decisions made on their behalf. The social model distinguished disability then as a social creation, a relationship between people with impairment and a disabling society, which removed barriers to accessibility and gave credence to the idea that 'normal' is a societal construction. The full enactment of the 2015 Act paves the way for a real and meaningful departure from the errors of the past and provides a solid framework upon which we can all hope to have our capacity maximized in decisions taken that affect our lives.

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## TODAY'S CHALLENGES

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Things have moved on and a seismic shift in thinking about disability has occurred. This has enabled a move from a deficit-based model to a human rights based, person-centred approach, which is about ensuring that people with disabilities are entitled to equal recognition before the law and have the right to exercise legal capacity and receive the required support to exercise that capacity if required. Key to this progression is the promotion of language, attitudes, cultures and processes that focus on strengths, promote ability, build capacity

and empower individuals to exercise choice and autonomy. However, some remnants of old mindsets persist and lead to the ongoing need for advocacy involvement for many people with disabilities in order to uphold rights and keep the person at the centre of decisions about their own lives.

To make decisions for oneself is a core human right and the 2015 Act is central to ensuring that every person's right to self-determination is honoured to the greatest extent possible. But in order for the 2015 Act to bring about the kind of change that is envisaged and essential, intentional support must be given to assist people who are accustomed to being the subjects of decisions. This is key in order for these individuals to realise fully their right to autonomy, their civil and human rights and their full range of abilities, so that they can be afforded the maximum opportunity for experiential decision-making and meaningful choice.

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## INGREDIENTS FOR SUCCESSFUL DECISION-MAKING

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Experiential decision-making is key to affording people the opportunity to exercise and build their decision-making muscle, so to speak. Choice only becomes meaningful when one understands what the options involve in practice. Choice involves the engagement of our varied senses to be truly meaningful on a human level and the cumulative effect of exposure to decision-making is essential to recognise. It is impossible to learn without experiencing negative consequences and people must be afforded the opportunity to try, fail, get up, dust themselves off and try again to master new skills and experiences. This truth is vital in good advocacy practice when supporting people with disabilities to make their own decisions. The supported decision-making process has to enable the person to know what their options are in reality, to understand them experientially, to get support to weigh the potential pros and cons of the options, to be afforded a space to discuss their decision with others and thereby be best positioned to make a decision. All interventions must be proportionate only for so long as needed, to ensure the least restrictive option to promote the greatest level of freedom and independence possible for the person.

Would anybody have ever learned how to ride a bike without adequate support and a few failed attempts or falls? Stabilisers might be required for some time as well as someone to teach us or hold the bike, all with the purpose of one day being able to cycle without assistance and gain mastery of the new skill. It is no different for decision-making. If in implementing the 2015 Act, such an approach is not adopted, we run a real risk of an over-emphasis on the 'capacity test' element of the Act to the detriment of the exhaustion of every possible effort to promote a supported capacity approach. That type of approach will not result in the change envisaged. The type of support offered must be individually tailored for each person. It must maximise the accessibility of information to promote understanding. It must choose the best time of day for the persons understanding and must ensure an optimum location that works best for the person. Every support must be exhausted before

resorting to a functional assessment of capacity and even then, it is time- and decision-specific. There is a real risk that steps in this process will be skipped and, for this reason, a strong onus must be placed on all of us to evidence the extensive support afforded to those who require it, so that the process is not reduced to a tokenistic one.

Understanding will and preference is at the very heart of good advocacy. Advocates have for years been practicing and mastering the skill of understanding the past and present will and preference of individuals through a set of well-honed skills and approaches. These skills are critical to the successful positioning of individuals at the centre of decision-making when the 2015 Act is fully in force. Advocates will continue to play a vital role in ensuring that decision support roles identify and represent the person's will and preference fairly and accurately and speak up when that is not occurring to ensure people's rights are upheld.

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#### OUT WITH THE OLD AND IN WITH THE NEW

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Implementation of the 2015 Act requires new approaches to interacting with people and new approaches to justice, equality, diversity, human rights, services and supports to enable people to live ordinary lives on an equal basis with others. Without education of health care providers, service providers, the judiciary and indeed a public awareness campaign to promote a solid understanding of the ADM principles in practice, there is a risk that the legislation could be implemented in word and not in deed. The question that we all must continually ask ourselves is not 'Do I understand the legislation?', but rather 'Have I acted according to the principles and values inherent in the Act?' At the very core of the 2015 Act are the principles and values of how individuals are to be treated. Congruence between the law and our actions, attitudes and values in this regard is vital. In addition, how the Act will be interpreted by the courts will be a defining factor in the potential it holds to bring about necessary change.

Leadership will be critical to securing the cultural shift that is required to lay the foundations for the principles to be implemented meaningfully. As the saying goes, 'culture is caught not taught.' This means that the desired culture must continually and consistently be promoted. Those who embrace it must be rewarded and praised; behaviours that are not conducive to promoting that culture must be addressed immediately and without exception. It is fundamentally all about person-centred decision-making that places the person in the driving seat of their own lives, to give voice to their will and preference and ensure human and civil rights are truly upheld. The impact of the legislative changes will be directly linked to the leadership, the education, the understanding and the implementation of the key principles. The various codes of practice will be a critical component to this.

Crucial to the successful roll out of the 2015 Act will be a clear definition of the various decision support roles being firmly rooted in empowerment and supported autonomy, rather than in authority and power over the person. The 2015 Act emphasizes the necessity

of all decisions taking account of the person's own will and preference and this will be the litmus test for the successful implementation of the legislation. The 2015 Act places an obligation on others to support them to make their own decisions as far as possible. There is an obligation to provide all practicable support to facilitate their decision-making.

Mitigating for potential risks of abuse by support persons will be vital to ensure that they do not override the will and preference of the individual. Advocacy has a central role to play in such situations and is well positioned to further bolster the person's voice in decision-making arrangements, where necessary. The legislation does not include a statutory right to advocacy, which could further promote people's ability to exercise their rights under the act. Equally, the ongoing absence of statutory powers for Independent Advocates in Ireland can, at times, limit the potential for effective intervention or representation when barriers of access to the person, to places, to information and to meetings arise. The gap in the legislation regarding the issue of deprivation of liberty for people with disabilities must also be addressed and progressed now in order to fully promote rights and enable full compliance with the UNCRPD.

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## CONCLUSION

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In a true departure from the 'othering' approach of the past, Ireland now holds an incredible opportunity to make significant advances in the promotion of human rights – importantly, not just for people with disabilities, but potentially for all of us. There should be no distinguishing the 2015 Act as legislation that only applies to 'other people' but rather a clear appreciation that at any moment any of us could find ourselves very grateful of the promotion of our voice and choice should circumstances present challenges of that nature.

In order for the 2015 Act to bring about the change that is greatly anticipated, there must be congruence in every respect with the legislative detail and attitudes, mindsets, values, language and an unswerving commitment to exhausting supported decision-making efforts and communication methods. Education and tools to support its correct implementation are the vehicles to truly empowering all people to live with dignity and to progress their autonomy and their self-determination. Clear mechanisms to ensure decision support roles do not overstep the mark will safeguard these rights. Presumption of capacity must be taken seriously and people must be given time to unpick decisions and have opportunity for experiential decision-making. Interventions must be proportionate and the consent of the person must be sought. Risk and the right to make unwise decisions must be re-framed. Outdated substituted decision-making approaches that are 'in the best interests of others' belongs with the Victorian-era legislation of the Lunacy Regulation (Ireland) Act 1871. The bringing into force of the 2015 Act holds enormous potential as a significant catalyst for Irish society to now truly become committed capacity enhancers who are solution focused to maximize people's human rights.

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## 5 Preserving Autonomy: Advance Decision-Making

### 5.1 Advance Healthcare Directives: Respecting the Voice of the Person in Mental Healthcare

*Fiona Morrissey*

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#### INTRODUCTION

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The capacity to make healthcare or other decisions may be impacted at any stage during our lives due to a myriad of factors including illness, a road traffic accident, ageing, or a period of mental distress. This is an issue which affects all of us. If we don't plan for these eventualities, someone will make these decisions for us, and the decision may not be based on our wishes. It is critical, therefore, that we plan for periods when our decision-making capacity may be impacted – not just for ourselves, but for those around us. The issue of planning for our future healthcare has become even more important in the advent of the COVID-19 crisis. Currently, less than one in ten Irish people have discussed their future care needs with family and friends (Safeguarding Ireland, 2018). An advance healthcare directive (AHD) is a legal statement which enables us to continue to have a 'voice' in our own care by allowing us to state our healthcare treatment wishes or other life choices in advance, and/or to appoint a trusted person to communicate these wishes. AHDs differ from advance care plans in that they are statements which are legally enforceable. The measure is increasingly recognised as an important decision-making tool, which enables the wishes of the person to be respected during periods when decision-making capacity may be impacted. This makes us less vulnerable to abuse, and avoids the need for us to enter into higher level supported decision-making agreements at a later stage. Fundamentally, an AHD allows healthcare treatment to be provided in accordance with the person's wishes, and provides respect for the voice of the person. Ultimately, this is better for all of us.

Part 8 of the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) provides increased clarity in relation to AHDs and healthcare decision-making in Ireland. The UN Special Rapporteur on the Rights of Persons with Disabilities has stated that AHDs are one of the support measures that

‘states must develop’ under the United Nations Convention on the Rights of Persons with Disabilities (2017, paras 27, 44, 54).

An AHD only comes into effect when a person is unable to make healthcare treatment decisions, including general health, mental health or end-of-life decisions. It can include advance request and/or refusal of treatment. The 2015 Act includes a presumption that everyone has the capacity to make an AHD and the onus is on the person challenging the AHD that the person lacked capacity when s/he made it. While there are certain criteria, and exclusions in the legislation, an advance refusal generally guarantees you will not be given the treatment specified. However, an advance request for treatment does not guarantee the treatment requested. AHDs can be associated with more treatment requests than refusal in some contexts (Swartz, 2005).

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## AHDS: BENEFITS FOR THE PERSON

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### **Control**

The most frequently cited motivation for developing an AHD is to provide an increased sense of control over future treatment (Swanson, 2003; Edwards, 2010). AHDs are perceived as giving greater control and choice. The ability to exercise control and choice over life decisions is pivotal to social and mental well-being (Roehrer Institute, 1993). The psychological effect of loss of control and non-consensual treatment was evident in an Irish study (Morrissey, 2015). The potential for increased control over treatment was the most frequently cited motivation for developing an AHD. The findings suggest that 61% of participants who used mental health services perceived that they lacked control over future treatment (Morrissey, 2015). A sense of security and control were particularly important for those who had been detained under mental health legislation, many of whom stated that an AHD would give them ‘peace of mind’. 78% of people who had been involuntarily detained under mental health legislation wanted an AHD to provide control over future treatment (Morrissey, 2015). AHDs propose to give a greater sense of control and choice in situations where people often feel they have no control over what happens to them (Ambrosini, 2008).

### **Listening and Communication**

The provision of a forum for listening and communication is a frequently cited motivation for developing an AHD. AHDs have an important role in enhancing listening, control and increasing treatment satisfaction (Scheyett and Rooks, 2012). The perception of ‘not being listened to’ is a common theme for individuals using health services (Murphy, 2019; Berry, 2017). The majority of participants in an Irish study wanted to use AHDs as a forum for listening (Morrissey, 2015). One-third of participants who used mental health services felt their treatment wishes were not listened to, while almost a quarter were uncertain (Morrissey, 2015). Previous research shows individuals view AHDs as communication tools, providing a forum for dialogue and the exchange of information (Atkinson, 2003).

Some commentators argue that the major benefit of AHDs is that they force providers to listen to the person (Brooks, 1987). AHDs can also provide a forum for reflection whereby a person can articulate their values, reflect on past health experiences and identify future wishes. The research suggests the process of developing an AHD is an empowering experience conferring recovery and capacity-building benefits for the person (Swartz and Swanson). Many of the benefits lie in the development process rather than activation. AHDs have an important role in promoting active listening and communication, and thereby increasing trust.

AHDs confer a range of other health benefits. When a person is treated in accordance with their wishes, it is more likely to meet their needs and result in better healthcare outcomes (Vahdat, 2014; Carr and Luth, 2017). Consistent studies suggest that individuals are more likely to engage in treatment and experience better outcomes when given a choice (Davidson, 2012; Swartz, 2002). In an Irish study, participants stated that they would be more likely to engage with treatment and to seek help in future mental health crises if they knew their wishes were legally protected. In fact, three-quarters stated they would be more willing to engage with treatment (Morrissey, 2015).

### **Alternative to Coercion**

AHDs are at the forefront of contemporary measures to reduce the need for coercive treatment. The CRPD requires us to move towards the elimination of forced treatment through the provision of alternative support measures (CRPD Committee, para. 22-23; CRPD, art. 12 and 14; General Comment No. 1; Guidelines). AHDs are proposed to provide an alternative to coercion (Swanson, 2000). Coercive treatment can be anti-therapeutic, can negatively impact on self-esteem and induce feelings of apathy, distrust, submissiveness, and dehumanisation (Gallagher, 1998). In an Irish study, coercion was shown to have a detrimental impact on the person leading to a loss of control, trust and breakdown in family and therapeutic relationships, and a higher level of hospital readmission (Morrissey, 2015). AHDs can negate the trauma of coercion, can increase control and engagement and promote trust and respect. Individuals who believe their choices will be respected are more likely to engage and benefit from treatment than those who feel coerced and disrespected (Wexler and Winnick 1992; Swartz, 2003). A systematic review showed AHDs reduced involuntary admissions to the mental health system by 23% (de Jong, 2016). Coercive interventions were reduced by half for individuals who completed an AHD in a US study (Swanson, 2008). AHDs are also associated with a reduced need for readmission into hospital (Henderson, 2004; Flood, 2006), and enhanced recovery (Swartz and Swanson, 2007). This is particularly relevant in the Irish mental health system, where 65% of admissions are readmissions (Daly and Craig, 2019). The majority of individuals who used Irish mental health services believed that AHDs would assist their recovery (Morrissey, 2015). AHDs provide an alternative response to mental health crises by moving from 'coercion to collaboration' (Bonnie, 2012). This can result in significant therapeutic and recovery benefits for the person. Thus, an AHD is believed to assist in the recovery

process by enabling individuals to express treatment preferences, develop capacity, acquire information and become empowered by the process (Bisson, 2009).

Under the 2015 Act, individuals who are involuntarily detained under the Mental Health Act 2001 or the Criminal Law (Insanity) Act are excluded from having their treatment decisions respected on an equal basis with others. An AHD can be taken into consideration, but it is not legally enforceable for mental health treatment decisions if a person is detained under this legislation (2015 Act, s. 85(7)(a)(b)). 13% of admissions to the Irish mental health system are involuntary. In 2019, a Private Member's Bill to remove the exclusion was proposed and, although this Bill lapsed with the dissolution of the Government, there are plans to resurrect this. Irish research suggests that the group who need AHDs the most to increase trust and respect are excluded from the legislation (Morrissey, 2015). This provision does not comply with the CRPD as it discriminates on the grounds of disability. Similar legislative provisions were litigated as discriminatory under the American with Disabilities Act in the US in 2003 (Hargrave v State of Vermont, No.2: 99-CV 128 [2001]; Hargrave v State of Vermont, 340 F 3d 27 [2nd Cir 2003]). After filing a legal challenge for differential treatment for failing to respect her AHD during involuntary commitment, Nancy Hargrave asserted 'it seems fundamentally unfair that I choose or refuse chemotherapy which is saving my life, but I don't have the same right to choose or refuse psychiatric medication.'

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#### AHDS: BENEFITS FOR HEALTH AND SOCIAL CARE PROFESSIONALS

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AHDs confer a range of benefits for health and social care professionals. While AHDs have not achieved high completion rates, they have succeeded in bringing about a paradigm shift in the therapeutic relationship (Ausilio, 2014). AHDs can promote trust and respect, and lead to enhanced outcomes (Summers and Barber, 2003; Priebe and McCabe, 2006). The most frequently cited motivation for using AHDs by Irish mental health professionals was enhancement of the therapeutic relationship (Morrissey, 2015). Lack of trust was a pervading theme for those who had been coerced (Morrissey, 2015). A relationship of trust and communication were common themes underlying AHD preferences (Morrissey, 2015; Ambrosini, 2012). A trusting therapeutic relationship is associated with more treatment requests than refusals (Swartz, 2006). AHDs also provide important information and clarity about the person's treatment preferences. The quality of communication improves decision-making, reduces the burden on professionals and leads to better care outcomes (Vahdat, 2014). The increased satisfaction from enhanced communication can also decrease litigation (Levinson, 1997). Legal liability was a major concern for professionals in an Irish study on AHDs (Morrissey, 2015). International research suggests there are very few cases against healthcare professionals for failing to abide by an AHD (Lynch, 2008). Despite professional concerns around treatment refusal, the evidence suggests that AHDs are rarely used to refuse all treatment and contain clear, valuable information consistent with clinical standards (Swanson, 2006; Reilly and Atkinson, '(2010); Srebnik, 2005). AHDs are

generally used to assist professionals make decisions or inform them of concerns (Elbogen, 2006). Participation and the reduced need for coercive interventions can increase staff satisfaction and morale and lead to cultural change in the health system (Ridley and Jones, 2002; Coney, 2004; Gregory, 2007).

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### AHDS: BENEFITS FOR FAMILY MEMBERS

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AHDS are also beneficial for family members. The use of AHDS can reduce the decision-making burden and stress on families, and are associated with fewer anxiety and depressive symptoms (Stein, 2013). Family members often become substitute decision-makers in healthcare crises, even though there is no legal basis for this under current Irish law. An AHD articulates what the person would or would not want in this situation, or through a trusted designated healthcare representative. This eases the decision-making burden on family members and healthcare professionals. A general values conversation is useful, as it can be difficult to specify particular treatments in advance (Carr and Luth, 2017). The timing of this conversation is also critical (Pfeifer, 2003). Often the conversation is triggered by a health crisis, when the person may be too distressed to make a decision. It is important, therefore, to have these conversations in advance of a health crisis, if possible.

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### AHDS: CHALLENGES AND OPPORTUNITIES

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While the implementation of AHDS presents many opportunities, it also poses significant challenges. International research suggests substantial barriers to AHD use in practice (Van Dorn, 2010). The barriers present the greatest challenge to AHD implementation in Ireland and other jurisdictions. Among the barriers to AHD usage are low completion rates. The international evidence suggests that completion rates are low among individuals with lower levels of education, women and younger people. AHDS tend to be used more by older adults from higher socio-economic backgrounds (Carr and Luth, 2017). The findings of an Irish study found one-third of individuals who used mental health services did not have anyone they trusted to communicate their wishes (Morrissey, 2015). The majority of individuals want and need support to develop an AHD (Morrissey, 2015). Ideally, support should be provided from an independent trained facilitator to prevent undue influence. The international evidence suggests that AHDS developed with facilitated support achieve significantly higher completion rates, are more responsive to the person's needs and contain more valuable information (Swanson, 2006; Elbogen, 2007).

Healthcare professional 'buy-in' is also needed to increase completion rates. Professionals can increase usage by encouraging individuals to develop an AHD and referring them for appropriate support for completion. The first step is for all healthcare professionals to develop their own AHD. Education and training are also needed. A recent study showed human rights training can lead to significant attitudinal change (20-40%) among healthcare professionals in relation to AHDS and supported decision-making (Morrissey, 2020). The

implementation of AHDs requires a cultural shift in the healthcare system. The renowned Gundersen Lutheran ‘Respecting Choices’ programme in Wisconsin has achieved over 90% completion and compliance rates through training on advance care planning (Hammes, 2010). Public awareness campaigns are also needed.

Other operational barriers also exist in relation to AHD implementation including accessing the document in crisis situations. These issues can be addressed, somewhat, through the provision of a central electronic registry, electronic medical records, crisis cards, and mobile applications. Example of mobile applications for advance care planning include the ACP Tools app (<https://acpdecisions.org/app/>). The AHD should also be reviewed on a regular basis to ensure it reflects the current preferences of the person. It is important for the person to discuss their wishes with the designated healthcare representative (DHR), so that they are aware of any changes. One of the major limitations of Irish legislation in its current format is the primacy of the instructions. The DHR can only give effect to AHD instructions under the ADMCA (s. 87(1)(b)). In other jurisdictions, the representative has wider scope to make decisions in accordance with the person’s wishes as they change over time (e.g. Virginia, Va Code s.54.1-2986.1(b)). Many experts suggest the most valuable part of the AHD is the relationship of trust between the person and the DHR, as it allows decisions to be made in accordance with the person’s changing preferences (Oliver, 2018; Sabatino). Another limitation is the prescriptive nature of the legislation, which requires the AHD instructions to be specific in relation to the circumstances in which they should apply (ADMCA, s. 85(2)(b)(c)). It is very difficult to be specific in relation to future treatment in the absence of a known medical condition or past mental health experience, and this leaves the validity of the AHD open to challenge. Few individuals are able to specify particular interventions, therefore, a general values conversation with a trusted DHR is often more useful (Carr and Luth, 2017). The legislation re-emphasises the importance of allowing a trusted DHR the authority to interpret the person’s will and preferences in accordance with their values in these circumstances.

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## CONCLUSION

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Despite the implementation challenges, AHDs are powerful communication tools, which enable us to respect the ‘voice’ of the person in healthcare and other decisions, and avoid the need for non-consensual treatment. AHDs are much more than legal statements completed at a single point in time, but a means of engaging with the ‘will and preferences’ of the person over a prolonged period. AHDs are measures, which support the articulation of wishes and values, and provide the person with an increased sense of control, respect and value. The most significant benefits are in the development process. The establishment of a strong ethos of respect for the ‘voice’ of the person is one of the most important aspects of AHDs. AHDs can help affect the cultural shift towards supported decision-making under the 2015 Act and help us to respect human rights in healthcare decision-making. This is beneficial for everyone. The first step is for ‘all of us’ is to start having a conversation around

our wishes and values. An AHD is way to have your ‘voice’ heard and respected. Have you had the conversation?

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## 5.2 Why Advance Planning Matters to Me: Personal and Professional Reflections

*Rosy Wilson*

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### MY BACKGROUND

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I grew up in Blackrock, Co. Dublin, studied in Trinity College Dublin then emigrated to London in 1960 where I worked as a College Lecturer and then as Access Development Officer with London Open College Federation, working with all sectors of adult, further and higher education to develop Access programmes to enable mature students coming from educationally disadvantaged backgrounds to enter and succeed in higher education. Our work covered the whole of Greater London. I was also bringing up our four children and helping my mother and stepfather as they grew older.

Although I have always been an anxious person, I never experienced any episodes of mental illness until I retired in my sixties and returned to Ireland, which I'd always hoped to do.

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### MY EXPERIENCE OF MENTAL ILLNESS AND HOSPITAL TREATMENT

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At the end of 2001, I had my first breakdown. I use this term because on each occasion this is what I experienced, a total breakdown of my 'normal' self and life. The diagnosis was deep depression with psychotic symptoms. My consultant on my third episode described it as like 'a massive heart attack to the brain', which my daughter found helpful.

My main symptom was an overwhelming sense of guilt that I was totally evil, had destroyed my four children, and also caused the Iraq War although I had joined the Dublin march against it. These were convictions, not thoughts or beliefs. My husband and sister, on my doctor's advice, committed me to a mental hospital where they were advised the best treatment was ECT. I had eight sessions, which calmed me down but badly affected my memory and reinforced my feeling of not coping. The truest account of this experience is my poem ECT, written shortly after leaving hospital.

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ECT

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*Men in white coats bend over her trolley,  
are your teeth false or all your own  
they're mostly crowned she says*

*her only memory of a month in there  
eight sessions under anaesthetic  
a sectioned patient.*

*Believe us you were very ill  
electric currents have switched  
your brain towards normal*

*take your pills, come to the clinic;  
but she needs to scrape up snatches  
of events, half-remembered words*

*like helicopter, dehydration. Her sister  
showed her a photo taken in hospital  
after she fell and her nose was broken  
two black eyes stare from hollows  
when she wakes up she can no longer  
reach underground caverns*

*where fears and dreams linger  
among stalagmites, stalactites  
currents washed them away*

*along with months of memories  
leaving a cavity she may not peer into  
nor fall down there again.*

For the next six years, I carried on with my poetry groups and work as a volunteer at Glencree Centre for Peace and Reconciliation, teaching English and Peace Studies and as a member of the Policy Council, as well as visits to and from my family in England.

In 2007, out of the blue, I had another breakdown and was admitted as a voluntary patient to the same hospital. It was clear if I hadn't agreed I would have been committed. This time, I again knew I had destroyed my four children and 'knew' that I was responsible for the downfall of the Peace Centre. I was not given ECT though offered it. Instead, too many pills continuing for years afterwards. The Mental Health Commission affirmed that 88% of patients in this hospital were over-medicated.

My third episode was in August 2017 when my doctor referred me to a different hospital where I remained until 2 February 2018. Here I was, convinced I was the most evil person ever lived, worse than Hitler or Stalin, that I'd destroyed my family, they were all out in the street, even the baby, being bullied and worse, that I'd taken away all the fresh water in the world, that I was using up all the oxygen so killing my roommates, that I'd murdered 3 close family members and several other psychotic illusions.

The consultant tried every form of medication but I wasn't improving, so he decided on ECT as last resort. I refused but the tribunal agreed with the consultant, so I was made an involuntary patient and received twelve sessions. For the last one, my consultant asked me to be voluntary and I agreed. After this I slowly recovered.

My experience of this hospital is of the great patience and kindness of nearly all the nurses, although I was so distressed that it felt like hell at the time. I receive very good aftercare with a psychologist, community consultant and an excellent community nurse who continues to call and visit two and a half years later and I am in my own home on minimum medication, as I requested. However, after three breakdowns I always fear another, which brings me to the importance of the 2015 Act and advance healthcare directives.

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#### MENTAL HEALTH CAMPAIGN WORK

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In 2000, we formed the Bray and N Wicklow Amnesty group and took part in the Amnesty Ireland mental health campaign 2003-2013, which informed us of the scant resources and need for reform of the Irish mental health system. We read a Vision for Change and were like many others hopeful of early improvement. In 2012, Amnesty invited me to take part in a Citizens' Jury where fourteen 'Experts by Experience' informed by legal and medical experts teased out issues related to the proposed capacity legislation related to the UN Convention of Human Rights for People with Disabilities, which Ireland had signed up to but could not ratify under current mental health provision. We learned the difference between legal capacity, which every citizen has, and mental capacity, which some people may

lose from time to time. We agreed that people's will and preferences expressed in advance healthcare directive (AHD) or elsewhere should be followed. In 2013, we completed the Report that was launched and distributed to considerable acclaim. Subsequently a group of us formed REE, Recovery Experts by Experience, who have campaigned and participated in all the work of the Disability Coalition based in NUI Galway.

Naively, I believed that once the 2015 Act was passed into law it would be binding. However, in July 2020 I learned the difference between 'enacted' and 'commenced'. How long can factions hold up a legal requirement to recognise the wishes of ordinary people regarding their treatment at critical times when we may not have the mental capacity to explain our wishes?

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## CONCLUSION

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In 2012, I drew up with my solicitor, approved by my doctor, an Advance Directive that includes this sentence 'Any mental health care that I require is to centre on rest, counselling and minimal short-term medication. In any episode treatment will assume my recovery and return to normal living. It is an illness, not a condition. I specifically never want to be subjected to ECT again.' My four children and my doctor all have copies but clearly this protection has not commenced. The present situation leaves many of us terrified and find the only protection is to stay well which, as my history shows, is not in our control.



## 5.3 Advance Care Planning and the Assisted Decision-Making (Capacity) Act 2015: A Perspective from the Irish Hospice Foundation

*Rebecca Lloyd and Deirdre Shanagher*

‘What do you mean? Why isn’t it in law? You just said there was a new law...’

Imagine the scene: We have brought together over 100 people in their community. A solicitor is giving advice on drawing up a will. The importance of creating an enduring power of attorney is highlighted. An advance healthcare directive (AHD) is explained. ‘Above all, it’s important you understand your rights and responsibilities. Please act. This is vital. Think Ahead. Think about what matters to you. Document your wishes,’ the solicitor says. We proceed to tell them about the things they can do to let those who are important to them know what they want and what they don’t want for their life and death. Finally, we proceed to inform them that we are still being governed by the Lunacy Regulation (Ireland) Act 1871 and all the information shared offers no certainty.

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### ADVANCE PLANNING AND ADVANCE CARE PLANNING

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The concept of planning ahead for life and death is not a new one. Although research in the area is largely carried out within healthcare, the concept is much broader and encompasses financial, legal, cultural and other personal areas (Irish Hospice Foundation, 2016). Advance Planning is generally regarded as a process, rather than a once-off event that enables people to think, record and share with others their wishes, values, beliefs and preferences so they are heard and understood, should a time come when they cannot speak for themselves (Irish Hospice Foundation, 2016). Unfortunately for many people, the concept of putting plans in place only comes into focus when they have been jolted by a diagnosis that brings living and dying into a new light. It is common at this point for people to be introduced to the topic of Advance Care Planning (ACP), which is a process of discussion and reflection about goals, values and preferences for future treatment in the context of an anticipated deterioration in a person’s condition with loss of capacity to make decisions and communicate these to others (HSE, 2014).

Sometimes, within healthcare, conversations take place about people's wishes and preferences for future care and these discussions are documented in an Advance Care Plan. Some people are advised to go away from the healthcare environment to 'put affairs in order'. For some people, this means writing a will or creating an enduring power of attorney. Some people wish to be more specific and seriously consider what treatments they would not like to receive in the future and write these down in an AHD. Although there is common law jurisprudence (Supreme Court judgment in *Re a Ward of Court (No2)* [1996] 2 IR 79) to support the use of AHDs in Ireland, there is little guidance available to health and social care professionals with regard to helping people write an AHD and/or honouring an AHD if they are presented with one. This means people who have put a lot of thought and energy into the process, who have been courageous enough to think about their wishes and preferences and record them are not guaranteed their wishes as autonomous individuals will be respected if they are unable to speak for themselves in the future. It also places health and social care professionals in a precarious situation where they could be presented with an AHD and are forced to make a judgement on the validity and applicability of the document as well as on the competency of the person when they wrote it.

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#### PLANNING AHEAD AND THE IRISH HOSPICE FOUNDATION

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For many years, the Irish Hospice Foundation (IHF) has supported the concept of planning ahead for life and for death. The Forum on End-of-Life in Ireland (Forum) was established by the IHF in 2009. The Forum aimed to raise awareness and promote public debate on issues relating to dying, death and bereavement. The flagship programme of the Forum was Think Ahead, an initiative designed to facilitate people to discuss and record their preferences for end of life. The Think Ahead form was born. Since 2009, it has gone through testing and refinement to make it into a more user-friendly document. It is a planning tool that allows people to think about and plan for all aspects of their end of life by capturing health preferences, their views on life-sustaining treatment, their thoughts on CPR and organ donation, their legal and financial information and their funeral and burial arrangements (Irish Hospice Foundation, 2016). An AHD is included in the form and a public engagement initiative to support the use of the form is being rolled out. Over 80,000 Think Ahead forms are now in circulation and requests for the form are received regularly from a range of individuals and groups including: Safeguarding Ireland, SAGE Advocacy, Age Friendly Ireland, Citizens Advice Centres, Active Retirement Ireland, Men's Sheds, Irish Cancer Society, Alzheimer Society of Ireland, Irish Heart Foundation, Family Carers Ireland, GP surgeries and solicitors nationwide.

The experience of the IHF's national public engagement programme focused on thinking ahead for end of life shows there is evidently a desire for Irish people to engage with the topic of Advance Planning. This was confirmed in 2016 when the IHF carried out a survey of people in relation to dying, death and bereavement. Nearly 3,000 people told the IHF what they wanted for their end of life. This work is synthesised in the People's Charter on

Dying, Death and Bereavement. Of significance is line two of the Charter: ‘I can prepare for what lies ahead’ (Irish Hospice Foundation, 2016). What is important about the Charter is that it captures what is important to people as individuals and for the people that matter to them. It also helps us imagine a brighter future, an Ireland that is more compassionate, a place that’s great to live and great to die in.

As well as engaging with the public on the topic of planning ahead, the IHF has engaged with other NGOs as well as people living with long-term life-limiting illnesses. Resources have been developed that address the topic of planning ahead in the context of living with long-term life-limiting illnesses, including heart failure, dementia, neurological illnesses and chronic obstructive pulmonary disease (COPD). People with these illnesses have been involved in the development of these resources and have welcomed the opportunity to engage with the topic of ACP and develop information previously perceived to be difficult or too emotive for them. We have found that most people want to have conversations with their families and with the health and social care professionals they engage with (Korn, et al, 2016). This is supported by recent Irish research that indicates that most older people want their general practitioner to raise the issue of ACP with them (Lombard, 2020).

Thinking and planning ahead is a process that moves across a spectrum from thinking about wishes and preferences, to having conversations and then in some cases recording the wishes and preferences expressed. Sometimes this process can happen with family members, friends, solicitors and/or health and social care professionals. Due to the nature of this process it is important that all people, be it in their personal or professional lives are supported with regard to having these conversations. Unfortunately, we are aware that some health and social care professionals hold a lot of uncertainty when the topic of Advance Planning arises. In its submission to the Department of Health on the draft general scheme for AHDs, the Royal College of Physicians of Ireland expressed ‘significant reservations’ about ACP where they include legally-binding directives (RCPI, 2014). Healthcare staff have also been found to lack confidence regarding ACP and report a lack of training in this area. As a result, they don’t know when to start the process and are uncertain about the types of interventions that work best (Gott et al, 2009, Almack et al, 2012, and Baughman et al, 2014). It has also been pointed out that discussing bad news is perceived by some health and social care professionals as jeopardising the clinician-client relationship and could result in diminished hope for people (Sleeman, 2013).

Our work with health and social care professionals via our Hospice Friendly Hospitals programme, CEOL programme as well as our Primary Palliative Care programme supports this research. These programmes aim to support health and social care professionals to enhance the quality of end-of-life care they deliver. An important aspect of this is addressing the topic of ACP. We know through our work that most health and social care professionals want to have meaningful conversations with people and be able to help them plan ahead but are not equipped with the skills to engage in or capture these important conversations.

Our work with health and social care professionals in relation to communication is strongly linked to the concept of ACP. By enabling more people to communicate compassionately in all care settings and to be able to recognise when people want to engage in meaningful conversation, there is an opportunity for people to be provided with a real chance to engage in some form of Advance Planning. Indeed, the overwhelming evidence on ACP suggests it is a positive feature of healthcare and if carried out well can generate better quality of care to include better end-of-life care (Dixon et al, 2018). Additionally, ACP accrues benefits for more than just the individual, for example bereaved families of older people who engaged in ACP report lower levels of stress, anxiety and depression than those who had not engaged with it. (Detering et al, 2010). Both health and social care professionals and people who wish to plan ahead exist in a time of uncertainty, a limbo between 1871 legislation and 2015 legislation, legislation that is here but not fully here.

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#### ADVANCE PLANNING AND THE ASSISTED DECISION- MAKING (CAPACITY) ACT 2015

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A greater, more positive vision for people and health and social care professionals that want to engage with ACP is put forward via the Assisted Decision-Making (Capacity) Act 2015 (2015 Act). This legislation, with its roots in human rights aims to uphold people's autonomy and right to self-determination. In doing so, it addresses Advance Planning via the legal processes of enduring powers of attorney and AHDs. Both legal agreements allow a person to make plans for their future, should a time come when they lack the capacity to make decisions for themselves.

The principles supporting these legal agreements are already set out in guidance that is available to health and social care professionals via the HSE National Consent Policy (2013 as amended), the Medical Council Guidance 2016 as well as the NMBI Code of Professional Conduct for Nurses and Midwives 2014. However, what is lacking is clear guidance about these legal arrangements for both health and social care professionals and for people who wish to plan ahead. Clarity and some guidance are required about the various scenarios that arise in practice and the ethical dilemmas that could result. For example, we know documentation about Do Not Attempt Resuscitation Orders is not transferrable across settings and that many first responders believe they are mandated to deliver cardiopulmonary resuscitation (Shanagher et al, 2016). Additionally, many health and social care professionals have also expressed concern about the validity of documents or even about knowing where to go to find out if a person has an AHD.

The 2015 Act, when fully commenced, can provide certainty for all people in relation to upholding people's rights to self-determination and autonomy. It indicates that a register for AHDs may be established. It is abundantly clear that without a register for AHDs uncertainty will prevail and people who have been courageous enough to plan ahead and document their wishes and preferences will not be guaranteed that their wishes will even be

accessible to view by the people who will be caring for them. Additionally, health and social care professionals will remain in a vacuum of uncertainty not knowing where to check if an AHD exists or if it is valid and applicable.

As a forward-thinking nation, we had a vision in Ireland for a better future for all people when the UN Convention of the Rights of Persons with Disabilities was signed in 2007 and was ratified in 2018. However, we have failed so far to make this a reality. In doing so, all we have created is a sense of confusion, uncertainty, anger and inequality.

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## CONCLUSION

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Through our work at the IHF, we have met many people at various stages of life, living with or without long-term life-limiting illnesses, who have been brave enough to open their hearts and minds and consider what they want for their lives and end of life. These people who have been brave enough to think about what they want, have shared their preferences and have planned for their future are left feeling distressed worried, angry and let down by a lack of progress and a lack of certainty. We have also met many health and social care professionals who want certainty for themselves at work, who want to be able to offer certainty to the people they care for without fear of litigation or negative repercussions.

We all have a responsibility to ensure each citizen of Ireland is heard and seen as a person with views, values, wishes and opinions about the care they wish to receive or wish not to receive. Real people with real lives, real opinions, real beliefs and real values are the forgotten people in all of this. Policies and professional guidance to date cannot offer certainty. Neither the IHF nor any other organisation can offer certainty. Signature and ratification of the CRPD cannot offer certainty. Only the letter of the law can. Law not partly in force but fully in force. A lack of certainty makes people nervous in a world already overflowing with uncertainty and worry. On behalf of ourselves as individuals and the people we meet, we need this legislation commenced in full. To finish with a direct quote from a person we met recently:

‘Why bother with a law if there is no intention to make it law?’

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## 5.4 End-of-Life Care – Ensuring the Voice of the Individual is Heard and Acted on

*Brendan O’Shea*

Ensuring the voice of the individual is heard and acted on in the course of end of life planning and care is a key concern for them, for their families, health care professionals and social carers. This chapter reflects the view from general practice, which is important in the context of Irish healthcare. Most doctor/patient and nurse/patient interactions occur in general practice within the Irish health system. The perspective of general practice is that of personalised medical care, provided for individuals and households, in communities, over years and through a series of life events, including onset of long-term medical conditions, supporting and guiding their progression, through the process of dying, death and bereavement.

In the context of general practice, it is particularly important that people believe and feel their expressed end-of-life wishes are considered, recorded and as far as practically possible, and acted on. We have a lot done on this, but there is more to do.

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### WHAT MIGHT GOOD END OF LIFE PLANNING LOOK LIKE?

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Our society is only now moving back towards a better culture and societal acceptance of death as an important fact of life. When caring for people that we are either fond of, or feel responsible for, sometimes it is easier to avoid and ignore difficult topics, which are wrongly assumed to be upsetting. All of this is most recently described for clinicians and people by Kathryn Mannix (2019). Sometimes, our own level of busyness, in a health care system known to be understaffed in terms of clinical health care professionals, can be a reason to shirk important discussions. Sometimes complex and fragmented care also leads to avoiding conversations (surely somebody else will have the discussion?). Legal uncertainties can cause us to phobically avoid or defer having conversations, which we often erroneously believe to be complex (but when we start having them, they frequently are not anything as complex as we might fear!).

A further reason we don’t think ahead is that end-of-life care is not actually a professional value. When we are designing systems of integrated care for diabetes, heart failure or complex neurological conditions, we never factor in the reality that all of these people will die, and sometimes sooner rather than later. Underlying all of this is a strong sense of professional inexperience and unease. But in Ireland, many of us now believe that this inexperience and unease is improving. Many of us who are concerned about this area of



care look forward to the enactment of the Assisted Decision-Making (Capacity) Act 2015, which will require us all to modify and improve the way that we are consulting around this important issue. Our collective experience will grow. We will get better at this.

In practical terms, in the present however, the sum total of all of these factors relating to why we don't think ahead causes us to procrastinate. When we procrastinate, people for whom we care for drift inevitably towards crises, which, were we looking out for them, we could anticipate so much better and make provision for, in a way that does reflect the desires, the concerns and the expressed wishes of people under our care, who are moving towards an accelerated deterioration, with death and bereavement as inevitable and predictable outcomes.

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#### WHY WE DON'T THINK AHEAD

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Our society is only now moving back towards a better culture and societal acceptance of death as an important fact of life. When caring for people that we are either fond of, or feel responsible for, sometimes it is easier to avoid and ignore difficult topics, which are wrongly assumed to be upsetting. All of this is most recently described for clinicians and people by Kathryn Mannix (2019). Sometimes, our own level of busyness, in a health care system known to be understaffed in terms of clinical health care professionals, can be a reason to shirk important discussions. Sometimes complex and fragmented care also leads to avoiding conversations (surely somebody else will have the discussion?). Legal uncertainties can cause us to phobically avoid or defer having conversations, which we often erroneously believe to be complex (but when we start having them, they frequently are not anything as complex as we might fear!).

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### WHY DO WE NEED TO THINK AHEAD?

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Thinking ahead and having these conversations reduces the level of avoidable uncertainty both for the individual, their social carers and indeed for your own clinical service. Everybody benefits, as uncertainty is frequently associated with anxiety and suffering on both sides of the consultation. A second pragmatic reason we need to think ahead is that thinking ahead reduces costs for the health system. If costs can be reduced in this area of care, the funding can be used in other areas of care. This is demonstrated in the work of Dr Katherine Sleeman, who has been researching on the population health-based end-of-life planning in the NHS during the last decade. Key findings from her extensive research include that domiciliary-based palliative care extends life span, is preferred by more people, and is significantly less expensive than hospital-based palliative care.

Finally, a very simple reason to think ahead in our consulting is that once you engage in it, and put the toe in the water, you will develop a level of expertise in a relatively short period of time (there are a lot of people dying out there who need your involvement!).

So, the next questions are as follows: When do you have these conversations? How do you have them? Where do you have them? And what do you do then?

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### WHEN TO THINK AHEAD?

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The best time to think ahead is today. Think Ahead ([www.thinkahead.ie](http://www.thinkahead.ie)) can be viewed in the vernacular, but it is important to understand that it is also an end-of-life planning tool, now being used in Ireland by increasing numbers of people since 2012. It was a key and considered output of The National Forum on End of Life, itself established by the Oireachtas. So, if you haven't done so, you should obtain your own personal copy of Think Ahead from the Irish Hospice Foundation ([www.ihf.ie](http://www.ihf.ie)) and complete it. You will die, and anecdotally many of us feel that once we complete this exercise for ourselves in relation to our death, it actually has a positive impact on our life! More importantly, if you intend using Think Ahead in your consulting, either as a nurse, as an allied health care professional or as a registered medical practitioner, you will use it with greater conviction and with more credibility in the consultation if you actually understand it, so complete it for yourself. There is a case to be made that Think Ahead should be completed by everybody on reaching 50 years of age, or shortly after they are diagnosed with the common comorbidities of middle age, or indeed any potentially life-limiting condition. At the heart of Think Ahead are the questions and decisions known to be important for most people, together with background information relevant to informing and addressing these questions.

We have conducted research on the use of Think Ahead in the general practice setting at the Trinity College Dublin Department of Public Health and Primary Care, and the TCD HSE GP Training Scheme, including two studies that are worthwhile detailing. 'Are

we ready to Think Ahead - an acceptability study using an innovative end of life planning tool' (O'Shea et al, 2016), where Think Ahead was systematically administered to a sample of 40- to 70-year-old people attending for routine care in the general practice setting. These were people who were clinically well, they were attending for a diabetic review for example, and they were given Think Ahead. They were subsequently given a telephone survey at 2 and 4 weeks for their responses. Their responses were overwhelmingly positive; over three-quarters of them indicated 'no significant upset' and very high proportions of them were very positive about the experience of having Think Ahead administered in the general practice setting in this manner. Over three-quarters of them subsequently had discussions with their family as a result of being given Think Ahead in this way.

Encouraged by this, we conducted a second study using a similar protocol on people who were likely to die within the next 6 months, using the SPICT prognosticator tool (Dunphy et al, 2016). Again, we found very high levels of acceptability in this far more fragile sample. However, we found a lower level of engagement in terms of completing the Think Ahead tool. This leads us to believe that, in a practical way, delivering Think Ahead to a younger (well, actually middle-aged) population is more effective in terms of encouraging people to begin to have the conversation with themselves, earlier, and with their families. Leaving it to later, with an older more medically complex and frailer group was acceptable but not as effective in terms of their level of engagement. This is the approach we recommend in the years ahead – begin the discussions earlier.

Key learning points from our two studies are that Think Ahead is very effective at having the work done, with the family, outside of the consultation. People to whom this was given to in consultation usually worked through it themselves, and frequently initiated discussions with their social care network, and then returned to practice with very particular and focused questions, which in hindsight, were easy and quick to resolve for the GP. Families, therefore, and care networks are actually really efficient at making what we consider to be difficult decisions, once they are provided with guidance, direction and the availability of skilled healthcare professionals who can answer their remaining focused queries. This is a different place from stressed specialist care, traumatised families, and an actively dying individual, struggling to work out important issues in the acute hospital setting.

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## IMPROVING THE CARE IN FUTURE

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At the Irish College of General Practitioners, we have devised an e-learning module on the use of Think Ahead with the support of The Irish Hospice Foundation, which is currently now being reviewed, but has been running on the ICGP e-learning platform for five years.

The Irish Hospice Foundation, in conjunction with COPD Ireland, the Irish Heart Foundation and the Neurological Alliance of Ireland, have devised high-quality leaflets

suitable for people with these important conditions (COPD, heart failure and progressive neurological conditions), which positively explore the topic of end-of-life planning, and detail the use of Think Ahead. Think Ahead is also detailed in the ICGP Dementia Guidelines (2019, Foley et al). Full details regarding primary care end-of-life planning resources are available through the Irish Hospice Foundation ([www.irishhospicefoundation.ie](http://www.irishhospicefoundation.ie)). CEOL (Compassion at End of Life) is an Irish Hospice Foundation learning program designed to upskill all nursing home staff in supporting end-of-life care planning, now delivered on line in the post-COVID-19 era.

You can obtain copies of Think Ahead for your own clinical service by directly contacting the Irish Hospice Foundation.

Don't procrastinate.

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#### ACKNOWLEDGEMENTS

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People attending for medical care, colleagues at the TCD HSE GP Training Scheme, and the team at the Irish Hospice Foundation for all they do.

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## 5.5 Preparing for the Future: Advance Planning and Disabilities

*Suzy Byrne*

In 2015, I was admitted to hospital for emergency surgery. I named my partner of nine years as my next of kin, knowing that it had no legal status but expecting that my wishes would be respected and that she would be the first point of contact. We were not married and had not yet entered into a civil partnership. I was a disabled adult in my 40s and had been informed of the risks involved in the surgery and why I needed it and my consent had been sought for the surgery and given and understood. A nursing care plan was prepared and information on my supports at home were part of the plan and information requested and obtained. On admission I felt informed and respected. Surely my wishes as to whom the hospital should speak to would be followed if I was not in a position to tell people close to me what was going on. I knew I did not have an enduring power of attorney but I did trust the clinicians making the decisions – I just wanted my life and points of contact to be respected in the process.

However, I had not been informed that there was a possibility I could be placed in ICU following the surgery. My partner therefore was extremely concerned and no one explained what was going on – neither about my condition, nor why I needed to be in ICU or the delay in getting there from the recovery room where I was being held. Twice the request for information was refused. I was not returned to the ward I was initially admitted to and nobody would tell Karen why. This breakdown in communication distressed her hugely. Nurses told her that they could not discuss my condition even though I had set out in the care plan what I wanted to happen. Eventually my father (who I had not mentioned at any stage in my hospital treatment or admission) thankfully got access for my partner simply by stating his relationship to me – rather than anything I had indicated previously in terms of my wishes. The entire experience has led me to further reflect on decision-making in all arenas and the way systems respond and make assumptions.

In the previous eight years, I had worked to support other disabled people in decision-making, sometimes in relation to medical decisions and who they wished to support them in those situations. I had used my personal experiences of healthcare together with legislation and human rights frameworks to support people to be listened to by medical professionals, who often made assumptions regarding capacity based on where the person lived or what

their underlying condition was. I had witnessed people who had capacity and knowledge to make decisions being dismissed by doctors and nurses due to their disability. This situation also exists in banking, legal matters and other engagement with professionals – even when someone tries to enforce their rights to a refund as a consumer. Now here I was in a position that my wishes were not listened to and hospital staff were making decisions on my behalf without my consent because they could. I should not have been surprised but I was. The experience has further strengthened my resolve that those who require decision-making supports are heard but more fundamentally, that everyone should be assumed to be able to make decisions or be supported to make them and those decisions should be respected.

With an Advance Healthcare Directive in place, my wishes regarding my care would be clear should I not be able to make decisions. I am aware that clinical decision-making will take precedence in relation to my requests for treatment, but my wishes would be set out formally. I would be able to indicate who I wished to make decisions for me should I not be able to and the person appointed would be able to use the directive and contents where appropriate.

Later in 2015, Karen and I entered into a civil partnership, and at the dinner following the ceremony (referred to as ‘the do’) I spoke about the injustice I felt that my wishes and directions were not respected while in hospital. I do not believe that a person should have to be married to someone to have their wishes respected. Neither do I think it is fair that a person’s family member is able to make decisions on behalf of or receive information regarding someone unless it is what the person wished to happen or they are formally appointed to do so. As a chronically ill person, subsequent interactions with hospitals have been approached nervously and it remains an issue of unneeded stress when remembering what happened before. I look forward to the full commencement of the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) and being able to prepare for future situations personally, but also for everyone else who may need decision-making support.

While the delays to commencing the 2015 Act have been often frustrating, I believe that it is an important time in preparing and upskilling everyone who will be involved in such fundamental and welcome change in how people are supported to live their lives.

Disabled people have been waiting decades for recognition of our autonomy in decision-making and the need for assistance where and when it is needed, which focuses on our will and preference and agency as individuals. Disabled people need to be valued as rights holders from the off rather than the property or duty of others.

The inputs of disabled people and others who will be supported by the 2015 Act into the training and support of those making decisions and ensuring access to supports and services is vital. Disabled people must have direct input into the organisations responsible

for supporting us, be that the Decision Support Service, the Oireachtas, disability support services or those commissioning those services.

Medical and legal professionals need knowledge and information about communication, community supports that are possible and real lived experiences to counter the models and imagery of disability, which have emerged from a disabling and institutional society. Too often, the information provided to decision-makers is based on medical and functional reports devoid of what is possible, indeed what could be possible and should be provided to assist in all aspects of our lives.

There are 640,000 people with disabilities in Ireland – less than 10,000 live in institutional care. However, we still do not participate in all aspects of life and community and are featured as recipients of care or users of particular services rather than members of community. The policy, culture and practice of safeguarding must continue to respect risk-taking and differences in communication and independence and agency of all. The institutional barriers and paternalism endemic in society needs to be tackled so that the guiding principles of the legislation are fully expedited.

If we are unable to communicate our wishes directly, there have to be real efforts and checks made to ensure our wishes, intentions and needs are heard and recognised by those appointed. It may be that our friends, neighbours and staff who support us will know more about this than our families – those views should be included and checked on, and assumptions not made. Time also needs to be taken and respected as a resource – time to get to know us, to allow us to express our wishes, to experience life so that we can make the decisions that need to be made.

We have much work to do and now is the time to do it. We've had decades of assumptions and we must ensure that these assumptions are not replaced by new ones with a fully commenced law so that the spirit of the law is everywhere and society sees it in action.

## 5.6 Advance Healthcare Directives: Protecting the Rights and Values of the Person with Schizophrenia

*Michael John Norton, Margaret Sweeney*

‘The concept of recovery is rooted in the simple yet profound realisation that people who have been diagnosed with mental illness are human beings.’

—Patricia Deegan

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### INTRODUCTION

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This chapter aims to illustrate a narrative from two individuals who have used the services in the past and are presently in recovery from schizophrenia, a condition that consists of abnormal interpretation of reality which presents itself in the form of hallucinations, delusions and disordered thinking (American Psychiatric Association 2013). It affects approximately 4.6 per 1000 population (Bhugra 2005) and is classified as an Axis I mental disorder, suggesting that persons with this condition are likely to have long-term needs that are only available through secondary services. Due to the poor prognosis associated with the condition, along with the high likelihood of relapse, the rights and values of these service users, especially in acute phases of ill health, are often neglected. However, the recovery philosophy that has gripped the western world has provided those in receipt of these services a voice.

The authors of this chapter are service users with a diagnosis of schizophrenia. Margaret worked as a psychiatric nurse for fourteen years. However, in 1997, at the prime of her long-standing career and as a wife to Padraig and a mother of two children, she became unwell and was hospitalised several times over a six-year period in what was then a psychiatric asylum – a practice that was prevalent in Ireland at that time. Michael, although in receipt of the same service, became unwell in a different era in mental health care in Ireland. Before becoming unwell, Michael was training to be a general nurse. In 2011, he was hospitalised in a psychiatric unit adjacent to a general hospital. Although their experiences differ in many ways and are literally decades apart, both have felt the powerlessness associated with inpatient psychiatric treatment and the lack of control over what was happening in their lives.

In Ireland, the mental health services have made massive adjustments in recent years. Since 2013, the services began the transition, as discussed in ‘A Vision for Change’, to a more



recovery-orientated service. This became apparent through the involvement of service users in all aspects of services and the uptake of recovery principles, particularly co-production. Co-production is a process where service users, their family members and carers enter a space in which they can work alongside service providers in an equal and reciprocal capacity to influence aspects of service provision (Norton 2019). As services developed in the years that followed, the service users' voice and lived knowledge became recognised as a valuable resource.

In 2015, society turned a corner in relation to their thinking through the publication of the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act). The purpose of this was to enshrine in law the right, opinions, and values of service users when they are deemed incapacitated to make informed decisions about their care. This paved the way for services to realise the importance of the service user's voice in the delivery of mental health care. One way this can be achieved is through the development of a Wellness Recovery Action Plan, otherwise known as WRAP.

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### WELLNESS RECOVERY ACTION PLANNING [WRAP]

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Wellness Recovery Action Planning, also known as WRAP, was developed by a group of peers in Vermont in 1997. This project was spearheaded by Mary Ellen Copeland, who later received a PhD for her study on mental health recovery in which WRAP was based. According to Mary Ellen Copeland:

‘WRAP is a self-determined management programme that people use...to get through difficult times, both mental health issues or any other kind of life issues, and to live day by day to keep healthy and well and happy.’

By undertaking WRAP, participants learn various aspects of wellness and unwellness on their own recovery journey. However, in relation to the 2015 Act, the true benefit of the programme is achieved through the ‘crisis planning’ phase. This is essentially what we call an advance healthcare directive – a necessary component of anyone's recovery journey. However, it was one that was not present during the authors' hospitalisations. According to the 2015 Act, an advance healthcare directive is:

‘an advance expression made by the person...of his or her will and preference concerning treatment decisions that may arise in respect of him or her if he or she subsequently lacks capacity.’

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## REFLECTIONS

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Now that we have established a picture of service development and examined how services are starting to listen to the voices of service users, the authors wish to express the potential impact of the 2015 Act on their own lives and how it would make a positive difference to them and their families if such advance healthcare directives, enshrined in the 2015 Act, were available to them.

### **Margaret's Reflections**

For me, Margaret Sweeney, this Act means so much for my peace of mind. It means that, in the future, if I lack capacity and am unable to make decisions about my life, that I will have the opportunity to prepare beforehand and nominate a significant other, in my case, my husband, Pdraig, to carry out my decisions and wishes. As a person who has a condition called paranoid schizophrenia, it means that, unlike before, when I was challenged by my mental health 22 years ago, where my children's care came into question, my home was being sold, there was even the question should I be made a Ward of Court and have no control over my affairs and presently as a married women with two adult children and my own home, this Act means that I can make decisions, in law, about my affairs.

During a period of severe paranoia, I have in the past wanted to sell my home, leave my husband, and make other life decisions that were driven by my mental state. All of which I would have regretted so much now that I have recovered. This Act, I feel, is important when I am deemed incapable of making decisions for myself. I know, with this Act, I will be assisted as much as possible to make decisions for myself. Even as I get older, there will be more decisions about my physical and mental health that will have to be addressed – for example, due to the medication I presently take, due to physical reasons I may have to come off this medication – and now I have time to discuss, educate and prepare myself for when I am in that position and if I relapse into a state of psychosis, my decisions and wishes will be adhered to and I will have informed choices of my care.

This Act, overall, protects me and gives me a sense of control over what happens to me in my life. I want to be the driver in my life. Having a vulnerability to psychosis makes me, at certain stages of my life, move from a position of capability, possibility and ability to a position of disability, dependency and mental confusion. That is why this Act means so much to me. So that during those vulnerable periods of my life, my wishes are protected.

There is also the chance, during a period of psychosis, you could lose yourself, your sense of yourself, your values and the deterioration of your personality. That's why it is important to be prepared for these times, because with the right approach and empowering care recovery is possible and setbacks are seen as new learning and education and keeping my life intact during periods of unwellness.

## Michael's Reflections

In my life, I have had the unique opportunity of seeing both sides of the coin when it comes to capacity, both from my past professional experiences and my personal experiences of mental health and recovery. During my time as a general nurse, and more recently as a peer support worker, I have seen many instances of people in a state where capacity is either lost or under question. In many of these situations, particularly in older adult services, a person was made a Ward of Court and all decisions passed on to their next of kin which, at times, was not the person's wishes and not in their best interests. From my general nursing days, if the person was unconscious or in a position whereby they couldn't express their wishes, the decision, in the absence of next of kin, was often left to the doctor. Obviously, this was not ideal but this has happened and continues to happen to this day.

Equally to this, as a service user of the mental health services, I have experienced times, specifically when being treated as an inpatient, where my wishes were not respected. A lot of the time, this was due to another disorder or label they put on me: Emotionally Unstable Personality Disorder (EUPD). When I was first hospitalised, immediately after discharge, I was told by my treating team and parents to return to my nursing education, which I did, despite the fact I knew deep inside of me that this was not right. I knew I was not safe or even ready for this to happen. But I felt, unknowingly to my parents and treating team, under extreme pressure to comply, as this is what was expected of me both at home and in society.

Through my recovery, I have discovered WRAP, which was invaluable to both my recovery and my sense of autonomy. For the first time, I could put down my wishes into a document that would allow my parents, siblings and significant others to know what exactly works for me along with what I felt didn't help when I was in a place of unwellness. This truly empowered me, and provided a basis in which I could work on my recovery.

This Act would be so important to both myself and my fellow service users as it would allow such documents, including the WRAP crisis plan, to become a legally binding document. This would mean that if I was to become unwell again, my treating team would have to put my will and preferences on the table as a viable option thus giving me a voice. It would also mean that I can choose how I want to be treated, and due to my employment within the health service, it will also provide me with the freedom, which I didn't have before, to decide who exactly treats me (i.e. someone who knows me from my work or someone completely unbiased). Overall, from my work and personal experiences, I can truly see the positive and empowering difference this act will make to the way service users experience the service going forward.

As demonstrated within these reflections, the absence of the Act has somewhat of a negative effect in terms of both authors' recovery to this point. It is clear from these reflections that a call should be made for this Act to be enacted as quickly as possible so that the wishes,

opinions, values and perspectives of the individual are protected and considered within treatment regimens going forward.

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## CONCLUSION

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In this chapter, the importance of the voice of lived experience of people with schizophrenia in their own treatment and recovery journeys is demonstrated. It highlights how mental health service in Ireland has come to a point where lived experience and the service users' voice have become a knowledge subset that is on par with traditional learned knowledge when formulating decisions on treatment. However, to fully create a service that is centred on lived experience, one must allow such avenues that give voice to those who are incapacitated to be fully enacted and further protected within future governmental policy.

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## 6 Challenges and Opportunities for Health and Social Care Professionals

### 6.1 The Assisted Decision-Making Capacity Act, 2015: Reflections for the Profession of Social Work

*Sarah Donnelly*

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#### INTRODUCTION

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In recent years there has been a move towards a more human rights-based approach to the issue of supported and assisted decision-making (ADM), with current legislative changes strengthening the formal right of all citizens to participate in care planning and decision-making. The Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) ratifies the United Nations Convention on the Rights of People with Disabilities (UNCRPD) in the Irish context, and has established a legal framework for ADM. However, debates remain as to how ADM, as envisaged by the UNCRPD, should be interpreted and applied in practice raising important considerations for social workers and other health and social care professionals (HSCPs) who will be required to assist and support those whose decision-making capacity may be impaired or compromised. This chapter will reflect on the practice implications, challenges, and barriers and enablers to the full implementation of the Act for the social work profession. In particular, it will focus on issues of human rights and emancipatory social work practice.

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#### SOCIAL WORK, HUMAN RIGHTS AND ADM

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Advocating and upholding human rights and social justice are fundamental to social work policy and practice so it may be assumed that values and principles of the Act align strongly with the underlying values and principles of the profession. The International Federation of Social Workers highlights the overarching principles for the profession in terms of the inherent worth and dignity of human beings, doing no harm, respect for diversity and upholding human rights and social justice (IFSW, 2014). In Ireland, the national social work code of ethics states that all social workers must promote social justice in practice, through: challenging negative discrimination and

unjust policies and practices; respecting diversity; advocating for the fair distribution of resources based on identified levels of risk/need; and, working towards social inclusion (CORU, 2019). It is argued that a strong focus on systems theory (Bronfenbrenner, 2005) enables the profession to pay attention to the microsystem at the level of the individual (for example, in terms of the will and preferences of the individual), the exosystem (which encompasses family, community and local services), the meso system (which examines relationships and connections), the chronosystem (which acknowledges changes over time) and finally the macrosystem (including social and cultural values all of which contribute to a person-in-environment) (Germain and Glitterman, 1980). Social workers are also expected to embrace a strengths perspective (Saleeby, 1992), focusing on the client's 'ability' rather than 'inability'. Bronfenbrenner's ideas are most helpful to social workers within the context of ADM and the understanding that a person-process-context-time approach should be adopted.

Practitioners, however, can face a range of challenges and dilemmas in applying ADM principles:

- In managing potentially conflicting interests between the rights of clients and their carers
- In delivering both care and control functions
- In protecting the interests of the people with whom they work yet dealing with agency and societal expectations about managing risk
- In providing services that are often inadequately resourced (IFSW, 2014).

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#### PROMOTING PARTICIPATION AND AUTONOMY

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Decision-making often becomes more complex and challenging for some individuals who may have multiple health and care needs, a physical, sensory or cognitive disability, social problems such as housing, or addictions issues meaning that the capacity to self-manage and to make decisions is made more difficult (Sinclair et al. 2019). ADM has specific legal expectations, which assumes that relevant individuals should be placed at the centre of decision-making processes, in terms of will and preferences. Social workers, as with other professionals, should provide appropriate assistance which maximises the decision-making capacity of a relevant individual; this can be achieved by offering different types of decision-making supports. A significant challenge to the full implementation of ADM is the legacy of a paternalistic culture of care and the overemphasis of biomedical models which, historically, justified surrogate decision-making between HSCPs and family members (Baker, 2017; Donnelly et al. 2019). Despite an increased policy emphasis on ensuring that all individuals should be central to decision-making processes, Irish social workers report that some people are still excluded from decision-making due to cognitive impairment or

dementia (Donnelly et al. 2019). In order for the 2015 Act to be fully implemented, these attitudes and assumptions need to be challenged in order that the individual's voice and participation in decision-making is ensured through a purposeful, supported decision-making environment. Early engagement with, and elicitation of a person's values and preferences, is regarded as key to the ADM process (Davies et al. 2019), and social workers have been recognised as being well positioned to take a leadership role in important processes such as advance care planning (Otis-Green et al., 2019). There are, however, clear tensions for the social work profession between the commitment in the 2015 Act to uphold 'will and preference' and the CORU Code of Ethics, which emphasises the need to adhere to notions of 'best interests' (often viewed to be an older, paternalistic approach in this field). The 'best interest' principle appears to contradict contemporary practices characterised in requirements of the Act as described above.

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#### THERAPEUTIC RELATIONSHIPS, SOCIAL ENVIRONMENT AND INTERPROFESSIONAL COLLABORATION

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Social workers seek to develop and strengthen therapeutic relationships with the people they work with and their families, often contextualised in systems and person-in-environment approaches. A key enabler for ADM is the quality of individual practitioner's communication skills (Bunn et al., 2018), the building of a therapeutic relationship and creating an emotionally secure environment (Donnelly et al., 2019), which can assist in establishing trust and understanding the individual's priorities and wishes. ADM is more likely to be effective where time is given to the person to recognise their needs in question and, to consider a range of decision-making choices in order to deliver good outcomes (Fetherstonhaugh et al, 2013). To facilitate this, social workers and HSCPs should avoid viewing ADM as a one-off event and should seek to build a relationship with the person over time (Marshall and Tibbs, 2006). The importance of having adequate time to employ these supportive strategies has been repeatedly highlighted in the literature (Tarzia et al., 2015). This can take place in many contexts and fora – for example, through the advocacy for the routine inclusion of all individuals in care planning or family meetings/case conferences.

The environment where discussions take place and decision-making occurs is also pertinent. Family and consultation rooms in hospital and other facilities are essential to enhance the environment for the purposes of privacy, dignity and good communication when making decisions (Ó Coimín et al. 2019). Studies suggest that significant decisions should not be made in the acute care setting and instead, in a community setting or ideally, the person's own home (St Amant et al. 2012). Interprofessional collaboration is also viewed as fundamental to supporting individuals in complex care planning and decision-making (Sinclair et al., 2019; Bunn et al., 2018). Positive interprofessional working has been identified as a significant enabler to promoting ADM while a weak interprofessional culture or where there is a dominance of the biomedical model has been shown to be a barrier (Davies et al., 2019; Bunn et al., 2018). Teams that function where there is recognition and

value placed on the differing roles of each professional often helps promote and enhance ADM (Davies et al.2019). Existing research suggests a link between organisational ‘buy-in’ (for example, identifying ADM as an organisational priority) through positive working practices and leadership skills and the prioritisation of ADM in practice (Bunn et al., 2018; Davies et al., 2019).

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### PATERNALISM, RISK AND RESOURCES

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Where individuals have complex conditions, ADM is often hindered by perceptions of risk and uncertain knowledge about health and cognitive impairment (Joseph Williams et al., 2017). A major challenge for social workers and other HSCPs will be how to actualise an individual’s expressed will and preference when there are obvious risk issues or when the necessary community supports such as home care, equipment or housing cannot be accessed. A climate of austerity and cuts to health and social care budgets, in conjunction with a population that is ageing, is creating particular impediments in the provision of supportive, community-based services (Lymbery, 2014). Social workers are increasingly reliant on informal caregivers, mainly family members, to provide care and support leading to the dilemmas described above; it can be difficult to uphold the rights of the individual when their expressed will and preference are dependent on receiving care and support from family members. It is on this boundary between a life in the community and a life in residential care that fundamental issues of citizenship, human rights, need and protection will be played out for social work practitioners (McDonald, 2010). For example, the individual, faced with the inadequacy of resources to maintain an acceptable life in the community, may have ‘no choice’ but to agree to accept nursing home/residential care despite this not being their will and preference. A legislative entitlement to homecare is therefore critically important to help ensure equality of access to both home care and nursing home care for Irish citizens.

ADM is further complicated when there are issues around the protection of the individual within the context of adult safeguarding services where a person may be experiencing paternalism, manipulation or undue influence by others, or when they may be unaware of the consequences of decisions that carry grave dangers (Gooding, 2015). The concept of proportionality is an important consideration in these situations. It is crucial that social workers weigh up obvious concerns for a person’s welfare in the context of a ‘dignity of risk’ approach which supports the individual’s right to autonomy, freedom of choice, and control over what is important to the individual, not what is important for them (Mackay, 2017:10).

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### CONCLUSION

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The full enactment of the 2015 Act should be welcomed because it belatedly offers a transparent legal framework that can be used to enable people to make informed decisions wherever possible and in circumstances that respect the person’s dignity, beliefs, individual



choice and privacy (WHO, 2015). Emerging Irish research has identified a number of factors that influence the adoption of ADM in practice settings. These include supporting capacity through adopting a functional approach, the creation of a physical environment where decision-making takes place, meeting information and support needs, methods of communication, upholding will and preferences, relationships and trust. Recognition of concepts of time and timing and the need for specialised education and training on ADM practice were also recognised (Donnelly et al., 2019). There should, however, be a note of caution about such hopes and aspirations. Fifteen years after the introduction of similar legislation in England, concerns remain about a lack of understanding about how to interpret the Mental Capacity Act amongst practitioners (McDonald, 2010). The author reported variations in competencies and confidence levels within professionals, suggesting a role for formal training in the skills and techniques underpinning the practice of ADM (Sinclair et al., 2019).

These lessons should be addressed in policy and practice in Ireland. There is a need for the development of appropriate interdisciplinary education and training at undergraduate, professional or postgraduate levels. In doing so, there is a greater chance that practitioners are better equipped to deliver interventions that have to benefit the person, be the least restrictive alternative and that the person's ascertainable views be sought. In working with individuals and relevant others, the person's participation in the process can be maximised, their individuality respected, and the person should not be treated less favourably than any adult not so affected by disability. As social workers, we must ensure that we are not pressurised to abandon a rights-based approach in favour of risk-based legalistic and procedural approaches by our employing organisations. Although autonomy may be seen as the guiding principle of ADM, it is in the application of the 2015 Act that we will see whether or not ADM, human rights and positive risk-taking are supported by social workers and other professionals.

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## 6.2 Best Interests and the Transition to a Rights-Based Approach in Irish Health and Social Care

*Gerry Maley*

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### INTRODUCTION

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This chapter seeks to briefly explore some of the current considerations about the implementation of the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) in terms of the move in practice and shift in culture from a best interests approach to one based on rights.

It seems to the writer that whilst this change would be agreed as good by most managers and clinicians, and actively supported by many individuals and professional groups, it may be that the practical implications are somewhat underestimated. These include the impact of moving away – in a very significant fashion – from what has been the cultural norm in health and social care, in my experience, for over 25 years: from the fact that professionals have made decisions, often in consultation with services users and families, in terms of the best interests of service users. This has been the shared expectation and custom that has guided decision-making behaviours of staff within their working environment and professional groups. This has been the case when people cannot or will not make decisions on their own behalf, but has also been used as a yardstick to gauge decisions that maybe service users or their families have not been in agreement with.

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### THE ROLE OF CULTURE

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Culture is discussed extensively in health service management theory, and indeed in practice. It is ultimately a very practical – if, at times, hard to define – matter as it drives behaviours: what we say and do. This is very true in decision-making processes, and the cultural norms around decisions are learned and reinforced by employers through policies and procedures and by managers and colleagues on a daily basis.

Yet these cultural norms are about to be challenged – significantly.

It seems to me, as a manager in the health services, with 25 years of health and social care practice (in social care, social work and administrative management across various sectors and two countries) that Ireland is in a very early phase of major change and transition to a rights-based approach. It is really in the pre-implementation phase. That is, most staff are not fully aware of the train that is hurtling towards them. The resources required to ensure that staff are aware of the 2015 Act, that they are trained in how it will impact on their

practice and that the additional staff required to take up roles to ensure implementation and compliance, is one major challenge. The other is the change that needs to happen in the way staff consider, discuss and approach decisions that they make that affect service users – all decisions.

I recall in my first role in social care, whilst an unqualified support worker in Scotland in 1995. I worked in residential care with adults who had mostly left the institutions as they were shut down during that period. One lady was Mary (a pseudonym) who had a mild ID and significant mental illness. She had been in a large institution in Glasgow in the 1960s-1990s. Mary talked about how she had had a baby and that the baby had died at birth. She often mentioned this and would be tearful and distressed, especially when her mental health was very poor. However, I learned through discussion with the unit manager and the community psychiatric nurse that visited her that it was very likely that the child did not die at birth, as Mary had been told.

It is believed that Mary had a child and her child was adopted, most likely without her knowledge: a decision that would have been seen in as being in the child's and possibly Mary's own best interests. A good example of how that approach can be deeply flawed and override a more reasonable rights-based approach, but then again would I have done different in the 1960s? And then, what of me and the others involved in her life in the 1990s and after: was our decision to carry on an apparent deception – again couched in terms of being in her best interests – acceptable? Didn't she and her child have rights to know each other, to be a family? Yet her circumstances were very particular. Her illness by that point was controlled by medication but well established. Her ability to self-care was very poor; she was institutionalised. All this was the rationale for making those decisions without her voice being heard. Yet her distress was apparently caused much by the 'death' of her child in childbirth. A difficult dilemma in theory, but one easily dealt with at the time by practice. This was the cultural norm, and undoubtedly repeated throughout many similar circumstances.

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## DEALING WITH COMPLEX DILEMMAS

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Complex dilemmas are not uncommon within health and social care, and just as complex decisions on shorter-term issues are common. For example, a decision as to whether to admit a person into acute mental health care is taken with the careful consideration of the best interests of that service user informing the clinical decision, but this can sometimes go against the expressed wishes of a person who has the capacity to state their will and preference. For people with certain issues, they may wish to be admitted, but the decision is a clinical one, based on the best interests of the person as decided by the clinician. It is hard to see how else that would be done. It can still present clinical staff with a dilemma, but they use the accepted yardstick of what is in the best interests, in their professional opinion, to guide them. It is a good example of will and preference not being the same as wish fulfilled.

But such decisions are not taken lightly, and are part of the continuum of clinical decision-making required in mental health services and, as such, are not often in the public domain, due to patient confidentiality and the impervious nature of such intricate decisions.

But there are those who are more upfront and candid about their dilemmas. Take, for example, the feted UK neurosurgeon Dr Henry Marsh, in his riveting, candid and moving 2014 book *Do No Harm: Stories of Life, Death and Brain Surgery*, where he describes sending out his junior doctor to tell families that a loved one is not able to be operated on, but where he sets out his own rationale – not to be shared with the family as he finds them to be too emotional at such a time for rational discussion – that the chance of leaving the person alive but needing full-time care just too great to justify the operation. A dilemma solved by the surgeon making a best interests decision, apparently. I do not envy anyone having to make such decisions in a rights-based environment.

Dr Marsh saved many lives, is candid about the difficult decisions he had to make, often taking risks against his professionally reasoned intuition, in an attempt to save loved ones or increase their life quality, and he comes across as, and by reputation is, a warm and caring surgeon. But it struck me when I read it, and still does, that the power in his ability to make a best interests decision cannot come without its pressures and very complex dilemmas.

It is unclear to the writer how a move to a more graded decision-making process would change the methods described above – all based on the best interests approach, and as noted by Wasserman (2018):

‘The criteria for decision-making in clinical ethics is often conceptualized as a simple hierarchy of successive standards: patient autonomy, surrogate decision-making, and best interests. Reality is more complicated.’

And the reality is that the best interests approach – albeit with increasing consultation and involvement over time – has been practical in its operation, even in regulation. On more routine and everyday processes there is very much a need to be practical.

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## SERVICE USERS’ EXPERIENCE

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Health and social care staff are increasingly aware of service users’ rights. However, do the people who use our service experience this? The HSE National Office for Human Rights and Equality Policy Newsletter Autumn 2020, from the HSE’s Quality Improvement Division, shows that amongst the public there is a very mixed experience in terms of the what’s and how’s of gaining consent – and low responses for positive experiences of how much information was shared with them, and being given enough time. As noted in Ní Shé et al (2020):

‘There is now a formal recognition within health and social care systems that patients should be assisted in the decisions about their care.’

Yet the service users that the researchers interviewed noted that their experience of the health services was one of resource shortages, very busy staff and a lack of time spent face to face (pre-Covid) with them. This is the reality for most clinicians in the HSE – the pressure to stay on top of administrative and compliance driven tasks takes away from time with service users.

The paper by Ní Shé et al (2020) is focused on the pre-implementation stage of the 2015 Act and explores how receptive the HSE systems are currently to the application of the legislation.

The paper concludes:

‘Responsiveness is high in health care systems when health and social care staff members have enough skills, autonomy, flexibility and resources to identify and adapt to the needs and expectations of older people and family carers., and that adequate resources are ‘critical’ to successful implementation of the new legislation.’

It is good to see that in research, but it is no surprise to anyone in the health services. Indeed, a logistical approach – the right people in the right number in the right place at the right time doing the right thing – is the core of every operational function. If any stage is compromised, the desired outcome is less likely. And there are challenges at every stage, especially if there are simply not enough of the right people (the correctly qualified and trained professionals) in the first instance. That is not going to change dramatically any time soon. It leaves the implementation in the front line open to significant risks. As noted, the move from a best interest to a rights-based approach will require considerable reflection, practice change and training, as well as complex administrative systems to ensure staff are clear in how to operate within this new framework. Without the right number and the right people, this will be extremely challenging, and my concern is that the fear of getting it wrong may increase the likelihood of exactly that, getting it wrong, as a result of fear rather than knowledge drives the practice.

The importance of documentation and the need to justify decisions in a clear and logical way, especially around decisions that may be challenged, is increasingly emphasised in health and social care. However, it is also right and respectful to do so for those situations where a challenge or complaint doesn't seem likely. It is respectful to have a good record of views and comments in any serious decision, which giving consent should always be regarded as.

Also, whilst the HSE's Incident Management Framework 2020 outlines the positives of promotion of a ‘just culture’ and the risks involved in a ‘blame culture’, the writer’s

experience is that many staff feel the sword of Damocles of the latter – perhaps less recently within the HSE, but mention is still heard of the courts or external inquiries, statutory or otherwise, which are not regarded as learning opportunities or reflective experiences; they are expressed in terms relating to fear and threat. This remains unhelpful.

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## CONCLUSION

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In the writer's experience, an excellent person-centred approach, based on sound and ethical values with good supervisory and management structures can result in staff working very closely and in a nuanced way, to allow even those service users that cannot make major decisions to express and realise preference, despite many challenges in terms of their intellectual functioning or ability to communicate. Knowing the person and respecting their autonomy are the key ingredients – those take a lot of time, a skilled approach and self-confidence; neither exist in resource short, administration heavy and blame ridden cultures.

So, what do Davies et al (2019) conclude about how best to adopt decision-making practice? They conclude that this requires methodical implementation, through planning, and ongoing evaluations are required, including '...close collaboration among policymakers; educators, practice leaders, advocacy groups and patients.'

I strongly believe that such practices are already in place where they can be in health and social care, that people absolutely do consult, include and listen to people's views and take on board – and record those views – in as much as is practical. However, ultimately they are used to acting – and indeed are expected in the law, in regulation and in professional codes of conduct – to act in service users' best interests. This is a long-engrained practice.

Expanding this by giving people rights to information, in an understandable format, giving them time to consider this, to taking a nuanced approach to different decisions, and consulting with relevant decision supporter under the 2015 Act, and then family, friends or independent advocates in the decision supporter's absence, as well as considering any written documentation including advance healthcare directives, is all welcome development in this area. However, it is a change and it does raise a higher bar for staff.

In health and social care services that have so many competing demands and so little that is truly adequate, I can only stress that the time for reflection, consideration and training is now, before the train pulls up at the station.



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## 6.3 Social Work as Partnership

*Seamus Moran*

When growing up in rural north Mayo in the 1960s, even as a child I was conscious of the power and authority that certain professional people had in the community, such as primary school teachers, doctors, Gardaí and the district nurse. A power and authority that did not invite questioning or challenging. I think on reflection we were a community that didn't believe in itself enough, didn't value itself enough, a community that had low incomes, high unemployment, limited education, high levels of emigration with distant echoes of the famine, the workhouse and evictions still reverberating. As a community, we were vulnerable to our lives being directed by the powerful forces of Church and State.

Fast forward to mid-1980s when I joined the Health Board as a social worker. I realised that many times I was advocating for my clients with fellow public servants and voluntary organisations, having to prove that the client was a 'deserving case'. So many services were, and are, discretionary. There were scant services that were legislated for as an entitlement.

I believe the concept of the deserving person stretches back to the Poor Law of the 1800s, where there was a differentiation made between deserving and undeserving poor. Many times, I found myself sharing far too much personal information with service providers about my clients in order to procure a service, be it supplementary welfare, emergency housing, etc.

In the early 2000s, I began working as a Medical Social Worker in an acute hospital that provides services and care for patients and service users from cradle to grave. While recognising for the most part that good quality and compassionate care were being delivered, it also struck me that the medical model at that time seemed to promote the notion of the compliant patient who followed advice and instructions without too many questions. It was a very paternalistic model – the health professionals were in the driving seat and the patients, family/carers were the silent passengers. We, the health professionals, ultimately in our own view thought we knew best. Sometimes family and carers can fall into the same way of thinking, believing that they, as next of kin, have the right to make decisions around treatment and care when their family member's legal capacity may be compromised or non-existent.

In my experience, there are so many reasons why patients can lose control over their lives and well-being in an acute hospital, such as literally losing their voice due to a stroke, to culturally accepting that they have no right to voice their opinions, concerns, wishes about their treatment/care plans, leaving it to the experts, the healthcare professionals or family members to decide. In recent years, patient advocacy groups, individual patients, family members and carers have begun to challenge the traditional medical model, emphasising

that the patient must be central in the decision-making process around their treatment and care planning. This is encapsulated by the slogans ‘nothing about me, without me’, ‘respect me’, ‘hear me’, ‘work with me’.

In Mayo University Hospital, there has been a lot of work done to try and enhance the participation of patients and family members at every level of treatment and care delivery. We have a Patient & Family Experience Advisory Committee, which reports directly to the Hospital Management Team and whose members are actively involved in delivering a mandatory education session to all hospital staff outlining the absolute necessity to involve patients in decision-making around their care.

In HIQA’s document, *Supporting People’s Autonomy*, it states:

‘People who use health and social services have the right to control their own lives, and the right to make informed decisions on matters that relate to them. Individuals may require different levels of assistance to exercise this control and make their own decisions, and therefore health and social care providers have a key role in this process. This involves providers taking practical steps to promote and support people’s autonomy.’

As one of the leads in establishing Patient & Family Engagement in the hospital, I have found a number of HSE Policies and certain pieces of legislation to be enormously beneficial in supporting the key concepts of patient engagement and partnership. One central policy is the HSE’s National Consent Policy (2013 as amended), which clearly outlines ‘the importance of consent is the need to respect the service user’s right to self-determination (or autonomy) – their right to control their own life and to decide what happens to their own body’ (2019: 20).

The HSE National Consent Policy acknowledges the expertise of the health care and social care providers alongside the expertise of the service users in determining what their key goals are as regards their health and social care needs. Both set of experts need to work in partnership to achieve the best outcomes for the well-being of the patient/service user.

The Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) is now, in my opinion, a cornerstone piece of legislation that, once fully implemented, enshrines the human right of self-determination and places the service user/patient rightfully back in the driving seat. It mandates health and social care providers to provide different levels of supports to patients whose legal capacity is in question. Its key tenets are very much in keeping with core social work values, as outlined in *Social Work’s Code of Professional Conduct and Ethics 2018*. It also leads from this that social workers should be in the vanguard of promoting and implementing this Act.

The 2015 Act will mean a role reversal for us health professionals from capacity assessor to capacity enhancer.

A patient who is very ill or who is experiencing an acute delirium requires time to see if they recover and regain significant decision-making capacity. They will also need time if elements of the 2015 Act are to come into play. For example, a real worry I have as an experienced social work practitioner is that, due to bed pressures, patients may be assessed too early as lacking decision-making capacity and they will thus lose their autonomy over many areas of their lives. I also fear some of these patients will be put on a conveyor belt to long-term care, which will entail significant restrictions on their personal independence and freedom. In this context, I would be a strong advocate that good step-down care, such as district hospitals, needs to be in place to allow the time both for the patient to recover as much as possible and to allow for the appropriate support mechanisms in the 2015 Act to be implemented.

The 2015 Act needs to be fully implemented and resourced. This Act should be central to all health and social care providers in ensuring that we promote and support patients' autonomy. The right to have our voice heard and our wishes respected is indeed a precious and sacred right.

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## 6.4 The Assisted Decision-Making (Capacity) Act 2015 and Dentistry: Opportunities and Challenges

*Patrick Quinn*

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### INTRODUCTION

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According to Professor Brendan Kelly, studies have shown that between 30% and 51% of medical inpatients, 29% of psychiatry patients and over 60% of nursing home residents lack mental capacity to make healthcare decisions (Kelly, 2017: 356). Like all of us, those lacking the capacity to make healthcare decisions will most likely need to see a dentist at some stage in their lives and the percentages presented above give an indication of the scale of the problem faced by members of the dental profession as they endeavour to provide dental care for this group in the legal vacuum that currently exists in the Republic of Ireland. As a dentist who has worked with people with disabilities for the majority of my career and who has also studied law, I have always been acutely aware of how vulnerable both service users with impaired mental capacity and the dentists who provide care for them are in the current legal landscape. The HSE's National Consent Policy and guidance documents from organisations such as the British Society for Disability and Oral Health assist the dental profession in this landscape of uncertainty (see the British Society for Disability and Oral Health website at <https://www.bsdl.org/index.php/bsdl-guidelines>) but many areas of concern remain.

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### THE CURRENT LEGAL POSITION

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The current starting point is that we must presume that all service users have the required mental capacity to make a healthcare decision unless proven otherwise and a functional approach to capacity is adopted, meaning that it is the specific decision to be made at a particular moment in time that is important rather than a general assumption about one's ability or otherwise to make all decisions. It is considered best practice to support the individual to the best of one's ability in order to allow them to make their own decisions and, if this fails, only then should an assessment of capacity be made. According to the Health Service Executive National Consent Policy,

‘[t]he possibility of incapacity and the need to assess capacity formally should only be considered, if, having been given all appropriate help and support, a service user:

- Is unable to communicate a clear and consistent choice or
- Is obviously unable to understand and use the information and choices provided.’ (2019: 32).

It is suggested that, at this point, the dentist is entering particularly challenging territory as an assessment of capacity has to be made taking into account factors such as the service user’s ability to understand the nature of the decision to be made, the risks and benefits of the proposed procedure as well as alternatives and their ability to retain this information for long enough to make a voluntary decision. If the dentist is of the opinion that the service user does not have the mental capacity to make the required decision, they then proceed to provide care for the service user having made an assessment of what would be in their best interests as the law does not currently provide for any other means of making a decision for the service user in such circumstances. An assessment of best interests would usually involve those close to the service user where possible and factors taken into account include whether or not the service user’s lack of capacity is temporary or permanent, what would be the least restrictive treatment option in terms of the service user’s future choices, and any available evidence of previously expressed wishes or preferences.

The process described above is problematic for a number of reasons. Dental procedures, by their very nature, can be worrying and stressful for many of us and this does not lend itself to maximising an individual’s own decision-making ability. Many dentists will not be trained in the various techniques and methodologies that may be used to help support a service user in making their own autonomous decision, nor will many be trained or experienced in assessing an individual’s mental capacity. Involving those close to a service user in the decision-making process can be problematic as there are often many people involved in caring for a service user and each may have differing views as to what is in their best interests. Conflicts of opinion can and do arise. Indeed, the concept of best interests is susceptible to bias on the part of all those involved in the decision, including the dentist, and we should always be mindful of the question ‘In whose best interests?’ when contemplating a decision in relation to a service user with impaired mental capacity. Finally, a decision taken in the service user’s best interests can be particularly burdensome for the dentist in cases where treatment is quite restrictive, such as multiple extractions, or in cases where there are potentially serious risks to the service user’s health, such as providing care under general anaesthesia. Therefore, the current legal scheme leaves both the service user and dentist in a vulnerable position and the changes proposed in the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) cannot come soon enough in many respects.

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## THE ASSISTED DECISION-MAKING (CAPACITY) ACT 2015

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The introductory sections of the new Act are particularly helpful as they place on a legal footing many of the principles followed by the dental profession to date, as discussed in the previous paragraphs. Section 3 confirms that a person's capacity is to be construed functionally, explaining in detail what this means as well as outlining the factors that determine whether or not a person has decision-making capacity in sub-section (2) as follows:

‘A person lacks the capacity to make a decision if he or she is unable:

- a. to understand the information relevant to the decision,
- b. to retain that information long enough to make a voluntary choice,
- c. to use or weigh that information as part of the process of making the decision,  
or
- d. to communicate his or her decision (whether by talking, writing, using sign language, assistive technology, or any other means) or, if the implementation of the decision requires the act of a third party, to communicate by any means with that third party.’

Section 8 of the 2015 Act sets out the guiding principles that underpin the new legislation and again places on a legal footing many of the principles that those who provide care for people with impaired mental capacity are familiar with. The 2015 Act states that a presumption of capacity exists unless proven otherwise and that all practicable steps should be taken before a person is deemed to lack the capacity to make a particular decision. Unwise decisions should not be construed as meaning a lack of capacity and interventions in relation to relevant persons are not permitted unless necessary, taking into account their individual circumstances. Interventions should minimise any restriction of an individual's rights or freedom of action and should be proportionate to the significance and urgency of the proposed intervention and for as short a period as possible in order to respect rights such as dignity, bodily integrity and autonomy. Service users should be supported to participate as much as possible and their past and present preferences, values and beliefs should be taken into account. Unless deemed inappropriate or not practicable, the views of those appointed in a decision-making role should be taken into account and the views of others, such as carers and healthcare professionals, may be taken into account. Those making any intervention with respect to an individual who lacks capacity should at all times act in good faith and for the person's benefit and factors such as the urgency of the proposed procedure and the likelihood of the person regaining capacity should be taken into consideration.

However, arguably the greatest benefit to dentists and other healthcare professionals brought about by the new legislation are the provisions for the appointment of various decision-making support persons for the service user, thereby removing the need for the

dentist to assume decision-making responsibility and filling the legal vacuum that has existed for so long and that has been a cause of concern to so many. Section 10 allows an individual who feels their capacity is or is about to be in question to appoint one or more decision-making assistants, the details of the appointment being contained in a decision-making assistance agreement. Decision-making assistants will assist the service user in obtaining information, advise them in relation to a particular decision, ascertain their will and preferences, assist them to make and communicate a decision, and attempt to ensure that the decision is implemented. They will not, however, have the power to make decisions on behalf of the person who appointed them. This development will be of great relevance in the dental context as it will empower people to maximise their decision-making ability by affording them trusted support in what can often be a frightening and stressful environment, and will assist the dentist in ensuring that the will and preferences of the service user are taken into account and enhance the consent process.

Section 17 allows an individual to make a co-decision-making agreement and appoint one or more co-decision-makers who will perform similar functions to the previously described decision-making assistants, but with the additional power of the ability to make decisions jointly with the person who appointed them. In contrast to the decision-making assistant, who merely has to be 18 years of age, a co-decision-maker must be a relative or friend who has a relationship of trust with the person who wishes to appoint them. There are more formalities associated with this arrangement, such as the requirement to register the agreement and to provide a copy of the agreement to those involved in the affairs of the appointer such as their spouse, adult children and attorney. The Director of the Decision Support Service will be required to maintain a register of co-decision-making agreements and periodically review such agreements, and the co-decision-maker will be required to provide the Director with an annual report outlining details of the discharge of their duties under the agreement.

Furthermore, as many individuals will not be able to plan one of the aforementioned agreements as they already lack capacity, Section 38 empowers the court to appoint a decision-making representative to make decisions on their behalf. Also, Part 7 of the 2015 Act will allow an individual to appoint an enduring power of attorney who may be given the authority to act on their behalf in relation to all or a specified part of their property and affairs and to do specified things on their behalf in relation to their personal welfare or property and affairs or both. The enduring power of attorney would not come into force until the individual lacks capacity and the agreement would need to be registered with similar requirements in terms of notice and reporting as previously described for co-decision-making agreements. And finally, of further relevance to dentists is the fact that Part 8 of the Act provides for the making of advance healthcare directives to enable people to be treated in accordance with their will and preferences and to provide healthcare professionals with information about treatment choices. A directive-maker may also designate a named individual in the advance healthcare directive to exercise the powers contained in the



directive. Refusals of treatment set out in an advance healthcare directive will need to be complied with if at the time of the decision the directive-maker lacks capacity and the treatment to be refused as well as the circumstances in which the refusal is to apply are clearly identified in the directive. Requests for specific treatment set out in an advance healthcare directive will not be legally binding but should be taken into consideration when making treatment decisions and, if not complied with the reasons for non-compliance, should be documented in the directive-maker's medical records and a copy of the recorded reasons should be provided to the person's designated healthcare representative.

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## CONCLUSION

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It is generally accepted that the 2015 Act represents a radical transformation in the way in which those with impaired mental capacity are treated in legal terms and makes significant progress in recognising and respecting their human rights. From a dental perspective, the legislation provides for many forms of supported decision-making that will surely enhance service user experience and maximise opportunities for service users to give their own consent to treatment. In situations where this will not be possible, the 2015 Act takes decision-making responsibility away from the dentist and places it in the hands of individuals appointed either by the service user themselves or by the courts, which ought to be a more satisfactory arrangement for all concerned. However, the implementation of this legislation will not be without its challenges. It is a particularly complicated and cumbersome piece of legislation and an accessible code of practice as well as extensive training resources will be required for all parties involved to ensure successful implementation. Nonetheless, we need to strive for success so that the current unsatisfactory legal scheme is brought to an end in favour of a new era of supported decision-making and respecting the fundamental rights of those with impaired mental capacity.

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## 6.5 The Assisted Decision-Making (Capacity) Act 2015: Nurses Effecting Change

*Margaret Williams*

The Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) is a key piece of legislation that will protect the rights and privileges of all citizens in Ireland in many ways. This is especially true in our health and social care services. The 2015 Act will change the way in which healthcare workers provide support as it legislates the requirement for service providers to provide a range of supports to assist people in decision-making. When the 2015 Act comes into full force, there will be a requirement for all healthcare workers to reflect on how they ensure that individual autonomy is at the forefront of everything they do.

Having almost 20 years nursing experience in the acute care setting, predominantly in nursing management and acute older person services, I believe the 2015 Act is key to positively supporting the rights of vulnerable members of our society. In my view, one of the biggest changes that the 2015 Act will bring is the effect it will have on the rights of older people with capacity. Their rights will be upheld and supported through this legislation. The 2015 Act applies to a person where their capacity to make a decision is called into question presently or may be called into question in the future. However, the 2015 Act will also protect people who have capacity but whose decision-making is called in to question based on disability or age. The 2015 Act stipulates that it is presumed that a person has capacity to make decisions unless proven otherwise. Yet, in society, older people have a perceived diminished right to decision-making based on one criterion: their age.

The Irish Longitudinal Study on Ageing (TILDA) is a large scale, ongoing research project on ageing in Ireland. This study's main aim is to make Ireland the best place in the world to grow old. TILDA researches many aspects of ageing in Ireland and uses that data to inform future policy. In a research piece conducted by TILDA, Robertson (2016) found that negative attitudes towards ageing affected health in later life. The research states that 'societal attitude towards ageing are predominantly negative' with the view that older people were 'physically weak, forgetful, stubborn and selfish' (Robertson, 2016 p. 1). It is concerning that research into this negative stereotype of older adults not only negatively affected how older people perceived themselves, but that also affected their functional ability, their heart activity, reduced memory performance and their will to live. The study report goes on say that the omnipresence of ageism in Irish society is having a detrimental effect on our older population.

The 2015 Act will positively force reflection on the way in which we provide care for our older population. Our use of language needs to adjust if we are to class ourselves as true

advocates. Terms like ‘acopia’, ‘difficult’, ‘bed blocker’ and ‘non-compliant’ do not have a place in a world where a person has the right to be autonomous. Autonomy is a basic human right and relates to being human and worthy of respect. In the HIQA (2017) guidance document Supporting People’s Autonomy, autonomy pertains to an individual’s right to decide how they live their life on a day-to-day basis, influenced by their values, beliefs and preferences. Furthermore, the document states that, from the perspective of health and social care, true autonomy requires that the service user is involved in making decisions about their care, supports required and care received. Healthcare workers must enable a service user’s ability to make supported and informed decisions. The 2015 Act supports the concept of true individual autonomy by assisting healthcare workers to advocate when capacity is called into question.

As nursing professionals, it is our legislative duty under our regulator, the Nursing and Midwifery Board of Ireland’s Code of Professional Conduct, to ‘act as an advocate on behalf of patients who require you to do so to ensure their rights and interests are protected’ (NMBI, 2021, p14). This is further supported by the National Healthcare Charter (HSE, 2012). Despite this, our ability to advocate for our service users is often hampered by competing organisational priorities: ‘[i]n the messy reality of highly pressured healthcare environments, the clinical and managerial leaders tasked with delivering change are doing so with competing operational imperatives’ (Harnett et al, 2020: 296). From my experience, nurses are often placed in this push-pull dynamic of wanting to meet service users’ needs and balancing the limited resources in the healthcare setting. As a nursing manager, a significant amount of my time was often spent discussing beds with hospital management, not the individuals that occupied them and conversely trying to instil a person-centred approach to care with my team.

As nurses, we have a duty of care to our service users to ensure that we educate ourselves as to what capacity is and is not. We have a key role in relation to supporting a person who has capacity to make decisions even if those decisions are viewed as unwise by others. We need to know enough to look at how a decision was made rather than its predicted outcome. We must know enough about the 2015 Act to be in a position to be comfortable and proactive to discuss the need for a decision-making assistant with service users if capacity may become an issue for them in the future. We should be confident to advocate for advance healthcare directives with service users who are living with chronic illness and are currently well enough to make decisions about their care and treatment in the future. By doing this, we are normalising assisted decision-making and role-modelling to our peers.

While family’s wishes are key to providing holistic care, as they too are advocating for their loved one, they must not supersede or be used as an alternative to the service user’s views and opinions. As nurses, we sometimes fear the repercussions of not following the family’s wishes, for example when we hear statements like ‘Don’t tell mam’. It is imperative that we trust the skills we have been taught and the experiences we have gained when

communicating bad news while also taking our cues from the individual as regards what they wish to know and what they do not. The 2015 Act supports healthcare workers to actively advocate on behalf of their service users and reduces the fear of repercussions by supporting them to support the service user. This is also true for consent.

There is a paradoxical existence in which legislation and policy state that the next of kin has no legal standing to make decisions, yet there is a perceived requirement to get their signature and consent for procedures, home care supports and also for requesting long-term care. The HSE National Consent Policy states that '[n]o other person such as a family member, friend or carer and no organisation can give or refuse consent to a health or social care service on behalf of an adult service user who lacks capacity to consent unless they have specific legal authority to do so'. We need to question and change this practice as not only are these signatures insufficient, but they are also detrimental from a legal perspective if that person is presumed to have capacity and it is not proven otherwise.

Nurses are in an ideal position to affect change and support the full implementation of the 2015 Act. In both the acute care and community setting, nurses are the professionals that spend the most amount of time communicating to the service user. We are in a prime position to give insight into a person's functional capacity. Our information is also trusted as being accurate by the service user. In the National Patient Experience Survey (2018), 97% of inpatients in the acute care setting said that nurses on the ward always or sometimes answered questions in a manner that they could understand. Of the almost 13,000 inpatients surveyed 53.5% were aged 66 and older. Conversely, 36% of people surveyed answered that they were not, or were only to some extent involved in decisions about their care and treatment. This indicates that there are many older people in acute care that are not getting the opportunity to be involved in decision-making in relation to their own health. Under the 2015 Act, everyone has the right to be supported to make decisions and, as nurses, it is our duty to support and advocate for this right.

There is so much that we can do to ensure that the 2015 Act is fully implemented by healthcare professionals. The complete implementation of this legislation is one of the most important gifts we can give to our future selves. Growing old is not a given; it is a privilege. When I am older, I want to decide when I get up and when I go to bed. I want to have a say in where I choose to live. I want a healthcare system that fits around me instead of me fitting around it. I want to be listened to and to be heard. If it appears that I don't understand, make an effort to help me understand. In the words of Barack Obama: '[c]hange will not come if we wait for some other person or some other time. We are the ones we've been waiting for. We are the change we seek.'

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## 6.6 Personal Reflections as a Lawyer on Experiences with the Assisted Decision-Making (Capacity) Act 2015

*Mary Condell*

I have been involved with the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) and its concepts from before its enactment. Post its enactment, in my role as legal adviser to Sage Advocacy, I have given presentations on the 2015 Act to a variety of professionals. That, along with my input into Sage Advocacy case work, has led to me believing that the following are four cornerstones of the effective use of the concepts enshrined in the 2015 Act:

- always assume that everyone is capable of being supported to make decisions about themselves for themselves, and if they patently cannot (for example, if they are in a coma), still honour their right as a human being to self-determine by finding out what they would want for themselves in these particular circumstances
- the functional approach to capacity is not about ‘what to do’, it is about ‘how to do it effectively’
- the legislation is not just about ‘the relevant person’s’ rights, it is about balancing and prioritising ‘the relevant person’s’ rights against the similar rights of everyone else, whilst realising that systems have rules, not ‘rights’
- it is about collaboration between all professionals and others called upon to support a ‘relevant person’, which requires us to recognise the skillset of others as being potentially more suitable to support this particular individual ‘relevant person’ to make this particular decision.

Alternatively, and more simply put, (by the Sage Advocacy colleague who organised and accompanied me when I gave presentations on the 2015 Act around the country and who had no previous experience of law) ‘it’s really about plain, ordinary good manners!’ That is so, because it is good manners to recognise the humanity in others and, therefore, their right to self-determination.

So why, if it is that simple, do we need legislation to ensure that vulnerable people are treated with plain, ordinary good manners?

For those of you who think that the ‘how’ and ‘why’ don’t actually matter, I disagree, on the basis that the change in behaviour required to comply with the 2015 Act on the part

of all citizens, including those who may be classed as ‘relevant persons’, is, in my opinion, best explained by contrasting it with previously accepted behaviours.

I feel it is only fair to explain this by reference to myself and my own professional training and behaviour as a solicitor in private practice (for a very long time now!) and as a mediator. It is a fact that the vast majority of instructions received by solicitors in practice follow the exercise by the solicitor of the functional approach to capacity in relation to their client’s ability to comprehend the legal matter being undertaken, whether that is the purchase or mortgaging of a property, bringing or defending a court case, or making a will or an enduring power of attorney. However (although to be fair, not always), when it came to the assessment of a person’s questionable ‘ability to manage their own affairs’ either because of an illness (for example, a diagnosis of dementia) or because the instruction they were giving their solicitor was, in the opinion of that solicitor or others, an ‘unwise decision’ (the outcome approach to capacity, now outlawed in the 2015 Act), that functional approach went straight out the window and in instead came the ‘status approach’.

This was partly because of the Lunacy Regulation (Ireland) Act 1871, partly because very few solicitors were aware that there are three distinct internationally recognised approaches to capacity, and partly because, historically and culturally, a person making what society in general regarded as an unwise decision was seen as being, literally, mad. This came home to me when I remarked upon the large size of a particular rural (and no longer functioning) ‘county mental home’, and I was told that people had been ‘put away’ there for such things as ‘not wanting to take over the family farm’, presumably on account of the ‘unwiseness’ of that particular decision.

Needless to say, those with an intellectual disability or brain injury would very seldom get as far as a solicitor’s office anyway, such was the presumption of lack of capacity. The fact that this presumption was the opposite to that enshrined in common law was ignored, hence the need to specifically incorporate it into statute law as the starting point for all decision-making for everything and everyone.

So, to my next cornerstone, how to ‘do’ the functional approach? I was struck by the House of Lords stating in their review of the England and Wales Mental Capacity Act 2005 (MCA) that professionals ‘did not understand the functional approach to capacity’. Somehow, the statutory explanation that it is issue- and time-specific clearly was not assisting that much. Like the MCA, the 2015 Act does not define the functional approach in terms of what it is, so much as what it is not, when it states that a person will only be regarded as not having the ability to make a particular decision if they are not, at that time, able to understand the decision to be made (even when an explanation in terms appropriate to them has been given), retain that information for long enough to use it to make the decision and then communicate their decision.

It wasn't until doing a Master's Degree in Mediation and Conflict Resolution that I came across a positive explanation for the functional approach to capacity. This was in an article entitled *From Determining Capacity to Facilitating Competencies: A New Mediation Framework* and it described it in terms of 'facilitating a person's competency' which 'defaults to inclusion in the process in a way that determining capacity does not' (Crawford et al, 2003). From this description, I have come to use the analogy of a tunnel to describe both the difference between the status and functional approaches to capacity as well as the 'how to do it' of the functional approach. I ask people to imagine, that as someone gradually becomes unable to make all decisions without support, they enter a tunnel which, naturally enough, becomes darker the further in they go.

A professional is not facilitating a 'relevant person's' capacity by standing at the mouth of the tunnel and calling upon the relevant person to come and engage with them there. This is the old status approach where a 'relevant person' was marked down or defined by what they cannot do compared to a 'normal' person, as in for example the Mini-Mental State Examination (MMSE). Facilitating a 'relevant person's' capacity is the direct opposite to this. It requires the decision supporter to enter the tunnel themselves, locate where the relevant person is, stay there with them and communicate and work with them in their space in order to find and then enhance whatever decision-making ability they have. It is this difference in approach, which necessitates a complete change of culture that is causing tensions amongst doctors and other professionals.

'Doing' the functional approach inevitably requires good competent communication skills. Those skills, such as paraphrasing, summarising, reframing and the different types of questions can be learnt.

Personally speaking, it was only when training as a mediator that I truly understood and learnt these skills along with, and just as importantly, when to use them to best effect. This, in turn, increased my confidence in my own ability to make people's decision-making ability as good as it possibly could be. It also shortened the time I needed to spend with them.

Storytelling is a communication skill that can be used to great effect too, as well as simple, ordinary explanations using analogies. For example, I once calmed an angry gentleman (with dementia) who couldn't understand why his money no longer appeared to be 'his' after his EPA had been registered (by me as his solicitor), by asking him if he still did all the heavy work in his garden himself. He answered no, of course not, 'he had a man who did that for him'. I then pointed out that it was the same with his money as with the garden. It was still his garden, (and by analogy his money) and his adult children (the attorneys) were, like the gardener, just giving him assistance with it. He immediately understood and relaxed and even thanked his attorneys for their help.



A knowledge of a person's background can also greatly assist with communication. A person who has worked all their life, as a builder or engineer for example, will not forget the meaning of terms used in their profession, like foundations, bricks etc.

My final cornerstone comes from my experience with a woman who asked me, after she had listened to a presentation I gave on the 2015 Act, 'whether it meant that her mother had the right to expect her to stay at home and look after her'. I promptly replied 'absolutely no, that she herself has her own right to make decisions for herself about how she wants to live her life'. The 2015 Act is (quite rightly) described as 'rights-based'. Its purpose is to ensure that the rights of 'relevant persons' are respected and honoured. It does not mean, however, that the rights of those people who surround a relevant person do not also have to be taken into account and balanced against those of the relevant person.

The reality is that in our modern world 'no man is an island', and therefore most decisions, for example such as where a relevant person who needs supports wants to live, affects other family members too, some of whom may themselves also be vulnerable. This is where it becomes necessary for us to view human rights as being part of a hierarchy, with those higher up on the scale needing to give way to those rights which are lower in rating. For example, the right of adult children or healthcare professionals to 'put' an older person in residential care so that they can be free of worry about their parent/patient is a far lower right in the hierarchy than the right of that elderly person to remain living at home even if they may be a 'fall risk' once that risk is understood and accepted by them.

However, the right of hard-pressed adult children rearing their own young families as well as holding down jobs to say that they cannot meet an elderly parent's expectations that they be attended upon daily by their adult children, may just trump the right of that parent to remain at home with the sole assistance of their adult children.

Every person's circumstances and needs are unique to them, but we all have identical rights. Good communication in these circumstances is crucial and the family may well benefit from the intervention of a skilled mediator. Systems, however, do not have rights, they just have rules. The rights of an individual will always, therefore, trump the rules of a system. This is the essence of 'person-centred care'. This is also why an independent advocate who is outside the 'system' may be the best person to support a relevant person in their decision-making.

We are all aware from our own experiences, both professional and personal, that 'there is no bright line separating capacity (to make decisions) from incapacity' (Wood, 2003). In other words, the 2015 Act does not 'do' black and white, it only does grey. If we therefore undertake work where we are likely to encounter a relevant person, we need to become comfortable 'working in the grey', even though it is seldom a comfortable place to be!

In Sage Advocacy, we have a policy that where a particular client's ability to make an informed decision is in doubt, more than one of us will attend upon that client to endeavour to support them. In other words, we collaborate to support a client in recognition of their right to self-determine. In my opinion, it takes a professional with a deep down belief in the fundamental human right of all persons to make decisions for themselves to accept that, where this particular relevant person is concerned, I am on my own not enough to honour that right of theirs with regard to this particular decision and they deserve the help of another. That other person may be another professional, or, as I found when unable to understand a question being asked of me by a gentleman with Down Syndrome, the assistance of someone more able to understand him, which in this case was his friend who also had Down Syndrome. In my experience, even when you fundamentally believe in what the 2015 Act is seeking to achieve, expect that you will find yourself being challenged in that belief both internally and externally. This is par for the course when 'working in the grey'.

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## 6.7 Peggy

*John O'Brien*

This is a story of the not so long ago. Peggy had Down Syndrome and lived most of her life in a residential care home setting. If it was today, she would have been cared for in the community, but they were different times. She had a happy disposition, had friends, had activities she liked and was much loved by those who cared for her. But Alzheimer's disease comes early to those with Down Syndrome and so it was for Peggy. She began first to lose her memory but as time progressed her disease worsened, as it does, to a point where she couldn't swallow properly, and she developed recurring pneumonias. In hospital, a tube was inserted through her abdominal wall into her stomach and she was thereafter fed a liquid feed through this. She, who had loved her food, was no longer allowed any by mouth and so she lived a further eighteen months. The tube was uncomfortable and irritated her, it often became infected and still her pneumonias persisted. In hindsight, although what was done was with the best of intentions, Peggy's wishes had not been considered or respected. She would not have wanted to have lived like this and the dawning of that realisation crystallised what we all knew – that what we think is best is only so if seen through the eyes of the person themselves.

Dying is not something different or separate from life but is, or should be, the fullness of living right up to life's end: It is no less than the continuum of a life and the gateway from it. Death is usually seen as a time of great sorrow, and undoubtedly it is, but the manner of the dying is important and a good death, as much to be valued as the good life that precedes it: it will be different for us all. How much is done to prevent dying must be weighed against what must be endured to achieve that end. The location of a death, those who are in attendance, the manner of the care and its content are all worthy of careful attention and should accord as much as possible to the wishes of the person dying.

It is now more than 20 years since the team I have worked with commenced their formal multidisciplinary end-of-life care discussions, and the awareness of the need grew out of stories such as Peggy's. The unfairness of how some of those we cared for lived out their dying days, confused and frightened in an alien hospital setting instead of in the loving environment which was their home, was unsupportable. It shaped the consideration of how we supported our charges as they entered into the final phases of their lives, the consideration not just of palliative care but also the ceilings of care commensurate with

their stated or perceived wishes. There was no template for this evaluation and no definitive legislation, but it was guided by the ethical principles of autonomy, of fairness, of doing good and avoiding harm.

Since then, we have had many such discussions and they are never easy. All those who are vulnerable, and especially those with a learning disability, have rights as have we all. When planning for the end-of-life care, the opportunity for the individual to make their own decisions is central, but understanding what those decisions might be for someone who cannot articulate them for themselves is not always clear. The power of a meeting is most enhanced if the person being discussed can contribute for themselves, even if that is to the smallest degree. It is worthwhile for carers to take time to explain the issues involved and uncover that personal contribution if they can, even if it is over an extended period. This accords with the 2015 Act, where capacity is recognised to be different at different times and where revisiting the discussion can overcome some of the obstacles. If the wishes and preferences of the person cannot be articulated by them, the collective voices of carers, of family, of significant others and an independent advocate must strive to fill that gap.

The assumption that next of kin or significant others will know what is best for the person is not always completely true and furthermore has no standing in the law. There is now to be a presumption of capacity until shown otherwise and a right of a person to make decisions that do not appear to others to be in their best interests. That said, family along with the day-to-day carers of the person are important voices in the uncovering of what the person's wishes are. For all of us, our certainties, our prejudices and our biases are often invisible to us. This is no less true in a family where the invisible dynamics and assumptions unique to every family are at play. To get the best of outcomes, we let go and replace our own priorities with those of the person being discussed, insofar as we can know or imagine them: we place ourselves in their shoes.

Where capacity is such that the wishes of the person cannot be ascertained directly, the value of prior knowledge of their likes and otherwise is extremely helpful in decision-making. Prior conversations, preferences and fears, behaviours in different circumstances – these are the ways we piece together the picture of the person and infer their desires. A ceiling of care, that is to say a limit on the possible medical intervention, is a clinical decision but must be informed by the wishes of the person. We have used close family, key workers and others who have formed a significant bond with the individual to help us. They have been asked not to contribute out of what their own wishes might be, but rather what they think the person themselves might wish had they the capacity to express it. This is not always easy for people to do and for family members, it can be a very challenging and emotional experience. Issues of conflict within the family, promises made to a parent, religious beliefs and many others can intrude, and it is not always possible to reach agreement or a decision in one meeting. But patience, time to reflect and, if needed, repeated meetings can lead to consensus as to the course of action which most reflects the wishes of the person. It

is for these very reasons, and indeed it is true that similar struggles can play out for the individual with capacity, that addressing such issues well in advance and before they are urgently needed is the preferred course.

Incurable and relentlessly deteriorating illness is the warning of the oncoming of death, but the pace of this can be very different for different illnesses. Some cancers, although not curable, progress quite slowly but for others, time is very short. Alzheimer's disease, although relentless in its progress and deterioration and eventually terminal, can extend over many years, even when it has progressed into its advanced stages. For all eventualities, the earlier that end-of-life planning begins, the more considered it will be and the more it will truly reflect the wishes of the individual. For one who can articulate their wishes, it is a journey to the realisation of what those wishes are, and this is no less so for a group who would try to do so for another. Time, reflection and ongoing communication are the means to making the best decisions.

The decision to not attempt resuscitation in the event of a cardiac arrest or the refusal of other medical interventions would be a very difficult one for any of us to make. The implication that we are letting go of life would mark such change in our attitude, our aspirations and thinking it would likely be frightening and very troubling. If this is so for ourselves, it can be no less so when we discuss such ceilings of care for another person. Very many of those with an intellectual disability would have difficulty understanding the mechanics of resuscitation and why it would be done, but they would understand death and the implications of going to hospital. Many would find it hard to project themselves into a future hypothetical situation but would fully understand pain and loneliness and wanting to come back home from hospital. For many of us, the statistics around survivability post-cardiac arrest and what subsequent morbidities might be like are hard to imagine and this is no less so for those with an intellectual disability. However, with patience as well as repeated and easy-to-understand explanations, a great deal can be achieved to establish their consent or otherwise.

The end-of-life multidisciplinary meeting seeks only to determine the type, content and location of care the person wishes to have. Those in attendance should include the person themselves, if possible or appropriate, and all the other relevant people, which could include the doctor, the nursing staff, the key worker linked to the person, one or more staff members with whom she had a significant bond and family members or other advocate. Depending on the circumstances, there could also be speech and language, dietetics or social worker attending. This could extend to a big group, which would be daunting for the person and even the family. Smaller, supplementary meetings with doctor and key worker might be better in such circumstances. Where the person is deemed to have capacity, and this would be a low bar, they should be included for all or part of the discussion, and a less pressurised sense-checking discussion carried out afterwards with the key worker and or others. The process is iterative and the wishes of the person where they can be directly obtained are paramount.

Any law must reflect the values and the ethics of society and for a law concerning assisted decision-making, it is all the more so. So many of the colleagues I have encountered in my own experience have held a resolute belief in the intrinsic value of every person and this no less so for those who live with disability and who need our ongoing care and support. Their unbending insistence that their service users would have the same rights and entitlements in a medical context as any other has not always been respected and has sometimes had to be fought for. What has been included in the 2015 Act very much accords with what has been happening in my service for some time now, however, this now provides a formal legal structure which was deficient before. The inclusion of various levels of decision-making support allows for a more flexible usage and should allow for the different circumstances different people find themselves in. Reporting, surveillance and complaints procedures are all also welcome additions. How the law will be fully used in the day-to-day delivery of advanced care planning must await its full implementation. Of course, the law is the backstop and the final arbiter, but it is the values and the ethics which will continue to determine day-to-day practice. The law will provide the clear framework within which these operate.

A young doctor starting out has much to learn and all those years ago I had no idea of the privilege that was being accorded to me. I was being invited into what was the home for these ladies and they have held me in their affectionate and loving kindness since. General practice is a holistic care, embracing the biomedical, the social and the psychological, and it is continuing care very often extending over a lifetime. I have had great friendships with the ladies in my care and they have taught me a great deal about fortitude and generosity, the inherent dignity of the individual and what it is to be a human being. Many have been non-verbal and many have had physical disabilities also, but they have lived full and contented lives within the narrow confines of their possible world. We who have grown old together, patient and doctor, now face the end of life and its attendant challenge: it is another chapter for us all. This law and the beliefs and values of those who might be our carers gives confidence that our decisions will be respected.

## 6.8 The Promise of the Assisted Decision-Making (Capacity) Act 2015—From the Perspective of a Speech and Language Therapist

*Elaine McCaughley*

As a speech and language therapist, I have had the privilege of working with a wide variety of people. One of the best parts of the job is getting to know each individual, being introduced to the people (or pets!) in their circle of support and finding out what really matters to them. It rarely matches what is written on the referral form.

For most of my career I have worked with adults with acquired conditions such as dementia, stroke, Parkinson's, multiple sclerosis, motor neuron disease, brain injury, COPD. As a speech and language therapist my role is to support them with their communication, and their eating, drinking and swallowing. I have met them at home, in nursing homes, in day-hospitals or in their local health centre.

Over the years I have marvelled at how unique each person is. There is no standard phrase book that will meet the needs of a person with a communication difficulty. The number one priority messages some of my clients wished to communicate were as diverse and individualistic as themselves, from their usual order in the local takeaway, a nickname for a loved one, their dog's name, to some choice phrases to shout at their favourite sport on TV.

I worked with people who were experiencing a series of losses as their disease progressed. Among these losses was the presumption that they would play the central role in all decision-making about their own life, health and well-being. I often struggled with how decisions were made within health and social care settings. I have been invited to multidisciplinary meetings where decisions were made without the person or their view represented, and I have witnessed staff asking family members to make decisions and sign care plans with no legal authority. I have heard a lot of talk about 'non-compliance' when a person chooses not to follow a professional's recommendation. I have met wealthy individuals living in nursing homes, who were not supported to access their own funds to pay for any extras such as a hairdresser or a special outing. It did not seem right to me and I spent a lot of time trying to figure out – how do I make sure this doesn't happen to my parents? How do I make sure this doesn't happen to me?!

Through the Irish Hospice Foundation, I discovered the Think Ahead form and mentioned it to my clients as a means of expressing their wishes about their future care. In February 2016, I attended the HSE National Conference on the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act). The 2015 Act promises a means to facilitate people to participate as fully as possible in decisions, and to give effect to their will and preferences. It requires that all practicable steps are taken to help people to make their own decisions. It gave me hope that things were set to improve and ultimately changed my career path.

I'm going to describe two scenarios involving individuals I worked with, to illustrate what difference I think the 2015 Act could have made to them. Their stories are anonymised and I do not intend to make any generalisations based on these individual case studies, nor do I presume that either of the individuals lacked decision-making capacity, or that they would have been certain to use any of the provisions of the 2015 Act. Rather, I hope to use their stories to signpost where the provisions of 2015 Act could have made a difference.

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### MORRIS

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Morris is unforgettable, a small man with a strong character. When I first met him, he was a 73-year-old bachelor living alone in his large home in an affluent Dublin suburb. He was retired from a successful career in finance, and had a number of supportive neighbours and friends from his sporting club. Morris' only family member was his brother who lived abroad, with whom he was not close.

Four years before I met him, at the age of 69, Morris had a stroke which left him with some weakness and a severe communication problem called 'aphasia'. Morris could understand most of what was said to him and could read single words or short phrases. However, Morris could not say, or write, or type any words in spite of previous support from a speech and language therapist. He expressed himself through facial expression, gestures such as pointing, and whistles, and relied heavily on others to interpret his intentions and meaning.

Morris was fiercely independent. He made his own decisions and did things his way. He tried to refuse to wear a seat belt in my car when I gave him a lift. Morris did not like anyone telling him what to do.

When Morris had his stroke, he was admitted to hospital. His brother returned to Ireland to help and was advised by the medical team to look for a nursing home, as Morris would no longer be able to live alone. Morris was moved to a step-down facility further from the city to wait for a nursing home place. He was not involved in the discussions with the medical team about his prognosis, or about where he would live. The 2015 Act would have required that Morris could not have been considered unable to make this decision unless all practicable steps had been taken without success to help him decide for himself. The 2015



Act would have enabled Morris to have appointed a trusted friend, who was familiar with his wishes, to support him in this.

Unfamiliar with Morris's lifestyle and friends, unable to communicate 'normally' with Morris, and with no knowledge of the Irish health system, Morris's brother started to research nursing homes with the best of intentions. The 2015 Act would have required that the views of any person named by Morris be sought on the matter. This could have led to an outcome better aligned with his will and preferences on this question.

After a couple of weeks, Morris absconded from the step-down facility. He caught an infrequent bus into the city centre and another bus to his home, with a total journey time of about two hours. Once he got home, he refused to allow his brother or the Public Health Nurse to enter his house. He had not been involved in decision-making but had managed to clearly express his decision against all the odds. Morris was not going to a nursing home.

Most people are not like Morris. Most people cannot assert their autonomy so ferociously, nor should they have to. I hate to think what might have happened if Morris had been unable to get on that bus. What if he had not owned his own home? The 2015 Act would have enabled Morris to appoint someone to assist him in exercising his decision-making capacity and facilitate him to participate as fully as possible in any decisions to be made. Morris would have required some support to access information, but it is likely that once this information was presented in a way that he could understand, he could have retained it long enough to use and weigh it to make a voluntary choice. Mainly, Morris needed support to communicate his decisions once they were made.

By the time I met him, Morris had proven that he could indeed manage living at home alone. At my first visit, he had very clear objectives that he wanted support with: his medical care and his investments. He had prepared two piles on his desk, each containing the relevant documents for each of his objectives. It strikes me that Morris would have appreciated the provisions of the 2015 Act whereby he might have appointed in advance a trusted person or persons to assist him with both of these areas in accordance with his will and preference.

Morris had large quantities of unused prescription medication in his home. He had questions about his medication and was not following the prescribed doses. Communication with his GP had broken down and he expressed frustration and anger with his GP. I was able to support Morris's communication with his pharmacist, who provided an accessible list of his medicines which explained what each tablet was for. I supported Morris's communication with his public health nurse, who helped Morris change his GP on the medical card scheme. Under 2015 Act, Morris might have appointed a decision-making assistant from his own circle of support to assist him to obtain the relevant information, advise him by explaining relevant information and considerations, ascertain his will and preferences on the subject and assist him in expressing them, and endeavour to ensure they are complied with.

The same applied to Morris' other objective. He had received a letter from an investment company in the UK, which requested that Morris or his 'personal representative' reply by phone. Morris was very anxious about this investment and unable to communicate by phone or reply in writing. With support, he was able to submit the relevant documentation and resolve the issue. Morris could have made decision-making assistance agreements with one or more people, to assist him making these and other decisions about his personal welfare and/or property and affairs.

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### NOREEN

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Noreen was an 86-year-old lady I met in a nursing home. She was a widow with three attentive adult children involved. While this story raises a number of ethical, legal and clinical issues, for the purpose of this chapter, I am taking a narrow focus on what difference the 2015 Act might have made.

Noreen's medical background included stroke, COPD, heart disease, and above-knee amputation. A decision had been made that Noreen was 'not for transfer' to the acute hospital. Since moving to the nursing home, Noreen's condition had continued to deteriorate. She became increasingly weak and generally unwell, refusing food and drink. Noreen was referred to me for a swallow assessment and I made several attempts to complete this assessment. On each attempt I found Noreen was either asleep and unrousable, or she refused to try anything to eat or drink. Noreen was very weak and communicated non-verbally using facial expression and gesture. She communicated her refusal of small trial amounts of food or drink through facial grimacing and turning her head away when anything was offered. Noreen similarly refused extra oxygen by turning away and grimacing when a nurse tried to place a small thin tube to deliver oxygen just inside her nose (O<sub>2</sub> prongs).

Noreen's family were distressed at their mother's deteriorating condition and they requested that a nasogastric feeding tube (NGT) be placed. They had seen the benefits of an NGT during an earlier phase of Noreen's illness and hoped it might work again this time. The doctor agreed to the family's request. Several attempts were made to place an NGT, during which Noreen became distressed, trying to turn away and attempting to remove the NGT. Noreen died three days later.

I believe that Noreen's facial expressions, grimacing, turning away, becoming agitated and attempting to remove the NGT were examples of Noreen expressing and trying to exercise her right of autonomy, by refusing treatments (NGT, O<sub>2</sub> prongs and oral trials). The decision to place an NGT was made by her family and doctor and she was not placed at the centre of decision-making by her medical team. Her non-verbal expressions were not accepted as valid and her wishes had not been documented.

The 2015 Act would have enabled Noreen, if she had wished, to make an advance healthcare directive of her will and preferences concerning artificial nutrition and hydration. This could have included an advance refusal of treatment, even where this refusal might lead to her death. The 2015 Act would also have enabled her to appoint a designated healthcare representative with the power to ensure that the relevant advance healthcare directive was complied with in the relevant circumstances. The designated healthcare representative could have countered any decisions or requests for treatment from her family or others which were add odds with Noreen's will and preferences.

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## CONCLUSION

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We are still waiting for the promise of 2015 Act to be fulfilled with full commencement. Morris, Noreen and so many others have been denied the decision-making supports it would deliver. As we await full commencement, I hope that more healthcare workers will feel encouraged to start delivering on some of that promise, by bringing the presumption of capacity to life in their practice and supporting people to make their own decisions. If I reflect back on my questions, 'How do I make sure this doesn't happen to my parents? How do I make sure this doesn't happen to me?', I see that a genuine presumption of capacity, supported decision-making and advance care planning will play a pivotal role in ensuring a future in keeping with our will and preferences.

## 6.9 From the Other Side

*Marie Tighe*

‘Because to take away a man's freedom of choice, even his freedom to make the wrong choice is to manipulate him as though he were a puppet and not a person’

—Madeline L'Engle

Having worked both as a Hospital Manager and a Director of Nursing in a number of acute services, the challenges of managing ingress and egress are a day-to-day reality and the focus of acute hospital life. The moral and ethical dilemmas of respecting and supporting a person's decision and autonomy as set out in the Assisted Decision-Making Capacity Act 2015 (the 2015 Act) while also managing a service is a fine balancing act for every manager.

Undoubtedly, the focus of care for all staff in an acute hospital is to ensure that the sickest people are in the right place. Many of the people who access our services are older people, people with intellectual disabilities, people with diminished decision-making capacity, delirium or dementia, or people whose decision-making capacity has been affected by a traumatic injury. While the 2015 Act recognises that all people have equal legal rights and respects the right of everyone to make decisions for themselves, in practice this is not always the case.

This became a reality for me when I had to adjust to being on the ‘other’ side of the healthcare system and had the experience of supporting my 90-year-old mother when she experienced an acute gall bladder issue which involved a prolonged and complex hospital admission.

Prior to her admission to hospital, my mother lived independently, was driving her car and attended many social activities on a regular basis. For as long as I can remember, she had a fear of health services. She believed that they were ageist in their approach to care and frequently referred to older people being seen as bed blockers. As a result, on many occasions she frequently advocated for friends and neighbours in healthcare facilities. She was also a firm believer in having a family member present with a person as much as possible while they were in hospital, particularly if they were older, to ensure that they did not become confused in a strange environment. In my mother's case, I was frequently that ‘nominated person’.

Early on in my mother's admission to hospital, I too was surprised at the ageist attitude of some healthcare workers' assumptions regarding her functional and cognitive ability. Many questions from healthcare workers were directed at me while my mother, despite

being present, was ignored. On one occasion I can recall a healthcare worker addressing me regarding whether she had taken a specific medication that morning. I directed the question back to my mother because she was always aware of all the medications she took. She responded by stating that she had taken the medication. The healthcare worker completely ignored her response and requested to see her medication record, which confirmed that she had taken the medication that morning.

The impact on the person as a result of healthcare workers presuming that a person has functional and cognitive decline is that family members and others become decision-makers, and are given this authority by healthcare workers, while the person at the centre of the decision is excluded from conversations and consent processes resulting in a loss of autonomy for the person. These situations deprive people of their independence, their voice, and are a far cry from the presumption of decision-making capacity as outlined in the 2015 Act.

Decision-making regarding discharges is a critical aspect of managing egress from an acute hospital. While decisions regarding discharge are theoretically made at ward level with the person involved and central to the decision-making process, these are frequently expedited by senior managers at bed management meetings. The pressure to secure a vacant bed for a sicker person requiring admission becomes the priority. The person who has completed their acute episode of care is then progressed along a pathway of care where decisions are made frequently by senior managers, in haste, under pressure, and with limited support or resources. The principle of supporting the person to participate and their right to autonomy and self-determination as set out in the 2015 Act is frequently lost in the process as the system seeks to prioritise the acutely ill person.

The 2015 Act places a responsibility on people to give effect to the past and present will and preferences of a person. The person's involvement in decision-making at the time of discharge is equally critical to managing a satisfactory discharge. Many older people experience longer lengths of stay in hospital than average and as a result suffer physical and cognitive decline. This has implications on the person's ability to return home and function as they did prior to admission. The ability of an organisation to support the person on discharge is limited. The Nursing Home Support Scheme is most often readily available while on the other hand there is limited availability of home care packages. This impacts on the person and their decision-making regarding discharge. Many older people will advise that it is their will and preference to return home, but the availability of home care supports is limited. The result is that the system is biased towards long-term care and the ability to support people in accordance with their will and preference to return home is limited.

This is compounded by healthcare workers being risk-averse. While the prime focus of the care being delivered is that the person is kept safe, the proportionality of restrictions imposed on the person is measured in ways relating to what the healthcare workers and/or what families believe to be safe. The paternalistic but caring view of some healthcare workers

and their belief of what is in the ‘best interests’ of a person while also being risk-averse takes precedence over the persons’ will and preferences and their expressed wishes.

The harsh reality in many situations is that to honour a person’s expressed will and preferences and to be able to discharge an older person home remains a hugely difficult challenge unless the person can afford to pay for private home care and has the ability to organise it. The HSE’s ability to provide home care hours is limited and it frequently requires someone to die in a particular area to free up available hours for a new person requiring support.

All of this became a reality for me too when my mother’s discharge was imminent. The challenge of supporting my mother’s will and preference to return home and the harsh cold reality of her new physically deconditioned state highlighted to me the tensions that exist between a hospital manager expediting a discharge and, on the other side, a family struggling to support a person’s will and preferences. Undoubtedly, integrated approaches to caring for older people, which are comprised of multidisciplinary care teams, have made significant strides in this area. While these developments are welcomed, they are a scarce resource and are not available everywhere. My mother was fortunate to be part of one of these teams and despite this she struggled to rehabilitate.

In preparation for my mother’s discharge, the hospital requested a family meeting with my mother present. The purpose of the meeting was to ensure the person, the family and the multidisciplinary team were all on the same page. As a senior hospital manager, I too convened such meetings and found them extremely helpful. As a family member and advocate for my mother, I struggled to see the purpose of the meeting as my mother was involved in all her care decisions on a day-to-day basis, and I too assisted and participated in her care daily. The meeting took place in a spacious room where all the team sat around in a large circle and the family were invited to sit with them. I was struck by the power imbalance that existed between the number of senior hospital staff and the small number of family members present. The seating arrangements further defined this. I found that this was very stressful and an intimidating experience for me, despite my previously held belief of the benefits of these meetings. I was taken aback by the message delivered at the meeting. It appeared that my mother was struggling to rehabilitate and most likely would never walk again. It was suggested that physiotherapy was not beneficial and that it be discontinued. I was shocked and devastated by this news and cannot imagine how my mother felt. This was the first time that my mother or I had been made aware of this. Following the meeting my mum, brother and I had a conversation and my mother clearly stated that she would walk again, to take ‘no heed of them’ and that she wanted to continue her rehabilitation. This was communicated to the team, and they agreed to continue with it. This situation demonstrates the vulnerability of people and the significant role advocacy, albeit in our case, by a family member, can have in supporting people. While my mother had decision-making capacity, her acceptance of the view of people in authority did not empower her to freely express her own firmly held views. Nor had she been asked this question directly.

I believe my role in advocating for her in this situation would have had much more authority or credence had I been appointed as decision-making assistant under the 2015 Act.

Three years on, my mother continues to live with a family member. In an effort to fulfil her will and preference, my mother is taken for regular visits back to her home where she meets up with her friends and engages in social activities that she did prior to her admission.

The cognitive decline suffered by my mother during her hospital stay did improve a little on her discharge but overall, her memory remains poor. She continues to be involved in all aspects of her decision-making for herself but requires various levels of support depending on the decision. If the 2015 Act were in place, many of the decisions could be formally supported with a decision-making assistant. For example, when the first wave of COVID-19 became a reality in Ireland, my mother was faced with the problem of not being able to physically collect her pension at the post office and having to switch to having it being paid directly into her bank account. The task of collecting her pension was not merely a task but a social occasion, where she frequently met some of her friends and went for lunch. However, the restrictions imposed, and the fear of COVID-19 influenced her decision into getting her pension paid into the bank. In making this decision, I spent time explaining the situation to her, how long it was going to last, and the risks involved for her. I assisted with getting the forms for her to make this happen. I did not have any authority to take on this role, but if I had been appointed by her as her decision-making assistant, this would have formalised my role and provided clarity for others that I was dealing with.

In other cases where there are more complex decisions to be made, it would be helpful if my mother had a co-decision-maker. My mother continues to run a small farm and has, for years, made decisions regarding the various business aspects of it with another family member whom she has always trusted in his judgement and input. Since her illness, she continues to make decisions regarding the farm with this family member. This is where I believe that if the 2015 Act were commenced, this family member could be appointed as a co-decision maker, and in doing so, it would give this family member the legal authority to make decisions jointly with my mother.

It is all of our responsibility, regardless of whether we are the senior manager in a hospital, a carer, or a family member, to respect everyone's legal right to autonomy and self-determination. Any of us could find ourselves in a situation where our decision-making is hampered by disease or injury, and this is where the various levels of support of the 2015 Act will ensure that we as individuals have the necessary supports and safeguards to ensure that the decisions we make are our own.

## 6.10 The Assisted Decision-Making (Capacity) Act 2015: An Occupational Therapist's Perspective

*Niamh Kelly*

The Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) will affect the work of everyone in healthcare. While the HSE National Consent Policy is already in place, the 2015 Act will provide additional support to the way healthcare professionals make their decisions. Under the 2015 Act, we are obliged to provide all practicable support to someone to make a decision.

I am an occupational therapist (OT) in an acute hospital. As an OT, I am trained to look at the person as a whole to identify the difficulties they might be having, including how physical, cognitive, mental health or social issues are impacting on their ability to carry out the things that they do - and want to do - every day. As OTs, our goal is to enable people to live life to the fullest.

Due to service constraints in the acute hospital setting, a lot of the emphasis of my role can be around the decision whether somebody is ready to go back to a home setting and to help explore what supports they may need to get there such as rehabilitation, equipment, strategies etc. Through occupational therapy sessions we can help the patient to identify the difficulties they might have on discharge and help inform their decision.

The question of capacity can arise if the person wants to go home, and some of the people surrounding the person, be they hospital or community workers, their family and/or friends, do not think this is a safe possibility.

These discussions can create pressure, with the argument of 'Sure, you can't send them home', being heard on a regular basis. Often the basis of this argument is in relation to the safety risk posed to the person, such as clutter in the home, wandering, falls or other hazards in the home or community. It can be difficult in a small rural area, where the people telling you that a person can't go home are people you know from your own community, your friends, your local shopkeeper or your children's sports coaches. Phrases such as 'Well, you'll be to blame if something goes wrong', 'Can you guarantee me they won't fall when they go home?', 'Have you talked to the sister? She said there's no way he can go home' are pushing responsibility back to the healthcare professional. These concerns are for the most part coming from a good place, as the carers are worried about the safety of the person and want to feel they have done everything they can to prevent any harm.



Concerns should of course be listened to and can often be helpful in identifying risks and developing plans to manage them; however they should not be the entire basis of a decision around discharge.

Clement Freud said not smoking, drinking and loving doesn't make life longer, it just makes life seem longer. In a lot of cases, going into a nursing home could be added to this list. By ensuring that the person has made that decision themselves and is aware of the potential consequences, we can hopefully help people live out the rest of their lives in the knowledge that it has been their informed choice. In the past, we may have kept them physically safer through admission to nursing homes, but in doing so we perhaps deprived them of their right to live their lives the way they wanted to.

Often, the impediment to discharge relates to the lack of supports available in the community or to families who may want to support somebody to go home but feel that they cannot provide the level of input needed. There can be long waits for follow-up occupational therapy assessments in the community as resources in both community and hospital settings are extremely limited. This can mean that follow-up sessions do not take place, so the discharge then 'fails'. Technological advancements have helped reduce the need for physical supervision; however skilled assessment is still crucial at this time to identify risk.

I hope that as we move forward, we will see increases in staffing of healthcare professionals and improved support services and resources to deliver the level of care and support needed. We need to build supportive communities to make it possible for everyone to stay in their own homes if they so wish.

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## COGNITION AND FUNCTION

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In the past, occupational therapists have been asked at times by a medical team to do a Montreal Cognitive Assessment (MOCA) or a Mini Mental State Examination (MMSE) (cognitive screens), looking for a score 'to determine capacity'. With the enforcement of the 2015 Act, professionals will no longer be able to ask for a cognitive assessment to determine capacity. A score on a standardised test does not always correlate with someone's ability to perform their daily routine; a low score does not always mean poor performance in daily tasks, in the same way that a person may be able to tell us what they will do, but it may not translate in reality.

These cognitive screening tools can still be useful for OTs as part of our assessment process. When using them, I am never just looking at the score, I am observing how the person approached the questions, strategies they may have, subtle difficulties, for example visual perceptual difficulties. I then combine this observation with what I see when talking to the person and observe the impact of any potential impairments in their performance of a daily

task. I try to ascertain a person's values and interests and listen to their fears and hopes. I try to find out how they may already be managing the risks they have at home. I also believe it is important to talk to someone who knows the person outside of the setting, to find out what they were like before their impairment, what difficulties they have noticed and what barriers they perceive to the person returning home. I help point out to the person the risks and explore strategies of how to manage them.

This process can be time consuming, but is important. I have observed that in completing an everyday task such as making a cup of tea or getting themselves washed or dressed, the person has the opportunity to chat in a relaxed manner about what they really want and can identify their own challenges, which can help them organise their thoughts before sitting down for the functional capacity assessment. It can also help to reassure the person that the aim of the assessment of capacity is to help them make a decision and in turn develop trust in me as a professional and also in the process.

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## RISK

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There will always be situations when someone wants to pursue an activity that has the potential for significant injury. As OTs, we try to help people have choice and control over their lives. We help people recognise that their choice can involve risk. We can help them to understand their responsibilities and the implications of their choices.

As OTs, we can try to mitigate risk by analysing the activity the person wishes to perform, identifying likelihood and degree of risk, and exploring possible solutions. We can look at less restrictive options when a person doesn't have capacity (e.g. sensor alarms within the home or equipment to make a transfer easier). This is core to occupational therapy teaching at universities. However, working in institutions can often lead us to operate in a way that protects ourselves more than the patient with a fear of the headline 'OT sent patient home and X happened!' I think the new Act will increase awareness of the potential good that an OT can do.

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## MULTIDISCIPLINARY TEAM (MDT) WORKING

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Working as part of a multidisciplinary team (MDT) is key to helping the person to make their decision. Each professional has their own skill set and expertise that can be utilised at various times for different decisions, with each professional taking varying roles. Ward-based staff, such as nursing staff and healthcare attendants, tend to be able to see the 24-7 picture of the patient and their needs in this setting. Support staff (e.g. Catering) can get an insight into the person in a more relaxed, 'off-guard' format. Families and community workers know the person before their admission.

When a straightforward conversation is not possible, an MDT approach can be an effective way to identify the areas where the communication is breaking down. OTs can play an important role, particularly if cognition or visual-perceptual skills are an issue. I have found that working closely with my speech and language therapy and social work colleagues can be very helpful. We can work closely together to determine what tools and approaches are needed to help the person access the relevant information and build their capacity around decision-making. Joint working also helps share the responsibility associated with the process and can help us feel more confident in how we have supported the person to make their decision.

I hope that the 2015 Act will help relieve the pressure that may be felt by families and professionals. Increased availability of support from psychology and social work is also needed to help families and professionals manage those feelings of guilt, and to help professionals guide carers through the decision making so that there is a common understanding that we are all supporting the decision of the person. Our language will hopefully change from 'will you take them home?' to 'what can we do to get them home?'

In summary, I hope the 2015 Act will create a better culture of 'assuming capacity', embracing the risks and enabling choices. I hope OTs will play a growing part in empowering people to make their decisions. We have a long way to go, but the 2015 Act gives us a good place to start.

## 6.11 Learning to Listen

*Philip Crowley*

Any of us, at any time, could find ourselves incapable of making decisions in relation to our healthcare treatment, where we want to live or our finances. This could be due to illness, an accident or a disability and can be permanent or temporary. A lot of the patients I work with would require support to make decisions – in addition to my role as National Director of Strategy and Research in the HSE, I am also a GP working with the homeless population in Dublin's inner city. This is a very vulnerable cohort of people that isn't always listened too, their point of view isn't always taken seriously, and they regularly make decisions that many of us would think of as unwise. And a lot of them require additional support and extra time when making decisions, maybe due to an additional mental health condition, a brain injury or dementia, drug or alcohol abuse or a number of comorbid medical conditions. But that doesn't mean that they lack the capacity to make those decisions.

I believe that the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act) will make a positive difference to everybody in Ireland, but I think it will have a visible impact on vulnerable and marginalised groups. This cohort of patients regularly have their capacity to make their own decisions called into question for a variety of reasons.

As a GP, I would like to think that we are cognisant of the decision-making ability of the person we are working with, our patients. I believe that we seek to support people to speak up for themselves and help them to make their preferences clear. But in practice, when you are under time constraints, or when you have a clear idea in your head about the pathway of care that you think is in the patients 'best interests', we might impose our own views on what is best for the patient rather than what the patient thinks is best for them. Or we might default to what is dictated by evidence and what we know works. We might discuss the options with the person, but in our heads we can be pretty fixed on what intervention would work here. I think that the 2015 Act will help to challenge some of the assumptions that we have as doctors, and make our practice much more person-centred, making sure that the patient is involved in the decisions that are being made about their care.

I would like to think that when I am working, I put the person at the centre of every consultation, but I don't think we all do it all of the time. When I was training as a GP I participated in a consultation with a mother and her child, who was about 6 or 7 years of age, and the consultation was recorded. I thought that the consultation had gone very well. When we reviewed the video with my colleagues, I nearly hid behind the chair because I realised that I had spent the entire consultation talking to the mother, talking over the child's head. I didn't address a single question to the child or listen to what they had to say. While this example is about a mother and a child, it also applies for people whose

decision-making capacity is in question. When a person's decision-making capacity is being questioned, we can default to asking the next of kin for consent. However, the HSE National Consent Policy and the Medical Council Guidelines are clear that next of kin should not consent to an intervention on behalf of another adult. While you can consult with those closest to the person to ascertain their will and preference about the intervention, they should not be consenting on someone else's behalf.

When you are under time pressure, there are a number of incentives to not practice optimally and to bypass areas of good practice. If we are to implement the 2015 Act to its fullest, in practice, we need to ensure that we have supported the person to consent, and that we need to give them every chance to express their preference, and we consider that they might be able to consent at a future point in time. We must really listen to what they are telling us, and don't just dismiss their view because what they want to do is unwise.

A study published in the *British Medical Journal* in 2012, written by three healthcare experts from the Dartmouth Centre for Health Care Delivery Science in New Hampshire in the US, stated that 'preference misdiagnosis' is a significant problem in health services that is damaging to both doctors and patients (Mulley, 2012). Preference misdiagnosis happens when the healthcare worker misinterprets or ignores the patient's wishes. This can lead to 'silent misdiagnosis', when the doctors choose the wrong treatments because they fail to listen to their patients and assess their preferences correctly. The study emphasises the importance of engaging the patient in discussion about treatment possibilities so that they are more informed about the options, therefore making it less likely that their preferences will be misinterpreted or misdiagnosed.

The above study leads me to ask if we do this with patients where their capacity isn't in question, to what extent do we do this with patients where their capacity is in question? Do we present them with all of the options? Do we tell them in a way that they can understand? We need to make every effort that we can to clarify what the person's preference is in relation to any treatment choices that they are making. Anything that causes us to pause on the treatment pathway, to seriously consider with some depth what the individual's will and preference is, is a good thing. And that is what the 2015 Act is trying to do. And it is a really welcome change. But it is a huge change for practice. But will practice only change when people challenge what is happening under the 2015 Act? Embedding the ethos of the 2015 Act in services will be a challenge in time-poor, under pressure services.

One particularly challenging situation for clinicians will be when they are unsure about a person's decision-making capacity, or the clinician is unsure about their ability to assess that person's capacity. And even if you think that you can assess that person's capacity, you're left with the question of whether you have done it correctly, especially if you are under time pressures or need to move on to your next task. I think this will be the most challenging – the pressure for clinicians to deliver care effectively and fast, while also ensuring that

they are properly supporting the person to make an informed choice about their care and treatment pathway.

For the homeless community that I work with, and other marginalised communities, the 2015 Act will have a huge impact. A lot of the people I would see might be under the influence of alcohol or drugs, affecting their capacity to make decisions. One recent consultation springs to mind – it was my last consultation on a Friday evening, I was running late for my next commitment and I thought I was finished in the clinic. When the patient came in to me, I was distracted. He was inebriated. I eventually took the time to start listening to what he was saying, to actually listen to him. I managed to unpack what it was he wanted, reported it back to him, asked him if that was the support that he was seeking, gave him what options were available and suggested a number of courses of action that he could implement if he wanted. If I hadn't taken the time to listen to him, if I had rushed the consultation to head to my next commitment, I might never have got to the bottom of what support he was seeking.

The 2015 Act will be a challenge for health and social care services to implement. It is a fundamental change to existing practices and to a lot of existing thinking, and it will make practitioners question how they support their patients and service users. And this change will not happen overnight. But ultimately, it will make people's experiences of the health service better. They should be receiving a more person-centred service, where their wishes and preferences are truly listened to, where all treatment options are presented to them in a manner that they can understand and where they are supported to make the decision that is right for them, not what the clinician thinks is the best option. We need to work in a clear rights-based framework that understands and emphasises the individual's right to choose, even if their decision-making capacity is in question. If all practitioners implement the guiding principles of the 2015 Act, we can achieve a truly person-centred health service for everyone accessing it.

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## 6.12 Towards Commencement – Reflections on Opportunities and Delays

*Caoimhe Gleeson*

In the autumn of 2015, I was working with a group of autistic people, autistic allies and parents of autistic children and adults on a community education programme in Donegal. As a means of gaining hands-on experience of learning how legislation and policy is created, we collectively, over the weeks from September until 17 December, watched Dáil and Seanad debates on the Assisted Decision-Making (Capacity) Bill. We had many discussions on what the Bill would mean for the collective lives of the group – those of their children, themselves, their partners or those to whom they provided professional support. For some, there were great concerns about what would happen to their adult child or disabled partner if they were to get acutely ill or die. How would their needs be catered for when they were no longer around to advocate for them? They spoke about their fears of abuse and exploitation, about the lack of legal clarity and about how they could plan for this eventuality. Some voiced great hope and a belief that a new dawn was coming because of the Bill. They believed that their years of activism, lobbying and unrelenting fighting for services and recognition of their rights and those of the people in their lives were about to be realised. One member of the class was friends with then Minister for State for Mental Health and Disability, Ms Kathleen Lynch TD. During one of the final debates, the Minister drew the class into the actual world of legislative reform when she sent a text from the Dáil to the class acknowledging their efforts at engaging with and supporting the development of such an important piece of legislation in its final stages. There was much celebration and anticipation at the news that the Bill had passed all stages and would be signed into law by the end of 2015. Everyone in that class would in some way benefit from the protections offered by the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act).

Shortly after the 2015 Act was passed and buoyed by the energy of that process, HSE colleagues and I developed a proposal with Dr Philip Crowley, then the National Director of Quality Improvement, to establish a programme to support the implementation of the 2015 Act when it was fully commenced. We received resounding support from our then Director General, Mr Tony O'Brien, and the HSE leadership team of over 20 senior leaders. We quickly set about having a national conference in February 2016 to start to engage the hearts and minds of people about the opportunity and challenges we would now face with the commencement of such an ambitious and complex act. Over

550 people attended the conference in person and an additional 1,000 people joined virtually. Justice Catherine McGuinness chaired the proceedings while Lord Justice Baker shared the experiences and lessons from the Court of Protection in England and Wales. Thereafter, we established a national steering group to identify key enablers for commencement of the Act. This was formerly chaired by Professor Deirdre Madden and latterly by Professor Mary Donnelly, both from the School of Law in University College Cork. The then Minister for Health, Mr Simon Harris TD, appointed the HSE Assisted Decision-Making Steering Group and the Advance Healthcare Directives Multi-Disciplinary Working Group to draft the codes of practice on advance healthcare directives. On her appointment, the Director of the Decision Support Service, Áine Flynn, requested the Steering Group to draft the Code of Practice for Health and Social Care professionals. We worked in close collaboration with our colleagues in the National Disability Authority on the drafting on the non-healthcare codes. We designed and delivered information sessions on the requirements of the 2015 Act to thousands of healthcare workers in hundreds of healthcare settings. We produced an explainer video on the 2015 Act, have developed a series of online webinars and are currently designing a suite of e-learning programmes to support the training and education needs of staff. We continue to build a broad village of committed, engaged health and social care workers wanting and wishing to realise and respect the dignity and autonomy of the people they serve – in the absence of a clear and unambiguous legal framework in which to do so. In late 2019, before the COVID-19 pandemic took hold of our lives, we co-hosted a number of national conferences to draw attention to the failure to commence the 2015 Act and to ensure that the 2015 Act and those it was written for were not going to be forgotten. Many of the names in this book provided engaging testimony at those events giving us the inspiration to create a record of how far we have come in our pursuit of commencement.

Since December 2015, we have remained unflinching in our commitment in preparing health and social care services for commencement of the 2015 Act. We have remained on task in spite of protracted delays and persistent cynicism from some sectors about the practicality and, indeed, the need for the 2015 Act. We have continued with this commitment throughout the pandemic and throughout the national vaccination programme in response to the pandemic. As I write our efforts will remain as we work our way through the after-effects of a national cyber-attack of catastrophic proportions for the HSE.

In all of this time, the overwhelming message from people, their supporters, families and staff has been that, in spite of ongoing delays in commencement, this 2015 Act is long overdue for a multiplicity of interconnected and separate reasons. For some, it is the fear that their voice will be lost if they develop a condition that will challenge their decision-making capacity. For others, it is the lack of clarity about who can make a health and/or social care decision for a person when there is no one with legal authority to do so. There are those who are afraid to have difficult conversations with loved ones about their future selves and wishes, but know that there may be consequences in saying nothing now. There are others who want to face the end stages of their acute illness safe in the knowledge that



their wishes for their final days will be honoured and respected and that those they leave behind will be protected, especially if they lack capacity to make decisions.

Over the last year in particular, the disparities between those who have the autonomy to make decisions and those who rely on a system of supports to make decisions have really come into sharp focus – in particular in the absence of a legal framework to ensure the will and preference of the person is sought and protected. While commencement of the 2015 Act will not instantly solve generational discriminatory ideology and practice towards people who need support with decision-making capacity, the commencement of this Act which places the person at the centre of all decisions about their lives through the use of respectful and purposeful language and mechanisms is one that is long anticipated and necessary. The prevalence of legal frameworks based on paradigms of lunacy and unsoundness of mind remain offensive and disempowering for those they most affect and for those who one day may require the protection of the law. Such frameworks are an anathema to the almost three decades of transformative human rights and equality dialogue in health and social services in Ireland with people who use services and are anomalous with spirit and the letter of the UN Convention on the Rights of People with Disabilities.

It is now over 18 months since lockdowns, restricted visiting, containment on travel beyond 5 km have become our new normal. And yet, a question remains – was this a normal for some people whose decision-making and freedom has been restricted and curtailed far beyond those restrictions imposed by the public health response to the global pandemic? The last year has raised many questions about equality and human rights and has begged greater questions as to the parity of these rights for certain groups of people. When things are unequal, a slight adjustment towards the further restriction of rights can really make the wheels come off the proverbial truck. A restricted life becomes almost unbearable – for the person and for those struggling to stay central to that person's life. Small decisions that have meant autonomy and independence for the person have been curtailed for the good of the nation. No heading off on the town. No visits to or from family or beloved friends. No life beyond the bubble. No work. No gatherings. No overnights. Silence.

For those of us who have the freedom and capacity to control the content of what goes on in our restricted bubble, things have been challenging, testing and wearing. Some of us have been stretched into places that we have had no desire to go – mentally and spiritually. But what of those where every decision is predetermined or contingent on the support of others? And for those in circumstances where there has been no time or space to accommodate independence or autonomy and where the preservation of the safety of the lives of others has resulted in an autonomy lockdown? Where the supports for those to enable more fulfilled lives have been diverted elsewhere in this recurring emergency of surges and abatements? And then what of those whose lives have always been a type of lockdown due to lack of supports or geographical isolation? The arrival of the pandemic did not alter this reality very much for some and perhaps has made others realise that we certainly are not all in this together.

As we move closer to the review of Ireland's adherence to its commitments of the United Nations Convention on the Rights of Persons with Disabilities, the Oireachtas has publicly stated its commitment to commencing the Assisted Decision-Making (Capacity) Act 2015 in full in 2022 – seven years after it was signed into law by the President Michael D. Higgins. However, this is the first time in the short history of this law that we have a firm commitment across Government and clear signs of mechanisms advancing to prepare the groundwork for commencement across other sectors.

This is a time to be hopeful that the days and the nights of unrelenting advocacy by civil society groups will finally be realised. And that those autumn evenings in Donegal in late 2015 will come to good effect. The architects of the Act from the Departments of Justice and the Department of Health, with the unfaltering support of the then Minister for State for Mental Health and Disability, Ms Kathleen Lynch TD, were visionary and ambitious in their drafting. Our goal is to continue to create stable foundations within health and social care to give effect to their ambitions.



# We all make decisions...

...big and small, every day of our lives. Most of us are able to make these decisions by ourselves. Some of us may require additional support to make decisions. The Assisted Decision-Making (Capacity) Act 2015 will provide the legal framework to maximise a person's right to make their own decisions, with legally recognised supports. Once commenced, this significant piece of legislation will change everyone's approach when working with and supporting people whose capacity is in question.

This collection of essays, written from both personal and professional perspectives, highlights the importance of this ground-breaking piece of legislation. The powerful essays demonstrate the scale of impact that the Act may have on people's lives — from the ability to write a legally binding advance healthcare directive to being supported to make their own decisions if they have difficulties with decision-making capacity.