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Editorial

Advance healthcare directives – their importance within Irish health services: the lived experience perspective of a service user, advocate, and campaigner

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I have been invited to contribute an article to this Journal. I have no academic expertise in the field of mental health. In 1960 I graduated from Trinity College Dublin with a degree in History and Political Science and a diploma in Social Science. My work has been in education, a lecturer in London Colleges from 1963 to 1990, part time with the Open University from 1970, and from 1990 to 2000 as Access Development Officer for London Open College Network, working with tutors in London Universities, Colleges of Further Education and Adult Community Colleges to provide, deliver, and validate programmes, primarily for people from groups disadvantaged in their earlier educational experience. We worked on curricula appropriate to these learners, who came from diverse countries and cultures, that would enable them to enter and do well in Higher Education. When I retired in 2000 over 4000 mature students had entered Universities with their London Open College Access Certificates.

While I was still in London, working and raising our four children, my mother was taken ill with pneumonia. She had become very depressed in her eighties and would say to me, 'I want to be D-E-A-D, I can't spell suicide'. Her doctor said they could try treating her and she might recover. I said she didn't want that; she'd prefer to go quietly. Her doctor understood and said she would talk to her consultant while I asked my brother and sister. We all agreed, the hospital would withdraw food and drink and not medicate, I stayed at her bedside and she was peaceful in a way she had not been for several years, gave me lovely smiles saying how much she loved me; my brother, sister, and husband all visited and she died within the week. Although I thought then and still think now that we made the right call, it was a very hard one which I certainly would not want my four children to have to take for me.

This leads me on to the purpose of this article. Advance Healthcare Directives (AHDs) are central to a human rights centred health service, not only but especially for people who experience mental health episodes, roughly a quarter of the Irish population. My interest in and advocacy for AHDs arises from my own experience of breakdowns in later life and from campaigning with groups for reform of mental health legislation to conform with the United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD) and to replace the nineteenth century Lunacy Act still in place at that time (the Regulation of Lunacy (Ireland) Act 1871, governing wardship). Ireland had signed up to UNCRPD but could not ratify it as current mental health laws and practice were not compliant with the Convention.

Over the years I have campaigned for reform of Irish mental health services with several groups: Amnesty International Ireland ran a ten year (2003–13) campaign for a human rights centred mental health service; the University of Galway School of Law carried on this work, leading a coalition of many groups of activists nationwide; Mental Health Reform, an umbrella group of many organisations are involved; many smaller groups including Recovery Experts by Experience (REE) and most recently a group led by law lecturers and researchers at the University of Galway, all working for a human rights centred mental health service in line with UNCRPD. The UNCRPD states that a person's will and preference rather than a psychiatrist's opinion of best interests should determine our treatment, that everyone has legal capacity even if at times our mental capacity is impaired, and that our wishes can be stated in a legally binding AHDs drawn up with or without help and signed by witnesses.

In 2012, I was invited by Amnesty International Ireland to participate in a Citizens' Jury of fifteen people with experience of treatment within Irish psychiatric health system. We shared our histories, stories, and opinions. We were informed of UNCRPD and its emphasis on a human rights centred mental health service which acknowledges every person's capacity to express, with or without help, what our will and preferences are for treatment of physical/mental health issues, what treatments to choose or to resist. Many members of the Jury had been subject to chemical or physical restraints, repeated involuntary admissions, sessions of electro-convulsive therapy (ECT), over-medication, and other practices. Amnesty invited experts to talk to and discuss with us. The Mental Health Commissioner spoke of results of his inspections. He said that 88% of patients in the hospital I was committed to in late 2001 were over-medicated with antidepressants and sleeping pills. In my own experience, a male nurse stood over us as we queued for tablets at 10 pm each night and made us take whatever we were given. In addition, I had eight sessions of ECT under anaesthetic with no

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explanation. After one I fell and broke my nose which, in my view, was a failure of care. A psychiatrist also informed us of many shortcomings within the service and a lawyer clarified the need for legislation which recognised everyone's legal capacity.

We prepared a report which was launched with considerable acclaim to a full house at the Department of Justice. In 2015, Capacity Legislation was passed by the Oireachtas and the Irish State could now ratify the UNCRPD. I believed that I could make a legally binding AHD which I did with my solicitor and with my general practice (GP)'s approval. This primarily concerns my wishes for end of life, organ donation, and so on but it includes this paragraph:

> *Any Mental Healthcare that I require is to centre on rest, counselling, and minimal short-term medication preferably in my own home. In any episode, treatment will assume my recovery and return to normal living. I specifically never want to be subjected to ECT again unless medical advice deems it to be absolutely necessary.*

I have given copies of my AHD to my GP, my community psychiatric consultant, and my four children, and the original is with my solicitor. They welcomed this. My consultant invited me to talk, in a one to one interview with him, which lasted for forty-five minutes, to thirty members of the hospital's mental health team who expressed interest and asked questions. Mine was the first AHD they had received.

In fact, I mistakenly believed that AHDs were legally binding once the Act was passed. I didn't realise that it had to be commenced. This finally happened in 2023 after further campaigning by our activist groups.

After the Amnesty Campaign, leadership passed to a Coalition of Mental Health Organisations coordinated at University of Galway School of Law, specifically the Centre for Disability Law and Policy. We formed a small activist group, REE, part of the Coalition. Although we welcomed the Assisted Decision-Making (Capacity) Act of 2015, which recognised a person's will and preference rather than a psychiatrist's view of a patient's best interests with regard to psychiatric treatments, the law could not be commenced because the mental health services in Ireland did not correspond to its provisions.

In 2018, after I had recovered from a very serious breakdown, acute depression with many terrifying psychoses, and six months in a hospital psychiatric ward, culminating in twelve sessions of ECT under anaesthetic for which I was made an involuntary patient as I did not consent, I was invited by a lecturer in the University of Galway, the late Dr Fiona Morrissey, to join a small group to continue our campaign for a human rights centred mental health service. The group, Advocates for Human Rights in Mental Health Care, comprised three of us from REE, three lecturers and researchers from the University of Galway, one from University College Cork who was previously a mental health nurse, an advocate working in the Social Health Education Project, Galway, and a family member. Our work was founded on the UNCRPD, which states that no one should be detained or treated against their will in any kind of mental health facility, and World Health Organisation guidelines which espouse moving away from coercion towards a more human rights based approach. Research also shows that cooperation, mutual respect, and belief in recovery shared between staff and users of a mental health service result in more positive outcomes. Currently a high percentage of admissions to psychiatric facilities are re-admissions. Coercion by, for example, chemical and physical restraints or ECT, without consent may have immediate results but, because underlying causes remain, these may be temporary and have side effects, loss of memory, of autonomy, of confidence.

In 2022 our group were invited to present papers and meet the Oireachtas Committee advising about the reform of the 2015 Capacity Act prior to enacting it and preparing the Mental Health Bill which passed all stages in 2024 but is delayed because of the General Election last November. We also worked closely with Mental Health Reform. I was invited by Katie Hannon to participate in a News at One discussion which included the Minister Roderic O'Gorman, the then Minister for Children, Equality, Disability, Integration, and Youth, and others. Katie came to my house to record me. The issue was the exclusion from protection of our AHDs of people detained in psychiatric facilities based on notion of 'risk', although research shows we present no greater risk to ourselves and others than the general population. A Sinn Fein TD member of the panel pointed out that I was an 84-year-old woman so unlikely to be a risk to anyone.

The College of Psychiatrists of Ireland asked me to make a video to form part of an event they were holding. On two occasions they sent a taxi to take me to the College to make and then revise a video in which I spoke of my good and bad experiences of treatments in Irish mental health facilities. I was invited to the event also held at the College of Psychiatrists of Ireland but declined. I watched it on video link - the response to my video was minimal, one positive from the Mental Health Reform panel member, one very hostile, and mostly none at all. I felt angry that I had put myself on the line for a hostile audience.

I was also asked to write an article for an HSE book 'The Assisted Decision Making (Capacity) Act 2015: Personal and Professional Reflections' edited by Mary Donnelly and Caoimhe Gleeson, which includes contributions by lawyers, hospice workers, doctors, nurses, ASIAM Ireland's National Autism Charity, people with lived experience, and so on, all positive about the value of AHDs which express our will and preference for treatments we receive, both physical and mental and our end of life wishes. They give clarity to doctors, nurses, family members. Returning to the start of this article where I write of my mother's end of life, it would have been so less hard if there was one and each of my four children have a copy of mine.

All this campaigning and activism is exhausting. It necessitates revisiting very painful episodes and exposing our mental health issues which still carry stigma both within the medical profession and the wider society. It is time consuming and nearly always unpaid. We do it because we know from our experience how terrifying both our episodes and current treatments are and believe a human rights centred mental health service is kinder, more effective and beneficial to all concerned, to patients, their families and the nurses and doctors treating us.

I would like to end on a more positive note. Since being discharged from St Vincent's University Hospital in 2018, I have received excellent after care from their Old Age Psychiatry team, recently renamed Mental Health Service for Older Persons. The consultant and nurses visit me at home, spend time conversing as friends, and show respect and belief in my recovery. I can call on their team if and when I need help. My consultant helped me to gradually give up all psychiatric medication which results in my being more open to others, more spontaneous and compassionate. I am very grateful and wish a service like this could be available more widely.

Break down-Make up

When I go M-A-D
I break completely
body and mind
won't comply.

Defences are broken
i've reached the depths
chaotic P S Y C H E
fractured psychoses.

Cutters tear fences
no limits to spaces
reality recedes
fearful intensity.

A kind of necessity
to cut through pretences
uncover a pathway
towards self-awareness.

Assisted by friends
kindness of nurses
determination
I make a RECOVERY.

Shapes and Shades

I raise my arms
mindful stretching
barefoot on frosty grass

look up at banks
of clouds like mountain
ranges

a sunrise line
borders ridges before
transforming

dark clusters
chalk-white while
the sky above

becomes cerulean and
the sun shines even though
cold winds blow

. . . . . .

O the mind has mountains
I've struggled up many
reached rugged cairns

lost my footing
fallen into crevices
felt torn apart

sharp stones pierce
granite rocks bruise
thorn bushes prick

hand over foot
I clamber out
of the abyss

gaze upwards -
fireworks of
falling stars

Treatments

In their urgency to cure my psychoses
anti-depressants, SSRIs, are prescribed
with lithium to settle moods and,
as a last measure, twelve sessions
of ECT under anaesthetic.

No one slows down, explores reasons
for extreme symptoms at this stage of
a long life. Can they be traced to early trauma,
father's death when only nine months old,
mother smothering her own powerful grief?

My friend says *this is not a breakdown
but a break through*. Maybe afterwards
we find deeper insights and compassion
for ourselves and others.

We ask for respect, gentler places
than mental hospital detention - rooms
for rest and recovery in communities,
care and helpful conversations.

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