

Re(al)Productive Justice: Gender and Disability

Closing Conference Programme

Friday, 27th, January 2023 Institute for Lifecourse and Society (ILAS), University of Galway, Galway H91 C7DK





OLLSCOIL NA GAILLIMHE UNIVERSITY OF GALWAY Centre for Disability Law and Policy





Friday, 27th, January 2023, Hybrid, Institute for Lifecourse and Society (ILAS), University of Galway, Galway H91 C7DK

Re(al)Productive Justice: Gender and Disability

Closing Conference Programme

8:45 – 9:15	Registration
09:15 – 9.30 09:30 -10:15	Welcome Keynote Speech
Chair: Keynote: Response:	Eilionóir Flynn, University of Galway Freyja Haraldsdóttir, Activist, Iceland Suzy Byrne, Activist, Ireland Q&A
10:15 – 10.30	Coffee break
	Session One
10:30 – 11:15	Fertility and Contraception
Chair: Project Findings: Lived Experience: Int. Response:	Selina Bonnie, Activist and academic Emma Burns, University of Galway Orla & Bren O'Reilly Maulani Rotinsulu, ASEAN Disability Forum Q&A
11:15 – 12:00	Abortion
Chair: Project Findings: Lived Experience: Int. Response:	Mairéad Enright, Birmingham Law School Maria Ní Fhlatharta, University of Galway Nem Kearns Agnieszka Król, CREA, Poland Q&A
12:00 - 13:00	Lunch

Session Two

13:00 - 13:45	Pregnancy and Birth	
Chair: Project Findings: Lived Experience: Int. Response:	Sarah Fitzgerald, Writer and Activist Eilionóir Flynn, University of Galway Grace Kelly Theresia Degener, Bochum Centre for Disabilities Studies Q&A	
13:45 - 14:30	Parenting	
Chair: Project Findings: Lived Experience: Int. Response:	Louise Milicevic, Advocate Jenny Dagg, University of Galway Michelle McLaughlin Florencia Herrera Oesterheld, DISCA, Chile Q&A	
14:30 - 14:45	Coffee Break	
Session Three		
14:45 – 15:30	Professional Roundtable discussion	
Chair: Panel:	Suzy Byrne, Activist Denise Lawler, NMBI/HIQA Deirdre Lally, IASW/Sunbeam House Marion Dyer, Start Doctors Jennifer Donnelly, Obstetrician & Gynaecologist Gerry Hone, Tusla Caoimhe Gleeson, HSE	
15:30 – 15:45	Q&A	
15:45 - 16:00	Closing remarks	

Speaker profiles



Selina Bonnie is an Indian-Irish disabled woman who holds a master's degree in Disability Studies from the University of Leeds and a Professional Diploma in Human Rights and Equality from the IPA / IHREC. She has been an activist, lecturer and trainer in the international disabled people's movement for more than 25 years. Her particular research interests centre on sexuality, sexual expression and reproductive rights for disabled people. Selina has been published on related topics in various fora including a chapter titled 'Towards Sexual

Citizenship: Dispelling the Myth of Disabled People's Asexuality', in the book Sexualities and Irish Society: A Reader. She is currently the Vice Chair of Independent Living Movement Ireland (ILMI), represents ILMI on the Assisted Human Reproduction Coalition, and is a Regional Ambassador for the NUIG Centre for Disability Law and Policy Re(al) Productive Justice Research project. She is also a busy wife, mother and passionate home chef who works full time for South Dublin County Council as their Disability Liaison, Access and Equality Officer. **Email:** <u>selinabonnie@gmail.com</u> / Twitter: @SexualCitizens

Suzy Byrne is a disabled woman who has been involved in community work and campaigning on disability and equality issues for over 30 years. She works as a regional manager for the National Advocacy Service for People with Disabilities which provides professional independent representative advocacy for disabled individuals who may need support in decision making. Suzy is also a Director of Iarnród Éireann as one of the first disabled people to be specifically recruited to a state public transport board. She also chairs the board of Irish Council of Civil Liberties.





Theresia Degener is Professor of law and disability studies at Protestant University of Applied Sciences in Bochum, Germany and Visiting Researcher at Ritsmuneikan University, Kyoto, Japan. She is the director of the Bochum Centre for Disability Studies BODYS. From 2011 to 2018 she was a member (and for the last 2 years the Chair) of the United Nations Committee on the Rights of Persons with Disabilities. She co-authored the background study of the Convention

on the Rights of Persons with Disabilities (Quinn / Degener (2002) Human rights and disability: The current use and future potential of United Nations human rights instruments in the context of disability, OHCHR, United Nations) and has participated in drafting the CRPD. Her research fields are anti-discrimination law, human rights, disability studies and gender studies. **Website:** www.bodys-wissen.de. Professor Jennifer Donnelly is a Consultant Obstetrician and Gynaecologist working in the Rotunda Hospital and the Mater Misericordiae University Hospital with Subspecialty Accreditation in Maternal Fetal Medicine. She has developed nationally recognised services for women with complex pregnancy problems including critical illness, complex medical disorders, medicines in pregnancy, placenta accreta spectrum and provision of a national fetal surgery service. She is an advocate for many issues affecting women and people accessing maternity services including abortion, disability rights, gender bias and vaccines in pregnancy.





Marion Dyer completed medical school in NUIG in 1985, and General Practice Training at the Wessex Deanery UK in 1993. She worked as an NHS GP and Senior Lecturer in Primary Care at the University of Southampton until returning to Ireland in 1999 and founding her practice in Blanchardstown, Dublin which she led for over 20 years. Marion's professional interests are in women's health, child protection, violence in intimate partner relationships and medical education. She worked on the Programme Directing Team for GP

Training in the Northeast from 2006 until 2021 & is an Assistant Professor in Primary Care at Trinity College Dublin. Marion has volunteered at a women's refuge in Dublin and as a counsellor at the Dublin Rape Crisis Centre. She has been a committee member of Doctors for Choice since 2012 and worked actively in the campaign to repeal the 8th amendment. She is a member of the START provider group of GPs in Ireland.

Sarah Fitzgerald is a disabled woman and a mother to elevenyear-old, Alison. Following a series of traumatic experiences at the hands of healthcare professionals after the birth of her daughter, she set up her blog, <u>wobblyyummymummy.com</u>, to share these experiences and to highlight the obstacles facing disabled parents. Sarah has been involved with the (Re)al Productive Justice project since the beginning and shared her experiences of maternity services and the early days of parenting at the 11th Disability Law Summer School in Galway in 2019.



Caoimhe Gleeson is General Manager for the National Office for Human Rights and Equality Policy at the Health Service Executive (HSE). She is the HSE representative on the Inter-departmental Steering Board for the commencement of the Assisted Decision Making (Capacity) Act 2015 and has overseen the drafting of the Healthcare Codes of Practice on the Assisted Decision Making (Capacity) Act (2015) on behalf of the Minister for Health. As a member of the NDA Technical Group, she participated in the



drafting of the non-healthcare Codes of Practice on the 2015 Act on behalf of the Department of Justice. Caoimhe has responsibility for the oversight of HSE National Consent Policy and oversight of the implementation programme to support compliance with the ADM (Capacity) Act 2015 in the HSE. Prior to joining the HSE, Caoimhe worked in community development across the border counties and Northern Ireland. Throughout her career, Caoimhe has worked on and volunteered in several international programmes with a focus on gender equality, youth work, intercultural education, conflict transformation and mediation. Caoimhe holds a master's degree in Community Development, a professional diploma in Equality and Human Rights, an LLB, is a trained mediator and is studying for the Barrister at Law degree in Kings Inns.



Freyja Haraldsdóttir is a disability rights activist, disability rights protection officer and a foster parent in Iceland. She has a bachelor's degree in social pedagogy, a master's degree in gender studies and is currently working on her PhD in education, where she is researching disabled motherhood in neoliberal times. Freyja was active in establishing personal assistance in Iceland based on the Independent Living movement and founded the feminist disability movement Tabú.

Gerry Hone is the current Regional Chief Officer for Tusla covering the West and Northwest. He has responsibility for the safe and effective delivery of all Tusla Child and Family Services within the region. A qualified Social Worker since 1993, Gerry has built his experience in advocating for those most marginalized in society as identified through statutory child protection and child welfare services - especially young people and adults affected by disability. At various different management levels in his career, Gerry has



sought to ensure that the barriers preventing young people and adults with disability from full participation in family life and society are addressed at practice and policy levels within statutory services.



Nem Kearns is a sexual and reproductive rights, LGBTQIA+ and disability justice advocate, with a particular passion for grassroots community building within these intersections. They enjoy establishing connections and collaborations across selfrepresentative groups, and bridges between marginalised communities, and believe these voices must be heard to create a meaningful shared vision of equality for all who live here. Nem has formerly worked with Dublin LGBTQ+ Pride, LGBT Ireland and Full Spectrum Ireland, the all-island organisation for

disabled LGBTQIA+ queer people, and currently acts as a disability policy advisor to a range of elected officials. One of the founding members of Neuro Pride Ireland - a Disabled Persons Organisation which advocates for the equality and rights of the neurodivergent community and holds the annual Neuro Pride Festival celebrating Neurodivergent identities, culture and community - Nem also serves as spokesperson and Board Secretary to Disabled Women Ireland and is part of the inter-organisational Disabled Gender-Based Violence Taskforce. Having volunteered with the Abortion Rights Campaign (ARC) for a number of years, Nem was honoured to have the opportunity to fulfil the role of External Communications Lead for the national Together for Yes campaign to Repeal the 8th Amendment, and was invited to join ARC's Board in November 2021. As a multiply-disabled queer non-binary person, Nem believes in the power of reclaiming our own narratives to challenge the silencing and stigmatising of marginalised voices and seeks to apply the maxim Nothing About Us, Without Us in all their work.

Grace Kelly is a solo mother to her son, Patrick (age 3) and a person with a physical disability. Grace currently works as a primary school teacher, with a particular interest in special education. In the past, Grace has carried out academic research on the topic of sexual rights and intellectual disability and has published papers on the attitudes and perspectives of people with intellectual disabilities and the attitudes and perspectives of their parents and staff in disability services. Grace has worked with disability organisations to raise awareness of disabled



people's rights in the area of relationships and sexuality. As part of her work with the Connect People Network, she helped to organise social events for people with disabilities, sexuality education and training events and compiled a database of resources in the area of sexuality and disability. Working with the Forum of People with Disabilities and Inclusion Ireland, Grace organised the SDR 2003 conference - a conference for disabled people to talk about sexuality, disability and relationships.



Agnieszka Król is a sociologist, researcher, and activist as well as a member of Strefa Wenus z Milo - an association advocating for the rights of women with disabilities. As an academic, she is affiliated at Jagiellonian University (Kraków, Poland) where she conducts research on "Disability, motherhood, care. Reproductive autonomy and experiences of motherhood of women with disabilities in Poland". Her main interests are located in the fields of gender, disability, and diversity studies as well as qualitative and participatory methodology.

Agnieszka's work spans various research projects tackling social exclusion to reduce inequalities and she has authored several publications on reproductive justice, gender and disability, as well as LGBT rights. She has served as a national expert for Poland in the Academic Network of European Disability Experts (ANED) since 2017. As an activist, she engages in diverse antidiscriminatory civil society initiatives both locally and internationally, focusing especially on developing intersectional approaches.

My name is **Deirdre Lally**. I live in Bray Co. Wicklow and I am the mother of a large family. I always studied alongside my children as they were going through school and I owned and managed a Montessori playschool for over twenty years. I passed the reins of managing this business on to my eldest daughter. While I was at college, I worked in Bray women's refuge which I absolutely loved. Seven years ago, I graduated as a Social Worker in UCD. I've been working as a Social Worker with Sunbeam House Services,



Bray since April 2017. This is a service to support adults with an intellectual disability.

I have a particular interest in Raising Understanding and Awareness of (RUA), Friendships, Relationships & Sexuality which I trained in at the Callan institute. I am a practitioner in the Marte Meo approach and qualified as a family mediator with Friary Law. I also qualified in Thera play and DDP and include this in my daily work. I enjoy working in SHS with the clients and their families, I am also part of the new Multidisciplinary Team. I recently completed a Postgraduate Diploma in Social work practice teaching, supervision and management at University of Galway. I will be starting a Specialist Diploma in Developmental Trauma in February 2023. I believe in an anti-oppressive social work practice and had the pleasure of engaging with Prospera Tedam recently during her presentation at University of Galway. I particularly enjoyed learning about the concepts of diversity, oppression, power and powerlessness and how to continue to practice in an ethically appropriate way. **Denise Lawler** has extensive experience of the healthcare service having worked for over 30 years in nursing and – primarily midwifery. She has worked across the areas of clinical practice, education and now in the regulation of services. After training as a nurse, Denise studied midwifery and moved from midwifery practice into midwifery education in 2000, teaching initially in the School of Midwifery in the Coombe Women and Infants University Hospital, and later in the School of Nursing and Midwifery, Trinity College Dublin. While in Trinity College Dublin, she was Head of Midwifery and Director of Midwifery Programmes for almost five years. In 2018, Denise joined the Health Information and Quality Authority (HIQA) as an inspector in the Healthcare Directorate and in 2019, she was appointed Regional Manager. Denise was a



member of the Board of Nursing and Midwifery Board of Ireland (NMBI) and has just completed her second time of office in December 2022. During her time in NMBI, she was chairperson of the Midwives Committee and chairperson of the Fitness to Practise Committee. Denise's doctoral thesis focused on the transition to motherhood for women with a disability. In addition to a PhD, Denise also holds an MSc in Advanced Midwifery from the University of Ulster and an MA in International Law and Government from Dublin City University.



My name is **Michelle McLaughlin.** I was born Deaf and my first language is Irish Sign Language (ISL). I am married and have five children aged 15 to 24. My husband and children are all hearing, but they are fluent in ISL and mostly talk in English. I grew up in care homes in Tipperary in the 1970s, where the use of Sign Language was banned at school and in boarding. This was part of a policy called Oralism, where Deaf people were taught spoken English instead of ISL. This lack of access to education and employment opportunities has led to marginalization of the Deaf community. However, my family and I have overcome many challenges. In 2018, when we

decided to foster, our social worker provided me with an ISL interpreter at every meeting, allowing me full access to all communications. Without this interpreter, we would not have been able to foster, including fostering a Deaf teenager for three years. I am now employed as a Deaf social care worker, allowing me to communicate with Deaf children through our first language and empathize with them. I understand the struggles that some children face when communicating, especially those who attend mainstream schools with no access to their first language. Sign Language is essential for real inclusion and Human Rights. It is important for Deaf children to be included and be part of a family where they can communicate freely, express their feelings, ask questions, and share emotions. Louise Milicevic is a disability self-advocate and disabled parent. A mother of three she provides peer advice and support to parents with disabilities and has delivered bespoke disability equality training to national maternity services. She has written about her lived experience of being a parent with a disability in both national and online publications Louise has participated in a number of research projects on Maternity and Reproductive Health and contributed to a number of



forums run by the Disabled Women of Ireland. A long term employee of the Rehab Group Louise has been involved in numerous diversity and inclusion projects during her tenure with the organisation. This included managing and developing the organisations' Diversity and Inclusion blogs and supporting a variety of diversity and inclusion events. Louise has delivered a wide range of Disability Equality Programmes across the areas of Recruitment and Selection, Retention and Customer Service. Louise holds a MA in Classics and a BA from UCD. She has obtained QQI Level 7 certificates in both Learning and Development and Equality and Diversity from Maynooth University.



My name is **Orla O Reilly** (pictured on the right). I am from Dublin. My husband Bren and I both have special needs and we have our own apartment in Baldoyle. We are married 8 years now. We have gone on holidays on own to different places. I work for the Special Olympics. We both work in Trinity College as guest speakers.

My name is Brendan O Reilly (pictured on the left). I am part

of the Special Olympics for Killester in Dublin. I work in Starbucks for the last 15 years and I like to visit different colleges of Ireland. My wife and I really like to travel. I really enjoy working with Trinity College.

Florencia Herrera Oesterheld is a sociologist and associate professor at the School of Sociology at Diego Portales University, Chile. Her research interests are related to parenthood - particularly its non-hegemonic forms disability and qualitative methods. Her experience as a researcher and a mother with visual impairments have led her to be interested in the parental experiences of people with disabilities in Chile. Florencia currently directs the



research project "Reproductive processes and parental experiences of people with disabilities in Chile: discrimination and resistance." This project seeks to study how the meanings associated with disability, gender and parenthood impact the reproductive processes and parental experiences of women and men with disabilities. She is director of the Millennium Nucleus Studies on Disability and Citizenship (DISCA), Chile.



Maulani Agustiah Rotinsulu is a disability rights expert with more than 35 years of experience in the assessment, design, management and monitoring of national and international disability rights advocacy programs. Maulani is experienced in the capacity building of civil society organizations and is actively involved in numerous national, regional and international disability rights committees. She is an advisor to the Indonesian Ministry of Social Affairs and a Steering Committee member of the ASEAN Disability Forum, advising on the

ratification process for the UN Convention on the Rights of Persons with Disabilities. She is also one of the founders of the political rights of persons with disabilities movement in Indonesia, and has worked with United Nations agencies, the government and civil society organizations such as the Indonesian Association of Women with Disabilities, the Center of Ability Rehabilitation Effort in Jakarta, and the Indonesian Disabled People's Association (PPCI).

The research team

Professor Eilionóir Flynn is the Principal Investigator on the 'Re(al) Productive Justice: Gender and Disability perspectives' project, funded by Wellcome. Eilionóir is an Established Professor at the School of Law and Director of the Centre for Disability Law and Policy (CDLP) at the University of Galway. Her work on disability rights is widely published and her current research interests include legal capacity, access to justice, and the intersectionality of disability, gender and ageing. She is passionate about educating a



new generation of disability activists and scholars, and was the Scientific Co-Ordinator of a Marie Curie Initial Training Network known as DARE (Disability Advocacy Research in Europe) which funds 15 early stage researchers working on various disability rights issues across seven European countries. Prior to this project, Eilionóir held a European Research Council Starting Grant for the VOICES project, which documented the narratives of people with lived experience of legal capacity denial. She regularly collaborates with civil society organisations and disabled people's organisations at national and international levels. In Ireland, she co-ordinated the Civil Society Legal Capacity Coalition to influence the drafting of the Assisted Decision-Making (Capacity) Act and internationally she has supported the Secretariat of the United Nations Committee on the Rights of Persons with Disabilities, particularly the working group which developed General Comment 1.



Dr Jenny Dagg holds a PhD in Sociology from the University of Galway. She received PRTLI 4 funding for her doctoral research that explored the subjectivity of asylum seekers as they sought recognition within the refugee process. Her primary research interests lie at the intersection of sociology and politics and continually explores the dynamics of power; agency and subjectivity; exclusion and marginalisation; along with qualitative research methods including biographical interviews, narratives, life histories and lifelines, and visual methods. She

has published in the area of power, agency, and refugees; on biographical interviews and lifelines; coping with poverty; social resilience; and migration. Jenny was responsible for collecting the oral histories about disabled people's experiences of reproductive justice in Ireland that form the core of this project.



Maria Ní Fhlatharta has a particular interest in legal capacity and reproductive decision making, as well as access to reproductive health care for marginalised groups. She has addressed a number of conferences on issues relating to reproductive rights and disability, both in Europe and internationally. Maria is a co-chair of the Disability Rights Fund. She holds an LLM in Comparative International Disability Law and Policy and is a graduate of the

BCL in NUI Galway Law. She is a founding member of Disabled Women Ireland, which is a feminist disabled persons organisation representing disabled gender minority people.

Emma Burns holds an MA in Sociology from University of Limerick and a BSc in International Studies and Politics from the Open University. Currently in the end stages of a PhD at the Centre for Disability Law and Policy at University of Galway, Emma's research explores the collective self-advocacy of people with intellectual disabilities and their participation in political and public life. Her PhD is supervised by Prof. Eilionóir Flynn and is funded by the Irish Research Council. As a researcher, Emma has worked on a variety of social inclusion and



disability rights projects over the past 10 years. As a community organiser, she was a founding member of Tipp for Choice and co-directed the Tipperary Together for Yes campaign. She is a supporter to the National Platform of Self-Advocates and a founding committee member of the A-Team Youth Club, an innovative, volunteer-run, autism-positive club currently serving over 140 autistic children and young people in North Tipperary. Emma continues to be involved in monitoring and campaigning for improved access to abortion services in rural communities.



Centre for Disability Law and Policy The Institute for Lifecourse and Society Upper Newcastle Road University of Galway Ireland T. +353 86 4181673



realproductivejustice@nuigalway.ie



<u>@CDLPJustice</u>

Or visit the Re(al) Productive Justice website:

https://www.universityofgalway.ie/centre-disability-law-policy/research/projects/current/real



OLLSCOIL NA GAILLIMHE UNIVERSITY OF GALWAY CENTRE for DISABILITY

