**Book of Abstracts – 3 September**

**Session 1: Research Challenges and Co-Production**

Name: Dr Caroline O’Nolan and Dr Grainne Collins

Organisation: National Disability Authority (The views and opinions contained in this paper are those of the authors and do not necessarily reflect the views or opinions of the NDA).

**Abstract**

The discussion regarding the inclusion of people with an intellectual disability (ID) in research is now over three decades old. The inclusion of people with ID has been linked to the vindication of their human rights (Arscott et al, 1998; McDonald et al 2016; McDonald et al 2017, the promotion of agency and active citizenship (Fisher, 2012) and to better research outcomes as the voice of people with ID provides a distinct perspective (Booth et al 1989). However, whilst there are compelling reasons to include people with ID it must also be acknowledged that research with people with ID presents legal, ethical and methodological challenges. Some useful guides to assist researchers seeking to include people with ID have been developed (see Kidney and McDonald 2014, McDonald and Kidney 2012, Cridland et al 2015; Inglis and Cook, 2011, Watchman 2014) but fundamental difficulties remain, particularly with the inclusion of people with severe/profound intellectual disability.  This paper explores the changing context for the inclusion of people who cannot consent to research in Ireland.  In particular, it explores the recent legal changes with the establishment of the Consent Declaration Committee. We hope that our reflections in this paper will promote discourse and engagement on this issue.

Brief bio (100 words):

Both Caroline and Grainne are Senior Researchers at the National Disability Authority.  Presently they are conducting a research project on the quality of life and service provision for people with a disability in Ireland. This involves interviewing 600 people with a disability and the interviews are two thirds completed. Caroline is a Social Policy Analyst and author of ‘The Irish District Court: A Social Portrait’ (2013) Cork University Press. Grainne is an economist and has written widely on social inclusion.

Name: Clíona de Bhailís

Organisation (if relevant): Centre for Disability Law and Policy, NUI Galway

**Abstract**

“Nothing about us without us” was the motto of the disabled people’s movement during the drafting of the UN Convention on the Rights of Persons with Disabilities (CRPD). Since then disabled people’s organisations and activists strive to ensure that this often quoted maxim continues to be the touchstone under which law reform is achieved. However, some groups within the disability community, for example disabled children and young people, are often only consulted in a tokenistic fashion, if at all. This marginalisation occurs despite the Committee on the Rights of Persons with Disabilities placing clear obligations on States Parties for their inclusion in General Comment No. 7. This paper will describe how young people with disabilities, aged 15 – 20, from Ireland are involved in a PhD research project examining Article 12 CRPD. One of the core objectives in designing this research was to apply methods which ensured both meaningful and accessible participation with a diverse group of individuals. This paper will discuss the challenges this has presented thus far including issues around ethical approval and recruitment while also describing the benefits of the inclusion of a youth advisory group in a PhD research project.

Brief bio (100 words): Clíona de Bhailís is a PhD Candidate at the Centre for Disability Law and Policy (CDLP), NUI Galway. Her research focuses on supported decision making for young people with disabilities. In her previous role with the CDLP she worked as a Research Assistant on the European Research Council funded VOICES project. She holds a Bachelor of Civil Law and graduated with first class honours from the LL.M in Public Law in NUI Galway in 2013 with a minor thesis in the area of legal capacity and access to justice for people with disabilities.

Name: Nancy Leddin, Joan Body, Brian Donohoe, Nancy Salmon, Edurne Garcia Iriarte

Organisation: Inclusive Research Network

Doctors and Us: A Community-Based Project by the Inclusive Research Network

**Abstract**

People with learning disabilities endure health inequalities and have poorer health than most others. They face many barriers to healthcare access including: physical, societal, and language issues. Although there is a small amount of research about the health of people with learning disability, no studies were co-led by self-advocates. This project aimed to (1) describe stories of people with learning disabilities about going to see the doctor and (2) identify ways to help people feel more at ease at doctor’s visits.

A group of people with learning disabilities, their supporters and academic supporters conducted all phases of this study inclusively. Eleven focus groups were completed with 65 people with learning disabilities and 7 supporters. The average age was 46. We asked questions in the focus groups and showed pictures to participants to make it easier for them to talk. We made sense of what people said by reviewing focus group summaries and discussing the important things people talked about.

We found 3 key points: (1) people with learning disabilities want to feeling looked after; (2) they want to take charge of their health; (3) people with learning disabilities made explained how to make doctors visits better. People with learning disabilities want to be able to talk easily to their doctors. People want to have easy read handouts about their health to take away after a doctor’s visit. We have the right to know what is happening to our bodies and to feel looked after.

Bio: The Inclusive Research Network is a group of self-advocates, supporters from service organisations and university supporters who do research on issues that are important to people with learning disabilities since 2008

Name: Darlene Corry

Organisation: Disability Action

Is it me? – How do attitudes, within the social care system, impact on the independent living choices of disabled people?

**Abstract**

This coproduced research project aims to evidence the perception by disabled people that attitudes impact upon their independent living choices. This impact may come directly by those administering the systems or processes or by the systems and processes put in place to support disabled people to live independently.

The methodology focuses primarily on the experiences of disabled people. In focus groups and interviews disabled people from across multiple and varied sites of identity, and with different types of disabilities, explore how attitudes towards them have impacted upon how they live, what choices they make and their experience of social care. An online survey with domiciliary care workers and social workers triangulates the research by shedding light on the challenges and supports to workers in the field of adult social care.

Despite the efforts of individual care providers, constraints on resources, time and facilities restrict options for disabled people. The research will investigate where these are derived from assumptions about disabled people and find workable solutions, using the UNCRPD and other human rights instruments.

This research project is part of a UK wide research project called: Understanding and overcoming negative attitudes towards disabled people: What works in practice? The research is led by disabled people and managed through a partnership of Disability Action, the DRILL (Disability Research into Living and Learning) National Advisory Group and the Northern Ireland Social Care Council.

Short biography:

Darlene Corry is an experienced human rights researcher from within civil society. She is from Australia, has Multiple Sclerosis and other long-term health conditions, and is currently working at Disability Action Northern Ireland.

**Session 2: Operationalising Human Rights and Equality Instruments**

Name: Maria Ní Fhlatharta

Organisation: Centre for Disability Law and Policy

Reconciling Disability Rights and Bioethics in a European Context: The Failure of Oviedo to Recognise Changing Human Rights Norms.

**Abstract**

This paper will examine the diverging approaches of the Convention on the Rights of Persons with Disabilities and The Oviedo Draft Optional Protocol on the subject of forced treatment. The Oviedo Convention proports to bridge the gap between human rights, health law and bioethics however there is an incompatibility between it and the Convention on the Rights of Persons with Disabilities.

The most significant conflict between both conventions is the different approaches to forced treatment. This division is being further wrought by the drafting of an optional protocol which formalises the differing attitudes. The Convention on the Rights of Persons with Disabilities identifies forced treatment as a human rights abuse, and the Draft Optional Protocol is set to explicitly allow it.

This creates substantial questions on what obligations States are under given the majority of Council of Europe states have ratified both conventions. These conflicting obligations return to primary international law questions as to which treaties should be given preference when conflicts arise. This paper will explore the framework of both conventions, the divergence on the topic of forced treatment, the challenges of conflicting obligations in international human rights law and potential resolutions.

Brief bio:

Maria Ní Fhlatharta holds an LLM in Comparative International Disability Law and Policy, and is a graduate of the BCL in NUI Galway Law. She is currently working on the Re(al) Productive Justice project at the CDLP. As a founding member of Disabled Women Ireland, Maria is active in both the gender and disability equality movements in Ireland. Maria has addressed a number of conferences on issues relating to disability, gender, human rights and lgbtqi+ equality both in Europe and internationally.

Name: Dr Meredith Raley

Organisation: Disability Federation of Ireland

**Abstract**

This year, with a grant from the Irish Human Rights and Equality Commission’s (IHREC) Human Rights and Equality Grant Scheme 2018, the Disability Federation of Ireland (DFI) undertook a training programme with local authorities. Staff in 14 local authorities received training in the UN Convention on the Rights of Persons with Disabilities (UN CRPD), how it can be used by the local authority, and how it relates to the public sector duty. For my presentation, I would like to present the results of this training programme. Data collected included data on participants in the training, evaluations from the training, and qualitative data on the participants’ attitudes and thoughts about disability, human rights, and the UN CRPD. As part of the training, each group participated in a focus group that spoke about disability issues. This provided valuable information on how local authority staff think about disability, and what disability issues they are concerned with. Other information gathered at the training sessions includes how local authorities responded to the training, the existing level of knowledge around the UN CRPD, and how they felt about the UN CRPD and disability rights. This information could be useful to disability activists, academics, and others working on disability issues in Ireland. This conference will be the first chance that DFI’s has to present the results of our work on this to the public, and we hope that it will help discussions and prove useful to a wide variety of people.

Bio:

Meredith Raley earned her PhD from the Centre for Disability Law and Policy at the National University of Ireland, Galway in 2015. Her thesis was on Article 33 of the UN CRPD. Since then, she has work on policy and research for the Disability Federation of Ireland.

Name: Lorraine Lally

Organisation: Epilepsy Ireland (volunteer advocate)

Reasonable Accommodation - What does it mean for someone with a neurological condition?

**Abstract**

Reasonable accommodation applies to persons with a disability. The definition of “reasonable accommodation” will be discussed in this paper, exploring the recent case law in relation to further defining the concept for those with neurological conditions. It will focus on dealing with the following questions from the view of a person living with a neurological condition.

1.What disabilities are covered by reasonable accommodation?

2.What does reasonable accommodation mean in the law and in practice?

3.Who should pay for reasonable accommodations?

4.Do I have to disclose my disability in an interview or while employed if acquired during employment?

5.How does the current obligations of the employer under the Health and Safety, Welfare at Work legislation impact on the provision of reasonable accommodation?

This would include the use of health and safety assessments in the workplace.

6.What is the role of and use of occupational health reports in the assessment of the employee in a dispute of the ability to function with a disability?

7.Do public and private employers have different obligations having regard to persons

with disabilities?

8.What options/remedies are available to the employee if they are not provided with reasonable accommodation in the workplace?

Brief bio: I hold an LL.B in Irish Law as well as an LLM (International Human Rights) from the Irish Centre for Human Rights in the National University of Ireland Galway (NUIG). I am a practicing barrister and mediator who is a member of the Bar Council of Ireland.

Name: Donna McNamara,

Organisation: Dublin City University

Title: Reforming the Pre-Trial Criminal Justice Process in Ireland: A Disability-Rights Approach

**Abstract**

An individual’s first encounter with the criminal justice system usually involves contact with the police in the form of an arrest or an investigation, during which time the duties of the police will directly (and indirectly) challenge and potentially interfere with the personal rights of the individual suspect (including their right to privacy, property rights, the right to bodily integrity and most notably, freedom of liberty.) The individual suspect is said to be most vulnerable during the first few hours of custody and as such, the risk of abuse is highest during the early stages of detention (Association for the Prevention of Torture, 2013). It is, therefore, necessary to deliver a cross-collaborative response to the needs of persons in custody especially in the cases of persons with disabilities (including those with psychosocial or hidden disabilities). Such a response should include access to a medical professional to assess the individual following their arrest and to conduct an assessment for any signs of vulnerability or distress. This paper will argue that a cross-collaborative model should be developed going forward, with disability-rights at its heart. The focus of such an approach would include training and awareness-raising for all police officers in line with Article 13 of the CRPD and advocate for greater resources and procedural accommodations within the pre-trial criminal justice system for suspects with disabilities, including the development of an Appropriate Adult service.

Bio: Donna McNamara (BCL, LLM, PhD) is an Assistant Professor in Law at Dublin City University. In January 2020, she will be joining the University of Newcastle, Australia as a permanent Lecturer in Law, where she will be teaching health law and international law. Donna's research interests lie broadly in the areas of disability law, mental health law, children’s rights, and criminal justice. Her first book, ‘Disability, International Human Rights Law and the Criminal Justice System’ will be published with Routledge in 2021.

**Session 3: Models and Storytelling for Social Justice**

Name: Peter Kearns and Susan Carton

Organisation: St Angela’s College, Sligo

Acceptance, rejection and resistance: The Role of the Social Model of Disability in pursuing Disability Equality in Ireland.

**Abstract**

Disability equality is reflected in a society where disabled people are visible, empowered and participating in every sphere of public and private life.  Enabling the visibility, empowerment and participation of disabled people requires tackling the structural, environmental and attitudinal barriers that exist.  While these barriers - the causes of disablement – outlined and explored by British disabled academics for the last 40 years or more, have obvious resonances in Ireland, due to the closely aligned development of societal structures between Britain and Ireland, there remain key challenges here to dismantling them.

Despite our geographic proximity, there is a gulf in culture & practice between Britain and the Republic of Ireland which affects engagement with the Social Model of Disability in this country. There are several possible reasons for this; it may be attributable to the historical influence of the church on the state here, the dominance of centre right politics in this country and the difference in the relative size of the two economies.

We explore these reasons and suggest that the Social Model has been subject to much uncontested criticism in Irish academia and has been very poorly understood by policy makers and service providers. Our contention is that the pursuit of disability equality is strengthened if founded on a Social Model of Disability ideology.

(This work is based on a chapter for a textbook which is currently in preparation)

Biographies;

Peter Kearns.

Peter graduated from Trinity College in the late 1980s with an English Lit. Honours degree and followed this with an MA in Film & TV Studies at Dublin City University and a Higher Diploma in Adult & Community Education from Maynooth College. Peter has been a community development advisor, mentor & disability artist with the private & statutory sector in Ireland, Europe, USA and Asia since the early 1990s.

In terms of linking disability equality & community development practice on the ground, since 2008 Peter has been working for Disability Equality Specialist Support Agency (DESSA) and was Development & Policy Worker with Forum of People with Disabilities until it completed its work in 2007 this was the only 100% run disability Organisation in Ireland.  Peter is also writer/producer on a number of theatre projects & films/documentaries, such as UN anti-poverty broadcast programme for Bangladesh and worked at UN in New York on  disabled people’s charter of rights. Peter lectures part-time at St. Angela's College (NUIG) and Sligo IT.

Susan Carton.

Programme Director, Disability Studies, St Angela’s College, Sligo

Susan has been working in St Angela’s College in Sli

go since 2003. In 2009/2010, in Partnership with Peter and DESSA Susan worked on the first Disability Studies degree - BA (Health and Disability Studies) which is a three-year fulltime course. In 2014 the same team developed the BA (Disability Equality Studies) which is a four year online, part-time programme. The Post Graduate Pathway in Disability studies commences in September 2019. Susan is a member of the DESSA board, the Irish Disability Studies Association, the Sligo Disability Network and the Leitrim Disability Equality Network.

***19 Stories of Social Inclusion –Ireland: Stories of Belonging, Contributing and Connecting***

Name: Tomás Murphy, Margaret Turley, Christine Magee, Edurne Garcia, Michael Feely

**Abstract**

Irish disability policy aims to support people with intellectual disabilities to live included lives in their community. Despite people with intellectual disabilities being far more likely to experience social exclusion than non-disabled people, there are also people with intellectual disabilities living ordinary lives all over Ireland. The aims of this research were 1) to identity examples of people being included in the community; 2) to co-produce a piece of work with researchers with lived experience of intellectual disability;and3)to present people’s stories and key messages about their lives to inform the implementation of policy in accessible formats. Semi-structured interviews were conducted with a diverse group of 19participants,who lived in villages, towns and cities, and who accessed a range of supports. The data was analysed using thematic analysis. Participants reported on how social inclusion creates opportunities for further inclusion and on their roles in creating change. Seeing people with intellectual disabilities as individuals, the leadership qualities of participants, inclusive environments and the involvement of good support enabled socially included lives. The study provides strong evidence on the need to change from paternalistic notions of ‘care’ to that of support, choice and control if people with intellectual disabilities are to have their right to socially included lives recognised. It reinforces the importance of policies which seek to make mainstream spaces, services and supports accessible to people with intellectual disabilities

**Team bio**

Tomás Murphy is a graduate of the Trinity Centre for People with Intellectual Disabilities. Tomás is now working in a top Irish Law firm, A & L Goodbody.

Margaret Turley did the Certificate in Contemporary Living in Trinity College Dublin. Margaret currently works for Ernst and Young.

Christine Magee is an independent researcher and lead author of the research.

Edurne Garcia is a lecturer at Trinity College Dublin. Since 2009, Edurne has been a supporter of the Inclusive Research Network, a group of people with intellectual disabilities and their supporters who conduct research in Ireland

Michael Feely is a disability researcher at Trinity College Dublin. Michael is interested in supporting self-advocacy by people with intellectual disabilities.

Inclusion Ireland is the national association for people with an intellectual disability and led the overall project.

Name: Dr. Áine Sperrin

Organisation: Centre for Disability Law and Policy, NUI Galway, Ireland.

**Abstract**

The Re(al) Productive Justice project seeks to make visible the experiences of disabled people in Ireland accessing reproductive justice. The project is based at the Centre for Disability Law and Policy at the National University of Ireland, Galway. The project understands reproductive justice to span from fertility and contraception – including assisted reproduction, pregnancy (including surrogacy) and childbirth, abortion and parenting (including fostering and adoption). Re(al) Productive Justice will invite oral histories from anyone who identifies as having any type of disability – physical, intellectual, mental health, sensory, psycho-social, people who are neuro atypical, people who are Deaf, and Users and Survivors of psychiatry. We also recognise the interconnection of disability with other identities and consider the multiple discrimination experienced by the LGBTQI community, migrant and ethnic minority communities, people with experiences of Direct Provision, institutionalisation and Travellers.

This paper will discuss the initial work undertaken in addressing the question: What is the applicable regulatory framework that governs disabled people’s reproductive decision making in Ireland? This paper focuses on the contemporary legislative and policy provisions impacting persons with disabilities making decisions about whether to have, or to not have, a family. The paper will incorporate preliminary analysis of contributions from key informants and will be divided across the four themes referenced above. In the new landscape of reproductive justice in Ireland, and progress towards liberalising abortion law in the North, this paper will clearly demarcate the discrimination which continues to be experienced by disabled people accessing their right to reproductive health care services.

Name: Fionn and Jonathan Angus

Organisation: Fionnathan Productions

**Abstract**

With the support of renowned advocate Martin Naughton, Fionn became the first person with developmental disability to manage his own HSE funded support system. His father Jonathan had previously worked on the analysis of public feedback on the New Directions Report, and we became convinced that we could better achieve Fionn’s life goals through a Personal Budget than by becoming a client of the established Day Service sector. We have since consulted with the National Disability Authority on the Task Force on Personal Budgets and with the Department of Health on Transforming Lives Working Group 3.

We will provide an overview of how we have worked toward Fionn’s life goals these 4 years, including relocating to the city, running a social enterprise, international travel, film making, visual arts, teaching and lecturing, and musicianship. Our educational efforts include annual lectures to 10 of Ireland’s Social Care trainings at colleges and universities, as well as 14 guest lectures outside Ireland; Continuing Development trainings to Social Care Professionals; workshops at Day Services (which is somewhat ironic); and individual consultations with dozens of families. Jonathan, Fionn’s dad, is his primary paid supporter. We challenge the policy position that, in all cases, employing a family member for support is less beneficial than employing a non family member. As an employee of his social enterprise, Fionn is paid to design, manage, and administrate his support plan. We advocate strongly against volunteerism as a prerequisite to Personal Budgets, which would create a barrier to those without significant privilege.

Bio:

Fionn and Jonathan run a social enterprise called Fionnathan Productions, based out of Fionn's apartment in Galway and their art studio in Clarenbridge. Fionn has shown his artwork in New York and London, has played his fiddle in 23 countries, teaches children about wildlife, and has given over a hundred talks, including annual lectures to Social Care trainings around Ireland. Their film series, What Do You Love About Your Life? includes interviews with more than 500 people, with more than 300,000 views online.