Disability Research Seminar Series 2017

The Disability Research Seminar Series 2017 aims to provide an inter-disciplinary forum for discussion of disability research through 12 lectures on a range of topics and disability experiences, bringing together researchers from TCD and other universities and from disability-related organisations.

Post-graduate students, final year under-graduate students, researchers, academics, advocates, activists and professionals are welcome. Please contact Noreen O'Sullivan at noosulli@tcd.ie if you require access accommodations.

January

16th, 9-10 am | **The lived experience of disability during the transition to adulthood for young people with hemiplegic cerebral palsy**
Dr Michelle Spirtos, Discipline of Occupational Therapy, School of Medicine, Trinity College Dublin
Room 4012, Arts Building

23rd, 9-10 am | **Supporting people to live self-directed lives in the community: Learning from 54 Irish projects**
Dr Fiona Keogh, Director of Research and Policy, Genio
Room 4012, Arts Building

30th, 9-10 am | **Are we levelling the playing field? Exploring if reasonable accommodations for disabled students in higher education remove barriers and impact on the student experience**
Declan Reilly, School of Education, Trinity College Dublin
Room 4012, Arts Building

February

6th, 9-10 am | **Growing older with an intellectual disability in Ireland – service demands and policy implications. Lessons learnt from the Intellectual Disability Supplement to TILDA (IDS-TILDA)**
Mary-Ann O'Donovan, Project Coordinator, IDS-TILDA
Room 4012, Arts Building

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13th, 9-10 am   **Supporting people with psychosocial disabilities in the workplace: A comparative analysis of the EU member states**
Prof. Mark Bell, School of Law, Trinity College Dublin
Room 4012, Arts Building

20th, 9-10 am   **Partnerships between people with intellectual disabilities and academic researchers: A critical examination of inclusive research practices**
Dr Edurne Garcia Iriarte
Room 4012, Arts Building

March

6th, 14-16 pm   **The experiences of young carers living in households where illness and/or disability are present**
Dr Marlene McGibbon, University of Ulster
Room 3070, Arts Building

13th, 9-11 am   **Activism, Reality and Embodiment**
Rosaleen McDonagh, Northumbria University
7-9 LH – PX 206

20th, 14-16 pm   **Bullying and people with intellectual disabilities in Ireland**
Anti-Bullying Group
Room 4.02/4.03 in 3, College Green.

27th, 14-16 pm   **An analysis of regional differences in the provision of intellectual disability services in Ireland: Implications for the national implementation of policy**
Prof. Roy McConkey, Emeritus Professor, Ulster University and Visiting Professor, Trinity College Dublin
Room 4.02/4.03 in 3, College Green.

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April

3rd, 14-16 pm
Our Homes
Inclusive Research Network
Room 4.02/4.03 in 3, College Green.

10th, 9-11 am
A Guided Tour of the International Architecture for Empowering People with Disabilities: Bright Lights and Shady Conversations
Prof. Mac McLachlan, Global Health, Trinity College Dublin
7-9 LH – PX 206

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The lived experience of disability during the transition to adulthood for young people with hemiplegic cerebral palsy

Michelle Spirtos

Positioned at the intersection between transition to adulthood and disability theories, this qualitative study is an exploration of the lives of young people with hemiplegic cerebral palsy (CP) during the transition to adulthood. Using a constructivist ontological framework and guided by an interpretivist stance, this narrative inquiry aims to further our understanding of the experience of disability for young people with hemiplegic cerebral palsy during the transition to adulthood. Twenty five young people between 18 and 29 years participated in multiple in-depth interviews using methods influenced by the Biographic-Narrative Interpretive Method. Data analysis involved both a narrative analysis and an analysis of narratives. The results highlighted the impact of hemiplegic CP on the participants' lives and revealed how the participants construct themselves in relation to concepts of normalcy. The narratives show how within social interactions the participants are engaged in managing their physical impairment. Both the social construct of disability and the embodied experience of impairment are present in the participants' narratives and how the participants construct themselves in relation to disability has implications for research, practice and the wider socio-political context.

Supporting people to live self-directed lives in the community: Learning from 54 Irish projects

Dr Fiona Keogh

Genio Trust has grant-aided 54 projects in Ireland to support people with disabilities and people with mental health difficulties to move from institutional settings to live self-directed lives in their communities. Quantitative and qualitative data were collected over the lifetime of each project on at least three time points through interviews with informants and completion of an anonymous descriptive dataset for beneficiaries. Informants included project leads, managers and front-line staff. While there has been considerable research attention on the outcomes for individuals following deinstitutionalisation, little is documented on the processes involved from an implementation perspective. The aim of this paper is to synthesise the implementation learning across sites in order to inform the process of policy implementation in Ireland.   Since 2010, 359 people from these 54 projects have successfully moved to the community and a further 291 are being supported to move. The current biggest barrier to people moving is the availability of housing. The

factors which have supported effective implementation include; multi-level leadership, the person leading the process, involving families and allies, engaging and consulting with stakeholders, staff skills and training, intentional building of community networks, starting small and modelling change, addressing the challenge of reconfiguration, allowing sufficient time, a focus on outcomes and monitoring progress. These findings will be considered in the context of existing implementation frameworks with a particular focus on policy implementation versus programme implementation.

Are we levelling the playing field? Exploring if reasonable accommodations for disabled students in higher education remove barriers and impact on the student experience

Declan Reilly

The emergence of Disability Services in Higher Education Institutes (HEIs) in Ireland has coincided with significant increases in the numbers of students with disabilities attending HEIs. From 990 attending in 1993/4, to 9,694 in 2013/14 (Ahead, 2015), the increases have prompted a range of support services to develop in response to the growing demand for reasonable accommodations. The purpose of this research project is to explore the range of reasonable accommodations that are used in HE and evaluate their effectiveness in terms of impact on the student experience and overcoming barriers and progressing through HE. This research focuses on a case study of a single HEI through a mix of quantitative and qualitative data sets. Semi-structured interviews (37) with current and former students act as 'embedded case studies' (Yin, 2003) along with statistics on entry, progression, retention and completion rates. The findings demonstrate that students with disabilities are not a homogenous group in HE. Contrary to findings internationally, retention and completion rates are on a par with their non-disabled peers although many students with disabilities can take longer to complete their degrees. The experiences of HE for participating students were categorized as 'strider', 'struggler' or 'striker' to denote the range of experiences and challenges that students spoke about on their journeys into, through and out of HE. Using Actor Network Theory as an approach to interpret the findings demonstrated the complexity of factors involved in 'levelling the playing field'. 'Student factors', 'impairments', 'barriers' and 'reasonable accommodations' can be viewed by Actor Network Theory as both material and semiotic actors in HE. These actors can both 'disable' and 'enable' simultaneously. The playing field is not only constantly being levelled because it is in constant need of levelling but also because the barriers are constantly being assembled.

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Growing older with an intellectual disability in Ireland – service demands and policy implications. Lessons learnt from the Intellectual Disability Supplement to TILDA (IDS-TILDA)

Mary-Ann O'Donovan

There is a need to ensure that future planning, policies, services, support and allocation of resources are sufficient to meet the changing needs of ageing persons with ID, yet there are few population-based research studies on health status that include a national sample of persons with ID. Equally, reports on the health status of persons with ID extrapolated from international studies rarely include control or comparative groups of people without an intellectual disability. IDS-TILDA was designed to address these gaps in knowledge. Data from the first two waves of the study will be presented.

Supporting People with Psychosocial Disabilities in the Workplace: A Comparative Analysis of the EU Member States

Prof. Mark Bell

This lecture will explore the barriers that people with psychosocial disabilities can experience to participation in the labour market and the role that anti-discrimination legislation can play in seeking to remove or mitigate such obstacles. It will review existing social research on the labour market position of such people as well as the role that stigma plays in affecting working lives. It will identify the principal legal protections found in European and national legislation, in particular the duty to provide reasonable accommodation for persons with disabilities. It will consider how this concept can be applied to those with psychosocial disabilities and examples of how courts in the EU have applied this concept.

Partnerships between people with intellectual disabilities and academic researchers: A critical examination of inclusive research practices

Dr Edurne García iriarte

Research conducted in collaboration with people with intellectual disabilities (inclusive research) has gained momentum in recent years leading to a growing body of studies published in the academic literature. While inclusive research emerged in reaction to former ways of exclusion of people intellectual disabilities from research, the aim of this lecture is to examine recent efforts that critically evaluate the inclusive research work conducted to date. The lecture will firstly review the

underpinnings and development of inclusive research since Walmsley and Johnson published their seminal text in 2003. The lecture will secondly use the work of Nind and colleagues (2015) on training partnerships to analyse this critique. Examples of current inclusive research projects will be provided and challenges that lie ahead discussed.

The experiences of young carers living in households where illness and/or disability are present

Dr Marlene McGibbon

This presentation reflects upon a number of findings which were generated as part of a Doctoral Thesis focusing on the factors which contribute to or challenge the resilience of young carers. In total, twenty two children and young people aged between eight and eighteen years took part in the study; each was involved with the provision of informal care to one or more family members experiencing some form of illness and/or disability. All were drawn from a number of rural and urban locations across Northern Ireland and this presentation will centre upon their perceptions of and responses to a range of physical health problems, disabilities, mental illness and pervasive developmental disorders.

Overall, the findings of the study suggested that a number of factors were instrumental in shaping the experiences of young carers including the nature of the illness and/or disability, family structure and the wider ecological context. The study also identified a number of difficulties associated with statutory service provision and at the same time, laid challenge to the assertion that for children and young people, caring is in the main, a benign and short lived experience that has little impact on their daily lives.

Activism, reality and embodiment

Rosaleen McDonagh

Thomas (1999) highlights the linear dimensions of the social model by stating that the social model under-represents and marginalises specific groups on the basis of gender, race, sexuality and age, etc. She says that disabled men have created a model in "their own image" with white male concerns.

By and large most social and political movements are voiced, controlled and echo men's lives and experiences. This is no different in disability politics, culture and academia. Within the realm of disability studies in recent times, disabled feminists such as Rosemarie Garland Thomson, Carol Thomas, Liz Crow and Jenny Morris, have all questioned the social model and its application with regard to embodiment and gender in the context of impairment.

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Disabled feminists like Ayesha Vernon talk about the issue of race, gender and impairment and its impact. The feminist critique of the social model strengthens rather than weakens it. Adding race, ethnicity and sexual orientation to the mix in the context of impairment imbues a reality of diversity. The debate as to whether the social is still relevant continues.

Bullying and people with intellectual disability in Ireland

The National Anti-Bullying Group

In 2012 the national anti-bullying advocacy group with the former National Institute for Intellectual Disability at Trinity College Dublin conducted a study to find out more about bullying in Ireland through an inclusive research project funded by the National Disability Authority. The aim of this project was to document the nature and extent of bullying of people with intellectual disabilities, and to explore the experiences of those who are bullied. The study found that bullying is indeed a serious problem for many people with intellectual disabilities. The reasons for bullying are complex. Most people with intellectual disabilities told us that they had experienced bullying, in a variety of locations, and with regularity. Verbal bullying was the most prevalent, but incidents of physical assault and more indirect forms of bullying, such as exclusion and exploitation were also common. Bullying of adults with intellectual disabilities in public places was found to be a significant issue.

An analysis of regional differences in the provision of intellectual disability services in Ireland: Implications for the national implementation of policy.

Prof. Roy McConkey

The National Intellectual Disability Database (NIDD) collects data for each person with an intellectual disability in Ireland who is in receipt of services or is eligible for them. Data from the NIDD was analysed by Community Healthcare Organisation area (CHOs) for two cohorts involving around 17,000 persons in 2009 and again in 2014, to determine changes in service provision and use over a period of years when there were significant policy developments and fiscal changes.   Variations in the provision of residential services, day services and short breaks will be described. For example across the nine CHO areas, there was a two-fold difference in the numbers of persons resident in congregated settings and marked differences between day service provision, especially in persons in employment . CHO area was a more significant predictor of type of service provision than age or level of disability. The implications for the equitable implementation of national policy will be discussed and the value which national datasets bring to the monitoring of policy will be highlighted.

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Our Homes

The Inclusive Research Network

Our homes is the third study of the Inclusive Research Network, a group of people with intellectual disability, their supporters and academic researchers who conduct research in Ireland about intellectual disability issues. The study aimed to learn about 1) how people with intellectual disabilities had moved into new places and 2) the support people had for moving and living in their new home. Members of the IRN did 35 interviews with people with intellectual disabilities in the Republic of Ireland. The study found that most people lived in supported living apartments to where they had moved from family homes, group homes and residential institutions. Most people said their lives were good in their new homes. However, about half of them had not decided where to move or with whom. Support to move came from family members, staff and the council. In their new homes, all people were supported by staff. Most people had good relationships with their supporters although about half of them had not chosen the person supporting them. Most people in the study had positive experiences of living semi-independently in the community. The study also found challenges that need to be addressed if people with intellectual disabilities have to become decision-makers about where to live and with whom. An easy read summary of the study is available from:
http://www.fedvol.ie/_fileupload/Inclusive%20Research%20Network/IRN%20Our%20Homes%20Report-%20Final%202015.pdf.

A Guided Tour of the International Architecture for Empowering People with Disabilities: Bright Lights and Shady Conversation

Prof. Mac MacLachlan

This presentation reviews some of the Centre for Global Health's work in the area of disability and development. It particularly focuses on how to influence policy and promote structural change that can enhance the rights and opportunities of people with disabilities. We will consider work on influencing Poverty Reduction Strategy Papers in several African countries; ILO's work on employment in Africa and Asia; and the United Nations Partnership for Promoting the Rights of People with Disability (UNPRPD), currently working across 20 countries. Our collaboration with UNESCO on developing inclusive polices in Asia and our role in the work of WHO's GATE – the Global Cooperation on Assistive Technology – will also be briefly discussed. The explicit role of national and global initiatives will be considered alongside the implicit mechanisms by which they work, and some of the tools we have developed to promote social inclusion. These factors contribute to a macropsychology of social justice and inclusion.