

VIRTUAL AUTUMN RESEARCH CONFERENCE 2022

PARTNERSHIP IN PRACTICE

Wednesday 23rd November 10am - 12.30pm

CONFERENCE PROGRAMME

10am - 10.05am: Welcome Rob Anderson (Chair)

10.05am - 11am: The Costs of Care Arising from Disability Hannah Boylan - (Vincentian MESL Research Centre, SVP)

Brian Doyle (Family Carers Ireland and UCD) CAREWELL: Promoting health and self-care among family carers in the workplace

Dr Christine McGarrigle (TCD, TILDA) Care receipt and caring before and after the COVID-19 pandemic, evidence from The Irish Longitudinal Study on Ageing (TILDA)



11am - 11.15am: In Conversation

Prof. Mary Murphy & Dr Pauline Cullen (Maynooth University) in conversation with Dr Nikki Dunne (Family Carers Ireland) 'Valuing Care Work: Improving Family Carers' Access to Adequate Income Supports'

11.15am - 12.05pm: Partnerships in Practice Dr Sarah Donnelly (School of Social Policy, Social Work and Social Justice, UCD) Hidden Harm: Safeguarding Family Carers from Carer Harm

Dr Tamasine Grimes (School of Pharmacy, TCD) & Johanne Powell (PPI Contributor) Findings - Household Medication Safety Among Carers

Dr Carol Kelleher (ISS21, UCC); Faye Hayden (South Roscommon Young Carers Group) & Aoife Bowman-Grangel (UL); Niamh Finucane (Family Carers Ireland) Sharing the Caring: Young carer experiences and supports in Ireland

12.05 - 12.25pm: Reflections and Learning - Chair: Dr Avril Kennan (HRCI)

Dr Deirdre O'Donnell, UCD

Claire Devlin, Family Carers Ireland PPI contributor

Edel Murphy, Programme Manager, PPI Ignite Network

12.25pm - 12.30pm: Close - Rob Anderson (Chair)



Abstracts

The Costs of Care Arising from Disability (Hannah Boylan, Vincentian MESL Research Centre, SVP)

This presentation will discuss "Care at Home: Costs of Care Arising from Disability", a research report which the VPSJ (now the Vincentian MESL Research Centre) undertook in collaboration with Family Carers Ireland, which was published in April 2022. The research looks at the additional cost of a Minimum Essential Standard of Living for a household caring for an adolescent child with a profound intellectual disability. The presentation will give an overview of what the MESL research is, how it was used in the context of this research report, as well as the main findings of the research.

CAREWELL: Promoting health and self-care among family carers in the workplace (Brian Doyle, Family Carers Ireland and UCD)

CAREWELL is a collaborative project between researchers at University College Dublin and Family Carer's Ireland to examine how family carers can best be supported to balance work with their caring role. The CAREWELL project aims to promote health and self-care behaviours through the development of an evidence-informed workplace programme for family carers working in diverse work settings. To this end 3 different work packages have been designed and are at various stages of completion.

Work package 1 aimed to scope out the nature of available evidence on 'working family carers'. Findings are currently under journal review however results highlighted that research in the field is chiefly observational and descriptive, with a dearth of experimental studies; findings suggest the need for more reliable evidence to guide decision-making in the field. Thematic analyses indicated that caregiving was primarily a gendered activity, with women more likely to engage in this role. It was also evident that balancing employment and caregiving can have unfavourable outcomes in the spheres of physical and mental health, in addition to employment, hence, consideration needs to be given on how to address this.

Work package 2 aimed to examine working family carers' and employers' experiences of health promotion for carers in the workplace. Areas covered in this research that was implemented by way of surveys and focus groups covered various aspects of the role of working carers and the challenges in combining employment with their caregiving roles. The focus groups covered questions around their employment type, the workplace support available to them and the health and self-care behaviours they engaged in. Some common themes emerging out of surveys and focus groups were having supportive line managers, attending psychological support sessions and having peer support groups among carers. So far hundreds of responses have been received for the surveys sent out and pertinent themes underlined which illustrate the health and lifestyle related issues faced by working family carers. Findings from work package 1 and 2 will provide a concrete evidence-base for the design and co-creation of a workplace-based health promotion programme for working family carers—work package 3.



CAREWELL also runs a podcast—CAREWELL Conversations—whose mission is to raise awareness of the issues and challenges faced by working family carers. So far, the podcast has 10 episodes which have garnered over 3,000 plays. Guests on the podcast have included CIPD Ireland, Director Ms Mary Connaughton, Dr. Kara McGann from Ibec, Mr David Joyce from ICTU and Ms Lizzie Falconer a family carer combining her caring role with paid employment. Noteworthy themes highlighted in the podcast have included creating a supportive culture and environment within workplaces through policies and raising awareness of the diverse issues and challenges faced by family carers balancing caring and paid employment. Also how both employees and employers benefit from the retention of family carers within employees

All the different elements that makeup CAREWELL are geared towards enhancing health and wellbeing of working family carers.

Care receipt and caring before and after the COVID-19 pandemic, evidence from The Irish Longitudinal Study on Ageing (TILDA) (*Dr Christine McGarrigle, TCD TILDA*)

Research from the TILDA COVID study carried out in 2020, found that following stay-at-home recommendations from Government, 15% of the older population reported caring for someone during the COVID-19 pandemic. This had increased three-fold from Wave 5 (2018). There had also been important changes in who was providing care, and while one in four carers report that they have stopped caring since the pandemic, two-thirds of those providing care were new carers. We found that while the availability of both state-provided and family care for older people was reduced during the COVID-19 pandemic, there was a concomitant increase in caring by older household members.

This study will describe and quantify caring both given and received by the population aged 60 years and older in Ireland post the COVID-19 pandemic. This study uses data collected in Wave 6 of The Irish Longitudinal Study of Ageing (TILDA) from both the Computer Assisted Personal Interview (CAPI) (n=4,185) and the Self Completion Questionnaire (SCQ) (n= 3,385), which contains more sensitive questions. It compares data from Wave 6 (2021) with data from Wave 5 (2018) and the COVID-19 SCQ collected between July and November 2020.

The older population in Ireland contribute substantially to the informal care of their family and friends. Overall, 5% of women and 3% of men aged 60 years and older report they are a carer to family and friends in Wave 6, a slightly lower level than reported prior to the COVID-19 pandemic. However, we also found that the proportion of those who care who provided more than 50 hours in the past week has remained the same.

A new joint research project between TILDA and Family Carers Ireland, will help to identify how services and programmes may be improved to better support older caregivers. Data from TILDA will be used to describe the characteristics of people caring in middle and later life and will study how they differ from adults who do not offer care. This study will also evaluate patterns of mental health and well-being in adult caregivers aged 54 years and over as they transition into and out of caring responsibilities, as well as investigate how their



well-being may fluctuate depending on the quantity of social supports and formal care service supports received. The study's findings will also provide information to help establish training and advocacy programmes for caregivers.

'Valuing Care Work: Improving Family Carers' Access to Adequate Income Supports' (*Prof. Mary Murphy & Dr Pauline Cullen, Maynooth University*)

Income support is a key social institution and public policy tool that can be used to progress key societal goals related to socially valuing care, and supporting and rewarding family care. The report of the Citizens Assembly on Gender Equality has advocated a range of changes that would advance how family care can be better valued and supported including reform to means testing and individualisation of Carers Allowances. The report's recommendation for a constitutional amendment to Article 41.2 has been supported in 2022 by the Oireachtas Committee on Gender Equality with referendum anticipated in 2023. This session discusses ongoing research, funded by IHREC, which seeks to advance economic equality by socially valuing care work. Themes explored include the principle of individualisation of income support; income generosity or adequacy; and universal v targeted approaches to income support. The research seeks to advance a potential model for socially valuing family care work as an alternative to the means-tested Carer's Allowance.

Hidden Harm: Safeguarding Family Carers from Carer Harm (Dr Sarah Donnelly, School of Social Policy, Social Work and Social Justice, UCD)

'Carer harm' is when carers experience violence or become subject to controlling or coercive behaviour, either on an incidental or systematic basis, resulting in physical, psychological and/or sexual harm (Isham et al.2020, p.2). Little is known however about the harm experienced by carers at the hands of the person for whom they provide care to. Challenges are often faced by social workers and other professionals when care and violence intersect, and a service user is the alleged perpetrator of abuse against their family carer. Practitioners struggle to engage with families' testimonies about harm in the context of care and illness and there have been calls for all stakeholders to work more proactively with families where care and violence intersect (Isham et al.2020). This study explores the concept of carer harm from the perspective of family carers of people with dementia and autism and relevant professionals including, social workers, public health nurses, the police and non-government organisations. It set out to develop and co-design information and education resources in order to better understand, prevent and respond to family carers experiencing harm.

The project deploys an engaged research approach that produced knowledge in collaboration with family carers and professionals. The research design is mapped out over three work packages. Work Package 1 involved narrative interviews with six family carers of people with dementia and six family carers of children/adults with autism who self-identified as experiencing carer harm. Interviews were used to build four fictional case study typologies. Work Package 2 involved three focus groups with relevant professionals including social workers, utilising the four fictional case studies as a focus for discussion.



Work Package 3 comprised of one World Café Co-Design Workshop with family carers, professionals, and service providers where education and training materials were developed. Content for the World Café was informed by evidence gathered in Work Package 1 and 2 and explored the learning needs and readiness of professionals to have conversations and make interventions in cases of carer harm

The findings while not generalisable indicate high levels of unmet need and psychological distress with family carers of people with dementia and adults/children with autism reported regularly experiencing verbal and physical aggression. Those experiencing carer harm reported 'falling through the cracks' of support services and feeling abandoned by professionals. Key themes included fear, shame, stigma, helplessness, and despair. Health and social care professionals reported lacking confidence in dealing with cases of carer harm with social workers in particular reporting ethical dilemmas in practice contexts highlighting the need for specialised training. Information booklets for family carers were subsequently developed to raise awareness of carer harm and to empower family carers to protect themselves and seek help. A practice guide was also developed for professionals and support organisations in order to improve understandings of, and responses to those experiencing carer harm.

Public and Patient Involvement with a Descriptive Qualitative Study to Explore Household Medication Safety Among Carers (*Dr Tamasine Grimes, School of Pharmacy, TCD & Johanne Powell, PPI contributor*)

Background: Patient and public involvement (PPI) in research has been reported to enhance research validity, build research capacity and improve the relevance and reach of research to the public. However, involvement of patients and family carers in medication management research is relatively novel in Ireland.

Aim: To describe, from an academic's and a PPI contributor's perspectives, the development and implementation of a method for involving patients and family carers in a qualitative medication management study: The Covid-HoMeS (Household Medication Safety) Study.

Method: The research team engaged with a charity partner to collaborate on an application for exchequer funding to support PPI functions in the project. The description of PPI in the research study, was structured under the four domains of the INVOLVE framework for evaluating PPI in research: (1) Improved governance, (2) Social capital and social justice, (3) Improved quality of services / projects / programmes and (4) Capacity building and learning.

Results: The PPI research activities mapped to the four domains as follows: The research team and charity partner collaborated to recruit the PPI panel and to oversee project management (1, 2). The National PPI advisory office and university legal office were consulted to optimise research governance in PPI, for example, managing human resource and data confidentiality issues (1). International collaborators with expertise in PPI in qualitative research were engaged to deliver training generally on PPI in medication safety research and specifically on PPI in qualitative analysis (3, 4). The PPI occurred remotely with meetings held by video call, supported by use of collaborative online tools (2, 3). Interview transcripts were shared with three PPI panellists and iterative meetings held to develop and apply a coding frame and to cocreate research outputs intended for both laypeople and academics (2, 4). A PPI contributor with graphic design skills engaged to co-create, in collaboration with the charity partner and project team, an accessible booklet of key study findings and recommendations (3, 4).



Conclusion: The project developed a method to implement PPI partnership in the Covid HoMeS Study that aligned project and partnership objectives, created a research partnership with carers and patients, improved the study integrity and supported academic and PPI capacity building.

Sharing the Caring: Young carer experiences and supports in Ireland (Dr Carol Kelleher, ISS21 UCC, Faye Hayden, South Roscommon Young Carers Group & Aoife Bowman-Grangel, UL)

Young carers are a marginalised group who face significant obstacles in accessing services and supports, with consequences for participation in society, education, training and employment. This presentation focuses on two projects with young carers: Roscommon Young Carers and YOUNGCARERS projects.

The Roscommon Young Carers Project aims to develop a program that will set a national model and standard for support of young carers, recognising the harm that developmental restrictions exist in the way young carers access positive outcomes. The Roscommon Young Carers Project was established in 2020, the coordinator role is funded by CYPSC and Healthy Ireland with activities funded by various grant streams and also support from Family Carers Ireland. Our work is based on the restorative practices model, addressing the deficits that young carers face and restoring their life opportunities. The project offers support to young carers aged 8-21 in a primary or secondary carer role. The program focuses on three key areas: 1) accessing childhood 2) creating age appropriate communication channels and 3) developing the ability to self-care emotionally. In addition, an employable skills development program is offered to the young adult carer group (aged 15-21), generously funded by the Irish Youth Foundation, that helps to develop skills that young adult carers.

Underpinned by a participatory approach, YOUNGCARERS, a partnership between UCC, Family Carers Ireland (FCI) and the Irish Second-Level Students' Union (ISSU), will explore how best to support young carers, based on young carers' perspectives. YOUNGCARERS prioritises the co-design of proposals for alternative supports for young carers, using deliberative participatory methodologies. Outputs will include a national survey of Young Carers, six participatory workshops, a Young Carers Parliament and a position paper detailing recommended supports to be implemented by FCI.

The presentation will conclude with plans for co-creation and dissemination of both projects to influence supports and policy relating to Young Carers in Ireland.



Speaker Biographies

Rob Anderson

Rob Anderson is former Head of the Social Policies unit at Eurofound, where he worked as Research Manager from 1988-2018 on a range of topics relating to living conditions and quality of life, including several international research projects exploring aspects of family care across Europe. Prior to joining Eurofound, Rob worked as Programme Manager at the WHO European Office in Copenhagen, with responsibility for the European Regional Programme in Health Promotion. He studied human sciences at Oxford University, and sociology as applied to medicine at Bedford College, London. Rob served as President of Eurocarers from 2009 to 2012 and is the Chair of the Advisory Board at the ESRC Centre for Care. Rob has been appointed chairperson of Family Carers Ireland's Research & Policy Committee.

Hannah Boylan

Hannah Boylan is a MESL Researcher with the Vincentian MESL Research Centre at SVP. The research center uses the Consensual Budget Standards methodology to provide an evidenced-based benchmark of what is required to achieve a socially acceptable Minimum Essential Standard of Living (MESL) in Ireland, which contributes to the policy debate on income adequacy, poverty, and social inclusion. Some applications of the MESL research include, the Living Wage Technical Group's calculation of the Living Wage, the Insolvency Service of Ireland's calculation of Reasonable Living Expenses, and Safefood's calculation of the cost of a healthy food basket in both the Republic of Ireland and Northern Ireland.

Brian Doyle

Brian Doyle joined the CAREWELL team in June 2021. He completed a MSc in Applied Social Research in 2018 and worked as a Firefighter/Paramedic for over 28 years during which he conducted research on Critical Incident Stress Management within the emergency services. Brian is based within Family Carers Ireland focusing on the communication and outreach strategy of the CAREWELL project and is the producer of the podcast series CAREWELL Conversations. Brian is also working on the Hugs@home project with The RCSI Sim centre and an ADAPT Systemic Risk Management project with Trinity College Dublin.

Dr. Christine McGarrigle

Dr. Christine McGarrigle is a Senior Research Fellow with The Irish Longitudinal Study on Ageing (TILDA), Trinity College Dublin. She joined TILDA in 2012. She received her M.Sc. and PhD in Epidemiology from the London School of Hygiene and Tropical Medicine, University of London (UK). She previously received a B.Sc. in Chemistry from University College Dublin.

As part of the TILDA team her research is currently focused on (1) intergenerational transfers between generations; (2) the health and social determinants associated with successful ageing; (3) the health and well-being outcomes associated with caring and social participation, and the determinants that enable and constrain continued participation of older people in society. Her recent research investigated the mental health and well-being of carers in Ireland during the COVID-19 pandemic and found that Informal caregiving



increased during the pandemic and family carers reported increased adverse mental health and well-being and this continued throughout the early months of the pandemic.

Prof. Mary Murphy

Professor Mary P Murphy is Head of Department of Sociology in Maynooth University and has published widely on gender related issues. She has research interests in gender and social security, globalisation and welfare states, the politics of redistribution and power and civil society. An active advocate for social justice and gender equality, she was a member of the National Expert Advisory Group on Tax and Social Welfare (2011-2014), a Commissioner on the Irish Human Rights and Equality Commission (2013-2107) and in 2019 was appointed by President MD Higgin to the Council of State.

Dr. Pauline Cullen

Dr. Pauline Cullen is Associate Professor in the Department of Sociology, Maynooth University. She has published widely on gender, care and civil society. Her work examines civil society mobilization on social justice and gender equality at national and European Union level, women's movements and gender and political representation. She has worked as a gender expert for advocacy organisations working on gender justice and equality issues and has recently researched the experience of minoritised women in local representative democracy in Ireland.

Dr. Nikki Dunne

Dr. Nikki Dunne joined Family Carers Ireland in March 2019. As the organisation's Research Manager, Nikki leads Family Carers Ireland's programme of research and manages a diverse range of qualitative and quantitative projects relating to family carers. She is particularly focusing on building and coordinating research involvement and engagement among family carers, researchers and other stakeholders.

Dr. Sarah Donnelly

Dr. Sarah Donnelly is an Assistant Professor of Social Work in the School of Social Policy, Social Work and Social Justice. Prior to this Sarah worked as a medical social worker for 15 years in Tallaght University Hospital. Sarah's research interests include: ageing and dementia, adult safeguarding and capacity and decision-making. Sarah is currently Co-convenor for the European Network for Gerontological Social Work and Academic Advisor on Adult Safeguarding to the Irish Association of Social Workers.

Dr. Tamasine Grimes

Dr. Tamasine Grimes is Associate Professor in the Practice of Pharmacy at Trinity College Dublin. Over the past 20 years, she has worked as a pharmacist in university, hospital and community. Tamasine continues to practice and combines this with her research and teaching. Tamasine's research focuses on medication safety, exploring ways to enable people to get the most out of their medicines, to use medicines safely and to make the job of managing medicines, for one self or for loved ones, easier.



Johanne Powell

Johanne Powell, originally from Norway but living in Fethard-on-Sea, Co. Wexford, cared for over 36 years for her beloved daughter Siobhan who was born with a rare chromosome disorder and intellectual and physical disabilities, requiring 24/7 care. Sadly, Siobhan passed away in August 2020 amid Covid-19 causing additional stress in an already very difficult time for the family. Both Johanne and her husband Alan were truly devoted to their daughter who was their only child and spent many years lobbying on her behalf for the provision of services to cater for her needs. In recent years, Johanne had been fighting to secure residential care for Siobhan. Johanne continues to be a powerful advocate for family carers and people with disabilities.

Dr. Carol Kelleher

Dr. Carol Kelleher is a lecturer in Service Design at University College Cork. Her research focuses on care and care relations. Her current Irish Research Council New Foundations (IRC NF) YOUNGCARERS project involves a collaboration with Family Carers Ireland. YOUNGCARERS seeks to co-develop supports for Young Carers with Young Carers in Ireland. Previous IRC NF projects include POSTCARE, which explored the transitions explored by former carers and CARERENGAGE, which explore public patient involvement (PPI) with family carers.

Faye Hayden

Faye Hayden is a Carer to her three Neurodivergent children aged 9-15 years old in Leitrim. She runs the Roscommon Young Carers Project and is Chairwoman of the Not OK in School Ireland NOISI campaign, which advocates for more inclusive and meaningful education for all. Faye has recently completed her Masters in Social Justice and Public Policy and has conducted research into the area of support provision for Young Carers, particularly focusing on their need to access childhood fully and for Inclusive emotional support for all members of households supporting persons with disabilities. Faye has written three books, one about the Carer experience and two Children's books about disabilities and inclusion, 'United We Play' volumes 1&2 with all profits donated to the Join Our Boys Trust fighting Duchenne Muscular Dystrophy.

Aoife Bowman-Grangel

Aoife Bowman Grangel graduated from the University of Limerick's Bachelor of Science in Psychology with First Class Honours in 2021. Aoife recently enrolled in the second year of her PhD in the University of Limerick, under the supervision of Prof. Stephen Gallagher, Dr. Jennifer McMahon, and Dr. Nikki Dunne. Her PhD Project revolves around examining the mental and physical health of Young Carers, with a specific focus on the role of psychosocial factors (e.g., social support, caregiving intensity) in the youth caregiving-health relationship. Aoife has been collaborating with Family Carers Ireland and University College Cork on the IRC New Foundations Young Carer's Project, designing, conducting, and analysing the findings from the National Young Carers Survey.

Niamh Finucane

Niamh Finucane is Young Carer Support Manager (East) in Family Carers Ireland. Niamh has been in this role for 1 year and previously was Support Manager in the Waterford Centre. Her educational background is in Health Promotion (BA) and completed a MSc in Cognitive Behaviour Therapy & Motivational



Interviewing. Niamh works with young carers individually on the Young Carer Wellbeing Programme which involves assessing the young carer's needs and putting an action plan of supports in place. Her role also involved community work with young carers such as working with schools, raising awareness, young carer support groups and respite activity breaks. Niamh has been collaborating with UCC on this project by facilitating workshops and inviting young carers to engage with the project.

Dr. Avril Kennan

Dr. Avril Kennan is CEO of Health Research Charities Ireland (HRCI), an organisation that supports a community of 40 charities to engage in all aspects of health research. Under her leadership, HRCI runs the Irish Health Research Forum (IHRF), manages a funding scheme for patient-focused research projects in partnership with the Health Research Board and hosts a patient and public involvement (PPI) 'Shared Learning Group' for over 30 charities. HRCI is also a national partner on the National PPI Ignite Network. Avril's PhD and subsequent lab experience are in the field of molecular genetics. In previous roles in DEBRA Ireland and DEBRA International, she drove a range of international initiatives, including the management of a network of over 200 clinicians and patients to develop evidence-based clinical guidelines and the establishment of an international patient registry. She's passionate about improving lives through research.

Dr. Deirdre O'Donnell

Dr. Deirdre O'Donnell (Ph.D., H. Dip Stats, M.Phil., BA) is an Assistant Professor of Health Systems at the UCD School of Nursing, Midwifery and Health Systems, and the Associate Dean for Research, Innovation, and Impact. She is also a faculty member of the UCD Centre for Research, Education, and Innovation in Health Systems (UCD IRIS). Her research interests include inter-professional collaboration in the delivery of integrated health care, supported decision-making in health and social care, elder abuse prevention and intervention and later life well-being. Dr O'Donnell has a strong track record of collaborative and co-design research with older people and with family carers and is a co-founder of the OPEN Network which aims to promote the involvement of older people in academic health and social care research. Her research emphasises participatory collaboration in a grounded up and user-driven approach to health policy development and implementation. She is currently PI for an HRB-funded project which is investigating interprofessional collaboration within community specialist teams integrating the health and social care of older people in Ireland. This project involves a partnership with the National Clinical Programme for Older People (NCPOP) and collaboration with Age Friendly Ireland and Family Carers Ireland. The project aims to understand what works to support interprofessional collaboration in community specialist teams for older people and why does it work? It also seeks to know what doesn't work and why not. In addition, the project will explore the perspectives of older people and family carers on what is important to them when receiving care from a healthcare team

Claire Devlin

Claire Devlin is a family carer and an active PPI contributor through Family Carers Ireland. Since getting involved with Family Carers Ireland as a PPI contributor, Claire has been involved in multiple research projects relating to different aspects of family carers' lives. She has also recently been part of the



organising team for the PPI Gathering which took place during the National PPI Festival. Claire also acts as a PPI reviewer for Family Carers Ireland's grants schemes.

Edel Murphy

Edel Murphy is the national Programme Manager for the PPI Ignite Network. Edel has worked in the area of public and patient involvement (PPI) in research for a number of years, working with researchers across all disciplines and with the public to build PPI capacity among both constituencies, delivering education and training and providing support to help researchers understand how to plan for and embed the public and patient voice across their research. In her current role, Edel is driving the development and growth of an energetic, collaborative and innovative Network, which brings together a diverse range of stakeholders nationally and internationally to build a shared voice for PPI in research in Ireland. This involves curating the Network's online hub and PPI Calendar of Events, leading on the Network's communications, coordinating Network governance with a particular focus on the Public Advisory Board, as well as conducting wide ranging engagements and two-way dialog with numerous and diverse partner organisations.