



Session 2

10 April 2024

3:45 - 5:00

YOU HAVE 12 SESSIONS TO CHOOSE FROM THIS AFTERNOON. PLEASE CHOOSE ONE SESSION TO ATTEND

SYMPOSIUM (2 SYMPOSIUM SESSIONS ARE AVAILABLE)

S1. TOKYO SYMPOSIUM (4 PRESENTATIONS IN THIS SESSION)

a. Young Carers With Long-Term Caring Roles and Their Mental Health Outcomes **Sachiko Yokomori**

Young carers experience, on average, poorer mental health than non-caregiving young people. However, it is unknown to what extent these effects differ with age, or by length of caregiving role, as population-based research has typically assessed young carer status at a single time point. Using repeated assessment of young carer status during multiple waves of a large longitudinal birth cohort study (Tokyo Teen Cohort), we carried out the first examination of caring roles on depression, self-harm and suicidality spanning early-to-mid adolescence. Young carer status and time spent caregiving was ascertained from four waves of data, collected at 10y, 12y, 14y and 16y. Mental health outcomes assessed were depression, self-harm and suicidal feelings. At 14y, depression was elevated among long-term carers (OR 3.11 [1.33, 7.27], $p=.009$), and at 16y associations between long-term caring and self-harm (OR 3.14 [1.06, 9.35], $p=.039$) and suicidal feelings (OR 2.49 [0.98, 6.34], $p=.056$) were detected. No consistent associations with mental health outcomes were found for new carers, nor for any caregiving group at 12y. Adjustment for confounding and sensitivity analyses (complete case analysis, multiple imputation on exposure, depression as continuous score) did not substantively change these findings. Young carers with long-term caring roles are at the greatest risk for negative mental health outcomes, with these effects being most pronounced in later adolescence. These findings highlight the need for early identification and support for young carers to reduce care burdens.

b. Informal Caregiving in Adolescents from 10 to 16 Years Old: A Longitudinal Study Using Data from the Tokyo Teen Cohort **Atsushi Nishida**

The Centre for Social Science and Medicine at the Tokyo Metropolitan Institute of Medical Science manages a large-scale longitudinal population study, the "Tokyo Teen Cohort" (TTC), which has intensively gathered data from a cohort of over 3000 children and parents since 2012. This data collection has included repeated measurement of the health and development of children who report being young carers. In this study, with the goal of providing evidence for policymakers and service providers responding the needs of young carers in Tokyo, we aim to answer the following questions: What is the proportion of young carers with long-term care roles? What are the household characteristics likely to give rise to young carers with long-term care roles? What are the lifestyle, psychological and characteristics of young carers with long-term care roles? What are the environmental factors which support the development and growth of young carers? We will present the answers to the above questions based on our longitudinal data analysis.

c. About Young Carers Support Measures in Tokyo

Ms Sachiko Yokomori

The Tokyo Metropolitan Government provides multifaceted support for young carers living in Tokyo to meet the needs of each individual under multi-agency collaboration, taking into consideration the diverse situations of each young carer's feelings and families in need of care. The Liaison Office for Child-Oriented Policies is working to raise awareness of young carers, especially among elementary, junior high, and high school students, and to convey the voices of young carers to society. This year, we held a workshop with young carers and former young carers as an effort to convey the "real" voices of young carers. Opinions about what they have experienced and what they want to convey to society were exchanged and we have created a website that has been built and reflects their opinions. In addition, with reference to Manchester's ongoing initiatives, we have produced a documentary video depicting the experiences of young carers and a music video reflecting the voices of young carers in the lyrics and have shared this on our website to publicize young carers in Tokyo to society. Furthermore, the Bureaus responsible for welfare and education administration have also implemented initiatives such as teaching classes at metropolitan high schools "about" young carers "with" young carers, and preparing manuals for use by staffs of agencies involved in supporting young carers, such as those supporting children in need, people with disabilities, elderly, as well as for use by teachers and school staffs. With these manuals we are taking initiative to train and develop human resources.

d. Introduction of Tokyo Metropolitan Government's Young Carers Support Website **Daiki Hori**

The Tokyo Metropolitan Government has created a website to support young carers. The website is called "Young Carer's Plaza" based on the concept of a "place" where young carers and those around them, can gather to learn, think, converse about young carers. The contents of the website includes useful information about young carers to help people understand more about young carers. The website also shares survey data on young carers to introduce the level of society's awareness of the term "young carers", the percentage of assumed young carers, and what kind of care they are provided. Also, several detailed case studies are presented in the hope that they will help children who do not recognize themselves as young carers to become aware that they themselves may be a young carer. What is also unique is that we introduce the real voices of young carers on our website. We do this by introducing the opinions exchanged at the workshops held in the process of creating this website, the music video which lyrics reflect the opinions of young carers, and the documentary video based on the experience of a young carer, in order to provide a deeper understanding of the reality of young carers, as well as to encourage them to have positive dreams. Finally, the website introduces consultation services for children who may be a young carer, key points on how to support young carers for organization involved in support. We will continue to enhance our website to support young carers.

S2. Interventions and risk factors for siblings as young carers (4 presentations in this session)

a. The Development of SIBS and SIBS-ONLINE: Interventions Aiming to Strengthen Communication Between Siblings and Parents of Children with Disabilities **Torun M. Vatne**

Siblings of children with chronic disorders have an elevated risk of developing psychological difficulties, but the difficulties may be prevented. A main risk factor identified is poor family communication, but interventions targeting siblings-parent communication has been lacking. This presentation describes the development of an intervention called SIBS and the online version SIBS-ONLINE.

Objectives: SIBS was developed through 1) a descriptive study of support group sessions (n=56), b) six workshops with child and adult siblings, clinicians and user associations, and c) pilot testing (n=68). The result was a five-session intervention for siblings ages 8-16 years aiming to increase quality of the

parent-sibling communication. SIBS has three child support group sessions, three parent psychoeducational group sessions and two joint communication training sessions. SIBS-ONLINE was developed through 1) experience with five online support groups for siblings during the pandemic, 2) revision of the SIBS manual, 3) four pilot SIBS-ONLINE groups. The resulting SIBS-ONLINE manual and intervention material enable online delivery of SIBS.

b. Siblings as Young Carers: Predictors of Mental Health Problems in Siblings of Children with Chronic Disorders **Trude Frediksen**

Siblings of children with chronic disorders are at increased risk of mental health problems. Extra care needs among children with chronic disorders affect the entire family. We examined parents' mental health, family relationships, and communication as variables associated with how siblings' mental health is affected. This is important to identify those in need of interventions and to design effective care programs. Objectives: Siblings and parents of children with chronic disorders (N = 107) and their parents (N = 214) completed questionnaires about their own mental health. Parents completed questionnaires about siblings' mental health. Siblings completed questionnaires about communication and relation between them and their parents, and adjustment to the sibling situation. We examined if siblings' perceived quality of communication, the parent – sibling relationship, adjustment to the sibling situation, and parents' self-report on mental health predicted siblings' mental health. The main finding of the analysis was that siblings' perceived relation to parents and adjustment to the sibling situation predicted sibling mental health.

c. Social Support as a Key Variable for Siblings as Young Carers **Solveig Kirchofer**

Introduction: Siblings of children with chronic disorders (CD) are at risk of various negative emotional and behavioral outcomes. Social support is an important protective factor for siblings. Teachers, parents, and health care providers represent different and important sources of social support for siblings as young carers of children with CD. Supporting siblings is also supporting the child with a CD as the sibling relationship represents an important source of growth -and developmental possibilities throughout childhood.

Objectives: This presentation is based on our published and pre-registered (CRD42020207686) systematic review which investigated the level of social support received by siblings of children with CD, explored associated variables, and measurement instruments used to study social support. Multiple variables were found to be negatively related to social support (e.g., sibling depression, loneliness, and stress). Variables that were positively related to social support included prosocial behavior, total competence (academic, social and in activities), problem-focused coping and family quality of life. Potential moderators of the relationship between social support and psychosocial adjustment variables were found.

d. Results From the SIBS Intervention for Siblings and Parents of Children with Neurodevelopmental Disorders in Cambodia **Krister Fjermestad**

Siblings of children with neurodevelopmental disorders are at increased risk of mental health problems. The burden on families of children with neurodevelopmental disorders is exacerbated in low-income countries with limited health services and dependency on informal care systems. Yet, there is little research on family impacts of neurodevelopmental disorders in non-Western settings, and no evidence-based interventions for siblings. Objectives: We examined initial outcomes and feasibility of the manual-based SIBS intervention delivered in Cambodia. We delivered eight groups for 52 siblings (M age = 12.7 years, SD = 2.7; 44.0% female) and 56 caregivers (M age = 43.5 years, SD =

8.5; 61.1% mothers) of 54 children with neurodevelopmental disorders at the only public child mental health clinic in Cambodia. We aimed to improve sibling and parent mental health and family communication. The SIBS intervention comprises three separate sibling/parent group sessions and two joint sibling-parent dialogue sessions.

WORKSHOPS (5 WORKSHOP SESSIONS ARE AVAILABLE)

W1. The Important Role of Lecturers in Supporting Students with a Chronically Ill Family Member and Their Need for More Expertise

Hinke van der Werf and Marjet Karsenberg (YAC)

Children and young adults with a chronically ill family member experience a reduced wellbeing when the combination of family care and their educational programme is too demanding. The aim in this workshop is to combine personal stories from young carers combined with research among role views, competences and needs of lecturers regarding identifying and supporting these young carers to prevent further consequences. Our study findings indicate that lecturers have an important role to play in identifying students with chronically ill family members and offering low-key support or making referrals to external professionals when the students' needs exceed the capabilities of school professionals. We would like to discuss the role of education institutions and their responsibility towards young carers with our audience in a workshop. Therefore, we will present the Dutch model agreement for student caregivers allowing lecturers and psychologists to reach agreements with young-adult carers regarding their (study) needs. This template will be an example to start the discussion and learn from best practices across Europe.

W2. COVID-19: Challenges and Opportunities in Canada

Heather Chalmers

It has been well documented that Young Carers are "hidden" for a variety of reasons. While Covid-19 exacerbated many challenges for young carers, it highlighted the gaps in the Ontario Canada healthcare system and created opportunities to reach more young carers. This workshop will explore what our research has revealed about the challenges and rewards young carers experienced during Covid-19 and will discuss the difficulties and benefits for programs which tried to support young carers. Specifically, we will explore how the Young Caregivers Association in Ontario Canada addressed these challenges and how they turned the challenges into opportunities. Objectives for this session include: 1) To learn about how Covid-19 impacted young carers; 2) To learn about one program's response to Covid-19; and 3) To learn about how Covid-19 created positive opportunities for programs and services. This session will be of interest to practitioners/service providers and researchers. Participants of this workshop will come away with both a better understanding young carer experiences of providing care during Covid-19 and how this crisis also became an opportunity to improve the care and support to this "hidden" population.

W3. Model of the Young Carer Spectrum: Theory, Discussion, Activity and Next Steps

Ed Janes

Attempts have been made to theorise the young carer spectrum but, while this can be informed by past research concerning substantial responsibilities, knowledge of the wider population is limited by the challenge of how to identify a hidden group. Investigating this evidence gap is vital to understanding how the positive and negative impacts vary for children depending on their specific circumstances. Method: This workshop will begin with an introduction to the mixed methods Caring Lives study. This included a qualitative study that recruited young carers from the wider spectrum and the analysis of

secondary data to compare the mental health of young carers and children without caring responsibilities. This informed a model that differentiates between children with manageable caring tasks, substantial responsibilities, but also those with particularly problematic roles. This informs recommendations for tiered support by family members, specialist projects and mainstream services to suit the large and diverse population. Activities: The second part of the session will first enable delegates to suggest additions and modifications to an interactive version of the model. This could be based on their own research or their work supporting young carers, as well as their lived experiences as young carers. This will be followed by group work discussion on some of the long-term but unresolved issues faced by young carers, with consideration of how to make some of the study recommendations a reality.

W4. Identifying young carers from Seldom Heard Groups

Daniel Phelps

To increase understanding of barriers and solutions to improving the identification of young carers and especially those from disadvantaged and seldom heard groups. **Objectives:** The workshop will present findings from The Children's Society project 'Supporting young carers from hidden and seldom heard groups': (1) Findings from a literature review about how to improve identification of young carers from disadvantaged and seldom heard groups. (2) Examples of practice and case studies from the UK will be shared. The workshop will build on these findings by facilitating participant discussion about how to improve young carer identification in their own countries and regions: Firstly, by evaluating what is working with respect to young carer identification Secondly, by thinking about which groups currently remain largely unidentified. Facilitators will next introduce the second interactive part – a focus on *how* to improve the identification of young carers. Participants will consider: What strategic changes need to be made? How to improve identification of currently unidentified groups.

W5. Empowerment and Exposure - Informing Choice with Young Carers Voice

Hana Gill

Using current research as a backdrop to address/discuss the benefits and risks associated with young carers sharing their stories. Relating to the following conference themes: *INCLUDE TO EMPOWER: "nothing about us without us"*, and will include *Personal stories of young carers' involvement in advocacy work, policy, practice, or research*. Objectives: To learn from the experiences of young carers to equip others with the knowledge they need to make informed choices *before* being given opportunities to share stories; To include key themes/findings from GYC/Uni of Glos/SYC research focused on caring for someone with a stigmatised condition; To move towards a deeper understanding of ethical and meaningful participation

SHORT PRESENTATIONS (5 SESSIONS ARE AVAILABLE)

SP1. YOUNG ADULT CARERS INTO UNIVERSITY/HIGHER EDUCATION (3 presentations in this session)

a. The Caregiving Students Roadmap for Lecturers. Development of a Support Tool for Early Identification and Support of Informal Caregiving Students at a Nursing Faculty
Erica Witkamp, Saadet Paker, Ellen Bakker

In the Netherlands one in five students cares for someone with a condition. Gradually it becomes more difficult to combine study and informal care duties. In addition to personal problems these students are at risk of delaying or dropping out of their studies. Many caregiving students do not share their worries with their supervisor and make little or no use of support. Methods: Between September 2021 and

March 2022 we investigated the support offerings for caregiving students within and outside our university. At the nursing faculty we assessed the needs of lecturers to identify and support caregiving students. Results: Twenty two experts were interviewed, such as nurse faculty staff, researchers, student welfare advisors, student caregivers and informal care experts. This revealed a lack of systematic focus on informal caregiving; these students were identified by chance, often when they get stuck in their studies. Support was found to be fragmented and difficult to find, lecturers reported a need for additional knowledge and information about identifying, supporting and referring caregiving students. Subsequently we developed a *caregiving students roadmap for lecturers* and tested it's feasibility and potential impact among 12 nurse lecturers. Some lecturers also attended a workshop on young carers. Participants rated the roadmap positively and saw a workshop as a valuable addition to the roadmap. Besides, two caregiving students gave positive feedback on the roadmap. The roadmap is a promising tool for early identification of caregiving students, to early discuss their needs and refer them to appropriate support.

b. Caring and Learning at an English University **Su Corcoran**

Whilst Widening Participation in Higher education as a concept and practice has been around since the early 2000s, it was not until the creation of the Office for Students, and the guidance to institutions on developing the 2019-20 Access and Participation Plans, that Young Carers were included in the definition of under-represented groups. The Guidance encouraged universities to consider the services provided to support young carers and how these might align with or be strengthened through access and participation plans. The guidance also highlighted the lack of national data on the number of carers in higher education, as not all disclose their caring responsibilities and their carer status can change. Consequently, young adult carers are often a hidden population and can therefore be harder to reach and encourage into higher education. While there is evidence to support the widening participation of young carers in higher education, once they are encouraged to access university, they may have specific support needs once they start their academic journeys. Understanding these support needs is essential to the student experience. This presentation explores initial findings from a project aiming to understand the experiences of young carers studying at Manchester Metropolitan University in northwest England, through survey and interview data, to inform the development of future policy and support programmes.

c. Young Adult Carers Pursuing Higher Education in London: Application and Transition into University; Reconciliation Between Caring and Student Life; and Perceptions of University Support Services **Camille Bou**

Young adult carers (YAC) are people between the ages of 16–25 who provide unpaid care to family members and/or friends with chronic illnesses, disabilities, mental health conditions, and/or substance abuse problems. They make up an important part of the growing unpaid carer population in England, and their caring roles can impact their lives in positive and negative ways. Evidence suggests YACs have worse mental and physical health, and achieve lower outcomes in education, employment, and training relative to their non-carer peers. Higher education institutions have a particular position in tackling these inequalities, as they can provide support helping YAC reconcile their studies with their caring responsibilities and devise internal policies removing barriers in access to higher education. This qualitative study sought to understand the higher education experiences of YAC, focusing on their application and transition into the university, how they navigate their studies and student life alongside their caring responsibilities, and their engagement and perceptions with the support services offered by their institution. Five In-depth semi-structured interviews were conducted with undergraduate YAC enrolled in a public research university in Greater London. Transcripts were analysed using deductive

thematic analysis, with subthemes found inductively from the data to integrate into the overarching themes of the interview topic guide.

SP2. European Perspectives (3 presentations in this session)

a. Enabling Young Carers and Young Adult Carers to Care and Not Care in the Welfare State (Austria) Selma Kadi & Mirijam Pot

Young carers can be faced with very difficult situations that have effects on different domains (school, work, personal development, family relationships, friendships, health, financial resources) in their lives. We present findings from research conducted in Austria on support measures for young carers and young adult carers. The paper is based on data from a recently completed study in Austria. This study included 16 interviews with current and former young carers and young adult carers as well as experts on needs and preferences of young (adult) carers. It had a particular emphasis on existing as well as possible future support measures related to education and employment.

b. Unveiling the Work-Life Balance Directive: Identifying Gaps in Care-Related Needs (Europe) Paola Asja Butera

In recent decades, European labor law has increasingly emphasised work-life balance, a concept further underscored by the COVID-19 pandemic. Within this context, Directive 1158/2019 on work-life balance for parents and carers at the European level (WLBD) has been adopted. The new directive on work-life balance represents a crucial step towards the integration of care needs into labour legislation. Employing a gender-sensitive lens, this study provides a comprehensive assessment of the WLBD's implications for caregivers, with a specific emphasis on young carers. Drawing on extensive literature reviews and insightful interviews conducted in Italy, Ireland, and Finland, it examines how the directive and its subsequent implementation in these three distinct case studies effectively address the distinctive needs and goals of young carers. The findings underscore innovative elements within the directive, including provisions for paternity leave and parental leave remuneration. However, significant limitations are revealed, impacting caregiving definitions, cohabitation requirements, and flexibility in work arrangements, disproportionately affecting young carers and other vulnerable groups. The paper concludes with recommendations aimed at addressing these challenges, advocating for lifelong, inclusive caregiving support, tailored educational and employment systems, and collaborative endeavours among stakeholders to enhance the well-being of young carers and other marginalized groups. In alignment with the "Young Carers' Fair Futures" theme and the subtheme of "Whole family, multi-stakeholder approaches to support young carers", this paper offers profound insights into the struggles faced by young carers and other vulnerable groups, presenting a pathway towards a fairer and more inclusive future.

c. Young Carers in Germany - Gaps and Needs from a Legal Perspective (Germany) Stefanie Grohl

In Germany, there are currently approximately five million people in need of care, primarily provided by family members within their own homes. The need for care or increased support for a close family member has implications for the entire family structure. Consequently, children and adolescents often take on caregiving responsibilities. Especially in legal studies in Germany, young carers and young adult carers have been a largely overlooked group. This presentation aims to address this research gap and examine the legal gaps and needs of young carers from a legal perspective. The presentation will focus on the legislative concept of caregiving family members and their support and promotion. The first aspect to be examined is whether the German nursing law recognizes young carers and provides them

with appropriate support measures. In the concluding remarks, we will assess the need for legislative action and provide a perspective on this matter.

This presentation is intended for young (adult) carers and in particular for professional stakeholders, such as political actors, legal professionals, as well as school professionals and social and care professionals.

SP3. Caring for Parents with Various Conditions (4 presentations in this session)

a. The Meaning for Adolescents Living with a Parent Who Has Amyotrophic Lateral Sclerosis

Nina Malmström, S. Nilsson, B. Jakobsson Larsson, I. Nygren, J. Öhlén & A. Ozanne

Having a parent with the neurodegenerative and lethal disease amyotrophic lateral sclerosis (ALS) can be challenging and traumatic. The increased risk of health problems in adolescents with seriously ill parents is known, but research specifically examining experiences of adolescents of parents with ALS remains limited. For effective support, it is important to explore their own perspective further.

Objectives: The aim was to explore the meaning for adolescents of living with a parent who has ALS.

Research method: Data for this qualitatively designed study were collected through individual interviews with 11 adolescents (8-25y), who lived with a parent with ALS. Data were analyzed using phenomenological hermeneutics. Key findings: The interpreted whole of the adolescents' narratives revealed the meaning of living with a parent with ALS as struggling not to lose footing in a world torn apart. Experiences of being faced to an everyday life turned upside down was described, including facing uncertainty, trying to handle the situation, grieving, and dealing with changing family dynamics, and living in a workplace rather than a home. It also meant shouldering great responsibility which forced the adolescents to grow up faster and put the own life on hold. This, together with changing family roles yet being more attached to home, reinforced the imbalance in the adolescents' lives. Recommendations: The unbalanced life situation may hinder the adolescents' identity formation, leading to difficulties with managing independent adulthood. This emphasizes the importance of early support intervention to reach this vulnerable group, to promote or maintain their health.

b. Informal Care by Students for Relatives with Addiction Problems

Dorina Van Namen

Recent research among 5,662 students at Rotterdam University of Applied Sciences showed that 15.6% (that is 881 students) had relatives with addiction problems. These students were in worse physical and especially mental health than students whose relatives did not have such problems. They were also more likely to have study delays. Of these 881 students, 13% reported informal care duties. Half of them spent more than five hours a week on informal care tasks. A third felt heavily burdened to overburdened. Almost half had these duties for five years or more. Thirty (of the 881) students participated in a longitudinal (3 years), qualitative study and spoke about their caring tasks, among other things. They did (parts of) the housekeeping, cared for younger siblings and/or relatives with addiction problems, contributed financially to the family, and had caring duties for other family members, such as grandparents.

c. How to Reach Young Carers of Mentally Ill Parents

Jeanette Bonde Pollmann

In Denmark, the National Competence Centre for children and young people in families living with mental illness – Kombu was established in 2020. Kombu offers knowledge, tools and skills to improve the awareness, identification and support of young carers living in families affected by mental illness. Kombu was organized as a partnership between the Danish NGO, Psykiatrifonden and The Capital

Region of Denmark and the North Denmark Region. After the first phase of Kombu from 2019-2023, the second phase of Kombu has been granted funds to continue the Competence Centre.

Kombu has worked towards improving awareness and competencies of professionals in the field of young carers with mentally ill parents to enable them to identify and reach out to children and their families. This work has entailed close collaboration with municipalities in training professionals in schools, daycare and professionals meeting the

d. Mapping the Experiences of the Military Connected and Veteran Young Carers (USA) **Melinda S Kavanaugh, Lisell Perez-Rogers & Rachel Barrett**

Children and youth in military-connected and veteran families the United States have long provided care for their injured family members. Yet limited information exists as to how these young carers come to the role of carer, how care changes over time, and the needs of the family as a whole. Identifying these issues is critical as organisations engage young carers and develop programming and supports. Objectives: 1) To describe young carer in military and veteran families; 2) Identify potential interventions and support points for young carers; 3) Develop a “family Mapping” tool highlighting potential carers, experiences and intervention points for families and organisations. Results: participants are living with a range of injury/illness, including traumatic brain injury, spinal cord injury, PTSD, and loss of limbs. Participants were primarily Veteran families (n=6), with injury to father (n=5) most common. Young carers ranged in age from 8-23, provided care for an average of 5 years, for care needs including bathing, toileting, medications, and managing emotions. Thematic analysis of the interviews highlighted clear points for mental health and social interventions with young carers: when the injured parent returns home, when they family leave active service, when older siblings leave home, and when the illness/injury progresses. Support needs including assistance with care, whole family mental health support, school-based support and peer engagement.

SP4. Young Carers' Health Outcomes (3 presentations in this session)

a. Adolescent Young Carers Health Differences Between Sub Groups of Adolescent Young Carers (Sweden) **Miriam Svensson**

Adolescent young carers (AYCs) are 15–17-year-olds who are recognised as being in a critical transition period, as they balance their unpaid caring tasks with their education and/or work, leisure activities and their transition to adulthood. They largely remain an under-studied group of young carers. One way to contribute to a more in-depth understanding of this group of young people is to study potential health differences between subgroups of AYCs. Adult care research has namely showed that the presence and intensity of negative impacts on health strongly differ between various subgroups of carers. As it cannot be assumed that the same applies to AYCs, a research study is currently being carried out in Sweden that focuses on potential health differences among AYCs with varying demographic characteristics, care provision and received support. A better understanding of this could not only result in new knowledge, but also potentially inform policy and help target more responsive support programmes to those AYCs who could benefit the most from them.

b. Self-Rated Depressive Symptoms Among Young Carers - A Population-Based Study in Finland (Finland) **Ella Eronen-Levonen and Katja Joronen**

This study examines the associations between young carer status and depressive symptoms among high school and vocational school students in Finland. Using data from the 2019 School Health Promotion Study conducted by the Finnish Institute for Health and Welfare, this study examines self-

rated depressive symptoms among 32,636 respondents. Students were assessed using the Patient Health Questionnaire-2, which asked the following questions: In the past two weeks, how often did the following problems bother you? 1) Little interest in or enjoyment of various things 2) Low mood, depression, feeling of hopelessness. The response options were: Not at all, Several days, More than half the days, Almost every day. In addition, students were asked about their caring responsibilities, ranging from none to daily care for family members or significant others with illness or old age. The results showed that 4-5% of respondents experienced depressive symptoms almost every day. Notably, students with caring responsibilities had higher rates of depressive symptoms than their peers without such responsibilities. Specifically, those with caring responsibilities reported reduced interest in activities (6.5% vs. 3.7%) and increased feelings of low mood (8.4% vs. 5.0%) almost every day. The study highlights the importance of recognizing symptoms of depression and the caring role of family members. Early identification and appropriate referral for care and support, as well as specific support for young carers, are crucial to improving young people's well-being. These findings highlight the importance of tailored interventions and support services within the health and youth sectors.

c. The Cardiovascular Effects of Caregiving on Young Carers: The Role of Coping **Aoife Bowman Grangle**

Target audience: Professionals involved in designing and implementing services for young carers or general youth work services, NGO's, individuals and organizations involved in advocating for young carers, healthcare professionals, teachers and educators, psychologists, researchers, and family carers.
Background: From a psychological perspective, the caregiver-control model of chronic stress has confirmed that providing care to a family member with physical or mental illnesses, substance abuse issues, and disabilities is associated with poorer cardiovascular health. To date, older adult and parental caregivers have been the main focus of this research, with little attention paid to younger caregivers (aged 17-18). The present study will examine whether young carers differ from non-caring youths on resting heart rate (HR), systolic (SBP) and diastolic (DBP) blood pressure and explore the underlying psychosocial pathways. **Methods:** Data on cardiovascular outcomes and psychosocial factors (including lifestyle and psychological factors) will be extracted from Wave 3 of the Growing Up in Ireland Study, which is a population-based study of Irish young people. This study will investigate potential differences between 17/18-year-old carers (N = 1,168) and non-carers (N = 4,090) on cardiovascular parameters, as well as known risk factors such as smoking status, exercise habits, and BMI. Moreover, this study will explore whether coping styles influence cardiovascular outcomes in young carers. **Expected Findings:** We expect that young carers will be at greater risk for elevated blood pressure, due to the increased demands placed on them by their caregiving role. Additionally, there may be a difference between young caregivers and non-carers on cardiovascular risk factors e.g., smoking as well as coping styles and these may be underlying pathways behind the association. **Recommendations:** These findings could extend the caregiver-control model of caregiving by demonstrating that biological effects previously observed in adult carers are not age specific and will be discussed from a lifespan perspective.

SP5. Co-Production with Young Carers (3 presentations in this session)

a. Producing a Children's Story Book For and With Children/Parents/Caregivers Impacted by Parental Substance Misuse **Deborah Smart**

It is estimated that 472,000 children are impacted by parental substance misuse resulting in many being a young carer. Two parallel studies examined the experiences of families affected by parental substance use: one study with children and young people and another with non-substance using parents. The findings demonstrated that children in substance exposed families often felt alone and unsupported, adding to their burden of caring. Parents/caregivers also found it difficult to initiate

supportive conversations about the impact of parental substance use with the child. The findings of these studies informed the development of the children's book aimed at supporting conversations between trusted adults/parents and children about the impact of caring for a parent who uses substances with the message they are not alone. Objectives: A group of children (n=8), young people (n=1), young adults with experience of childhood parental substance use (n=1) and parents/caregivers (n=5) alongside an author and illustrator, co-created the storyline and character development of a children's story book to aid parent/child conversations about parental substance use.

b. Equality, Diversity and Inclusion: Designing a Young Carers Service Where Everyone Belongs **Sian Stamper**

Sense supports young carers with caring responsibilities for a brother, sister or parent with any disability. Most of our work with siblings and young carers happens online, so we're able to support young people across the whole of the UK. Through a model of staff and young person service design Sense's Siblings and Young Carers project has embedded diversity and inclusion throughout the programme. Staff and young person service delivery are based on a foundation of exploring and celebrating the differences of young carers. Collaborative work with external experts builds on the above to provide a range of learning opportunities. Young people are given the opportunity to share and celebrate their cultures, religions, ethnicities and experiences with other young carers, bringing their whole authentic self to the project

c. Hidden by Choice **Cornich Plumridge**

The difficulties of being a parent carer – things do not always work out 'okay' – raising awareness of the impact of this. What it's like to be a sibs carer – being responsible for not only the physical wellbeing but the emotional and moral upbringing of another who is close to your age (hidden young carers). An undercurrent theme that what I thought was a choice was pressure from professionals/ family/ society to stay hidden. Objective: Being a young carer for a parent, as it's 'the norm' the difficulties to then identify as a sibling young carer /show gender inequality / to share that things do break down sometimes, explore the feelings of guilt and failure and how that can impact life. Being a sibling carer, to show what is involved – to debunk the myth that sibs carers are not young carers. Young carers having aspirations – reframing thoughts.
