



# Session 4

11 April 2024

3:00 - 4:15

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

## **WORKSHOPS (8 WORKSHOP SESSIONS ARE AVAILABLE)**

### **W1. Learn about Key Elements in the SIBS Intervention for Siblings and Parents of Children with Chronic Disorders**

**Krister Fjermestad & Torun M. Vatne**

This SIBS group intervention for siblings and parents of children with chronic disorders is a five-session manual-based group intervention developed in Norway. The intervention comprises three parallel sibling-parent group sessions with multiple families and two joint sessions where each sibling-parent dyad meets separate from other families. The aim of the SIBS intervention is to enhance parent-child communication, and thereby prevent sibling mental health problems. The SIBS intervention rests on a decade of developmental research. This workshop addresses the conference themes Include to empower: The SIBS intervention was co-developed with young and adult sibling carers and revised based on user feedback; Identify and reach: Including participants in the SIBS intervention requires identification and need assessment; Support for impact: The SIBS intervention has demonstrated positive outcomes from trials in Norway and Cambodia and is currently evaluated in USA, Denmark, and Australia. Hence, the SIBS intervention represents a global effort to support siblings.

### **W2. Adapting the Ycare Caregiving Skills and Support Program to Diverse Populations: Example from South Africa Young Carers**

**Melinda Kavanaugh Melinda Kavanaugh, Lisell Perez-Rogers & Rachael Barrel**

The YCare program is a hands-on, peer engaged, care skills and support program for young carers. Developed in the US, YCare utilises a trained multidisciplinary team to conduct the day long program for young carers. Yet given cultural and social differences, YCare model must be adapted to be applicable to countries who have cultural variations, fewer health care professionals, and limited resources - including South Africa.

### **W3. Refining and Implementing the EU "ME-WE" Model for Adolescent Young Carers (Sweden)**

**Lennart Magnusson**

The European Union funded "ME-WE" project is the first major cross-national project (2018-2021) to focus on promoting the mental health and wellbeing of a largely under-studied group of young carers, namely adolescent young carers (AYCs) aged 15-17 years. AYCs are an important target group because they are facing the transition from adolescence to adulthood, whilst balancing their unpaid caring activities with their education and/or work life and personal life. The project was carried out in six European countries (Sweden, the Netherlands, Italy, Slovenia, Switzerland, and the UK). It led to the co-design of the ME-WE model, which is a psychosocial support intervention including group sessions and a mobile app, together with knowledge building and awareness raising about the situation of AYCs.

Post-project, work has continued to refine the model to a Swedish context and to offer an education programme to municipalities and organisations that are interested in implementing the model.

Objectives: The workshop aim is to introduce the ME-WE model and summarise the main outcomes of the EU funded project. The workshop will focus on the current work, supported by the National Board of Health and Welfare Sweden. In particular, the refined model, education programme, a follow-up and evaluation programme and an online network with participant municipalities and organisations will be described. This will be followed by a group discussion of the applicability of the programme to interested conference delegates from other countries.

#### **W4. Forum Theatre Workshop**

**Sally Duckers**

Our workshop aims to surface some of the dilemmas that Young Carers face during a key transitional stage in their life from child to adult through immersive 'Forum Theatre' techniques. This workshop fits within the selected theme of 'Support for Impact' changing the lives of Young Carers. Forum Theatre was pioneered by Augusto Boal to give a voice to the oppressed peoples of South America. This form of Theatre demands that the audience are spectators and not passive spectators by inviting them to engage and change the direction of the piece. The idea being that the answers to all of life's challenges are held within a group mind. The audience will determine the direction of the workshop by responding to an initial tableaux created by a group of Young Adult Carers. An experienced facilitator will take on the role of 'Joker' and will carefully steer the relationship between actors and spect-actors.

#### **W5. Engaging Professionals Across Sectors in Quebec to Support Young Carers**

**Oliver Fitzpatrick**

As young carers are only just gaining attention in Canada, AMI-Quebec's young carers initiative focuses largely on building professionals' capacity to offer support within their respective organizations. In so doing, we have discovered distinct strategies for working with the education, health, and community sectors. In this workshop, we will discuss what we've learned in trying to foster cross-sectoral collaboration in order to build a "no wrong door" network of support. This workshop is aimed at all young carer advocates who are looking to build interprofessional collaboration, or effectuate change across different sectors, such as education, community, and health. The goal of the workshop is that everyone leaves with an idea of what different sector champions need to make change, and ways of partnering with them. The presentation revolves around three questions: "what areas are a priority, according to young carers?", "what actions are achievable, according to professionals?" and "what does each stakeholder group need to engage in such a way as to make the most impact?" Takeaway messages will include how to frame the role of different stakeholder groups, the need to do so to avoid overwhelming potential champions, and an outcomes-based framework for examining potential or available supports, on an individual organizational level, or in the wider community context. Throughout the presentation, discussions will address key learnings, as well as integrating quiz portions to ask how this compares with what others have found.

#### **W6. "I Care. Do You?" Little Dreamers and the Power of Story Telling**

**Emma Woodward**

Driven by both lived and living experience, sharing Young Carer stories has always been a key part of the success of Little Dreamers, Australia's leading non-profit improving the quality of life of Young Carers. This session focuses on the "I Care. Do You?" fundraising campaign conducted by Little Dreamers. This presentation is deeply relevant to the conference theme, "Inclusion, Empowerment, Support and Impact," with a focus on community fundraising to directly support Young Carer specific programs.

## **W7. The Power of Young Carers' Voices Informing Advocacy and Policy Development**

### **Helen Leadbitter**

"It is important to involve all young carers in all aspects of policy making and decision making. We have a voice – listen to us!" (young carer). Hearing young carers voices from regional activities alongside strategic engagement with Commonwealth was the foundation of the development of the Commonwealth Charter for Young Carers. The Commonwealth Organisation for Social Work (COSW), collaborating with sector agencies locally and internationally has been supporting young carer programmes for almost 20 years and sponsored consultation with young people in several countries to develop the 'Commonwealth Charter for Young Carers'. The development of this international network grew from recognition from the Commonwealth Youth Programme of young carers in Kenya and East Africa in 2006 which enabled them to voice their opinions for the first time. Following this COSW partners across the Commonwealth have informed young carers of their Rights as children, as outlined in the articles of the UNCRC, and encouraged discussion about where these rights may not be upheld for young carers due to the impacts of their caring responsibilities. The Commonwealth Charter for Young Carers outlines ten core recommendations from young carers themselves. They want more people, including Heads of Government, to know about young carers and understand what they need and what would help them. This workshop will showcase the Commonwealth Charter for Young Carers and explore the strength of collaboration and partnership working. The voices of young carers themselves will be shared including short videos of young carers from some of the Commonwealth countries.

## **W8. Making Carers Count - Delivering New Services for Young and Young Adult Carers**

### **Tanya Coles**

Making Carers Count is a multi-partner programme aiming to identify and support carers who are under-represented amongst the community groups we currently reach and who have been disproportionately affected by the Covid-19 pandemic. This includes a significant focus on young and young adult carers. We are creating new and wider collaborations, extending engagement methods, increasing learning, and enhancing how support is delivered to unpaid carers.

The programme started in January 2021 and ends in March 2024, so the workshop aims to share learning generated from qualitative and quantitative impact measurement that is specific to young and young adult carers, including findings from our interim and final evaluation reports. The workshop will be co-created with support workers and young carers. Primary alignment is with the theme of *Support for Impact: Assessing young carers needs/goals and tailoring support; Supporting young carer mental health and wellbeing; Whole family, multi-stakeholder approaches.*

---

## **SHORT PRESENTATIONS (4 SESSIONS ARE AVAILABLE)**

### **SP1. YOUNG CARERS IN SCHOOLS - MODELS FOR PRACTICE (3 presentations in this session)**

#### **a. Parentification as Social Determinant of Health: Implications for School Councillors**

### **Kathryn Higdon**

School is often a place for the first identification of the young carers' situation. Therefore, school is seen as a suitable place to initiate support. Support can take different forms e.g. by teachers in the classroom, through advisory services/activities or exchange of experiences with other young carers. Research shows that young carers, parents and teachers perceive and favor different support structures in school. This raises the question of how successful support structures must be designed at schools in

order to be sustainable and accepted by all stakeholders. The variety of possible support measures and their differing evaluation makes clear that it is first of all important to look at the basic conditions that make these measures possible. A secondary analysis of qualitative data from different perspectives (young carers, parents, teachers, counsellors) leads to basic conditions of support structures for young carers in school. Aim of the presentation is to outline the Model of Basic Conditions of Support Structure for Young Carers in School and to discuss possible impacts. The presentation is directed to young carers and former young carers, researchers and practitioners to discuss the model from different perspectives. The Model shows that every school with its own resources can facilitate support for young carers.

### **b. The Role of a School-Based Counselling System in Identification and Support of Young Carers in School**

**Anna-Marie Spittel**

School can have different meanings for young carers: place of identification, place of support, place of meeting others, safe space or place of challenges. A coordinated interdisciplinary cooperation between all actors of the education system and also of the social and health system is needed to face the impacts of the family situation on the everyday school life of young carers. An important interface can be school-based counselling systems. The research project looked at the role of professionals within the "Regional Centres for Education and Counselling", a school counselling system in Hamburg, Germany. The project with a mixed-methods approach will be finished by the end of 2023. The aim of the presentation is to give an insight into the results of the research project in relation to identification and support of young carers of school. The focus is on the function of the counselling system in the contexts of cooperation and networking. The presentation is directed to young carers and former young carers, researchers, and practitioners to discuss the project from different perspectives. It will be shown how an entire system addresses the issue of young carers little by little.

### **c. Model of Basic Conditions of Support Structures for Young Carers in School**

**Anna-Marie Spittel & Steffen Kaise**

School is often a place for the first identification of the young carers' situation. Therefore, school is seen as a suitable place to initiate support. Support can take different forms e.g. by teachers in the classroom, through advisory services/activities or exchange of experiences with other young carers. Research shows that young carers, parents and teachers perceive and favour different support structures in school. This raises the question of how successful support structures must be designed at schools in order to be sustainable and accepted by all stakeholders. The variety of possible support measures and their differing evaluation makes clear that it is first of all important to look at the basic conditions that make these measures possible. A secondary analysis of qualitative data from different perspectives (young carers, parents, teachers, counsellors) leads to basic conditions of support structures for young carers in school. Aim of the presentation is to outline the Model of Basic Conditions of Support Structure for Young Carers in School and to discuss possible impacts. The presentation is directed to young carers and former young carers, researchers and practitioners to discuss the model from different perspectives. The Model shows that every school with its own resources can facilitate support for young carers.

---

## **SP2. OVERLOOKED YOUNG CARERS (INTERNATIONAL PERSPECTIVES) (3 presentations in this session)**

### **a. Falling Short: Examining Trends Over Time in Support for Young Carers in England**

**Charlotte Paddison**

In England there are at least 127,000 young carers aged under 18 years, according to the 2021 Census. All young people with caring responsibilities in England have the right to have their needs as carer assessed, and for support to be provided to meet eligible needs. Objectives: To assess trends in assessments for young carers, and in support for young carers in England, using national data collated in aggregate form from approximately 151 local councils in England. Results show a significant decline of 42% between 2020/21 and 2022/23 in the number of young carers in England receiving a young carers assessment (i.e., being identified as a carer and/or having needs for support reviewed). The number of young carers receiving direct support continues to decline and now stands at its lowest level since 2015/16. Compared to 7 years ago, the number of young carers now receiving direct support from local councils in England - through either a direct payment, local authority managed personal budget, or local authority commissioned support - has reduced from 2450 (2015/16) to 660 (2022/23) – a 73% decline. Conclusion and significance of results: Although in recent years schools have made some good progress in identifying young carers, a significant number of young carers are still not receiving appropriate support or even having their needs assessed.

### **b. Is Anyone Listening? A Partnership Approach to Identifying, Recognising and Meeting the Needs of Young Carers in South Asia** **Ruth Patil**

There is increasing understanding of the various and complex ways caregiving can adversely affect young carers' health, educational attainment and future employment prospects, accompanied by a welcome increase in the number of local and national initiatives focussed on young carers and encouraging moves towards streamlining young carers into broader child and young people-focussed strategies and action plans. The voices of young carers are being brought to the table for the first time. However, this is only happening in the global North. Perspectives of young carers in low and middle-income countries are rarely heard. The recognition of young carers as a vulnerable and marginalised group is not even close to the agenda of governments and practitioners in the global South. This can be partially attributed to the chronic lack of evidence concerning young carers in these settings. There is widespread lack of awareness amongst governments, policy makers, service providers and families. Without recognition and awareness, there will be no action to improve the lives and future prospects of young carers in low and middle-income countries. This presentation will focus on the current situation for young carers in South Asia and the need to ensure all young carers are heard, wherever they live in the world.

### **c. Hidden Carers in India** **Teemol Thomas**

Research on young carers from various global regions indicates that they dedicate extensive time to domestic and emotional caregiving, impacting their physical and mental well-being, education, career prospects, and personal relationships. However, a lack of literature, research, and awareness regarding child and adolescent carers in India, contributes to their invisibility and lack of recognition of their caregiving burdens. Thus, the topic aligns well with the theme of 'Identify and Reach' of this conference. Objective: Drawing from findings of a broader mixed-methods study conducted with young people aged 15-18, in New Delhi and Mumbai, India, this oral presentation aims to elucidate on the nuanced meanings and complexities of being young carers in the urban Indian context. Target Audience: This presentation is directed towards researchers, given that the subject matter constitutes a significantly underexplored area of work. There is a pressing need for additional research in this domain to ensure the provision of effective support for young carers. Learnings/ Take away message/s: There is a significant lack of awareness regarding the presence of young carers in India. They are not recognised as a distinct group needing care and protection by child safeguarding systems in India. Consequently, they find themselves grappling with the repercussions of assuming adult-like caregiving role in isolation.

Raising awareness about the existence of such a group of children is crucial for providing necessary support and to mitigate the profound impacts of their role.

---

### **SP3. IDENTIFY AND REACH (3 presentations in this session)**

#### **a. Are Ill Parents' Key Persons to Better Identify and Reach Young Carers? A Mixed Method Study** **Aurélié Untas, Julie Glatz, Pauline Justin, Géraldine Dorard, Michèle Koleck**

In France, awareness about young carers and the issues they face is increasing but identifying them is still a large challenge. Many studies have investigated caring activities provided by youth according to their point of view. However few studies have explored the perceptions of ill parents about their children's caring roles even though they might be key persons to identify and reach young carers. Objectives: The aims of this study were: (1) to describe ill parents' perception about the help provided by their children, and (2) to explore the factors associated with the help provided by children. Three hundred and fifty-nine parents took part in this study by completing an online questionnaire. The parents' responses showed they perceive quite low levels of help from their children, even if it depends on children's age and parental autonomy in daily activities, perceived help being higher when children were older and when parents had less autonomy. Sixteen parents also participated in a semi-structured interview. Several themes related to help came out: the type of help provided, organization related to help, communication about help, parents' experience and consciousness, impact on children and parent-child relation, thoughts about its evolution. Parents also reported their needs and suggested ways of improving supports. Target audience: Researchers, professionals, young carers themselves and their family. Take away message: Professionals need to be attentive to ill parents' autonomy to better identify young carers and to provide relevant support.

#### **b. Can We Really Identify Young Carers?** **Jade Pilato, Géraldine Dorard, Aurélié Untas**

Young carers (YCs) are often hidden and difficult to identify. Having a family approach and crossing perspectives could be helpful to better identify YCs. Yet, no research has crossed adolescents' and parents' perspectives to identify Young Carers (YCs). Objectives: The objectives of the study were: (1) to identify ill/disabled relatives within the household, (2) and to assess the levels of adolescents' caring activities, from adolescents' and parents' perspectives. Target audience: This communication aims at targeting both researchers and professionals who work with adolescents and could identify YCs. Learnings and take away messages: 776 middle school pupils and one of their parents completed questionnaires. Adolescents identified fewer ill/disabled relatives than their parents. Only 27.56% of the dyads agreed on the presence of an illness/disability within the household. Parents and adolescents agreed more when the ill/disabled relative was the mother, and when the relative had a serious illness. Adolescents reported higher levels of caring activities than their parents. YCs' identification based on self or parents' report solely appear to be unsatisfactory. Instead, a family approach could enable to better capture these caring situations. School and health professionals should be trained on weak signals to better identify the caring situations not to only rely on adolescents' or parents' report.

#### **c. How to Better Reach Male Young Carers** **Elena Guggiari**

Although international and national research shows that almost half of young carers are male, male adolescents and young men with a caring role are particularly hard to reach. Since male young carers also experience several challenges in coping with the caring role, e.g. more drop-outs from education or training than their female counter-part, a study in Switzerland aimed to investigate how support offers can better reach male young carers. The study included an analysis of quantitative and qualitative data

from previous studies, 5 interviews with male young carers and 11 with professionals working with male adolescents and/or young carers (e.g., school social workers or youth workers).

---

#### **SP4. TOOLS TO IDENTIFY YOUNG CARERS (4 presentations in this session)**

##### **a. Pretest of an Interactive and Pictorial Questionnaire Designed to Identify Young Carers Aged 7 to 12 Aude Villatte, Geneviève Piché, Rima Habib, Aurélie Untas & Géraldine Dorard**

This paper presents an interactive and pictorial questionnaire designed to help identify children aged 7 to 12 at risk of, or experiencing, a role of caregiver. To the best of our knowledge, this is the only screening tool whose modalities (visual, language, etc.) are specifically designed to enhance information processing and understanding of verbal concepts in this age group. By facilitating the identification of young caregivers by the professionals working with them, this questionnaire aims to promote early intervention and the prevention of potential negative impacts of caregivers on the life trajectory of the young people concerned.

##### **b. Identifying Young Carers in Child Protection Ulrika Järkestig Berggren**

Taking on a high degree of responsibility for care in their family may pose risks for children on their health and in their educational, social, and emotional development. Yet, it is not easy for children themselves to identify or even describe their caring. Therefore, it is of importance that social workers who meet children in need of support have the knowledge and methods to identify children who are young carers. We are currently conducting a research project in which we are testing a questionnaire together with social workers in child protection, in order to help them identify children who are taking on a high degree of responsibilities for care at home. The questionnaire is based on tested and validated questionnaires that has been translated into Swedish. Furthermore, it includes questions that relate violence against the child or family member to caregiving responsibilities. The aim of the project is to develop a questionnaire for our target group: social workers in their professional work with child protection. The first results show that social workers find the questionnaire to be a helpful tool in their efforts to identify children who are young carers and their need for support. A takeaway from the project is that children often find it easier to answer specific questions rather than enter a conversation about their responsibilities in their family.

##### **c. What Socio-demographic Factors are Associated with Caring Status of Young People as They Age Between 16-25 Years Old? Camille Bou**

The study sought to explore how young adult carers and their households divide the division of labour, and the factors influencing their division of household labour. In this way, this study proposes a novel analysis of household labour division by focusing on families with young adult carers. To understand the division of household labour from the young adult carer perspective, the study answers the following questions: How do young adult carers divide household labour with their families? Why do they organise their household labour in this way? How do young adult carers experience their household division of labour, including their reconciliation between their caring responsibilities and their other responsibilities? I analysed data from semi-structured interviews that I personally conducted with 23 individuals living across England using a framework approach. Most participants in the sample were female, and most cared for their parents (specifically, their mother), with others caring for siblings. From the analysis of the interview transcripts, two models of decision-making and two models of implementation of household division of labour task

emerged, influenced by several factors: 1) the illness of the care-recipient; 2) the care experience and specialisation of the young adult carer; 3) the agency and influence of the young adult carer in conversations about the division of household labour, and 4) the amount of support young adult carers and their households received, whether from formal or informal networks (e.g. health or social care system, or friends and family). Depending on the pattern of household labour in which they found themselves, and consequently how much care intensity they experienced, young adult carers were satisfied or dissatisfied. Nonetheless, most young adult carers saw themselves continuing to care in the future alongside the pursuit of their personal aspirations, although it was not always clear how they would achieve this. The division of household labour in homes with young adult carers is not something that had been studied before. This study provided insight into the daily lives of young adult carers and what happens within their home.

#### **d. MYTIME's Holistic Approach to Creating a Framework of Good Practice** **Dan Morris**

MYTIME's mission is to empower schools with a comprehensive toolkit of resources, strategies, and support to identify young carers and support them mentally and emotionally while boosting their academic prowess. We are determined to level the playing field, ensuring that young carers have every opportunity to reach their full potential. In this presentation, we will: Provide an in-depth understanding of our Level Up Programme's inner workings; Share compelling data on young carers' attendance and attainment, comparing it to their non-caring peers; Highlight our programme's profound impact on schools and its transformative effects on young carers. We aim for our audience to grasp our Level Up Programme's substantial influence on young carers' lives. It goes beyond staff training and data collection; it's about driving real change in schools and witnessing the incredible transformations it brings about in young carers. Our presentation is tailored for professionals in educational settings and other organisations, researchers, and policymakers looking to adopt best practices and make a genuine difference in the lives of young carers.

---